

## ABSTRACT

Title of dissertation: MATERNAL EXPERIENCES OF PARENTING CHILDREN WITH AUTISM SPECTRUM DISORDER: A QUALITATIVE ANALYSIS

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Despite the increased prevalence rates of autism spectrum disorders (ASD) over the last two decades (Centers for Disease Control and Prevention, 2015), little is known about the parenting of children with ASD, including parenting behaviors, parent-child interactions, and how the specific characteristics of children with ASD affect parenting practices. The goals of this qualitative study were: (1) To explore parenting practices and behaviors among mothers of children with ASD; and (2) To illuminate the unique experiences of mothers raising children with ASD. Three research questions guided the inquiry: 1) What are the parenting practices and behaviors that mothers use with their preschool age children with ASD?; 2) What are the beliefs and experiences of mothers relative to raising preschool aged children with ASD?; and 3) What

facilitates or hinders mothers' parenting of their preschool aged children with ASD? In this qualitative inquiry, six mothers and their preschool-age children with ASD were recruited from the Autism Center in a metropolitan children's hospital. Each mother participated in three 1-1 ½ hour long semi-structured audio-recorded interviews that entailed a series of open-ended questions about the unique experiences associated with raising a child with ASD. Two home observations and one public observation of mother-child interactions lasting 1-2 hours in length were conducted per family. Eleven themes emerged during the coding process: 1) positivity within the mother-child relationship, 2) schedules and routines, 3) strategies encouraging child cooperation, 4) crisis management, 5) perspectives on child's maladaptive behavior, 6) perspectives on child's abilities, 7) perceptions and experiences around public interfacing, 8) stress associated with caring for a child with ASD, 9) maternal resources, 10) interpersonal supports, and 11) ecological factors. These results shed light on factors that contribute to the everyday realities and experiences of parents who have children with ASD, thereby allowing for a more accurate understanding of their parenting approaches and behaviors. Findings from this study can be considered in the context of developing interventions focused on parenting children with ASD.

MATERNAL EXPERIENCES OF PARENTING CHILDREN WITH AUTISM SPECTRUM  
DISORDER: A QUALITATIVE ANALYSIS

by

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CHAPTER I  
**Maternal Experiences of Parenting Children with Autism Spectrum Disorder: A  
Qualitative Analysis**

Autism Spectrum Disorder (ASD) is a developmental disability characterized by pervasive impairments in social relationships and communicative skills (Centers for Disease Control, 2015). Prior to the release of the Diagnostic and Statistical Manual of Mental Disorders (5<sup>th</sup> edition), ASD was defined as an umbrella term for a wide range of disorders including Autistic disorder, Asperger's disorder, Pervasive Developmental Disorder (PDD), Rett's disorder, and Childhood Disintegrative disorder (American Psychiatric Association, 2000). Currently, a diagnosis of ASD includes a combination of four previously separate disorders (i.e., Autistic disorder, Asperger's disorder, Childhood Disintegrative disorder and Pervasive Developmental Disorder Not Otherwise Specified) into a single condition with varying symptom severity levels (i.e., Autism Spectrum Disorder) (American Psychiatric Association, 2013). Additionally, Rett's disorder is now separate from ASD.

When determining the severity of ASD, clinicians make classification distinctions between levels 1-3 with each level representing a different amount of assistance required - *support (least severe)*, *substantial support* and *very substantial support (most severe)* - in addressing social communication impairments and restricted repetitive behavior problems, respectively (American Psychiatric Association, 2014). Notably, individuals who possess deficits in social communication, without displays of other symptoms related to ASD (i.e., restricted and repetitive behavior) are considered for an evaluation of social (pragmatic) communication disorder. Finally, the term "spectrum" refers to the wide range of symptoms, behaviors, skills, and levels of impairments that individuals with this disorder possess. Despite the marked changes in the DSM-V, it is important to note that individuals with a well-established diagnosis

of Autistic disorder, Asperger's disorder, and Pervasive Developmental Disorder should still meet the criteria for ASD.

The purpose of revising the DSM-IV was to provide a more accurate and scientific way to diagnose individuals with ASD related symptoms. Prior to the revised edition, the diagnoses were wide-spread among the five separate disorders previously discussed which generated concerns regarding the uniformity and fidelity of the diagnosing process across centers. Despite these concerns, it remains clear that the prevalence of ASD has steadily increased over the last few decades with a near doubling of the rate since 2002 (Centers for Disease Control and Prevention, 2012). ASD affects individuals of all races, ethnicities, and socioeconomic statuses. There are stark differences relative to gender, with boys being almost five times more likely than girls to be diagnosed with ASD (boys 1 in 42; girls 1 in 189) (Centers for Disease Control and Prevention, 2014). Typically, children are diagnosed with this disorder during early childhood, specifically around the third year of life, although parents tend to report recognizing abnormalities in their children's development earlier than year three (ASD Society of America, 2012; National Institute of Mental Health, 2012).

The increase in the prevalence of ASD has profound effects at the macro-level (i.e., societal), specifically economic costs to the government to provide individualized therapy to affected children, to conduct research to better understand the disorder, and to implement interventions to optimize children's and parents' functioning. Issues within the micro-level (i.e., familial) have also been investigated in the ASD literature, including influences on family cohesion, the family's ability to adapt, and parents' psychological well-being. However, there is limited research that examines the *parenting* of children with ASD, including parenting practices and

behaviors, parent-child interactions, and how the specific characteristics of children with ASD affect parenting.

This introduction focuses on the need for research on parenting within families in which there is a child with ASD. To this end, I will briefly review the knowledge about children with ASD, the extant albeit limited literature on parenting children with ASD including parent-child interaction, a theoretical framework that can be applied to investigations of parenting in this population, and a methodological approach to such a study. Throughout this document, the terms parent-child interaction and mother-child interaction will be used interchangeably because most of the research has been conducted with mothers. Similarly, much of the literature will address the relation between child characteristics, maternal functioning, and maternal behavior.

### **Autism Spectrum Disorder (ASD)**

Although the DSM-V was released mid-year of 2013, it is important to still provide a section in this dissertation detailing the disorder and the criteria for diagnosing using the 4<sup>th</sup> edition as all of the participating families have children who were diagnosed using this version. As aforementioned, the DSM-V now combines symptomatology that was originally considered separate in the DSM-IV for Autistic disorder, Asperger's disorder, Pervasive Developmental Disorder (PDD), Rett's disorder, and Childhood Disintegrative disorder. Notably, although individuals who were diagnosed with Autistic disorder, Asperger's disorder, Childhood Disintegrative disorder and PDD should still meet the criteria for ASD, highlighting the differences in the DSM-IV versus the DSM-V provides clarification for the reader.

ASD is a very complex disorder about which there is considerable debate (e.g., c, impaired regions of the brain, time of onset, and role of genetic or environmental risk factors). Previous hallmark signs of ASD, as delineated by the Diagnostic and Statistical Manual, 4<sup>th</sup> edition

(DSM-IV), included: (1) restrictive and repetitive stereotyped behaviors, for example negatively overreacting to slight change; (2) impairments in communication, for example deficits in language development or in constructive play; and (3) deficits in social interactions, for example inattentiveness and lack of interest in others (American Psychiatric Association, 2000).

Currently in the DSM-V, the previous three hallmark signs have been reduced to two and include: (1) deficits in social interaction and communication and (2) restrictive/repetitive behaviors. Additionally, individuals with ASD manifest sensory integration issues that include (a) tactile challenges, (b) fine-motor/perceptual problems, (c) self-regulation, and (d) oral sensory sensitivity (Ayres, 1971; Leekam, 2007; Myles et al., 2004).

In order to meet the diagnostic criteria for the various ASDs denoted in the DSM-IV, an individual must exhibit a specific number of impairments from each of the hallmark categories. Classifications of high- to low-functioning ASD are therefore determined by and based on the diagnosis. For example, whereas high functioning individuals with ASD generally show impairments in their social interactions with minimal to no signs of deficits in repetitive behavior or communication, low functioning children with ASD exhibit significant impairments in all three. As aforementioned, the change made to the DSM-V now includes severity levels ranging from 1 (least severe) to 3 (most severe) in relation to the amount of support needed to address social communication impairments and restricted and repetitive behavior problems in individuals diagnosed with ASD. The current research project included children with ASD across the autism spectrum as diagnosed using the criteria outlined in the DSM-IV.

Over the last 15 years, there has been increasing interest in the early identification and diagnosis of children with ASD (Matson, Wilkins, & Gonzalez, 2008). Based on the existing evidence related to the stability of early diagnosis (Baron-Cohen et al. 1996; Eaves, & Ho, 2004;

Lord, 1995; Stone et al., 1999) and improved screening measures (Lund & Jensen, 1989; Matson, 2007b; Matson, Nebel-Schwalm, & Matson, 2007), children are being diagnosed with ASD at younger ages (Charman & Baird, 2002).

Early childhood is a time period when parents commonly begin to encounter difficulties with child management and behavioral issues. Behavioral problems exhibited by young children such as regulatory problems (e.g., eating, sleeping, and emotion regulation), defiance and temper tantrums, can influence parent-child interactions and the quality of their relationship (Guralnick, 2008). Notably, these issues have been reported in young children with ASD (Degangi et al. 2000; Dominick et al. 2007). The aim of the current project is to examine parenting during the early childhood period, which can shed light on mothers' early experiences with ASD.

### **Etiology**

Scholars have documented that the etiology of ASD is multi-faceted. There is strong and consistent evidence that ASD has its roots in early brain development, and as such is considered a neurodevelopmental disorder (Bauman & Kemper, 2005; Rodier, 2002). For example, the brains of children with ASD have been documented to grow at a faster rate in early childhood, but then plateau earlier than the brains of typically developing children (Redcay & Courchesne, 2005). However, individuals with ASD are typically not diagnosed until about the age of three (Centers for Disease Control and Prevention, 2012). Recently developed screening tests have become helpful at detecting ASD as early as 18 months or even younger (Filipek, et al., 2000; Landa, Holman, Garrett-Mayer, 2007).

Scientists have identified a number of gene mutations associated with ASD (Centers for Disease Control and Prevention, 2012; National Institute of Mental Health, 2012). Although the evidence regarding genetic etiology is compelling, most cases of ASD appear to be caused by a



combination of genetic and environmental risks factors (i.e., parental age [both mothers and fathers], maternal health, and prenatal complications) (Hall, 2009; Jones & Szatmari, 2002; Limperopoulos, 2008; Newschaffer et al. 2007). Extant research on gene-environment interaction in typically developing children and children with disabilities such as ASD has the potential to provide further insight into the early developmental processes that shape learning, behavior, and individuals' overall health (Fox, Levitt, & Nelson, 2010; Shonkoff, 2010). To address environmental processes more specifically, research is needed to address the parenting of children with ASD, including how parents interact with their children who have ASD and how these children's behaviors may play a role in parenting practices.

### **Prevalence**

The number of children with ASD is rising at an exponential rate, across all racial, ethnic, and socioeconomic groups (Naqvi, 2009). There is no established explanation for the increased rate, although factors such as better detection of the hallmark signs, increased access to services, and recent diagnosis of unrecognized ASD in adolescents between the ages of 14-17 have been postulated (Centers for Disease Control and Prevention, 2013). As the fastest growing developmental disability, ASD affects over 2 million individuals in the United States and millions worldwide (Barbareasi, et al., 2005; Honda, et al., 2005; Lauritsen, et al., 2004; Powell, et al., 2000; Williams et al., 2005; Wong & Hui, 2008; Yazbak, 2004). According to the Centers for Disease Control and Prevention (CDC), in 2004, 1 in 125 children were identified as having an ASD in the United States. This number accelerated to 1 in 110 children in 2006 and more recently, in 2015, to 1 in 68 children. Thus, there has been a 10-fold increase in the prevalence of ASD in the past 40 years. Globally, prevalence rates of 1 in 66, 1 in 38 and 1 in 147 have been reported in the United Kingdom (Baron-Cohen et al. 2009), South Korea (Kim et al., 2011),

and Canada (Norris, Pare, & Starky, 2006) respectively. Although the current study will focus on U.S. children with ASD, there is a need for more epidemiological studies with respect to other regions of the world (e.g., nations in Africa) in order to conduct accurate global comparisons of the prevalence rates.

Research on ASD has consistently revealed that boys are much more likely to be diagnosed with ASD relative to girls, with the exception of Rett's Disorder (a form of ASD that affects only girls) (National Institute of Child Health and Human Development, 2010). In the United States, studies show that boys are four to five times more likely than girls to be diagnosed with ASD. Current estimates are that 1 out of 42 boys and 1 in 189 girls in the US are diagnosed with ASD (Centers for Disease Control and Prevention, 2015).

The increase in the prevalence rates of ASD has considerable economic implications. The worldwide costs of ASD are estimated to be \$60 billion (Jarbrink & Knapp, 2001; Sharpe & Baker, 2007). Further, the estimated cost to care for individuals with ASD throughout their lifespans is \$3.2 million (Autism Society of America, 2009). This value includes U.S. health insurance mandates related to ASD diagnosis and treatment (Sharpe & Baker, 2007). Additionally, the annual cost of educating a child with ASD has been estimated to be \$18,000, which is triple the yearly amount for educating a typically developing child (ASD Society, 2011).

Expenditures for ASD research have also risen. For example, the leading federal agency for biomedical research on ASD, the National Institute of Mental Health, increased its funding for ASD from \$22 million in 1997 to \$108 million in 2006; this number continues to grow today (Singh, Illes, Lazzeroni, & Hallmayer, 2009; Vitiello & Wagner, 2007). Due to the high

prevalence rates and high costs of therapeutic treatments and research, ASD is now considered a significant public health concern (Newschaffer & Curran, 2003; Grossman and Barrozo, 2007).

### **The Role of Parenting in the Development of Children with ASDs**

Despite the increased prevalence rates of ASD and the empirical and clinical attention focused on ASD over the last two decades, little is known about parenting experiences and practices in the context of caring for a child with ASD. For example, there is scant evidence regarding the behaviors parent exhibit while interacting with their children with ASD. Such knowledge can inform the development of policies and interventions to promote the optimal functioning of children with ASDs and their families.

In particular, there is a need for more studies examining parenting among children with ASD in the early childhood period, as parents are coping with the initial diagnosis and are beginning to have concerns about their child's future. Siegel (1997) suggested that the diagnosis of a child with ASD is comparable to the feelings parents have when losing a child to death; parents grieve the loss of the "idealized" child. Accepting the diagnosis of ASD may be especially difficult for some parents given that many children with ASD develop typically during the first year of life and show regression during the second year of life. For example, Ozonoff, Williams, & Landa (2005) found that mothers of 60 children with ASD retrospectively reported regression as typically occurring at 14-20 months. Given that the diagnosis of ASD typically occurs around age 3, parents may be experiencing the challenges, as well as the benefits, of parenting a child with an ASD years prior to engaging with formal support systems.

### **Parental Well-Being**

Although there is limited evidence regarding *parenting*, the literature on the psychological well-being of parents of children with ASD is plentiful. In comparison to parents

of typically developing children and parents of children with other disabilities, parents of children with ASD report elevated levels of stress (Blancher & McIntyre, 2006; Eisenhower, Baker, & Blacher, 2005; Estes et al., 2009; Montes & Halterman, 2007; Randall & Parker, 1999; Rao & Beidel; 2009) and are at increased risk of depression (Olsson & Hwang, 2001). Factors associated with increased levels of stress in parents of children with ASD include gender of the parents (mothers report significantly higher levels of stress than fathers) (Dabrowska & Pisula, 2010; Tehee, Honan, & Hevey, 2009), child age (parents of school-aged children report more social support than parents of preschool-aged children and adolescents) (Tehee et al., 2009), and child characteristics linked with ASD (e.g., communication impairments, problems in social relations, and repetitive behavior) (Durate, Bordin, Yazigi, & Mooney, 2005; Hastings & Johnson, 2001; Kasari & Sigman, 1997; Tobing & Glenwick, 2002).

Specifically, the severity of the disorder is likely to contribute to the level of stress perceived by parents of children with ASD. For example, Hastings and Johnson (2001) found that parents of preschool and early school-aged children with ASD with severe impairments reported higher levels of stress than parents of children with lower levels of symptomatology. Child behavior problems (e.g., aggression and hyperactivity) have also been linked to parents' psychological functioning above and beyond the severity of ASD (Blancher & McIntyre 2006). Behavioral problems in children with ASD may manifest differently from the behaviors of typically developing children, or from children with other disorders distinct from ASD (Eisenhower, Baker, Blacher, 2005; Kasari & Sigman, 1997). Consequently, parents may have varying experiences depending on the unique behaviors presented by their children with ASD.

The literature is clear that parents of children with ASD show compromised psychological functioning and that child characteristics (e.g., severity of the disorder; behavioral

problems) contribute to parental psychological well-being. Thus, it is reasonable to propose that a bi-directional pathway exists between child behavior and parenting among families in which there is a child with ASD. Unfortunately, the literature on the bi-directional role of child behavior and parenting in this population is scant. Only two studies, to my knowledge, have examined the bi-directional pathway between child behavioral problems and parental functioning in families with children with ASD (see Osborne & Reed, 2010; Lecavalier, Leone, & Wiltz, 2006). The researchers noted a strong association between parenting stress and child behavior problems; parental stress was found to exacerbate child behavior problems over a 9-12 month period of time and vice versa. Notably, Osborne and Reed (2010) found that the severity of ASD symptoms in 2-4 year olds was strongly associated with higher levels of parental stress. This finding underscores the need for research on parenting processes in families in which there are children with severe impairments, given that the stress levels experienced by these parents can negatively impact parenting behaviors, practices, and interactions with children.

### **Parental Perceptions**

Parents are presented with a number of challenges when raising a child with ASD, which may affect the ways in which they perceive their children, and how they perceive their own parenting. There is evidence that mothers' perceptions of their typically developing children can influence how mothers perceive themselves (Leerkes & Crokenberg, 2002) and their interaction patterns with their children (Pierce et al., 2010; Teti & Gelfand 1991). Specific to ASD, research has shown that mothers of children with ASD tend to report lower parenting competency than mothers of children without disabilities (Fishman & Wolf, 1991; Kasari & Sigman, 1997; Sanders & Morgan, 1997).

Further, parental self-efficacy has been identified as influencing the behaviors of parents of

typically developing children (Coleman & Karraker, 1998). Additionally, Goodnow (1985) purports that parent perceptions about their parenting competencies are influenced by their daily interactions with their children. Regarding children with ASD, parents who feel competent about their parenting abilities tend to be more active in their children's lives and exhibit more positive behaviors in their interactions with their children than parents who have lower perceptions of their parenting abilities (Kuhn, & Carter, 2006; Meirsschaut et al., 2010). These associations may be a direct result of child characteristics. For example, atypical characteristics possessed by children with ASD, such as difficulty deviating from changes in schedules, may shape parents' perceptions about their children and their self-efficacy. Therefore, it is likely that these negative child behaviors coupled with low perceived parental self-efficacy is tied to parents' interactive behavior with their children.

In contrast, studies exist which paint a more positive picture of parenting children with ASD. For example, Sharpley, Bitsikia, & Efremidis (1997) found that although a large percentage of parents of children with ASD reported feelings of stress, 20% of the sample perceived their lives as manageable. Additionally, whereas some studies have found ASD to be a stressor that challenges parents' self-efficacy and negatively influences their psychological well-being (Kuhn & Carter, 2006; Meirsschaut et al., 2010), other studies report positive gains and outcomes among parents, such as improvements in relationships, increased patience, and enhanced spiritual growth (Ekas, Whitman, Shivers, 2009; Hastings, Allen, McDermott, & Still, 2002; Stainton & Besser, 1998; ). Moreover, Faso, Neal-Bervers, & Carlson (2013) found that 71 mothers and fathers of children with ASD between the ages of 4 and 12 who have hope for their children's future tend to be less stressed, depressed, and report more satisfaction with life than parents with less hope as reported in questionnaires. These data suggest that some parents fare

well with, or at least are not severely consumed by, the unique experiences associated with raising children with ASD.

### **Parenting Practices and Behaviors**

Examining parenting practices and behaviors is important as parents play an influential role in the early socialization experiences of children as well as in their cognitive and emotional development (Cabrera, Shannon, & Tamis-LeMonda, 2007). There is considerable literature on the positive effects of parenting practices, such as warmth and responsiveness, on typically developing children's social and emotional development (Chen et al. 2000a, b; Kim & Rohner 2002; Maccoby & Martin, 1983; Nelson et al. 2006). It stands to reason that parenting practices in families with a child with ASD would also affect these children's outcomes. However, few researchers have examined specific parenting experiences, practices, and behaviors of parents of children with ASD, including parent-child interactions.

The limited research on parenting children with ASD suggests that mothers of children with ASD generally display more similar parenting strategies than mothers of children with other disabilities and typically developing children (see Kasari, Sigman, Mundy, & Yirmiya, 1988). For example, parents of children with ASD tend to exhibit a higher frequency of control strategies and use of non-verbal prompts and physical proximity to engage their children than do mothers of children with other disabilities and typically developing children (Doussard-Roosevelt et al., 2003; Kasarari, Sigman, & Mundy, 1988; Lameneck, Stone, & Fishel, 1993).

In sum, though there is a robust literature on the psychological functioning of parents of children with ASD, there is little evidence that documents parenting processes (e.g., subjective experience, practices, behaviors, parent-child interaction) among this population. Further, increasing research shows a strong association between child factors such as behavior problems

and parental functioning (Blancher & McIntyre 2006), as well as parental functioning and parenting (Kuhn, & Carter, 2006; Meirsschaut et al., 2010). However, little attention has been given to these links among families in which there is a child with ASD. The paucity, limited scope, and ambiguity of the evidence on parenting children with ASD argue for more research on parenting practices, parent-child interactions, and child-specific influences on parenting with respect to this population.

### **Theoretical Foundation**

Bradley's (2002) identification of specific aspects of the parenting process offers an important framework for understanding how mothers conduct their parenting of children with ASD. This framework was used to guide the current exploration of parenting practices, behaviors, and interactions among mothers of young children with ASD. As Bradley asserts, parents perform critical tasks on a daily basis that will shape the outcomes of their children. Variability exists in what parents do in their interactions with their children. However, the goal is often the same: to prepare children for future adult participation in society. Parents have the responsibility to guide children toward reaching and achieving their developmental goals, in the physical, social, cognitive, and emotional domains (Bigner, 2002). Bradley (2002) describes specific parenting actions which are carried out over time to achieve these goals, and explicates how parents and children contribute to their mutual interactions. Specifically, he asserts that parents perform the following five tasks aimed at helping their children adapt to their environment: (1) sustenance, (2) stimulation, (3) support, (4) structure, and (5) surveillance.

**Sustenance.** The overarching goal of this parenting task is to sustain the health and functioning of the child. According to Bradley, parents must exhibit acts that promote health in their children such as providing adequate nutrients and shelter. Further, parents must protect



their children from teratogens and exposure to harmful substances during the child's development. The ways in which mothers support the health and development of their children with ASD may be different than what mothers do when their children are typically developing. Children with ASD have unique needs which can include impairments in their locomotor skills and ability to communicate. Parents' responses to these needs may differ based on parents' psychological resources, the degree of child impairment, and contextual factors (e.g., the availability of professional and/or family assistance). A clearer understanding of how mothers of children with ASDs perceive and conduct the sustenance parenting task is needed.

**Stimulation.** Parents must provide meaningful sensory experiences in the environment to engage the child, and to promote development and learning. Adequate exposure to stimulating objects, events, and experiences are beneficial to children's cognitive, psychomotor, and social development. This task is evident in the routines and activities that mothers engage in with their children with ASD. Because children with ASD do not have age-appropriate developmental functioning in multiple domains, there should be more empirical attention devoted to how parents of these children stimulate them to learn and develop. Further, since many family events and rituals are disrupted by children with ASD, it is important to consider whether having a child with ASD reduces the frequency and alters the content of these family processes.

Sensory abnormalities found in children with ASD can play a role in the amount of stimulation that mothers provide their children. For example, reading to children, displaying pictures on bedroom walls, providing access to musical instruments, and regularly engaging in family outdoor activities have all been found to be associated with more positive child outcomes (Bradley, 2002). These experiences may be overwhelming to the sensory systems of children with ASD. Further, the goals that mothers have for their children with ASD can play a role in

the type and frequency of stimulation afforded children. Finally, a hallmark sign of ASD is restrictive behavior, which may include overreactions to slight change. Deviations in family routines and activities may result in aberrant behavior from children with ASD; there is a need for a greater understanding of how mothers respond to their children's 'melt-downs' during parent-child interactions and family activities.

**Support.** Parents must respond to their children's needs in a timely, predictable, and satisfying manner for optimal child social-emotional development. Acts of support include providing positive affirmation of personal worth, guidance, and direction. There is robust evidence that children benefit from provisions of support and responsivity (Ainsworth, 1973; Bradley, Corwyn, McAdoo, & Garcia Coll, 2001; Whittaker, Jones Harden, Meisch, & Westbrook, 2011). Caring for a child with ASD who is low-functioning requires a significant amount of human resources including time and energy. The characteristics of these children may influence the level and type of support that parents provide.

**Structure.** The configuring or structuring of the sustenance, stimulation, and support that a child receives is vital for optimal child growth and development. Equal amounts of all three tasks do not automatically equate to healthy child development. Instead, fit must be considered as the needs of children vary. Additionally, parental management practices such as providing control and organization to children during activities is important for children's social-emotional and physical functioning (see Bradley, 2002 for a review of the literature). Mothers of children with ASD may provide different levels of structure to low-functioning children to ensure their positive adjustment than they would to high-functioning or typically developing children.

**Surveillance.** Parents must keep track of the child and the environmental conditions to which the child is exposed, in order to protect the child from potential dangers. Failure to provide adequate supervision and monitoring has been found to be associated with poor child outcomes (see Bradley, 2002 for a review). Caring for a child with mild to severe ASD requires significant surveillance. It is important to know the amount and type of parental monitoring which mothers provide to their low-functioning children with ASD as it can influence their perceptions.

Overall, one of the most significant relationships in human social interchange is that between a parent and child. The parent-child relationship carries numerous complex meanings and implications, which conspire to determine and shape parents' behavior during their interactions with their children. Our understanding of this significant family relationship has improved over the years in households that include typically developing children; however, a clearer understanding of this relationship in families with children with disabilities, specifically ASD, is needed. Moreover, mothers' interactions with their children are especially important to consider given that they typically provide the everyday caregiving of children; as such they are the focus of this study. Conducting research that explores the mother-child relationship in families that have children with ASD can provide scientists with a broader understanding of the determinants and processes of parenting a child with ASD. The findings from such studies can inform interventions that help families adapt to the challenges of caring for a child with an ASD. In the current study, parents' psychological resources and child characteristics will be used to explore parenting of children with ASD. Multiple maternal parenting processes will be explored, including parenting practices related to sustenance, stimulation, support, structure, and surveillance.

## Goals and Study Rationale

The parenting practices and behaviors that mothers exhibit during their early interactions with their typically developing children have been found to play a role in the quality of the parent child relationship and resultant child outcomes (Ainsworth, 1973; Bradley, Corwyn, McAdoo, & Garcia Coll, 2001; Whittaker, Jones Harden, Meisch, & Westbrook, 2011). However, less attention has been devoted to parenting practices in families in which there is a child with an ASD, particularly with respect to mother-child engagement in daily routines and activities. Additionally, knowledge about the perceptions and experiences of mothers raising preschool aged children with ASD is scant, including parental goals as well as the rewards and challenges associated with raising a child with an ASD. Moreover, knowledge about mothers' perceptions of factors that play a role in their parenting of children with ASD is critical, given that factors such as context, functioning of the mother, and characteristics of the child have been found to be associated with perceived parenting competencies and parental behaviors.

The goal of the current study is to explore parenting practices and behaviors among mothers of children with ASD, capitalizing on Bradley's depiction of specific categories of parenting practices. The current study also aims to illuminate the unique experiences of mothers raising children with ASD, including the benefits and challenges, as well as maternal perspectives on the parenting experience. I will further explore how child characteristics impact parenting of children with ASD, particularly the behavioral difficulties manifested by some children with ASD. Conducting more refined studies that take an in-depth look at maternal parenting in the ASD population are important in that a broader range of interconnected processes can be examined. Thus, a number of factors that contribute to the everyday realities and experiences associated with parenting children with ASD can be investigated. By

conducting such studies, a more accurate understanding of parenting children with ASD can be achieved.

### **Research Questions**

To more fully understand the experiences, behaviors, and practices of parents raising a child with ASD, the following three research overarching questions (and specific sub-questions) will guide this qualitative inquiry:

1. What are the parenting practices and behaviors that mothers use with their preschool aged children with ASD?
2. What are the beliefs and experiences of mothers relative to raising preschool aged children with ASD?
3. What facilitates or hinders mothers' parenting of their preschool aged children with ASD?

### **Methodology**

Qualitative methods represent an important strategy for taking an in-depth look at parenting behaviors and interactions among parents with children with ASD. Conducting a qualitative analysis affords researchers the opportunity to garner a better understanding of this understudied phenomenon in a scientific and rigorous manner, while allowing the stories of mothers raising children with ASD to be told. Given that parenting includes a broad range of interconnected processes and factors, employing qualitative methodologies (e.g., interviews and observations) is beneficial. Examining the parenting behaviors that mothers exhibit with their preschool aged children can provide researchers with more clarity on the behavioral strategies employed by these mothers on a daily basis within a natural setting.

The rich data gathered through qualitative methods are informative in that they provide

researchers with a deeper understanding of the complexities of parenting children with ASD. Moreover, qualitative methods afford scientists the opportunity to uncover patterns and themes that illuminate the experiences and practices of parents raising a child with ASD. Within the ASD literature, researchers have focused on improving the impairments in the child (e.g., social deficits) and have concentrated on how these child characteristics affect parents' psychological well-being (e.g., parental stress and depression). However, there is a paucity of empirical data exploring the specific experiences and practices of these parents. A more in-depth look at the experiences of parents is needed as the impairments in the development of children with ASD can influence parents' behaviors and interaction patterns with their youngsters.

To date, very little empirical or descriptive information exists about the experiences of parents raising a child with ASD. The data that do exist about parenting children with ASD come primarily from questionnaires, self-report surveys, and other quantitative approaches. Few researchers have attempted to document parenting practices and behaviors through in-depth interviews and naturalistic observations (Lasser, & Corley, 2008). These particular data collection processes can help researchers more thoroughly understand the phenomenon of raising a child with ASD and the nuances of these experiences.

Moreover, qualitative methodologies allow investigators to obtain data from the perspectives of mothers on the parenting practices in which they engage, as well as the factors that play a role in their parenting of children with ASD. Qualitative inquiry also allows the interpretation of data to be jointly conducted by researchers and study participants, in this case mothers of young children with ASD. This process will provide participant mothers the opportunity to place meaning on their experiences with their children with ASD.

## Definitions

The research conducted in this study will provide a better understanding of the parenting perceptions, practices, experiences and behaviors among mothers of children with ASD. A shared understanding of terms for this study is essential. Therefore, the terminology used throughout this dissertation will be based on the definitions presented below.

**Autism Spectrum Disorder.** According to the Centers for Disease Control and Prevention (2015), Autism spectrum disorder (ASD) is a developmental disability characterized by cognitive, communication, behavioral, and social impairments. The term “spectrum” refers to the wide range of skills, levels of impairment, and symptoms that individuals with these disorders possess ranging from mild to severe. The *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition - Text Revision* (DSM-IV-TR) previously defined five disorders under the umbrella of ASD:

- *Autistic disorder (also called classic ASD)*

Individuals with this severe form of ASD typically possess significant delays in communication, social skills, and intellectual skills. Additionally, displays of aberrant behavior are common.

- *Asperger's disorder (also called Asperger syndrome)*

Individuals with this form of ASD are typically high-functioning. Challenges with social problems and displays of atypical behavior may exist, however, unlike individuals with Autistic disorder, deficits in language or intellectual skills are uncommon.

- *Pervasive developmental disorder not otherwise specified (PDD-NOS) (also called atypical ASD)*

Individuals with PDD-NOS are those who meet some of the criteria for Autistic or Asperger's disorder but not all. Of those individuals exhibiting some criteria of Autistic disorder, the

symptoms are typically fewer and milder. For example, only social and communication impairments may be evident with little to no signs of deficits in intellectual skills. This diagnosis is used if there is a late age onset of symptoms, and severe impairments in reciprocal social interaction or communication skills, or displays of stereotyped behavior are noted.

- *Rett's disorder (Rett syndrome)*

This disorder is unique in that only girls with ASD can be diagnosed with this specific developmental disability. Individuals with Rett's disorder demonstrate losses in hand (i.e., fine motor) skills and have significant impairments in social interactions and communication skills (i.e., expressive and receptive language).

- *Childhood disintegrative disorder (CDD)*

Individuals with this disorder exhibit regression following two years of typical development. Impairments similar to those of Autistic disorder are evident in individuals with CDD including deficits in social, communication, and play skills. Importantly, individuals with CDD have different symptomatology from the other forms of ASD including psychosis.

**Parental experiences.** Mothers' involvement with their children with ASD, including their daily positive and challenging moments at home and in public.

**Parenting practices.** Strategies that mothers use during their daily interactions with their children, with the goal of socializing their youngsters to function successfully in their communities.

**Parenting behaviors.** Actions performed by parents that shape their children's development.



**Parental perceptions.** Parents' belief about their parenting skills, their children, and children's behavior in shaping their parenting during their interactions.

**Positive parenting.** Defined as behaviors exhibited by parents aimed at promoting optimal child development. Positive parenting behaviors include parental warmth, sensitivity, responsiveness, communication, and providing opportunities for cognitive stimulation. Additionally, provisions of sustenance, stimulation, support, structure, and surveillance is also associated with positive child outcomes.

**Negative parenting.** Defined as maladaptive behaviors exhibited by parents that are associated with adverse child outcomes. Negative parenting behaviors include over-sensitivity, lack of empathy, abnormalities in communication skills, detachment, and intrusiveness.

**Routines.** "Observable, repetitive behaviors which directly involve the child and at least one adult acting in an interactive or supervisory role, and which occur with predictable regularity in the daily or weekly life of the child" (Sytsma, Kelley, & Wymer, 2001, p. 243).

In the current study, the participating families have children with cognitive, communication, behavioral, and/or social deficits as diagnosed using the DSM-IV. Individuals with a well-established diagnosis of Autistic disorder, Asperger's disorder, Childhood Disintegrative disorder, and Pervasive Developmental Disorder, will still fall under the newly combined single condition of ASD Spectrum Disorder.

### **Conclusion**

Families of children with ASD have unique experiences. Despite a robust literature on the psychological functioning of parents with children with ASD, little is known about the perceptions, experiences, and parenting behaviors of mothers of children with ASD. Moreover, the atypical behaviors exhibited by children with ASD have been shown to have negative effects

on parents' psychological well-being, which could potentially affect parenting practices and behaviors. Examining maternal parenting experiences, practices, and behaviors is an important next step in the research on families of children with ASD. Because mothers of children with ASD report more stress than fathers (Dabrowska & Pisula, 2010; Tehee, Honan, & Hevey, 2009) and mothers are more likely to be caregivers of young children (Barnard & Solchany, 2002), it is important to consider the parenting experiences of mothers raising children with ASD. Further, given that children typically are diagnosed with ASD in the early childhood period, examining maternal parenting during this developmental phase is critical. The current study is designed to fill the gap in the literature on parenting of children in the preschool period who have ASD.

## CHAPTER II

### Literature Review

Autism spectrum disorder (ASD), a group of developmental disabilities characterized by cognitive, communication, and social impairments (American Psychiatric Association, 2013), has recently received widespread public health, media and empirical attention. Current estimates are that 1 million children in the United States alone are diagnosed with ASD, reflecting an average of approximately 1 in every 68 children (Centers for Disease Control and Prevention, 2015). These increasing numbers of children with ASD have created additional economic strain on the US health and educational system, specifically obtaining the necessary funding for therapy and health benefits during childhood and into adulthood. Further, the increase in the numbers of children with ASD over the years translates into larger numbers of families who have to adapt to the psychological and economic challenges of parenting a child with this disorder.

The family context as a socializing force plays a critical role in aiding or impeding the development of all children. Specific to children with ASD, the high levels of stress associated with raising these children (Baker, Blacher, Crnic, & Edelbrock, 2002) may affect parenting quality, including the nature of the parent-child relationship, which in turn may influence these children's development. Although there is a large literature on parenting children with disabilities (Bauminger, Shulman, & Agam, 2003; Rieffe, Terwogt, & Stockman, 2000), little is known about the experiences, practices, and behaviors of parents of children with ASD. DePape & Lindsay (2014) reviewed the literature on parental experiences associated with caring for a child with ASD. Findings from a metasynthesis of 31 articles with qualitative evidence shed light on (1) caregivers' emphasis on positivity within the parent-child relationship, (2) families' ability to adjust to having a child with ASD, (3) challenges associated with navigating the system, (4) parents' coping strategies, and (5) factors that provide families with a sense of

empowerment. These findings are consistent with data presented in this dissertation as it relates to mothers' realities raising children on the autism spectrum.

The goal of this literature review is to explore the perceptions, experiences, practices, and behaviors of parents of children with ASD, with a particular focus on parent-child interaction. I begin by proposing Bradley's conceptualization of parenting as a framework for understanding the link between parenting behaviors and child development among families in which there is a child with an ASD. Then, I provide a profile of children with ASD, and describe the impairments that these children exhibit. Although a major goal of this paper is to consider maternal parenting processes relevant to children with ASD, the paucity of empirical literature in this arena requires a broader examination of these processes in families of children with disabilities more generally. Thus, much of the literature on parenting processes in children with ASD will be presented in the context of the evidence on children with disabilities. Next, I will provide a methodological critique of the current literature on parenting behavior and factors associated with children with ASD, and recommendations for research. Finally, I will explore the implications of this literature for policy and practice.

### **Theoretical Framework**

Families of children with disabilities often experience higher levels of stress than families of typically developing children (Baker, Blacher, Crnic, & Edelbrock, 2002; Koegel, Schreibman, Loos, & Dirlich-Wilhelm, 1992). In particular, raising a child with ASD has been associated with parental psychological distress (see Glasberg, Martins, & Harris, 2006; Hastings, 2008 for recent reviews), which may negatively affect parenting, including the mother-child relationship and interactions. Although stressors can be detrimental to establishing and maintaining healthy familial relationships, some families are able to cope well with the stress of

raising a child with a disability (Benson, 2006; Benson & Karlof, 2009). Thus, it is important to consider the positive and negative aspects of raising children with disabilities and the factors involved in adapting to the challenges associated with raising such children. One theoretical framework that allows for these considerations is Bradley's (2002) parenting conceptualization.

In his review of the parenting literature, Bradley (2002) writes, "Both parent and child are active constructors of their environments as well as responders to what the environment affords...The actual process of parenting involves numerous moment-to-moment exchanges with the child and the environment" (Bradley, 2002, p.282). Further, Bradley describes the tasks that are critical for parents to perform in order to support children's development. He asserts that parents are regulators of their children's environments and that caregivers perform five tasks to enable their children to become competently functioning adults in society. These five tasks are (1) sustenance, (2) stimulation, (3) support, (4) structure, and (5) surveillance.

Sustenance involves parents' provision of nutrients and shelter to their children to maintain health and ensure survival. Stimulation entails providing an environment rich in sensory and meaningful information to keep the child engaged. Support is defined as parental response to the expressed and unexpressed needs of the child in order to lead to optimal social-emotional development (e.g., providing warmth and sensitivity). Structure not only ensures that sufficient amounts of the above inputs are provided to a child, but that the configuration of how much input each child receives in their environment fits the needs of that specific child. Finally, surveillance involves being aware of children's whereabouts and the activities that they engage in, with the goal of keeping the children safe from harm. Children need caregivers to perform all five tasks in order to achieve optimal growth and development.

In sum, Bradley's conceptualization of parenting can serve as a framework to explore parenting processes in families of children with ASD, specifically parenting behaviors and mother-child interaction. The current study capitalizes on this framework to explore the parenting exhibited by families of children with ASD and the factors that contribute to maternal parenting processes in this unique population.

### **The Development and Functioning of Children with ASD**

As Bradley (2002) emphasizes, an examination of parenting processes in families with children with ASD requires a consideration of both child and parent factors. With respect to the characteristics of affected children, ASD influences children's neurological capacities can cause specific impediments in social relationships and communicative skills. According to the DSM-IV, children with ASD exhibit hallmark signs that are classified as: (1) restrictive and repetitive stereotyped behaviors, for example negatively overreacting to slight change; (2) qualitative impairment in communication, for example deficits in language development or in constructive play; **AND** (3) qualitative impairment in social interactions, for example inattentiveness and lack of interest in others (American Psychiatric Association, 2002). As previously mentioned, the more recent DSM-V now considers severity levels of individuals' social and communication problems **OR** their tendency to display restricted and repetitive behavior when classifying individuals with ASD (American Psychiatric Association, 2015).

By definition, ASD is on a continuum of severity that spans from mild to severe, thus it is referred to as a spectrum disorder. As such, some individuals fall on the high end of the continuum and are categorized as high-functioning. Other individuals are perceived to be low-functioning and possess more severe impairments in social interactions, communication, or repetitive behavior (American Psychiatric Association, 2015). Despite the level of functioning,

ASD greatly affects children's brain, cognitive, language, and social-emotional development. It is important to note that the research presented in this literature review comes from different time periods. Therefore, the language used to describe the functioning levels of the children with ASD varies and has since evolved. For example, as of 2015, researchers are more aware of and highlight the variability within and between children with ASD than with other disorders. Throughout this chapter, I will use the language of study authors (e.g., high-functioning children with autism) to describe their findings on children with ASD and their families, though these terms may be inconsistent with current nomenclature.

### **Brain Development**

Several scholars have attempted to localize or uncover specific abnormalities that may play a role in causing ASD, however, the variations in the types of impairment make determining the brain etiology and localization of ASD difficult (see Grossberg & Seidman, 2006; Goldberg et al., 2005). Researchers have made some progress in identifying age-related differences in head circumference between children with ASD and those without (Aylward et al 2002; Courchesne et al 2001; 2003; Sparks et al 2002). In a meta-analysis, Redcay and Courchesne (2005) reported that during the first years of life, the brains of children with ASD grow at a much more rapid rate than those of typically developing children. The brain growth rate plateaus soon afterwards, such that during the later stages of childhood and adulthood, the brains of children with ASD are of more comparable size to those of their typically developing counterparts.

In addition to examining the head circumference of children with ASD, some researchers have examined specific structures in the brain. For example, the amygdala, which involves emotions, and the hippocampus, which is associated with memory, have both been identified as being of abnormal size in individuals with ASD, however, these findings are inconsistent

(Aylward, Minshew, Goldstein, Honeycutt, Augustine, Yates, et al. 1999; Nacewicz, Dalton, Johnstone, Long, McAuliff, Oakes, et al., 2006; Palmen, Durston, Nederveen, & van Engeland, 2006).

Neuroscientists have also documented distinctions between children with ASD and those who are typically developing in regard to brain activity (Just, Cherkassky, Keller, & Minshew, 2004), problem solving skills (Just, Cherkassky, Keller, Kana, & Minshew (2007), inhibition (Kana, Keller, Minshew, & Just (2007), and facial processing (Koshino, Kana, Keller, Cherkassky, Minshew, & Just (2008). The brain processes specific to children with ASD give rise to their many cognitive, language, and socioemotional impairments.

### **Cognition**

Depending on the severity of their diagnosis, children with ASD show great variability in their intellectual skills, which may range from well above average to well below average (Volkmar, Paul, Klin, & Cohen, 2005). For example, high-functioning children with ASD (HFCA) typically have IQs that are above 70 (Volkmar et al., 2005). Examining the cognitive functioning of children with ASD is important in that their level of cognitive ability may affect their functioning in other areas. For example, children with ASD who have less impaired intellectual ability may behave differently in their social relationships (e.g., with their parents) than children with greater impairment.

Further, researchers have documented impairments in executive functioning, specifically working memory, flexibility, inhibition, and planning, in children with a wide variety of developmental, psychiatric, and neurological disorders, including ASD (Goldberg et al, 1995; 2005 Ozonoff & Jensen, 1999). Working memory, which reflects the individual's ability to store



and manipulate information, is critical for children's cognitive problem-solving as well as their interpersonal relationships (Gutstein & Whitney, 2002).

One area of cognition which may shed light on the impaired social development of children with ASD is the development of theory of mind (Bauminger, Shulman, & Agam, 2003; Grossman, Carter, Volkmar, Grossman, 1997; Kanner, 1943). Theory of Mind (ToM) focuses on a child's "ability to attribute mental states, for example beliefs, desires, intentions, and emotions, to other persons and to predict behavior accordingly" (Bauminger, 2002, p.285). Research has documented deficits in the development of ToM in children with ASD (Baron-Cohen, Leslie, & Frith, 1985; Lind & Bowler, 2010). Thus, the particular cognitive deficits displayed by children with ASD may influence the nature of their relationships with others, particularly their parents.

### **Language**

Although not every individual with an ASD has deficits in their communication skills (Downs & Smith, 2004), communication impairments represent one of the hallmarks of ASD (American Psychiatric Association, 2013). The language development of children with ASD has been found to be delayed in multiple studies (Charman et al., 2003b; Hundry et al., 2010; Luyster et al., 2007, 2008). For children to be successful in their social interactions, conversational skills such as initiation and responsiveness to social bids are imperative (Adamson et al. 2001; Jones & Schwartz, 2009). Some findings suggest that children with ASD are indeed interacting with their family members albeit in a limited fashion (Jones & Schwartz, 2009). Other research has indicated that HFCA are able to communicate, comprehend, and express their desires better than low functioning children with ASD (Downs & Smith, 2004).

Scholars have examined the interactions between preschool children with ASD, as well as their typically developing children, with their communicative partners and have found that children with ASD are more likely to exhibit social communication challenges (Adamson et al. 2001; Doussard-Roosevelt et al. 2003; Marans, Rubin, & Laurent, 2005; Rubin & Lennon, 2004). Social communication deficits, including impairments in joint attention (JA), are one of the primary characteristics associated with ASD (APA, 2013) and may persist throughout the lifespan (Landa, Holman, Garrett-Mayer, 2007). JA is defined as the ability to attend to a stimulus being referenced by a conversation partner, a skill which is critical to children's language and social development. Many studies have shown that JA is related to (Charman et al., 2003; Dawson et al., 2004; Loveland & Landry, 1986; Mundy, Sigman, Ungerer, & Sherman, 1986) and predictive of (Charman et al., 2005; Mundy, Sigman, & Kasari, 1990; Sigman & Ruskin, 1999) children's language development. Overall, the language impairments observed in these children influence how they interact with others, including their parents.

### **Social Emotional Development**

There are many developmental processes associated with establishing quality interpersonal relationships which have been investigated in the ASD population. Historically, there was a perception that attempting to socially engage individuals with ASD was futile (e.g., Kanner, 1943). In recent years, however, researchers have noted variability in the engagement levels of individuals diagnosed with an ASD (Burack & Volkmar, 1992; Goldberg et al, 2005; Koegel, Werner, Vismara, & Koegel, 2005). For example, Rieffe, Terwogt and Stockman (2000) noted that, at least for HFCA, curiosity for others was trivial unless there was a need to obtain something from them. In the same vein, the evidence indicates that children with ASD have an impaired ability to perspective take, which is a necessary skill for interacting with others

(Baron-Cohen, Leslie, & Frith, 1985; Shabani et al., 2002). The inability to consider the perspectives of others can prevent individuals with ASD from developing closeness and intimacy in their relationships (Hobson, 2005), thus affecting the longevity of these social relationships.

Emotion recognition and expressiveness have been found to be associated with the social skills of typically developing children (Denham et al. 2002; Hubbard & Coie, 1994; Lemerise & Arsenio, 2000) as well as children with developmental delays (Wood & Kroese, 2007). There is evidence of impaired emotion recognition and expression skills in children with ASD (Tracy, Robins, Schriber, & Solomon, 2011). Finally, children with ASD have difficulty with emotional processes that are embedded within their relationships with others (Hobson, 2005).

Nevertheless, some research underscores the heterogeneity in children with ASD. For example, Downs and Smith (2004) found that HFCA had similar levels of emotion understanding as their typically developing counterparts and performed better on emotion recognition tasks than children with attention deficit hyperactivity disorder (ADHD). Additionally, these researchers documented that HFCA are better able to regulate their emotions than low functioning children with ASD (Downs & Smith, 2004). These skills can potentially decrease the risks of acquiring maladaptive behaviors, such as internalizing and/or externalizing problems (Rubin et al., 1991). It is important to consider that children with ASD who are low-functioning, who do not have this same level of skill with respect to emotion understanding and regulation, may present particular challenges for caregivers.

Further, children with ASD have difficulty developing and maintaining relationships. The literature on the social skills of children with ASD shows that these children have deficits that interfere with the quality of their relationships (Koegel et al. 2001; McConnell, 2002; Mathieson & Banerjee, 2010). Hartley, Sikora, & McCoy (2008) found that mothers of 1-5 year old

children with ASD tended to report that their children displayed high levels of maladaptive behavior. In a longitudinal study including children between the ages of 3 and 17 years old, Church, Alisanki, & Amanullah (2000) found that children with Asperger's disorder, who had no history of early cognitive and language delay but who did display social interaction deficits, performed well academically but had challenges with their social skills as rated by their parents.

Although they focused on HFCA, Bauminger and Kasari (2000) found that children with ASD reported feeling lonely and having a desire for involvement in relationships with others. Moreover, they rated their friendships as being lower in quality than typically developing children. As has been documented with typically developing children, these deficits in social skills may put children with ASD at risk for maladjustment in adolescence and adulthood (Asher & Paquette, 2003), as well as for internalizing and/or externalizing problems across the lifespan (Rubin et al, 1991; Smith & Hart, 2002).

It is important to note that some researchers have documented qualitative and quantitative differences in the friendships of high-functioning and low functioning children with ASD, illuminating the fact that some children with ASD are indeed able to establish social relationships (Bauminger & Kasari, 2000; Bauminger & Shulman, 2003; Green et al. 2000; Koning & Magill-Evans, 2001). However, low-functioning children tend to be at high risk for social relationship challenges. Overall, there is a preponderance of evidence suggesting that children with ASD, regardless of their functioning level, have considerable challenges in their social skills and interactions with others, which have implications for the parenting that they may experience.

## **Parenting Children with ASD**

Bradley's conceptualization of parenting emphasizes the critical role of parenting processes in all families, and thus can be applied to families with children with ASD. As aforementioned, the literature on parenting young children suggests that there are multiple foci of parental behavior (Bradley, 2002), including sustenance, stimulation, support, structure, and surveillance. There is some evidence of a unique parenting context in families in which there are children with disabilities. For example, parents of children who have developmental delays and exhibit emotional and behavioral problems may interact with their children differently than do parents with typically developing children (Hartley, Sikora, & McCoy, 2008).

DePape's and Lindsay's (2014) review of 31 articles related to the experiences of parents raising children with ASD, highlights the need for increased research that specifically addresses parenting processes in families in which there is a child with ASD. Thus, this section will somewhat rely on the literature on parenting processes found in families in which there is a child with a disability. I begin with an examination of the psychological functioning of parents, including their mental health and their perceptions about parenting their children with ASD. I then turn to the impact of child behaviors on parenting in families in which there is a child with ASD. Last, I will summarize the limited literature on parenting behaviors and practices exhibited with children with ASD, with a focus on how these factors are linked to these children's developmental outcomes.

### **Parental Psychological Functioning**

In the parenting literature, it has been contended that parents' psychological resources serve as the strongest buffer against any threats to the parent-child relationship (Belsky, 1984). Therefore, the psychological well-being of parents raising children with a disorder must be

considered when examining parent experiences in their interactions with their children. Caring for children with disabilities requires a significant amount of time, energy, financial resources, and patience. As a result of these care-giving demands, parents of children with a developmental disability are at increased risk for elevated levels of psychological difficulty (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005).

**Parental Stress.** Using a variety of measures to assess parental stress, several studies have shown that parents of young children with developmental delays report higher child-related stress than parents of typically developing children (Baker, Blacher, Crnic, & Edelbrock, 2002; Koegel, Schreibman, Loos, & Dirlich-Wilhelm, 1992; Wolfson & Grant, 2006). Similarly, the demands associated with raising a child with an ASD have been linked with parents' psychological distress (see Glasberg, Martins, & Harris, 2006; Hastings, 2008 for recent reviews). Findings of elevated stress felt by parents of children with ASD as compared to parents of children with other disabilities have been reported for decades (Bouma & Schweitzer, 1990; Dumas, Wolf, Fishman, & Culligan, 1991, Kasari & Sigman, 1997; Koegel et al., 1992; Sanders & Morgan, 1997; Wolf, Noh, Fishman, & Speechley, 1989). For example, Dabrowska and Pisula (2010) examined parental stress in 162 mothers and fathers of preschool children who were diagnosed with ASD ( $n = 51$ ), who had Down syndrome ( $n = 54$ ), and who were typically developing ( $n = 57$ ). Results from self-report measures show that parents of children with ASD reported higher levels of stress than parents of children with Down's syndrome and typically developing children. Many parents report elevated feelings of stress when the child was young, as they were contending with the initial shock of the diagnosis and were attempting to understand the atypical behaviors associated with the disorder (Gray, 2002).

In a 10 year longitudinal study, Gray (2002) examined the experiences of families coping with the difficulties of raising a child with ASD. In the original qualitative study, 35 parents (25 mothers and 10 fathers) living in England were drawn from a larger quantitative study (n = 172). These parents were asked to participate in a parent interview. The 24 children (age 4-19) participating in the study had been diagnosed with mild to severe ASD. Approximately, 8-10 years later, Gray (2002) conducted a follow-up qualitative study in which 28 of the parents agreed to participate (19 mothers and 9 fathers) in a 1-4 hour interview. These families included 20 (13 male and 7 female) adult children with ages ranging from 13-27 years old.

The results of the study showed that both mothers and fathers reported high levels of emotional distress including signs of depression and anxiety. Although both parents appear to be affected by the difficulties of raising a child with ASD, mothers were much more likely to suffer from emotional distress than fathers. Several reasons for greater bouts of emotional distress from mothers were revealed in the interviews, including more responsibility and involvement in child raising, inability to be employed given the increased time required to care for a child with ASD, and the negative social reactions from outsiders. Notably, the level of emotional distress was less in the follow up study as compared to the original qualitative study. According to many parents, as the children matured, improvements in their behavior were observed. Importantly, the parents who were most depressed had children who exhibited more severe behavior challenges, such as aggression.

In another study including mothers and fathers, Herring et al. (2006) documented that fathers (n = 106) of 123 children aged 21-51 months with pervasive developmental disorders (PDD; n = 84) and developmental delays (DD; n = 39) reported less stress than mothers (n = 112) of children with PDD and DD. Additionally, fathers of children with PDD (n = 72)

reported being more stressed than fathers of children in the DD group (n = 34). Taken together, the findings of these studies highlight the importance of examining particularly mothers' experiences of raising young children with ASD, as well as the experiences of parents who have children with lower levels of functioning.

**Parental Depression.** Parental stress has been found to be a risk factor for a variety of disorders including depression (Gray, 2003; Vitaliano, Zhang, & Scanlan, 2003). As expected, the literature does suggest that the stress of caring for a child with a disability places parents at higher risk of depression. Higher scores on measures of depression have been found for parents with children with disabilities than for parents with typically developing children (Blancher & Lopez, 1997; Hoare et al. 1998; Veisson, 1999). In an early study, Veisson (1999) examined depression and emotional states of mothers (n = 151) and fathers (n=57) of children with disabilities, as well as mothers (n = 101) and fathers (n = 55) of typically developing children, living in Estonia. The mean age of children in both developmental groups was 7.1 with 66% boys and 34% girls. Additionally, all of the fathers from both the target and control groups were married as compared to only 60% of mothers from both groups. Parents were asked to respond to questions about their emotional well-being using the Beck Depression Inventory (BDI) and a questionnaire in which parents used a 7-point scale to estimate their negative and positive emotional states (Leskinen, 1994).

Results revealed that parents of children with disabilities were more depressed than parents in the control group. Notably, mothers of children with disabilities were more depressed than fathers of these children. When examining parents' emotion states, parents in the control group reported more feelings of happiness, satisfaction, and hopefulness than parents of children with disabilities. These findings support the need for a deeper understanding of the experiences



of raising children with disabilities, specifically ASD, as mothers of children with ASD have been found to be at higher risk of depression than mothers of children with other disabilities (Abbeduto et al., 2004). Additionally, conducting interviews and observations would shed greater light on the lived experiences of mothers of children with ASD, and how their perceptions of their psychological well-being might influence their parenting.

In another study, Olsson & Hwang (2001) examined the severity of depression in families living in urban and rural areas of Sweden who had children with intellectual disabilities without ASD (ID) (n = 151), children diagnosed with an ASD (n = 65) for a total of 216 families, and children who were typically developing (n = 214 families). Parents of children representing a broad age range (i.e., newborn to 16 years) responded to questions on the Beck Depression Inventory (BDI). Results revealed that mothers of children with ASD had higher depression scores on the Beck Depression Inventory (BDI) (a widely used self-report measure of depression) than mothers of children with ID and mothers *and* fathers of typically developing children. This finding of elevated depression reported by mothers of children with ASD as compared to fathers of children with ASD and other disabilities is consistent in the literature (Hastings & Brown, 2002) and underscores the importance of examining how having a child with ASD affects mothers' psychological well-being, which in turn impacts mother-child interactions and ultimately child outcomes.

Hastings et al., (2005) examined the differences in feelings of depression and perceptions of their children with ASD between mothers and fathers in the same family. Parents of 48 preschool children with ASD (41 mother-father pairs) reported on their mental health, child characteristics and stress. Researchers administered six self-report measures to parents to assess child behavior and parents' psychological functioning including the Developmental Behavior

Checklist (DBC), the Hospital Anxiety and Depression Scale (HADS), and the Questionnaire on Resources and Stress Friedrich short form (QRS-F).

It was revealed that mothers reported more depressed symptomatology than fathers. Mothers also reported more positive perceptions about their children with ASD and the impact the child has on the mother as well as other family members. Additionally, the depression of the partner predicted their spouses' level of stress. Finally, child characteristics (i.e. behavior problems) also predicted maternal stress. Taken together, these findings suggest that mothers' psychological functioning (i.e., depression and stress) appears to be predicted by child characteristics and spousal functioning. Little is known about how these factors impact mother-child interactions; thus conducting an in-depth examination through the use of mother interviews and observations would shed much needed light on this phenomenon.

**Parental Perceptions of Coping and Competence.** Although there are a few studies that show positive perceptions of parents about their children with ASD (Hastings et. al., 2005), multiple studies have consistently pointed to difficulties in coping and adjustment of parents of children with ASD. Lee (2009) examined differences in coping strategies and emotional adjustment of 48 parents with children with high functioning autism and parents of typically developing children. Findings show that parents of children with ASD reported experiencing more stress, feeling less optimistic, and having lower self esteem than parents of their typically developing counterparts. Additionally, parents of children with ASD reported using more social support from relatives and spiritual guidance as a way of coping with the stress of rearing a child with ASD than parents of children without disabilities.

Dardas and Ahmad (2014) examined the coping strategies of 184 Arab mothers (n= 114) and fathers (n = 70) of children with ASD and the links to quality of life. Findings from

questionnaires revealed that parents who used more planful problem solving skills, that is, addressing the stress inducing problem head on and generating solutions, were more satisfied with their quality of life than parents who avoided the stressful situation by remaining disengaged. These findings are important in that avoidance coping can negatively affect parents' quality of life and their mental health which in turn can influence parental behavior in their interactions with their children.

Research suggests that parents develop ideas, attitudes, and beliefs about their parenting based on their interactions with their children (Rubin, Coplan, & Robert, 2004). Given that children with ASD behave in ways that are atypical, their parents' beliefs about their competencies may be lower as compared to parents of typically developing children. Indeed, mothers of children with ASD report lower parenting competency than mothers of children without disabilities. For example, Sanders & Morgan (1997) examined parental stress and coping in families of children with ASD (n = 18), Down syndrome (n = 18), and typically developing children (n = 18). Parents responded to questionnaires related to parental stress and adjustment. Results revealed that parents of children with ASD reported lower perceived parental competencies and more difficulties adjusting than parents of children with Down syndrome, who in turn reported more perceptions of incompetence and maladjustment than parents of typically developing children. Nevertheless, parents of children with ASD were found to be more resilient to the challenges associated with having a child with a disability in the family than parents of children with Down syndrome. These findings suggest that parents of children with ASD may possess a unique coping strategy that aids in their ability to adapt to having a child with an ASD in the family. This unique coping strategy may strengthen the quality of the parent-child relationship and interactions. Examining the perspectives and beliefs

of parents and how these constructs impact their parenting can help researchers garner a deeper understanding of parental experiences when raising a child with ASD.

In a seminal study, Kasari and Sigman (1997) examined parent perceptions and interaction patterns of parents with children with ASD ( $n = 28$ ), Down syndrome or other developmental delays ( $n = 26$ ), and typically developing children ( $n = 28$ ). Parents were asked to fill out questionnaires pertaining to child behavior and parental stress including the Parenting Stress Index (PSI). Researchers also examined parent-child interactions in the lab during two separate play sessions that lasted three minutes each on various days. Results revealed that those parents of children with ASD and other developmental delays, with the exclusion of Down syndrome, reported greater levels of stress and less competency than parents of typically developing children. Additionally, in the ASD sample, parents who reported their children as more difficult temperamentally spent less time engaged with their children during the play sessions and their children were less responsive to the experimenters. These findings highlight the influence of child characteristics on parental stress, perceived competency, and parent-child interactions.

Despite these negative perceptions some parents report that they adjust effectively and appear to have a smooth transition relative to the demands of raising a child with a disability. Some of the positive outcomes of raising a child with a disability may include increased patience (Hastings & Taunt, 2002; Pakenham, Sofronoff, & Samios, 2004), strengthening of relationships with family and others (Scorgie & Sobsey, 2000; Kausar et al. 2003), and more coping strategies to mitigate the negative outcomes of stress (Benson, 2009).

Ekas (2005) examined coping strategies and marital satisfaction of parents of children with ASD (mean age of 78 months). Sixty-seven cohabitating couples completed mailed

questionnaires pertaining to their coping strategies, the benefits of having a child with ASD to their lives, optimism, and relationship satisfaction. Results revealed that parents' feelings about their children's positive contribution to their lives predicted their level of relationship satisfaction. This finding highlights the importance of focusing on positive factors when faced with challenging circumstances (e.g., having a child with ASD), as positivity can be advantageous in not just the parent-child relationship, but the larger family context as well (e.g., spousal relationships).

Hastings and Taunt (2002) reviewed the literature on the positive perceptions and experiences of families with children with developmental disabilities. In their review, they summarized five descriptive research studies, of which two employed a qualitative methodology. In these two studies, individual and group interviews were conducted in which parents were asked to describe the positive impact that having a child with a disability has on the family and individual family members. Results from this review show that family members do indeed have some positive perceptions and experiences related to the child with a disability. Themes such as happiness, sense of purpose, strengthening family/marriage, increased spirituality, and clarity on what is important in life were some of the themes discussed in these studies.

In another study, Pakenham, Sofronoff, and Samios (2004) examined the role that "benefit finding", defined as positively evaluating one's circumstances, and "sense making", defined as developing explanations for adversity, have on parents' ability to adapt to having a child with Asperger syndrome (AS). Fifty nine parents (mothers  $n = 47$ , fathers  $n = 12$ ) of 10-12 year-old children with AS living in Australia completed questionnaires which included an open-ended question asking parents to describe the benefits and how they have made sense of having a child with AS. Results revealed that 44 parents indicated a benefit to their personalities which

included increased tolerance, patience, self-control, compassion, empathy, and open-mindedness. Regarding sense making, 41 parents reported making sense of their situation (i.e., having a child with AS) by reading more about the disorder, attending workshops, participating in support groups and seeking information from professionals.

In sum, the findings relative to parental perceptions of parenting children with disabilities, and the few on ASD, support the need for more qualitative studies that examine the impact that having a child with ASD has on parental experiences. The above findings are consistent with DePape and Lindsay (2014)'s review of the literature on parents' experiences raising children with ASD. Specifically, parents emphasized the need to have positive thoughts about their children and their experiences. In the general parenting literature, it has been suggested that parental beliefs and perceptions (e.g., self-efficacy) may influence parental practices, which in turn influences children's developmental outcomes (Hastings et al., 2007). However, the literature is virtually non-existent on the relation between parental beliefs and parenting practices with respect to children with ASD. Conducting interviews and observations with this population will help researchers garner a better understanding of the parenting processes and behaviors that accompany having children with ASD.

### **Child Behaviors and Parenting**

Examining the role of everyday child behavior in relation to parent responses is critical when attempting to garner a better understanding of parental experiences. One major factor that may contribute to the difference in coping with the stress of raising a child with an ASD is the functioning of the child. As previously mentioned, the severity of the disorder has been found to be linked with parental stress. Parents of children with more severe symptoms of ASD have reported higher levels of stress in studies of 35 parents (mothers  $n = 25$ , fathers  $n = 10$ ) of 4-19

year-old children with ASD living in New England (Gray, 2002), 141 parents of preschool aged children with ASD (mothers n = 130, fathers n = 11) living in the United Kingdom (Hastings & Johnson, 2001) and mothers and fathers of 123 children aged 20-51 months with or without ASD living in Australia (Herring et al., 2006).

Further, elevated stress and depression may be associated with the frequency and variability of maladaptive behavior exhibited by children with ASD. Griffith, Hastings, Petalas, & Lloyd (2014) examined the expressed emotions of 143 mothers of children with ASD and their non-disabled siblings. Results from questionnaires revealed that mothers expressed more criticism and less warmth when speaking of their children with ASD versus their non-disabled children. These findings are important because, research has shown that children with ASD are more likely to express behavior problems than their typically developing siblings (Beck et al., 2004) and these behavior problems have been linked to elevated levels of stress in mothers (Hastings, 2002; Baker et al. 2003; Blancher & McIntyre, 2006). Therefore, the behavior problems exhibited by children with ASD may shape how mothers perceive and interact with their children.

Tomanik, Harris, & Hawkins (2004) examined the relation between child behavior and maternal stress. Sixty mothers completed a battery of self report measures related to their 2-7 year-old children with ASD. Results revealed that child aberrant behavior significantly predicted maternal stress as determined by the Parental Stress Index. Mothers reported the greatest stress when their children were withdrawn, lacked self-help skills, were hyperactive, and were unable to communicate and interact with others. These findings underscore the need to garner a better understanding of mothers' experiences raising children who demonstrate low levels of functioning.

Child behavior problems appear to be one of the primary contributors to parent psychological functioning (e.g., parental stress) (Baker et al., 2003; Hastings et al., 2005; Richdale et al., 2000). For example, Baker et al. (2003) found that mothers' and fathers' ratings of stress regarding parenting of 205 preschoolers with ( $n = 82$ ) and without ( $n = 123$ ) developmental delays were related to the degree to which the child displayed behavioral problems as assessed by the Child Behavior Checklist (CBCL). Similarly, using the Questionnaire on Recourses and Stress (QRS; Holroyd, 1987) along with the CBCL, Floyd and Gallagher (1997) reported that parental stress was found to be associated with mothers' reports of behavioral problems exhibited by their intellectually delayed middle school aged children ( $n = 231$ ). More recently, Lacavalier, Leone, and Wiltz (2006) examined the correlates of caregiver stress and child behavior problems. Parents and teachers of 293 preschool aged children through adolescents with ASD responded to questions on the Nisonger Child Behavior Rating Form (NCBRF) (a rating scale used to assess the social competence and behavior problems of children and adolescents with developmental disabilities) (Aman et al., 1996; Tass et al., 1996). The Parental Stress Index (PSI) was also used to assess caregiver perceived level of stress. Researchers found that specific child behaviors, such as externalizing problems, were more predictive of parental psychopathology than adaptive behavior over time in their study. Further, in a longitudinal study, Herring et al. (2006) used questionnaires to assess the differential impact of 123 1-4 year olds' emotional and behavioral problems on parental distress. The children in the study were diagnosed with pervasive developmental disorder (PDD; i.e., a form of ASD;  $n = 84$ ) or were in a developmentally delayed group (DD;  $n = 39$ ) without ASD. Data were collected at three time points, revealing that those in the PDD group had more emotional and behavioral problems than



those in the DD group. Moreover, these problems persisted over time and were positively correlated with parent and family distress.

Taken together, the limited evidence suggests a bidirectional link between the behavior of children with ASD and parental functioning. Examining the bidirectional relationship between child and parent factors can help broaden the knowledge base about parents' early experiences with their children with ASD, and how their parenting is affected by their children's behavior. These findings also argue for exploration of how parents respond to children with lower levels of functioning, such as children with ASD who present severe social and emotional challenges.

### **Parenting Practices and Behaviors**

Bradley (2002) discusses parent actions aimed at fostering more positive developmental outcomes for their children. He contends that parents are regulators of their children's development and perform the following five tasks to help their offspring adapt to their environment: (1) sustenance, (2) stimulation, (3) support, (4) structure, and (5) surveillance.

The act of providing *sustenance* includes providing adequate nutrients and shelter to their children. Additionally, protecting them from teratogens and exposure to harmful substances is critical in promoting the health of their children. Parents must also provide adequate exposure to *stimulating* objects and events within the environment as these environments can promote competency ultimately leading to achievement of parents' life goals for their children. Moreover, it is clear in the parenting literature that *support* provided by parents to their children is beneficial to children's socio-emotional development. According to the parenting literature, optimal child development requires timely responses to children's needs (Bowlby, 1969). Acts such as providing positive affirmation of personal worth, guidance, and direction are included underneath

the 'support' umbrella and are beneficial to children's development. The parental act of providing *structure* includes providing activities aimed at enhancing child development. Additionally, Bradley (2002) describes the configuring or structuring of the amount of sustenance, stimulation, and support that a child receives and the benefits associated with these parenting tasks. Finally, in order to protect their children from harm, parents must keep track of the environmental conditions that their children are exposed to; therefore surveillance, along with the other four parenting tasks are crucial in promoting positive adaptation in children.

Although not specifically designed to address families with children with special needs, Bradley's framework is relevant to this population in that these families ultimate goal for their children with ASD are the same as families that have children without disabilities, that is prepare them for future adult participation in society. Unfortunately, there is very limited literature in the parenting arena on sustenance and surveillance. As such, the following section will address positive parenting (i.e., provisions for stimulation, support, and structure). There is emerging evidence about the unique parenting experiences of parents who have children with disabilities (Hodapp, 2002). However, some researchers have found no reported differences in the behaviors and practices of parents who have children with disabilities and those who do not (Rutgers et al., 2007). Further, some research has not documented differential effects of contextual, parental, and child characteristics on the parenting of children with disabilities versus those without disabilities (Verhoeven, Junger, Van Aken, Dekovic, & Van Aken, 2007). There is a dearth of research on parenting practices and behaviors displayed by mothers who care for children with ASD. Further, the relation between parental functioning, parenting behaviors, and child characteristics in children with ASD has not been well studied. In this section, I will review the limited evidence that describes ASD-specific parenting practices and behaviors.

Given the scant empirical evidence regarding specific parenting practices and behaviors with children with ASD, intervention studies will be used herein to help elucidate parenting processes in this population. Although the intention of a parent-child intervention study in behavioral science is to learn how to improve the quality of participant relationships and developmental outcomes, information pertaining to the participants' behavior at baseline and post intervention can help researchers better identify and understand the display of specific parenting behaviors and practices. Fortunately, there is an abundance of intervention studies related to children with ASD and the care-giving that they receive.

**Positive Parenting.** Researchers have discarded the notion that poor parenting, specifically rejecting mothers, is the cause of ASD (see Bettelheim, 1967). In more recent years, factors such as parental warmth, sensitivity, communication, and opportunities for cognitive stimulation have been examined as influential factors in shaping the cognitive and social skills of individuals with ASD (Kasari, & Sigman, 1997; Singh, Lancioni, Winton, Fisher, Wahler, McAleavery, & Singh, 2006; Skoto, Koppenhaver, & Erickson, 2004; Smith, Greenberg, Seltzer, & Hong, 2008). Bradley's discussion on providing support within parent-child interactions includes acts of warmth.

Parental warmth, as defined by displays of physical affection to the child, praise, telling the child that you love them, using terms of endearment and showing the child that you appreciate them, have all been associated with effective parenting of typically developing children and children with disorders (Alizaden, Applequist, & Coolidge, 2007; Chen et al., 2003; Eiden, Colder, Edwards, & Leonard, 2009; Geffen et al., 2008; Kim, 2008; Suchman, Rounsaville, DeCoste, & Luthar, 2007). In an early study, Cox, Rutter, Newman, and Bartak (1975) examined the parenting of 47 5-10 year-old children with ASD ( $n = 24$ ) and children with

dysphasia (a developmental language disorder) ( $n = 23$ ). Parents were interviewed regarding their expression of warmth, emotional responsiveness, and sociability. Parents were also asked to complete a questionnaire designed to assess their mental health. Results from the study revealed no significant difference between the two sets of parents in parental warmth, as assessed by an interview scale that measured tone of voice, quality of warm interactions, facial expressions, and gestures.

In a cross-lagged longitudinal study which included 406 families, Smith, Greenberg, Selzer, & Hong (2008) examined factors such as maternal warmth and praise and their links to subsequent behaviors of 11-48 year-old individuals with an ASD. Through the use of interviews, researchers found that positive maternal verbal expressions about the individual with ASD yielded fewer problem behaviors from these adolescents and adults with ASD. The results of this study highlight the important link between positive parenting and the resulting behavior of adolescent and adult children with ASD.

In a more recent study, Conti (2015) found that the compassionate parenting of 129 mothers of children with ASD between the ages of 4-18 was linked to parental efficacy. Specifically, mothers who endorsed compassionate parenting goals, defined as adopting a view of the world from the child's perspective, validating the child's feelings and abilities, and responding to the child based on his individual needs, were more satisfied with themselves as parents. Although this study did not examine child outcomes, it is still important to highlight as other studies have found that parents' psychological functioning can impact their parental self-efficacy thus influencing their interactions with their children with ASD (Kuhn, & Carter, 2006; Meirsschaut et al, 2010).

Albeit limited, there have been studies that examine the links between parenting young children with ASD and child outcomes. For example, Lemanek, Stone, & Fishel (1993) examined parenting behavior and compliance in children with ASD and with language delays. Forty-seven parents were observed explaining a list of tasks for their preschool age children to complete within an eight-minute time span, such as building a tower of blocks and playing catch. Parent behaviors such as seeking proximity to gain the child's attention as well as type of verbal instruction used (positive or negative) were assessed along with child compliance behavior. Parents who used more instructions and praise when explaining the task to their children had children who were more compliant for all groups. This finding sheds light on the importance of parental behaviors such as proximity-seeking during their interactions with their children.

Parental sensitivity has also been found to be associated with children's developmental outcomes, which is consistent with Bradley's notion of support. For example, in their groundbreaking investigations on the links between parenting and attachment styles of nineteen 3-5 year-olds with ASD, Capps, Sigman, and Mundy (1994) found that during an observed free play session, mothers of securely attached children with ASD were more sensitive than mothers of insecurely attached children with ASD. Van Ijzendoorn et al. (2007) replicated the Capps et al. study with 55 preschool children with ASD, and documented that parents of children with and without ASD were equally sensitive.

In an exploratory study, Lambrechets et al. (2011) sought to obtain more knowledge on the parenting behavior of parents of children with ASD by having them complete two questionnaires online. Participants included 305 parents with a child with an ASD between the ages of 8 and 18 years old with an IQ score > 70 (n = 268 biological mothers, 32 biological fathers, 4 adoptive mothers, and 1 adoptive father) and 325 parents with typically developing

children between the ages of 8 and 18 years old ( $n = 263$  biological mothers, 51 biological fathers, 1 adoptive mother, 1 adoptive father). The Parental Behavior Scale-Short Form (PBS, Van Leeuwen, 2002) was used to garner data on positive parenting, discipline, harsh punishment, material rewarding, and rules. The second questionnaire was a newly developed scale for parenting behavior more specifically relevant to children with ASD. The items in this scale used literature on children with ASD to make the survey more relevant to parents of children with ASD. Parents responded on a 5-point Likert scale about how they communicate with their children, promote autonomy in their children, provide a stimulating environment for their children, support executive functioning in their children, and devise their reward system.

Results revealed that parents of children with ASD stimulate their children's environment more and employ less harsh punishing methods than parents of typically developing children. Notably, the mean scores and effect sizes were very small for these findings suggesting that the parenting behavior of parents of children with ASD that possess an IQ score of  $> 70$  is similar to the parenting behavior of parents with typically developing children. Examining the parenting behaviors of parents of children with more severe ASD and impaired patterns of behavior (e.g., IQs  $< 70$ ) can highlight the rewards and challenges that these parents encounter on a daily basis. Additionally, conducting observations can serve as a method of corroborating parents' reports of their behavior which can result in a richer view of parenting behavior.

In sum, the limited research suggests that positive parenting is manifested in families with children with ASD, and may not differ from what occurs in families of other children with disabilities. Moreover, the link between positive parenting and child outcomes (e.g., secure attachment, decreased problem behaviors, and increased child compliance) has also been reported from parents with children, adolescent, and adult children with ASD. The results of

these studies underscore the importance of exploring more about the practices and behaviors of parents of children with ASD with more severe impairments, particularly with respect to their interactions with their children.

**Attachment.** Several studies have been conducted on parenting and attachment of children with ASD, which document that children with ASD can be securely attached to their parents. For example, Willemsen-Swinkels, Bakermans-Kranenburg, Buitelarr, van Ijzendoorn, and Engeland (2000) examined the attachment of children with Pervasive Developmental Disorder (PDD) ( $n = 32$ ), children with Developmental Language Disorder (DLD) ( $n = 22$ ), and typically developing children (TD) ( $n = 28$ ). Children and their parents (majority mothers, 76 out of 83 cases) participated in a 40-minute semi-structured playroom session which included a separation and reunion scenario. Researchers videotaped and coded the separation/reunion episodes. Findings revealed that children with PDD were able to have secure attachment to their caregivers. Bradley (2002) describes the benefits of parents' provision of sensitivity, stimulation and structure during their interactions with their children, which may lead to secure attachment.

Capps, Sigman, and Mundy (1994) examined the attachment security of 19 children with ASD using Ainsworth's Strange Situation. The researchers were able to classify the attachment style of 15 out of the 19 participant. The results revealed that 40% of the children were securely attached. Children with secure attachment displayed more frequent initiation of social interactions with their mothers, more responsiveness to bids for joint attention, and greater receptive language skills than insecurely attached children. Moreover, mothers of securely attached children were found to be more sensitive to their children's needs than mothers of insecurely attached children. This finding highlights the important role that mothers' parenting plays in the development of their children with ASD.

Further, in their study of 55 preschool children with and without ASD, van IJzendoorn et al. (2007) used the Strange Situation procedure to assess attachment. In this study, the severity of the disorder predicted the level of attachment, with higher functioning children exhibiting more secure attachments to their caregivers than their lower functioning peers. This study underscores the importance of examining parenting processes with children with ASD who are lower functioning.

Some studies have found no difference in attachment behaviors between children with ASD and other developmental disorders (Buitelaar, 1995; Rutgers, Bakermans-Kranenburg, Van IJzendoorn, & Van Berckelaer-Onnes, 2004; Sigman & Ungerer, 1984; Willemsen-Swinkels, Bakermans-Kranenburg, Buitelaar, Van IJzendoorn, & Van Engeland, 2000). For example, Rutgers, Bakermans-Kranenburg, Van IJzendoorn, and Van Berckelaer-Onnes (2004) conducted a meta-analysis in which they reviewed 16 studies that examined the attachment of children with ASD. The results of the meta-analysis showed that many of the children with ASD showed signs of secure attachment despite having impairments in social interaction. Additionally, many of the children showed a clear preference for their mothers over a stranger, and showed an increase in proximity-seeking after being reunited with their mothers.

In contrast, some researchers have documented attachment difficulties for children with ASD. For example, Rutgers et al, (2007) used Ainsworth's Strange Situation to assess the quality of the parent-child attachment relationship. Parents of children with ASD disorder (AD) (n = 13), pervasive developmental disorder not otherwise specified (PDD-NOS) (n = 8), intellectual disability without ASD (n = 10), language delay (n = 9), and nonclinical comparison children (n = 15) living in the Netherlands participated in this study. Results revealed that



children with AD exhibit more abnormal attachment behavior than all other children, due in part to the impairment of reciprocity in their social interactions.

In sum, empirical research on the attachment of children with ASD has been inconsistent. Some studies document that children with ASD do indeed exhibit some level of secure attachment to their caregiver which includes displays of proximity-seeking to their mothers when reunited and preference for mothers over a complete stranger. In contrast, other studies have found no difference in the attachment between children with ASD and other developmental delays. Further, a large literature exists on the attachment impairments of children with ASD. Researchers have found that children with ASD exhibit abnormal attachment behavior and that the severity of the disorder predicts the level of attachment.

All of the studies listed above examined the parent-child attachment relationship in a lab using the Strange Situation procedure. Observations conducted in naturalistic settings (e.g., the home) would allow for a more naturalistic assessment of the quality of the parent-child relationship. Additionally, conducting parent interviews can serve as a way for parents to explain in greater detail their perceptions about their relationships with children with ASD. Further, the studies reviewed above argue for a more refined examination of the parent-child relationship in situations in which the child has more severe impairments, as with low-functioning children with ASD.

**Negative Parenting.** Few researchers have examined maladaptive parenting of children with ASD. In the past, it was believed that the cause of ASD was attributed to the lack of warmth exhibited by mothers (Bettelheim, 1967; Kanner, 1943). As a result, many mothers harbored doubt about their parenting skills (Wing, 2004). This assumption was long ago abandoned by the scientific community and it is now known that ASD is a complex, multi-

factorial neurodevelopmental disorder believed to be caused by genetic and environmental factors (Centers for Disease Control and Prevention, 2013). Nevertheless, it is important to examine how this disorder plays a role in the parenting behavior exhibited by mothers of children with ASD, as researchers have consistently found that negative parenting behaviors are related to increases in the problem behaviors of children with disabilities (Dossetor, Nicol, & Stretch & Rajkhowa, 1994; Hastings, Daley, Burns, & Beck, 2006; Lam, Giles, & Lavander, 2003). For example, in their study on parenting behavior and children's externalizing problem behaviors, Schuiringa et al. (2015) found that mothers (n = 113) of children with intellectual disabilities (IQ ranging between 55 and 85) who employed more harsh parenting behavior (e.g., physical discipline and lack of warmth) had children who exhibited more externalizing problem behaviors. Moreover, these parents reported being less involved with and accepting of their children with intellectual disabilities and the quality of the parent-child relationship was found to be worse as compared to parents who displayed more positive parenting behavior.

Specific to children with ASD, impairments associated with ASD such as deficient communication skills and lack of reciprocal interactions may increase parental control, and decrease maternal warmth and overall parent-child interactions (Konstantareas, & Homatidis, 1992; Rutgers et.al, 2007). For example, Gau et al. (2010) examined parenting style and behavior problems among children with ASD aged 3-13 and their siblings in a Taiwanese population. A total of 151 families with one child with ASD, 134 siblings without ASD, and 113 control families with typically developing children participated in this study. Mothers and fathers completed questionnaires regarding their parenting style (assessed by the Chinese Parental Bonding Instrument, PBI) and their children's behavior (assessed by the Child Behavior Checklist, CBCL). Results revealed that children with ASD exhibited more severe behavior

problems than their siblings without ASD and typically developing children. Moreover, the parents of these children were less affectionate and more controlling than the parents of the other groups. This finding highlights the importance of contributing to the gap in the literature regarding how ASD impacts parenting processes.

In an early study in which the interviewers were blind to child diagnosis, Wolff, Narayan, & Moyes (1988) assessed the social communication skills of parents of 21 children aged 8-21 with ASD and children with other disabilities (e.g., epilepsy, Down's syndrome, and mild to moderate intellectual delay;  $n = 21$ ). Results from the interviews revealed that parents of children with ASD were less empathetic, responded poorly to clarification requests from the experimenters, tended to be over-sensitive, and had difficulty establishing rapport with the interviewers as compared to parents of children in the other groups. Landa, Folstein, and Isaacs (1991) found similar results specific to the abnormalities in the social communication abilities of these parents. In their study of 41 parents who had children with ASD and 23 parents who did not, they obtained the spontaneous narratives of parents via audiotaping; parents completed a story in which the beginning of the story was told to them. Researchers transcribed, coded, and placed parents' stories into categories. Findings revealed that the parents of children with ASD produced less complex and coherent narratives than those of controls, thus reflecting an impairment in the social use of language by parents of children with ASD.

In an 18-month longitudinal study, Greenberg, Seltzer, Hong, and Orsmond (2006) examined the types of emotions expressed in families in which there was a child with an ASD. Participants included 149 mothers and their adolescent and adult children residing with them. Through the use of interviews and questionnaires, researchers found that high levels of maternal

negative emotional expression, such as criticism and hostility, were associated with higher levels of maladaptive behaviors in adolescents and adult children with ASD.

A specific parenting behavior that may impact the parent-child relationship and impair the development of a child with an ASD is parental intrusiveness. Intrusiveness can be defined as any behavior that prevents children from independently completing a task that they are able to do on their own (Wood, 2006). Similarly, unsolicited parental assistance occurs when parents redirect their children from their play processes. Unsolicited parental assistance can lead to frustration within parent-child interactions, can prevent children from becoming self-sufficient, and in some cases can hinder their development (Wood, McLeod, Sigman, Hwang, Chu, 2003).

There have been some studies linking intrusive parenting behaviors to outcomes among children with ASD. In a longitudinal study, Siller and Sigman (2002) examined the relation between parenting and outcomes through the use of videotaping and coding four minute parent-child free play interactions in the lab. Parents were also asked to complete brief questionnaires pertaining to the nonverbal and verbal communication skills of 25 children with ASD, 18 children with developmental disorders such as Down's syndrome, and 18 typically developing children. Results revealed that parents who used verbalizations to redirect the child, as opposed to using language that was less demanding and more aligned with what the child was already attending to during their play interactions, had children with less advanced communication skills 1, 10, and 16 years after the baseline assessment.

In a similar study, Brigham, Yoder, Jarzynka, and Tapp (2010) examined the relation between parent attention cues during a free play session and the sustained attention of 25 preschool children. Parents who employed methods that redirected the child's attention instead of maintaining their child's focus to a particular object had children with lower object attention

levels. This finding is important as many researchers have found that joint attention between the caregiver and child is related to children's language development (Murray et al., 2008). The use of more supportive and less intrusive language within parent-child relationships is needed for better communication and synchrony.

The type of behavior exhibited by parents during their interactions with their children has been found to be predictive of varying child outcomes. For example, it has been shown that both permissive parenting and controlling parenting are risk factors for social and cognitive development for typically developing children (Baumrind, 1973) and children with psychopathology (Rogers, Wiener, Marton, Tannock, 2009). However, for children possessing the restrictive hallmark signs of ASD, control may serve as a beneficial parenting behavior. For example, provision of structure and rules makes it clear to the child the expectations of the day regarding scheduling, as well as what is expected regarding child behavior, especially his/her interactions with others. Importantly, this control needs to be accompanied with responsiveness and sensitivity on the part of the caregiver in order to receive positive child outcomes (Steijn, 2013).

In sum, although limited, research has examined a variety of negative parenting processes among families in which there is a child with an ASD. Many of the studies have examined a wide age range, so there is a need for a more careful exploration of parenting within a specific age range, such as the preschool period. Additionally, because children's negative behavior may contribute to the display of negative parenting, it is important to look more closely at parenting of children who present more severe impairment.

**Cognitive Stimulation/Scaffolding.** Given the neurological abnormalities observed in children with ASD, substantial parental attention may be devoted to stimulating children in order

to enhance their cognitive, language and social functioning. Specific parenting behaviors such as reading, teaching, and speaking directly to the child may promote better quality parent-child interactions and more advanced cognitive and language development in children with ASD. For example, Lamanek, Stone, & Fishel (1993) found that parents of children with ASD used more gestures to elicit children's attention as compared to parents of children with language delays. Skotko, Koppenhaver, and Erickson (2004) examined the communication patterns and levels of four 3-7 year-old girls with Rett syndrome, a form of ASD that is typically seen in girls and is characterized by language loss. Mother-daughter dyads were observed at home during story time for four months. Child and parent behaviors during these story time interactions were then coded. Results revealed that mothers who asked predictive questions, for example "What do you think will happen next?," used directives, for example "Touch the dog's tail," and pointed to pictures in the book more often, had children who were more accurate in their responses.

A number of intervention studies have found that specific parent teaching strategies promote better communication in children with ASD. For example, in certain parent-implemented interventions, techniques such as reinforcing, modeling, and prompting are all associated with positive effects on the communication skills of children with ASD (Kaiser, Hancock, & Nietfeld, 2000; Koegel, Bimbela, & Schreibman, 1996; Smith, Buch, & Gamby, 2000). Kaiser, Hancock, & Nietfeld (2000) trained six parents of preschool aged boys with ASD disorder, Asperger's, and Pervasive Developmental Delays. Mothers were taught a naturalistic language teaching procedure to promote child engagement, to build the social, conversational interactions of their children, and to help caregiver's model new, context specific language for their children. Twenty-four parent training sessions were held in a playroom at the University's clinic. Six months following the intervention in the clinic, home observations were

also conducted to assess the mothers' use of the intervention techniques. Measures including the Peabody Picture Vocabulary Test-Revised (Dunn & Dunn, 1981) were used to assess child language development. Positive outcomes were found for all children including the use of and diversity of the language produced.

Also in an intervention study, Kashinath, Woods, and Goldstein (2006) examined the effectiveness of six specific parenting strategies on the communication behaviors of five 2-6 year-old children with ASD. Results demonstrated that parents who used more time delay techniques during their daily routines with their children, which involves waiting for the child to request an item instead of delivering it to them unsolicited, had children who showed more gains in their communication patterns.

Many other positive child outcomes such as increased engagement and verbalizations, and decreases in behavioral problems, have been documented in intervention studies as a result of parents' employment of specific techniques, such as posting daily activity schedules as a way of ensuring smoother child transitions throughout the day and using verbal modeling and praise during play in the natural environment (Krantz, MacDuff, & McClannahan, 1993; Laski, Charlop, & Schreibman, 1988; Moran & Whitman, 1991). There is a need to garner more information on the parenting strategies and routines employed by mothers within their daily interactions with their children with ASD given that more cognitive and linguistic scaffolding has been linked to more gains in the development of children with ASD.

**Parenting Routines.** To date, few studies have examined the routines and rituals in families with children with ASD. Routines are defined as “observable, repetitive behaviors which directly involve the child and at least one adult acting in an interactive or supervisory role, and which occur with predictable regularity in the daily or weekly life of the child” (Sytsma,

Kelley, & Wymer, 2001, p. 243). Children with ASD often display a preference for routines (APA, 2000) and have been found to function best when in a structured environment (Hendricks, 1998), routines may be particularly beneficial to children with ASD. However, normal family routines may be disrupted by the presence of behaviors of children with ASD. In their review on routines in families of children with ASD, Boyd, Harkins, McCarty, & Sethi (2014) highlighted the challenges families face in maintaining routines, particularly those that encompass difficult behaviors on the part of the child and negatively affect family health and emotional bonds.

In their qualitative study, Schaaf et al. (2011) explored the routines of families with children with ASD. Of particular interest was how child sensory-related behavior (e.g., rocking back and forth, spinning, twirling, putting hands over ears, and not responding to parents' vocalizations) affected family routines. Four mothers of children with ASD between the ages of 7 and 12 were interviewed in their home. Findings revealed that families' participation in activities revolved around the child with ASD. Additionally, certain activities were avoided by these families if it threatened the sensory sensitivity of the child with ASD. Uncontrollable sensory stimuli in the environment (e.g., crowds and lighting) have been reported to adversely affect these children's ability to function, thus halting the families' engagement in activities.

Larson (2006) conducted a qualitative study to examine the development and use of routines for nine mothers residing in the U.S. with boys with ASD between the ages of 3 and 10 years old. The diagnosis of the children ranged from severe to high functioning. Two to four semi-structured, in-depth interviews ranging from 90 minutes to four hours were conducted over several months in the mother's home or by telephone. The interviews were then transcribed verbatim and themes were later created.



Results revealed that the unpredictable and difficult behavior exhibited by the boys with ASD in the families made it challenging for mothers to construct well-functioning daily routines. Impairments in the children such as poor communication, social, and attentional skills made it difficult to create family routines. Even for regular daily routines, such as doing homework and chores, behavioral disruptions would occur usually during transitions or between activities. These disruptions would produce anxiety in both the mothers and children for varying reasons. The boys often required regularity in scheduling and any deviation from this strict structure would result in emotionally charged responses (e.g., anger and tantrums). Mothers expressed feelings of anxiety over their failed attempts to employ strategies that facilitated participation from their children with ASD.

In a qualitative study, Werner DeGrace (2004) examined the daily experiences of five families and the meanings that parents place on their experiences. Interviews with parents (both mother and father) of 9-12 year old children with ASD were conducted once, for an average of two hours. Four families opted to be interviewed in the home and one family chose to be interviewed at a restaurant. The interviews were audio-taped and transcribed. Themes were then generated and results revealed that the lives of parents of children with severe ASD frequently revolved around the needs of the child. Further, the families reported spending most of their days occupying the child; however, they also reported struggles with finding ways to occupy the child. Finally, the families spent most of the day pacifying the child with ASD and described a lack of satisfaction in how they engaged in their daily lives. The constant worrying about preventing child behavioral outbursts expressed by these families may leave little time for families to share enjoyable activities.

Similar findings of disruption in the daily routines of families have been reported in other studies (Fox, Vaughn, Dunlap, & Bucy, 1997; Fox, Vaughn, Wyatt, & Dunlap, 2002; Turnbull & Ruef, 1996). These findings collectively suggest that children with severe ASD and the aberrant behaviors associated with this disorder can affect how families engage and the overall meaning that parents ascribe to their interactions with their children.

Research has examined routines associated with particular activities, such as bedtime and dinner routines. For example, Henderson, Barry, Bader, Sytsma Jordan (2010) examined the associations between sleep, routines, and externalizing behavior in 115 children ages 6 to 12 years in two groups: children with an ASD spectrum disorder ( $n = 58$ ) and children without an ASD ( $n = 57$ ). Parents completed a battery of questionnaires either on a secure, password protected website that was emailed to willing participants or a paper-and-pencil packet that was mailed to the participant's home, depending on their preference. The instruments included the Child Routines Questionnaire (CRQ; Jordan, 2003; Sytsma et al., 2001), the Bedtime Routines Questionnaire (BRQ; Henderson & Jordan, 2010), and the Children's Sleep Hygiene Scale (CSHS; Harsh, Easley, & LeBourgeois, 2002).

Findings show that lower levels of routines resulted in more externalizing behavior from both groups of children. Additionally, higher levels of routines were found to decrease externalizing behaviors only in the non-ASD group. Although frequent routines have been found to benefit typically developing children, this may not be the case for children with ASD. Finally, children who experienced better sleep quality, as reported by their parents, exhibited less externalizing behavior. This finding suggests that routines may play a role in the quality of sleep of children with ASD.

Marquenie, Rodger, Mangohig, and Cronin (2011) examined the dinner and bed time routines in Australian families of children with ASD. Fourteen mothers with 2-5 year old children with varied diagnoses of ASD participated in home and phone interviews about their parenting experiences and perceptions of dinner time and bed time routines. The semi-structured, open-ended interviews ranged between 40-90 minutes. Prior to the interview, demographic questionnaires and the interview questions were mailed to the participants. Following the interviews, participants were mailed individual interview summaries for member checking. Participants signed and returned the summaries as confirmation of correct interpretation of their experiences and meanings placed on their experiences.

Results for dinner time routines revealed that mothers of children with ASD spent a significant amount of time detailing the child's idiosyncrasies (e.g., preference for food and cutlery, and demands for same chair and position at the table). Mothers also reported behavioral challenges from their children when their demands were not accommodated. Further, many mothers explained how their children with ASD often did not easily participate in dinner time routines and were exempt from following rules at the dinner table as compared to other family members. Finally, many mothers cooked several meals to try to be more inclusive of the family's desires. These challenges exacerbated the stress levels as reported by mothers, with dinner time reported to be the most stressful time of the day. Overall, mothers described a sense of chaos during dinner time with no clear structure.

Similar to dinner time, the results for bedtime routines revealed that mothers were accommodating the demands from their children with ASD. Preferences for objects (e.g., stuffed animal or bottle), conditions (e.g., lighting), and positioning (e.g., positioning of the good night kiss and where mothers stood) were met with tantrums from the children if it was not to their

liking. However, unlike dinner time, mothers reported to have moments of meaningful interactions during bedtime albeit frustrating at times. Mothers reported an easier time during the bed time routine because the only participants in those routines were mothers and their children with ASD. As a result, bed time was more predictable than dinner time and allowed the child to be an active participant in the routine (e.g., bathing himself). These findings highlight the importance of garnering a better understanding of the experiences of mothers during their daily parenting routines with their children with ASD.

**Concluding Remarks.** In sum, caring for a child with an ASD can be very demanding on parents and has been found to be linked to elevated levels of stress (Baker-Ericzen, Brookman-Fraze, & Stahmer, 2005). The long-term stress may affect parents' perceptions of their parenting competencies which in turn may affect parenting behaviors and parent-child interactions. Positive parenting practices, such as the expression of warmth and sensitivity, and the use of verbal praise, have been linked with decreases in behavioral problems in children with ASD (Smith, Greenberg, Seltzer, & Hong, 2008) and has resulted in more securely attached children (Capps, Sigman, & Mundy, 1994).

In contrast, negative parenting such as parental intrusiveness has been found to be associated with less advanced communication skills of children with ASD longitudinally (Siller & Sigman, 2002), as well as lower attention levels of preschool children with ASD (Brigham, Yoder, Jarzynka, & Tapp, 2009). Given that negative parenting is associated with adverse child outcomes, research which examines parenting processes in this domain is critical. For example, because parental intrusiveness has been found to hinder children's development (Wood, McLeod, Sigman, Hwang, Chu, 2003) and because lower levels of self-sufficiency in children with ASD has been found to be negatively linked with parental stress (Tomanik, Harris, &

Hawkins, 2004), it is important to observe daily parent-child interactions as this can help researchers gain a better understanding of the experiences of mothers rearing children with ASD and ultimately children's later development.

Cognitive stimulation such as reading, speaking directly, and gesturing to children with ASD has also been linked to child outcomes but in a positive direction (i.e., stimulation can increase their cognitive abilities) (Lamanek, Stone, & Fishel, 1993; Skotko, Koppenhaver, & Erickson, 2004). The picture is not as clear for the relation between routines and the functioning of children with ASD. The data do suggest that the behaviors of these children disrupt family routines. However, there is inconsistent evidence regarding whether children with ASD benefit from routines in their homes. Research is needed to understand the routines in which parents of children with ASD engage. It is also important to gain a better understanding of how the behaviors of these children influence parents' daily interactions with their children, as these can shape parents' perceptions of and meanings of their experiences.

Taken together, similar to the research on typically developing children, these studies underscore the importance of parental functioning and parenting behaviors and practices for the quality of parent-child interactions and the resulting developmental outcomes of children with ASD. There is inconsistency in the literature regarding whether there are distinctions between parenting processes exhibited by parents of children with ASD and children with other disabilities. Further, apart from intervention research, very few studies have conducted in-depth examinations of parenting among mothers who have children with ASD. There is a clear need for more research which examines parenting processes within families in which there is a child with ASD, particularly in the early childhood period when children first receive the diagnosis. In

order to address this gap in the research, this dissertation study will directly address the parenting processes, daily experiences and perceptions of mothers raising children with ASD.

### **Methodological Implications and Future Research Directions**

There is limited evidence about the parenting processes in families in which there is a child with an ASD. Of the research that is available regarding this population, variability in child and respondent selection criteria, sample size, assessment methods, and selection of salient variables compromise the validity of the findings in this area. The evolution of methodologies to examine parenting and the quality of the parent-child relationship in families in which there is a child with ASD is in the infancy stage. There is a need for more rigorous designs that examine mechanisms of parenting beyond intervention studies. It is also essential to consider the appropriateness of measures used on typical populations with families of children with ASD, given that these children display significant within-group variability, and differ in many ways from the typically developing population. Further, this line of research would benefit from in-depth studies of parenting that can be achieved through qualitative designs. In the following paragraphs, I will address the methodological challenges and accompanying research directions for the study of parenting among families in which there is a child with an ASD.

#### **Child Selection Criteria**

In many studies, researchers have combined children with ASD and those with other disorders into a broad “developmentally delayed” group (Altiere & von Kluge, 2009; Guralnick, Hammond, Connor, & Neville, 2006; Kelso, French, & Fernandez, 2005; Pierce-Jordan & Lifter, 2005). The uniqueness of distinct disorders should be considered when selecting target groups to study. For example, there are ongoing debates about the inclusion of high functioning ASD, Asperger’s Disorder, and pervasive developmental disorder under the broader term of high-

functioning ASD spectrum disorders (Klin et al. 2005; Miller & Ozonoff, 2000). These individuals' advanced cognitive and language development as compared to others on the ASD spectrum have been used as justification for including these diagnoses into one grouping (LeGoff, 2004; Solomon et al., 2004).

In some instances, researchers have remained cognizant of the variability within disorders and have opted to solely include one disorder in a study or include children with or without other disabilities as comparison groups (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Bauminger, Shulman, & Agam, 2003; Carrington, Templeton, & Papinczak, 2003). For example, Rao & Beidel (2009) examined family functioning and parental stress within households that have high-functioning children with ASD between the ages of 8 and 14 years. Similarly, Bauminger et al., (2008) included children with high-functioning ASD and their typically developing peers to examine the friendships of these groups. Future research should carefully define samples and maintain as homogenous a group of research participants in a study as possible.

Moreover, even when solely considering children with ASD, scientists must be aware of the large variability within this particular disorder. Therefore, matching participants on mental age as opposed to chronological age can lead to more accurate results. Specifically, for children with high-functioning ASD (IQ >70), their thought processes during their interactions may be different from those individuals on the lower end of the spectrum given their cognitive abilities. Further, the tendency of many studies to include broad age ranges also compromises the validity of study. From a developmental perspective, psychological processes may manifest themselves differently dependent on the age of the child. Therefore, research participants must represent one age group, with a careful examination of mental age.

## Sample Size

Depending on the goals of a study, identifying participants who meet the selection criteria can be a daunting task. For studies that involve children with ASD, this may be even more difficult as the symptoms for this disorder vary greatly from individual to individual. Many of the studies which include children with ASD tend to have small sample sizes (Altieri & von Kluge, 2009; Bauminger, Solomon, Aviezer, Heung, Brown, & Rogers, 2008; Hastings, & Brown, 2002; Kasari & Sigman, 1997; Pottie, Cohen, & Ingram, 2009; Rao, & Beidel, 2009; Ruble, McDuffie, King, & Lorenz, 2008; Tomanik, Harris, & Hawkins, 2004). This number may be even smaller when a specific form of ASD is of particular interest (Bauminger, Shulman, & Agam, 2003; Webb, Miller, Pierce, Strawser, & Jones, 2004). Having larger sample sizes allows researchers to have more confidence about generalizing their findings to the larger population. Sample sizes must also be large enough to have an effect of scientific importance. Specific to ASD, larger sample sizes would allow for more research questions and answers that inform affected families' and the scientific communities' understanding of these children and how to promote their optimal outcomes.

However, there is also a need to have smaller sample sizes in which a question can be examined in a more refined way. In qualitative research there is no set requirement for determining sample size thereby allowing for the use of small sample sizes. The primary goal of qualitative research is to obtain a deeper and more refined understanding of a complex phenomenon; therefore an appropriate sample size would be one that adequately answers the research question(s) (Corbin & Strauss, 2008; Small, 2009). For example, a small group of participants would be appropriate to conduct an in-depth examination of parenting among families in which there is a child with an ASD. In practice, saturation determines whether or not



a researcher has recruited enough participants to uncover a phenomenon. Saturation will be discussed in greater detail in the methodology chapter of the document.

## **Design**

Although recent studies on the brain development of children with ASD have employed cutting-edge methodologies, the design of behavioral studies linking child factors and parenting processes that may ultimately lead to outcomes for children with ASD has not kept pace with the developmental literature. Assessing parents over multiple time points may help researchers better understand the long term effects of caring for a child with an ASD on the parent. Unfortunately, much of the data on parenting children with ASD emerges from single time-point assessments (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Dabrowska & Pisula, 2010; Estes et al, 2009; Hastings et al, 2005). This lack of longitudinal design is also evident in the literature on the developmental outcomes of children with ASD (Bauminger & Kasari, 2000; Carrington, Templeton, & Papinczak, 2003). Fortunately, there are some researchers who have taken a longitudinal approach to assessing parenting and child factors in families of children with ASD (Bauminger et al. 2008; Church, Alisanki, & Amanulla, 2000; Hartley, Sikora, & McCoy, 2008; Herring et al. 2006).

Another design issue relates to the use of correlation versus experimental designs. Whereas some researchers have conducted correlational studies when examining the outcomes of children with ASD and their families (Charman et al., 2003; Dawson, 2004), other scientists have executed studies to examine casual relations between variables (Howlin et al., 2004; Whitehouse et al., 2009). There is strength when conducting both correlation and experimental studies. For example, it is difficult to control human behavior; therefore a correlational design can be used to better inform researchers about particular phenomena. However, experimental designs can also

be beneficial to explaining variation in human behavior as researchers attempt to control all factors that may affect the result of an experiment.

Additionally, future research on the experiences of parents of children with ASD would benefit from qualitative designs that gathered information from the parents' daily experiences of raising a child with ASD. When attempting to garner a deeper understanding of parents' experiences when raising a child with ASD, conducting qualitative methodologies such as interviews and observations can (1) provide researchers with the experience of the participant from their point of view and help uncover the meaning of their experiences, and (2) provide researchers with personal first-hand experience with the role of the participant, thus heightening understanding of the construct of interest. Therefore, qualitative research can serve as a stage for parents of children with ASD to share their experiences which can ultimately lead to researchers discovering new ideas about the specific challenges associated with rearing a child on the ASD spectrum.

### **Methods of Data Collection**

Many researchers of ASD have relied on parent reports and have not attended to the advantages of collecting data from multiple assessments (Hastings & Brown, 2002, Kasari & Sigman, 1997; Sanders & Morgan, 1997). Unfortunately, the self-report format, which is typically completed by mothers, does not allow for the full story to be revealed. Therefore, researchers have no way of corroborating participants' responses to sample items. There is a need for more studies which include multiple observations. An additional limitation of self report measures relates to the truthfulness or accuracy of what is being told by the participant. For example, some participants may report what they believe to be the most socially desired response which may not accurately reflect perceptions or events.

Other modes of data collection should also be utilized. In addition to surveys, other methods of assessments can inform researchers about the experiences of parents rearing a child with an ASD. The use of multiple assessments is rare in the literature on parenting a child with ASD with most research entailing the distribution of questionnaires (Bauminger & Kasari, 2000; Church, Alisanki, & Amanullah, 2000; Davis & Carter, 2008; Estes et al, 2009). Conducting semi-structured parent interviews and observing children with ASD interact with their parents are other ways of obtaining data on parenting processes and children's outcomes. For example, to assess the quality of friendships of children with Asperger's disorder, Carrington, Templeton, & Papinczak (2003) used interviews to obtain the perspectives of these children. Similarly, Bauminger, Shulman, & Agam (2003) used interviews to understand feelings of loneliness in adolescents with high-functioning ASD. To a limited extent, there are researchers who opt to use multiple methods of assessment to obtain data on children with ASD and their families. For example, Bauminger et al. (2008) employed the use of self reports, observations, and interviews to examine the differences and similarities in friendships of children with ASD and their typically developing peers. The use of multiple methods, including qualitative methods, can better inform researchers about the mechanisms and outcomes of parenting children with ASD. In particular, interviews and observations are methodologies that will allow a more refined examination of parenting in this population.

### **Appropriateness of Measures**

Assessing human behavior requires complex designs and extensive procedures. Social scientists must be able to design measures that accurately assess the constructs of interest, and these tools must also be consistent across studies. One shortcoming of many studies is the utilization of measures with children who are diagnosed with an ASD, that were originally

developed and standardized for typically developing children (Feldman, Hancock, Rielly, Minnes, & Cairns, 2000; Guralnick, Hammond, Connor, & Neville, 2006). Employing such measures may not be the most appropriate way to assess this population of children. For example, although high-functioning adolescents with ASD have intelligence quotients that are comparable to their typically developing counterparts, their social development continues to be impaired. Consequently, these adolescents may not fully comprehend social conventions that lead to peer acceptance or rejection, which may lead to inaccurate responses to questions on measures that were designed for typically developing individuals.

Measures to assess behavior problems in normative samples have also been used in studies on children with ASD. In a study designed to examine the friendships of preschool children with mild developmental delays, Guralnick, Hammond, Connor, & Neville (2006) provided parents with the Child Behavior Checklist (CBCL) to report on their children's behavioral problems. The CBCL was designed for a normative population and, and thus may not accurately address the behavior that is unique to a specific disorder. Further, the utilization of a developmentally inappropriate measure for such populations of children may pose threats to *construct* validity, which refers to the extent to which measures tap into what they are designed to, and *criterion* validity, which refers to how well a measure predicts an outcome.

Finally, various measures have been employed to assess the coping techniques of parents with children with ASD (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Esdaile & Geenwood, 2003; Lee, 2009). This variability leads to difficulty in determining whether the existing differences are truly due to differences in the constructs or are measurement artifacts. Utilization of the same assessments would allow for conceptually clearer comparisons and would diminish measurement error. Until modes of assessment specific to this population are created and

validated, it remains important to uncover the particular themes that may lead to questions about parenting for this population. Qualitative methods that allow parents to contribute their own narratives about their experiences and allow researchers to observe parenting in situ are important to undertake.

In sum, there are many methodological issues which should be addressed to improve the rigor of the research on the parenting of children with ASD. Identification and assessment of children with ASD should be conducted with care, with attention to maintaining as homogenous a sample as possible. Future quantitative studies should include larger and more representative samples that are examined longitudinally via multiple informants and appropriate measurement. Finally, there is a need for qualitative research that could address understudied constructs in more depth, including parenting processes among mothers with children with ASD. Conducting observations and interviews with mothers of children with ASD can add to the limited evidence on how mothers interact with their children on a daily basis.

### **Practice Implications**

The research presented herein has implications for the development of policy and practice to support families with children with ASD. Overall, it is important that policies provide funding for interventions to promote the skills and well-being of parents of children with an ASD. There is a plethora of therapies and interventions available to assist parents with the challenges associated with rearing children with ASD. Most of these interventions address parental stimulation and scaffolding of the cognitive and language development of children with ASD. Specific parenting behaviors such as reading, teaching, speaking directly to and asking questions to children with ASD have been linked to advanced cognitive and language development in these individuals (Lemanek, Stone, & Fishel, 1993; Skotko, Koppenhaver, & Erickson, 2004).

Interventions that teach parents to utilize these strategies during their interactions with their children can help advance these youngsters' development.

Parenting interventions geared to families of typically developing children often focus on affective behaviors, such as increasing warmth, sensitivity, and attunement. There is a need to develop more interventions for families, in which there is a child with an ASD, which aim to facilitate parents' positive behaviors and reduce their negative behaviors. Parenting behaviors such as positive maternal verbal expressions and sensitivity have been found to be associated with child compliance (Lemanek, Stone, & Fishel, 1993) and secure attachment (Capps, Sigman, & Mundy, 1994) in children with ASD. Similarly, negative parenting such as use of criticism, hostility and intrusiveness has been found to be associated with maladaptive behaviors in children and adults with ASD (Greenberg, Seltzer, Hong, & Orsmond, 2006; Wood, McLeod, Sigman, Hwang, Chu, 2003). Interventions that target such parenting behaviors can enhance parents' relationships and interactions with their children who have ASD. Adapting evidence-based programs that have been found to be effective with typically developing children may be an important first step in these endeavors.

Finally, the challenges associated with parenting children with ASD call for the development of programs that address parental mental health and provide social support to parents. Funding is needed for mental health interventions that target parents of children with ASD, specifically in relation to decreasing their rates of depression and parenting stress. Additionally, group-based programs that rely on peer support, as well as interventions designed to engender support for parents from members of their families, can serve to increase the social support parents perceive they have. Obtaining effective treatment for parents, including mental health intervention and parenting interventions, can help families navigate through the challenges

of raising a child with ASD. Policy-makers and practitioners should move beyond funding programs geared solely toward enhancing the development of children with ASD, and foster the development of interventions to enhance the parenting skills of these families.

### **Summary and Conclusions**

The literature on parenting typically developing children and those with disabilities is robust; however, there is a paucity of literature on parenting children with ASD. Building on Bradley's (2002) conceptualization of parenting, children with ASD have a major impact on the functioning of their families, and vice-versa. Impairments in brain activity, facial processing, working memory, inhibition, planning, social skills, emotion recognition and theory of mind have been found in a number of children with ASD, which have implications for the quality of their relationships with their parents. Bradley asserts that parents perform five actions to assist their children to adapt to their environments: (1) sustenance, (2) stimulation, (3) support, (4) structure, and (5) surveillance. These five actions can be employed in mothers' interactions with their children across developmental functioning levels. These parental actions can be applied to an understanding of the parenting of children with ASD. Moreover, Bradley (2002) describes both parent and child as mutual creators of their environments. The characteristics of the child (e.g., severity of the disorder) can influence how parents perceive and parent their children who have ASD, which in turn can shape these children's behaviors during their interactions with their caregivers.

Parents play a pivotal role in shaping the developmental outcomes of children with ASD through their practices and behaviors, specifically their interactions with their children. The elevated levels of stress and depression found in parents of children with ASD affect their sense of parenting competence as well as their parenting behaviors. Through their interactions with

their children, parents can potentially enhance the cognitive, language, and social-emotional development of these youngsters. To a very limited extent, the relation between parenting behaviors and the outcomes of children with ASD have been examined. Positive parental displays of warmth, sensitivity, and scaffolding during parent-child interactions have been found to be associated with more compliant behavior and better communication skills in individuals with ASD. In contrast, high levels of negative emotion expression and intrusiveness exhibited by parents has been linked to higher levels of maladaptive behaviors and less advanced cognitive skills in children and adolescents with ASD.

In summary, there is considerable documentation regarding the developmental impairments of children with ASD, but there is a paucity of evidence regarding parenting processes with respect to this population. Further, the role of children and parents in shaping parenting practices and behaviors remains unclear. Examining these questions may help researchers better understand how these children's early socialization experiences within the family may aid or impede their development. Such research may help scholars and practitioners in the field of childhood disability promote optimal functioning in families that are affected by ASD.



### CHAPTER III

#### **Methodology**

Increasingly, children are being diagnosed with Autism Spectrum Disorder (ASD), a developmental disorder characterized by cognitive, communication, and social impairments (American Psychiatric Association, 2015). The increase in the numbers of children with ASD translates into larger numbers of families who have to adapt to the psychological and economic challenges associated with rearing a child with this disorder. Although there is a large literature on the development of children with ASD (Bauminger, Shulman, & Agam, 2003; Rieffe, Terwogt, & Stockman, 2000), little is known about the parenting practices that are employed with young children with ASD, particularly parent-child interactions. Additionally, the literature on the routines and activities that these parents engage in and expose their children to is scant. Moreover, parental perceptions regarding their roles and competencies when parenting a child with ASD have not been the subject of extant research. Finally, the influence of child behaviors on parenting in families in which there is a young child with ASD has received little attention. Notably, early childhood is a period marked with a number of challenges for parents that may be exacerbated when they have a child with ASD. Therefore, it is important to examine the early experiences of mothers raising children with ASD.

In the current study, I employed a qualitative approach to gain an increased understanding of the parenting practices and behaviors exhibited by mothers raising a young child with ASD and their overall parenting experience. It is important to retrieve the story from the actors who have a first-hand account of these experiences and interactions with their children. Interviews served as a way for mothers to tell their stories. Additionally, observations were conducted to (1) discover findings related to mother-child interactions that were not

discussed in the interviews, (2) corroborate mothers' experiences that they disclosed, and (3) increase the credibility of the research findings.

This chapter begins with a discussion of qualitative research and the appropriateness of employing such methods when conducting research on parenting among families of preschool children with ASD. It is then followed by a discussion of the two types of methods that were employed to gather data on parenting experiences, specifically observations and interviews, and the advantages of each. Thereafter, I discuss the researcher's role and potential biases that I may hold. Next, I present the research questions which guided the current study, followed by participant recruitment, data collection protocol and analysis procedures. Finally, I discuss verification of data and ethical considerations.

### **Qualitative Methodology and the Study of Parents of Children with ASD**

The nature and purpose of qualitative research are different from that of quantitative inquiry (Milinki, 1999). *Quantitative research* requires a large number of participants, analyzes numeric data, and aims to: (1) make predictions about human behavior; (2) examine causal relationships between factors; and (3) generalize to the larger population using a smaller representative sample. Additionally, quantitative studies are often designed to test a theory or a set of hypotheses about a phenomenon.

Conversely, the goal of *qualitative research* is to obtain a deeper and more refined understanding of complex issues. Thus, investigating the 'why' or 'how' is of greater interest than the 'what' in quantitative research (Daly, 2007; Marshall, 1996). It typically involves highly rich description of human behavior and opinions. Qualitative research can be hypothesis generating, particularly regarding an understudied phenomenon. This approach is particularly

well-suited to the study of parenting of children with ASD, given the need for rich data in this arena.

### **Approach**

When conducting a qualitative inquiry, there are a variety of research approaches that can be taken. Various authors have listed over 29 classifications of qualitative approaches throughout the years (see Creswell 2013 for an exhaustive list of approaches that have surfaced over time). However, the most commonly used approaches in the social, behavioral, and health science literature include ethnography, case studies, phenomenology, and grounded theory (Creswell, 2013; Mertens, 2009).

Common in qualitative research methodology, a grounded theory approach was employed in the current study to garner a better understanding of mothers' overall experiences of raising preschool aged children with ASD and the meanings placed on their experiences. Grounded theory is a research method that allows the investigator to generate a theory about the phenomenon of interest (Denzin & Lincoln, 2003; LaRassa, 2005; Padgett, 2004), rather than attempting to prove or disprove a hypothesis (Bogdan & Biklen, 1998) which is more akin to quantitative methodology. According to Strauss & Corbin (1990), "A grounded theory is one that is inductively derived from the study of the phenomenon it represents. That is, it is discovered, developed, and provisionally verified through systematic data collection and analysis of data pertaining to that phenomenon" (p. 23). Thus, to produce a theory about mothers' parenting practices, an inductive approach to data analysis was used (Bogdan & Biklen, 1998).

This inductive process involved me reviewing the raw data that emerged using the constant comparative method (Glaser & Strauss, 1967; Strauss & Corbin, 1990). Data from transcribed mother interviews and parent-child observations were reviewed line-by-line, as well

as per phrase, sentence and paragraph as codes were generated. I then compared the generated codes with all other created codes within and between families to identify similarities, differences, and general patterns. The final step of the analysis process involved making interpretations regarding the phenomenon of interest (i.e., parenting practices). It is important to note that this approach was dynamic in that it was revised throughout the varying steps of the data collection process, thereby affording me a better opportunity to generate codes and review the relationship between these categories. This coding process will be discussed in greater detail later in this chapter.

### **Sample Selection**

In general, there is no set requirement for determining sample size in qualitative research; an appropriate sample size would be one that adequately answers the research question(s) and reveals the perceptions of the sample (Corbin & Strauss, 2008; Small, 2009). For qualitative inquiries, sufficient sampling has occurred when the researcher has achieved depth and complete understanding about a phenomenon. Specific to interviewing, Johnson (2002) contends that, “Enough interviews must be conducted so that the interviewer feels he or she has learned all there is to be learned from the interviews and has checked out those understandings by re-interviewing the most trusted and knowledgeable informants” (p.113). This clarity about a category and its relation to other factors is known as saturation (Corbin & Strauss, 2008).

Although saturation is the guiding principle on sample size determination, there are some general rules of thumb to help guide researchers in determining sample size a-priori. For example, Marshall (1999) suggests that for simple research questions, a smaller sample size containing single numbers may be appropriate whereas larger sizes may be needed for more complex questions. Mason (2010) believes that sample sizes must be large enough so that all of

the perceptions that might be important can be disclosed. Mertens (2009) suggests that depending on the qualitative approach employed, approximately six participants may be sufficient. The goal of qualitative research is to conduct an in-depth investigation by immersing oneself in the lives of the studied participants. Therefore, in order to obtain a greater understanding of mothers' experiences raising preschool aged children with ASD, I recruited a small number of families thus placing emphasis on quality not quantity.

Qualitative researchers often gather data in natural environments through purposeful sampling. When conducting purposeful sampling, a particular group of people are targeted because they possess a specific characteristic that is central to the study of interest. This type of sampling is typically used when the population of interest is rare or difficult to locate (Coyne, 1997). Moreover, purposeful sampling allows the researcher to make inferences about the realities of the studied population. There are a wide range of purposive sampling approaches one could employ while conducting qualitative research (see Paton, 1990 for a complete list) with each having its own advantages and disadvantages ("Purposive sampling", n.d.).

The types of purposeful sampling that were used in this study are criterion, maximum variation, and expert sampling. *Criterion sampling* involves selecting cases that meet a specific criterion. For the purposes of this study, mothers of 3-5 year old children with a clinically confirmed diagnosis of ASD (as delineated in the DSM-V) or the separate ASDs (delineated in the DSM-IV) were eligible to participate. *Maximum variation sampling* is used to capture a wide range of perspectives related to the studied phenomenon (i.e., mother experiences raising children with ASD). This particular sampling procedure allowed for mothers' perspectives on parenting children with ASD, (e.g., parenting practices, behaviors, parent-child interactions, parental capacities, and child characteristics) to be gained. Mothers' expressed views, ranging

from typical to extreme, allowed me to identify common themes among families with children across the autism spectrum. I was able to get this range of perspectives and views by recruiting mothers from a variety of socioeconomic backgrounds, racial-ethnic groups, and family types, as well as mothers who were parenting children needing different levels of support. *Expert sampling* was used to investigate parent experiences from individuals that have expertise in the particular topic (i.e., the mothers of children with ASD). This type of purposeful sampling is especially useful when empirical data on the phenomenon of interest is scant. Given that the parenting process of mothers' raising preschool aged children with ASD has received little attention, the expertise of the mothers as told in the interviews can potentially highlight areas of study for future research thus further contributing to the parenting literature on families with children on the autism spectrum.

### **Data Collection Methods**

Qualitative research requires rigorous and systematic methods of data collection. As such, researchers can rely on a variety of methods to gain insight into parents' behaviors, beliefs, and perspectives. The information gathered can then be used to answer research questions and provide contextual descriptions about how parents experience their roles and how they perceive their children using their own narratives (Riessman, 2002). Moreover, qualitative methods can shed light on the role of factors that may influence a phenomenon such as parenting (e.g., child characteristics). There are a variety of ways to obtain data when conducting qualitative research including participant observation, in-depth interviews, and focus groups (Corbin & Strauss, 2008; Creswell, 2013).

In the current study of parenting of children with ASD, I primarily used observations and interviews. Both interviews and observations shed light on parenting practices and parents'

beliefs and perceptions. The use of both methods guarded against potential distortions of reality from the researcher or the participant. I used direct observation of reality as a way to support or contradict participants' responses during the interview portion of a study. In essence, the truth of the situation can be better obtained as compared to descriptions of the truth (Daly, 2007).

Observations were also beneficial in that new data relevant to the studied phenomenon emerged that were not discussed in the interviews.

**Observations.** As purported in Becker and Geer's (1970) seminal paper, observations allow researchers to obtain a "complete" story of the experience in an objective manner. It allows the reality of the situation to be brought to the surface by observing the behavior, in addition to relying on the constructed description of reality as told in the interviews.

Additionally, Daly (2007) believes that conducting observations requires the researcher to possess a "beginner's mind" (p. 131). When entering the participant's world, everything in the room plays a role in the participant's life, therefore it is important that the researcher uses all five senses to receive the full experience which aides in painting a clearer picture of the social setting.

Conducting observations is advantageous in qualitative research as it provides the researcher with personal first-hand experience with the role of the participant, thus heightening understanding of the construct of interest. Moreover, observations allow behavior to be observed in-situ. In other words, the interactions between the mothers and their children can be observed in real time. The natural occurrences of events and mothers' reactions to their children's behaviors can reveal how they navigate through and cope with their parenting experiences. There is a dearth of knowledge on the activities that parents engage in with their children with ASD and the practices that they employ while in private. Entering into the private world of

families of children with ASD provided me with a more lucid account of how parents typically respond to their children's behaviors when the "eye" of society is not on them.

In qualitative studies, the researcher aims to be as unobtrusive as possible so that neither research presence nor methods disturb the situation. Unfortunately, when attempting to gather direct observation of reality, the researcher inadvertently plays a role in the way the event unfolds (Daly, 2007). One of the biggest critiques about conducting observations is that the presence of the researcher places the investigator in a participatory role. The participants of the study are fully aware of the researcher's presence and may behave in a manner that contradicts how they would typically respond in the absence of the researcher. One way to circumvent such an outcome is to spend a significant amount of the time with the family, which I did with all 6 families in the study.

The amount of time a researcher spends with a family varies depending on the goal of the study. In general, the emerging data become more accurate when the stay is extended (Mack et al., 2005). In qualitative research, a snapshot of a person's life in that particular moment is being taken. In the hopes of getting closer to obtaining a full accurate image, multiple snapshots must be taken which requires the researcher to be in the field for an extensive period of time. Notably, the number of observations should not be determined prior to collecting the data. Instead, the researcher should make a determination of the number of observations needed to uncover a phenomenon on the basis of whether or not the salient themes have emerged without repetition over time (Mertens, 2009). In my study, the 6 contacts (see below) which I had with families allowed me to obtain multiple snapshots of these families experiences.

While conducting observations on families, it is important for researchers to consider their positions, which can range from being completely detached to being a full participant in the



experience (Daly, 2007). Being a passive participant affords a more natural occurrence of events thus leading to manifestation of certain types of behavior from the participants. For example, mothers of a child with ASD may respond negatively to their child's outbursts caused by an abrupt change in the routine schedule. Considering this same example, a parent may have responded differently if the researcher was a full participant and provided some assistance to make the transition a smoother one. Being a full participant allows the researcher to immerse themselves in the family experience; however, this type of positioning has been criticized in that it has the potential of obscuring the researcher's sight. It has been argued that in order for the investigator to receive the "whole" picture of an experience, they must provide some distance between themselves and the participant. Regardless of the caveats associated with this specific methodology, observing reality can inform researchers about the processes involved in creating and sustaining positive parenting practices and quality parent-child interactions in the population of interest – families in which there is a child with ASD. As described below, I attempted to immerse myself in the lives of the family, while maintaining sufficient distance so as to not influence mothers' actions.

**Interviews.** The purpose of an interview in qualitative research is to try and understand the experience of participants from their points of view and to uncover the meaning of their experiences (Mack et al. 2005). The statements told by the participants are therefore considered to be a representation of reality. According to Kvale (1996), interviews allow individuals to discuss their perceptions and interpretations regarding a particular situation thereby helping researchers obtain information and gain insight into a phenomenon of interest. Furthermore, interviews can be used as a follow-up tool to participants' responses on questionnaires (Mack et al. 2005). This method was elected for use in the current study.

Kvale and Brinkmann (2009) contend that these conversations aid in unfolding the meaning of people's experiences. In the current study, qualitative interviews served as a stage for parents of children with ASD to share their experiences, which ultimately led to discovery of new ideas about the specific rewards and challenges associated with rearing a child on the autism spectrum. The rich descriptions provided by parents of children with ASD were used to uncover themes that emerge among multiple participants. Learning about the ASD world through the "lenses" of a parent of a child with ASD offered me a new understanding about parenting processes within these families.

In sum, the research strategies of observing mother-child interactions and interviewing mothers were important for the current study in that they helped me to gather reality in real time and obtain information about the parenting experiences from the perspective of those who are familiar with and highly knowledgeable about the potential benefits and challenges associated with raising a child with ASD. Specifically, qualitative inquiry allowed me to gain more accurate representations of parenting practices from the parents' standpoint, thereby giving voice to their perceptions and illuminating their experiences caring for young children with ASD.

### **Research Questions**

Qualitative investigators' goals are to uncover the "truths" about a particular phenomenon. Research questions are therefore created prior to conducting the study to better guide the data collection and analysis process (Creswell, 1999). Essentially, research questions as opposed to objectives are stated in qualitative research. The central research questions are open-ended to allow room for flexibility. Additionally, the research questions should build on a body of existing literature in the field of interest and should serve as guidelines for the study (Creswell, 1999; Marshall & Rossman, 1995; Thomas, 1993). The research questions can evolve

and become more specific throughout the research process as new themes will emerge during the data collection and analysis phases (Creswell, 1993; Maxwell, 1996).

Capitalizing on this approach, I developed several open-ended research questions prior to the initiation of the current study. I used Bradley's (2002) conceptualization of parenting and the literature on parenting children with ASD (or lack thereof) as the foundation from which my research questions were developed. Bradley (2002) proposes that there are five parenting practices that are critical for children's positive development: (1) sustenance, (2) stimulation, (3) support, (4) structure, and (5) surveillance. Although a multitude of studies exist which examine parenting practices in families with typically developing children, there is a dearth of research on the parenting of young children with ASD. Thus, I devised the following overarching and more specific questions to guide the current qualitative inquiry:

1. What are the parenting practices and behaviors that mothers use with their preschool aged children with ASD?
2. What are the beliefs and experiences of mothers relative to raising preschool aged children with ASD?
3. What facilitates or hinders mothers' parenting of their preschool aged children with ASD?

### **Participants**

Purposeful sampling was used to select participants who were able to provide rich information on the experiences associated with raising a child with ASD. Purposeful sampling allowed me to have better insight into issues that were central to the study. Because ASD is a spectrum disorder, the cognitive and behavioral functioning of children can vary greatly, thereby

making the parent-child interactions vastly different. The “voices” of mothers raising children across the autism spectrum as told by their stories shed light on this understudied phenomenon. The diverse experiences and the meanings that participants placed on these experiences through their “lenses” led to my discovery of emerging and common themes associated with this disorder in the familial setting.

Prior to the initiation of the study, permission to collect and review documentation confirming the child’s diagnosis (e.g., formal diagnosis from a clinician according to the DSM-IV criteria; Individualized Family Service Plan or Individualized Education Plan) was granted by the University’s Institutional Review Board (IRB). A Health Insurance Portability and Accountability Act (HIPAA) form was also approved by the University’s IRB. This form served as protection of the confidentiality of participants’ health information.

The participants for this study were mothers with preschool age children who had been diagnosed with ASD. Six families were recruited to participate; others were targeted for recruitment. There is considerable evidence that mothers are primarily responsible for childrearing, and that mothers of children with ASD report higher levels of stress and depression than fathers of these children, which can greatly influence parenting. Because early childhood is typically the developmental period in which children receive the ASD diagnosis, there is a need to focus on early parental experiences, thus the focus on preschool children with ASD in the present sample. It is important to note that the participating families were recruited from a listserv of families that had received services through the Children’s Hospital (see recruitment section below). Thus, their experiences may be different from those families who are navigating the parenting world without assistance from support services.

The mothers described their ethnic or racial identity in the following categories: African American (n=3); Asian (n=1); or Caucasian (n=2). In terms of the highest level of education completed, one had a high school diploma, three completed some college, and two had a Bachelor's degree. Employment status varied with two mothers who worked full-time, one who worked part-time, and three who were unemployed. Five of the mothers were married and one was unmarried. All of the mothers with the exception of one had other children varying from ages 10 months to 17-years-old. Table 1 provides a summary of the mothers' demographic information.

Table 1  
*Mother Demographics*

	Age	Ethnicity/ Race	Education	Marital Status	Employment Status	Total # of Children	Ages of children
Anastasia	32	African American	Some College	Single	Full-time	3	4, 11, & 13-years- old
Briana	41	African American	Some College	Married	Unemployed	5	5,7,13,15, & 17- years old
Cynthia	35	Asian	College Degree	Married	Part-time	2	3 & 5- years-old
Danielle	39	Caucasian	College Degree	Married	Full-time	2	5-years- old & 6 month old
Erica	41	African American	High School Diploma	Married	Unemployed	1	3-years- old
Fatima	39	Caucasian	Some College	Married	Unemployed	2	3-years- old & 11- years-old

NOTE: Mothers' names are pseudonyms.

To better assist in the recollection of the pseudonyms for the mother-child dyads, the first initial of the mothers' first names matches the first initial of the children's first names (e.g., Anastasia and Alex, Briana and Bobby, etc.).

**Family 1: Anastasia and Alex.** Anastasia is an African American single mother of three children. At the time of the interview, the ages of the children were 4, 11, and 13 years-old. Anastasia and her children reside in a single family home in a middle class suburb in the greater Washington, DC area. As a parent who is also employed full-time, Anastasia acknowledges the support received from the children's grandmother and credits her for being able to adapt to the many experiences associated with being a single parent of three and rearing a child on the autism spectrum. Her son Alex, who has been diagnosed with Autistic disorder, is enrolled in a childcare center where he spends approximately six hours a day in a self-contained classroom with other children with special needs. Alex receives speech and behavioral therapy once a week in the home setting.

**Family 2: Briana and Bobby.** Briana is an African American married mother of five children. At the time of the interview the ages of the children were 5, 7, 13, 15, and 17 years-old. Briana and her family reside in a single family home in a middle class suburb in the greater Washington, DC area. As a stay-at-home parent, Briana spends her days taking care of daily household responsibilities, running errands, and chauffeuring children to and from school and their extracurricular activities. Briana has stated that her husband is a major source of support as he plays a critical and active role in their children's development. Her son Bobby, who has been diagnosed with PDD-NOS, attends school full-time and is in a mainstream classroom with typically developing children. Bobby also receives therapy once a week during school hours.

**Family 3: Cynthia and Charles.** Cynthia is an Asian American married mother of two children. At the time of the interview the ages of the children were 3 and 5 years-old. Cynthia and her family reside in a single family home in a city located in the greater Washington, DC area. As a parent who is employed part-time, Cynthia spends half of her days working remotely from home and caring for the youngest child who is not enrolled in childcare. The other half of her day is spent caring for the household and both children with Charles (the child with ASD) returning home from school. Cynthia stated that her husband is instrumental in making sure that the developmental outcomes of their children are positive. Her son Charles, who has been diagnosed with Asperger's syndrome, attends school full-time and is in a mainstream classroom with typically developing children. Although receiving therapeutic services in the past, which the parents paid for out-of-pocket, Charles has progressed to the point where the parents opted to no longer receive these services.

**Family 4: Danielle and David.** Danielle is a Caucasian married mother of two children. At the time of the interview the ages of the children were 6 months and 5 years-old. Danielle and her family reside in a single family home in a city located in the greater Washington, DC area. As a parent who is employed full-time, Danielle expressed her concerns regarding her limited time to interact with her children and husband on weekdays. Danielle's busy schedule has afforded the children's father a significant amount of time to interact with them, which may have resulted in David having a stronger emotional connection to his father, as reported by Danielle. Her son David, who has been diagnosed with Asperger's syndrome, attends school full-time and is in a mainstream classroom with typically developing children. He is enrolled in one hour therapy once a week at school. Danielle has expressed her internal struggles with herself as to

whether or not she should enroll him in more therapeutic hours. She questions whether the additional hours would serve useful given that David is already cognitively advanced.

**Family 5: Erica and Elijah.** Erica is an African American married mother of one child. At the time of the interview, her son was 3 years-old. Erica and her family reside in a multigenerational single family home in a middle class suburb in the greater Washington, DC area. At the beginning of the data collection phase, Erica was employed full-time and expressed her concerns for her limited interaction with her son during the week which was a direct result of her full-time employment status and long commute home. Towards the end of data collection, Erica opted to spend more time with her son and quit her job. Erica acknowledged the support received from her husband, albeit limited now that she is a stay-at-home parent. Her son Eric, who has been diagnosed with Autism Spectrum Disorder, is enrolled in a childcare center where he spends approximately six hours a day in a self-contained classroom with other children with special needs. Eric receives speech and behavioral therapy once a week in the home and school setting.

**Family 6: Fatima and Fabian.** Fatima is a Caucasian married mother of two children on the autism spectrum. At the time of the interview, the ages of the children were 3 and 11 years-old. Fatima and her children reside in a single family home in a middle class suburb in the greater Washington, DC area. As a stay-at-home mother, Fatima acknowledges the support received from her husband, although she wishes he would be more emotionally available. She has speculated that her husband too is on the autism spectrum, however, he has not been officially diagnosed. Her son Fabian, who has been diagnosed with Autism Spectrum Disorder, is enrolled in a childcare center where he spends approximately six hours a day in a self-contained classroom with other children with special needs. Fabian also receives speech and



behavioral therapy several times a week in the school setting as well as with a private therapist after school. Fatima has expressed her frustration with her insurance company and county for not funding more hours for her sons to receive therapy. In her personal narratives, she has disclosed her family's financial struggles and their monthly decisions to either pay the mortgage or therapy session bills.

The children participating in this study were all boys ranging in ages from 3-5 years-old. The ethnicity of the children included African American (n=3), Asian (n=1), and Caucasian (n=2). Given this unique demographic distribution (i.e., all boys half of the children being African American), this sample contributes to the literature on parenting children from multi-ethnic groups. The ages at which the children were diagnosed ranged from 2-years old to 4-years-old. Three of the children were verbal and displayed age-appropriate language skills based on observation (e.g., uttering more than three word sentences) and the other three demonstrated limited language skills (i.e., were saying single to three word utterances). The children had a variety of services in and out of school including Speech therapy, Occupational therapy, and Applied Behavior Analysis. All of the children were in school five days a week with hours ranging between 6 and 6.5 hours per day. Child demographics and descriptions are delineated in Table 2.

Table 2

*Child Demographics and Descriptions*

	Age (Years)	Gender	Ethnicity/Race	Diagnosis	Age Diagnosed (Years)	Language
Alex	4	Male	African American	Autistic Disorder	2	Delay-single to three words
Bobby	5	Male	African American	PDD-NOS	4	Verbal
Charles	4	Male	Asian	Asperger's	3	Verbal
David	5	Male	Caucasian	Asperger's	4	Verbal
Elijah	3	Male	African American	Autism Spectrum Disorder	2	Delay-single to three words
Fabian	3	Male	Caucasian	Autism Spectrum Disorder	2	Delay-single to three words

NOTE: Children's names are pseudonyms. Diagnostic labels were taken from child assessment documents provided to the researcher by mothers.

**Sampling Source**

Families were recruited for this study through Children's National Medical Center (CNMC), located in Washington, DC. CNMC provides a number of services to children and families in need of medical care and support. This premiere facility offers a myriad of medical diagnostic and treatment services, but also has research, advocacy, and education arms. A number of research teams are housed in the hospital with the mission of improving the knowledge, prevention and treatment pertinent to a variety of diseases and disorders, including ASD. Among these multidisciplinary teams is the Center for Autism Spectrum Disorders, which addresses the needs of children with ASD and specializes in diagnosing and evaluating these children.

## **Participant Recruitment**

To recruit the parents for this study, a flyer that briefly described the study was electronically sent to a listserv of willing participants who had previously provided their consent to CNMC to receive information regarding opportunities to participate in research studies. The flyer included a statement regarding the purpose of the study, specifically to learn about the experiences of mothers raising children with ASD. Additionally, the flyer stated that participants will be compensated \$150 for their time (see Appendix A). Mothers who expressed interest in the study were contacted through telephone. Once mothers had been contacted, more detailed information about the study, which included IRB approval, was discussed over the phone.

## **Procedures**

In the following paragraphs, I provide details about how the data collection was conducted for this study. Included are sections on how participants were identified, and descriptions of the frequency, content, and approaches to data collection. Although my goal was to continue observing and interviewing mothers until I reached the point of data saturation, I made a-priori decisions about the minimum frequency of observations and interviews based on my read of the literature on qualitative methodology. Specifically, I conducted at least 3 interviews and at least 3 observations of families. If new data continued to emerge, I continued to discuss these issues via telephone until the point of data saturation.

## **Telephone Screening Interview**

Mothers who expressed interest in the study called the number displayed on the flyer. Once contact had been made, a telephone screening interview was conducted in which I asked each mother if her child had been diagnosed with ASD. I also verified the age of the child (i.e., 3-5 years old) and that the child's caregiver was indeed the mother. If the child meet eligibility

criteria (i.e. diagnosis of ASD, age criteria, and resided in the greater Washington, DC area), I encouraged mothers to participate in the study and provided the mothers with greater detail about the study including the purpose (i.e., to get a better understanding of the experiences of mothers rearing a child with ASD, parenting processes pertinent to raising a child with ASD, and the quality of the parent-child interactions). On this call, I also described the data collection process, which included several hours of audiotaped in-person interviews and a minimum of three observations of parent-child interactions, as well as the voluntary and confidential nature of the study. Mothers then informed me of their willingness to participate in the study; if they agreed to participate, a time was set up for the first appointment. Additionally, I asked permission to view the IFSP, IEP, or whatever other documentation mothers had about their child's diagnosis as a part of the study during our first visit. For the screening interview, all eligible mothers were compensated \$10 cash compensation on the first visit. Approximately 11 mothers responded to the electronic flyer. Five of the families did not meet eligibility criteria (i.e. child was over the age limit or family resided outside of the greater Washington, DC area) and therefore could not participate resulting in a total of six eligible families.

### **Home Visit # 1**

During the first home visit, mothers first read and signed the consent form. I then conducted a brief interview on the first home visit to get a general understanding of mothers' history with and their perspective on raising a child with ASD. Within the first interview, mothers had an opportunity to tell me about their families, their children, and how having a child with ASD influenced their family. I also created a schedule with mothers for subsequent observations.

**Home Visits #'s 2-4**

In home visits 2-4, I observed mother-child interactions in a less formal and unobtrusive manner for 1-2 hours. Two observations occurred solely in the home setting, and one occurred in a public setting. Copious notes related to parenting practices, parent and child behaviors, and routines were taken to aid in a deeper understanding of the experiences associated with raising a child with ASD (discussed in detail below). Mothers were paid \$70 at the end of home visit # 3.

**Home Visit #5**

During home visit 5, I conducted an in-depth interview that addressed parenting practices, parent perceptions, and parent goals for their children. Additionally, I administered a brief questionnaire to obtain background information. Establishing rapport with the mothers is important prior to obtaining personal demographic data, therefore this questionnaire was administered later in the data collection process.

**Home Visit # 6**

During the 6th and final home visit, the last interview was conducted with mothers to capture the meaning of their parenting experiences. Additionally, member checking was done to determine the accuracy of the researcher's interpretation of mothers' reports. Mothers were also given an opportunity to share more details with the researcher as this was the last phase of the study. Mothers were thanked and paid an additional \$70, for a total of \$150 for their participation in the study. Table 3 summarizes the procedures for this study, which are explained in more detail in the subsequent section.

*Table 3. Summary of Study Procedures*

Initial Phone Call	<ul style="list-style-type: none"> <li>• Screening questions</li> <li>• Explain purpose of study</li> <li>• Payment of \$10</li> </ul>
Home Visit # 1	<ul style="list-style-type: none"> <li>• Complete consent form</li> <li>• Interview # 1</li> <li>• Create schedule for visits</li> </ul>
Home Visit # 2	<ul style="list-style-type: none"> <li>• General home observation</li> </ul>
Home Visit # 3	<ul style="list-style-type: none"> <li>• Dinner time routine home observation</li> <li>• Payment of \$70</li> </ul>
Home Visit # 4	<ul style="list-style-type: none"> <li>• Public setting observation</li> </ul>
Home Visit # 5	<ul style="list-style-type: none"> <li>• Interview #2</li> <li>• Demographic questionnaire</li> </ul>
Home Visit # 6	<ul style="list-style-type: none"> <li>• Interview # 3</li> <li>• Member checking</li> <li>• Opportunity to share more</li> <li>• Final payment of \$70</li> </ul>

## **Methods of Data Collection**

For the purposes of this study, several observations along with in-depth, semi-structured, open-ended interviews were used. Following is a description of the content and process of these observations and interviews. This will be followed by a description of the brief questionnaire that was administered to mothers to garner demographic information.

### **Observation and Interview Settings**

A naturalistic setting is preferable and highly recommended for qualitative research (Corbin & Strauss, 2008; Daly, 2007; Isaac & Michael, 1997). Inquiring about the lives of mothers of children with ASD and requesting personal information about the family dynamics can be viewed as intrusive to some parents thereby making them more reluctant to opening up to a stranger. By removing elements that may potentially make the study seem contrived (i.e., gathering data in a laboratory), centering the study in more natural environments (e.g., the families' home, grocery store, or park) may alleviate some hesitation on the part of the mothers. Gathering data in a natural environment is known as field research and is optimal for observing how people behave (Daly, 2007; Mack et al., 2005). Thus, I conducted both the observations and the interviews for this study primarily in participant families' homes, with one observation occurring in a public place that the mothers selected.

### **Observation Structuring**

When attempting to garner a deeper understanding of the quality of the parenting experience, it is important to observe the interactions between the participants (i.e., the parent and child with ASD). Observations are a way to gather full descriptions of events as the researcher watches the events unfold in front of her eyes. Observing mothers and children interact and behave in real time allows raw honesty of reactions to be expressed; hence the

“truths” of their behaviors are unveiled. As a result, mothers do not have time to think about how they would respond to a situation but instead will respond in an organic and uncensored manner. Specific to parents of children with ASD, observations of the parent-child interactions can shed light on the daily experiences of these parents including their uncensored reactions to some of the atypical behaviors exhibited by their children with ASD.

For the purposes of this study, three 1-2 hour observations were conducted with each family in which I observed mother-child interactions in the home and a public setting (e.g., grocery store). Mothers were informed ahead of time that I would be accompanying them on an outing to a public setting (e.g., grocery store or park) during one of the observations. I did not participate in the observations which allowed me to serve in a passive participant capacity. This role as an observer - simply watching what is naturally occurring within the mother-child interaction - decreases the chances that I am influencing the outcomes.

During these observations, field notes were taken to describe systematically and comprehensively what was happening in the field with the goal of capturing the most complete picture of what occurred in the observational setting. Copious notes were taken on several factors within the field including but not limited to: 1) the physical setting, 2) participants interactions, 3) routines, 4) rituals, 5) temporal elements, 6) frequency and duration of certain acts, and 7) conversations (Corbetta, 2003). While taking notes, I was as specific as possible with my descriptive terms. In addition to writing about what was observed, I also wrote brief notes regarding my thoughts about what an observed event might mean. These notes are referred to as observer comments. Finally, I used the research questions as an aid in my determination of what to focus on while in the field.



## **Interview Structuring**

In-depth, semi-structured interviews were used to better understand the perspectives and life experiences of mothers of children with ASD as well as the meaning that they place on these experiences. A set of open-ended questions, which I devised based on my reading of the literatures on parenting and ASD, was used throughout the interview and served as a guideline to offer structure and organization to the interview process (see Appendix E). According to Daly (2007), “The main advantages of semi-structured interviews is that they can help to maintain a focus on the key research questions, they can serve as a resource or a reference point for interviewers so that they can concentrate on what is being said and then come back to the guide, and they can facilitate data analysis by generating data within some general domains” (p.144).

The study included an initial phone screening interview to discuss the purpose of the study and some background information on the mothers and children was also retrieved. If mothers agreed to participate after the screening phone interview and the family meet the requirements of the study, then three in-person audiotaped interviews followed. The goal of the in-person interviews was to gather concrete details about the experiences of mothers raising a child with ASD. These conducted interviews varied per mother given her schedule of availability. While some interviews spanned over the course of two weeks others were conducted over several months.

A series of three interviews were conducted per family. The first interview allowed mothers generally to tell me about themselves and how having a child with ASD has affected them and their families. The second interview provided mothers the opportunity to discuss in detail their experiences of raising a child with ASD. The third interview allowed mothers of children with ASD to reflect on the meanings of their experiences. Salient parenting responses

to children's behaviors throughout the observations and mother responses to questions in previous interviews that needed to be clarified lead to the development of new questions which I posed in the third and final interview. The stories told in the participants' own words helped me better understand the daily experiences associated with raising a child with ASD and the impact it has on the quality of the parent-child relationship.

As the data were transcribed and analyzed, the final interview at the home was conducted to verify the data through the use of member checks. Member checking serves as a method of determining validity and establishing credibility in qualitative research (Maxwell, 2002). To conduct member checks, I met the participant after analyzing the data and asked them if I am correct with the findings or whether some constructs need to be elaborated (Bogdan & Biklen, 1998; Ratcliff, 1995; Creswell, 2000). This additional information also allowed me to better categorize the data into appropriate themes and to depict a more accurate life story of mothers rearing children with ASD without misinterpreting the participants' perspective. During the final interview, mothers also had an opportunity to share information that they may not have provided during the previous interviews.

### **Interview & Follow-up Questions**

According to Daly (2007), the interviewer is required to initiate the conversation and to use open-ended research questions as a guide to determine the direction of the conversation. Participants' responses may require more probing on the part of the researcher to fully delve into the subject matter. In the current study, participants were asked several semi-structured interview questions to gain insight into the unique experiences associated with rearing a child with ASD. Probing questions that asked mothers to elaborate on their stories were also asked. Literature related to parenting children with special needs guided the format of the questions

used in the study. Additionally, capitalizing on Bradley's (2002) conceptualization, questions related to parents' provision of sustenance, stimulation, support, structure, and surveillance were posed in order to gain insight into the tasks that mothers perform during their daily interactions with their children with ASD.

### **Background Questionnaire**

In order to obtain background information about factors that may play a role in how mothers interact with their children with ASD and the contexts surrounding these interactions, a brief demographic questionnaire was administered to mothers. Information about the mother, the child, and the family was obtained.

### **Establishing Rapport**

It has been advised that the investigator is aware of the boundaries between themselves and the participant when conducting qualitative research. By virtue of being a researcher, I am cognizant of my position as an outsider. One way to address mothers' reluctance to engage in the interview process was for me to disclose some appropriate personal and professional information as well. This technique allowed the participant to feel at ease which is important to the interview process (Mack et al., 2005). Additionally, the conversational style and questions used received great attention.

When attempting to establish rapport, the goal is to be a good listener. My demeanor during an interview may convince a participant to either disclose or withhold information. For example, a participant may feel uncomfortable speaking to a stoic and emotionally cold researcher as compared to conversing with a friendly and emotionally warm investigator. When questioning participants on topics that may be emotionally charged such as their experiences raising a child with a disability and the quality of the parent-child relationship, adopting a

humanistic approach is more appropriate than having the participants feel like you have selfish intentions in talking to them. Additionally, the attitude that the researchers walk into the room with, the “vibes” that they emit, and body language are all associated with having a successful or ineffective interview.

### **Method of Data Analysis**

The overarching goal of qualitative research is to provide richly textured evidence that details the social life and activities of those studied (Mack et al. 2005). As a qualitative researcher, I was able to explore the phenomenon of parenting young children with ASD, and the significance that mothers give to these experiences (Emerson, 1983). The process of gathering information through verbal descriptions as provided by these mothers led to my discovery of categories and themes. Systematizing and categorizing of the raw data was the foundation of my data analytic approach.

In qualitative research, data analysis can be viewed as a systematic process of breaking down the material or “transforming the data” so that the connections between relationships within a system, for example a family, can be better understood (Wolcott, 1994). Immediately following the observations and interviews, I began analyzing the data to provide order to the data collection process (Lofland, 1971). Analysis of data included interpreting the data and making decisions about what factors were better in helping to discover the phenomena of interest (Daly, 2007). Therefore, the analysis process was critical throughout the stages of research, from beginning to end. Just as important is the software program used to organize large amounts of data into manageable and clear sections. The qualitative data analysis software known as ATLAS.ti (Release 4.2. Muhr, 1997–2000) was used to sort the raw data from the interviews and observations to allow me to search for patterns.

The analyses were conducted in several parts and included: (1) transcribing the notes from the interviews verbatim; (2) rewriting notes from observations in a clear manner; (3) using raw data to code for themes; (4) interpreting the data; (5) verifying the data; and finally (6) reflecting on the findings and data collection process. Audio-taping the interviews was helpful so that I was not distracted by having to take notes but instead I was able to be alert and focused on the conversation. My transcription of the interview verbatim allowed for a complete account of the exchanges to be available. Additionally, rewriting notes from and soon after the observations allowed me to gather and organize my thoughts about what just occurred and to fill in details.

Coding is the process of reviewing and organizing the raw data which can come in the form of words, phrases, sentences, and paragraphs, and assigning labels to the information (Miles & Huberman, 1994), eventually resulting in categories and themes. As themes begin to emerge, it is customary in qualitative research that the process of collecting and analyzing data be done concurrently (Daly, 2007). This concurrent activity allowed for potential changes in data collection to occur as the data were transcribed, categorized and analyzed. The fluid nature of the analysis process also allowed for relevant themes that are central to the study to emerge.

As the data continued to filter in, it was difficult for me to keep factors in order as the sheer volume of data was overwhelming. Daly (2007) acknowledges the challenges some researchers might encounter when attempting to reduce the many possible codes from the abundance of data. This refinement process is illustrated within the Daly (2007) "Diamond Model of Analysis" (p. 239). The process of analyzing data can be viewed as a diamond where the researcher progresses through four stages.

From the bottom of the diamond, upward, stage 1 involves examining the data and remaining open to the many possibilities for how to code the data. It is in this beginning stage that I remained open to the many possible ways of coding the data from the interviews and observations related to mothers experiences raising preschool aged children with ASD. Stage 2 is where the process begins to become refined and categories or themes are created to narrow the possibilities of coding. During this stage, I grouped codes with similar concepts in order to build meaningful categories. I compared themes across mothers of preschool-aged children with ASD from different families. In stage 3, also known as axial coding, the relationships between the newly created categories were then examined. This stage is intended to reconstruct the data in a meaningful way to better understand the experiences of the participant. It is within this stage I took a closer look at how the categories were linked to each other in order to get a better understanding of mother experiences. Stage 4 is the final stage of analysis and involved describing the story of the participants once the phenomenon of interest was fully studied. During this stage, I wrote detailed descriptions about the themes, using excerpts from the interviews and observations to serve as examples of the themes (see chapter 4). The stories told from these themes serve as reflections of mothers' experiences during their parent-child interactions.

Similarly, Charmaz (1983) and Straus and Corbin (1990) describe disassembling and re-assembling the data throughout the coding process to help sort and categorize the information. Three types of coding are used in qualitative research to reduce the amount of data and help narrow the range. The first wave of coding is known as *open coding* (as represented in stage 1 of the Diamond Approach discussed earlier). In this wave, I opened up the data and exposed the many possible labels that were buried within the raw descriptive information. Whenever a

meaningful segment of text was found in the transcript or field notes, I assigned a code or labeled that segment. After labeling the data, I was left with a large number of codes that needed to be organized and sorted into groups. Advancing to the second wave of coding known as *axial coding*, allowed me to group similar data together based on factors such as behaviors, interactions, routines, strategies, and conditions or constraints, thus resulting in the creation of categories or themes (represented in stage 2 of the Diamond Approach) (see Appendix G for a full list of Lewins, Taylor & Gibbs, (2005) codable factors in qualitative research). It is here that I began to make deeper connections between the resulting themes and ignored codes that were insignificant and irrelevant to the topic (represented in stage 3 of the Diamond Approach).

During the categorization process, Atlas.Ti was used to assist in organizing the codes into categories also known as “code families”. This process allowed me to group the codes according to shared characteristics. This grouping was defined by the comparisons across families that I wanted to explore in my analysis. For instance, in wanting to explore mother experiences raising children on the autism spectrum, one option was for me to compare mothers’ responses to their children’s maladaptive behavior. In another instance, I opted to identify the interconnection between child characteristics and mother-child interactions. Several categories were created based on the coding of the raw data (see appendix I). It is important to note that memoing also served useful when organizing the raw data. During the data collection and analyzing phase, my thoughts regarding the interactions as they unfolded or post transaction were written down in the margins of the field notes. An important step in qualitative inductive logic is for the researcher to jot down her ideas and observations (Emerson, Fretz, & Shaw, 1997). This practice allowed me to identify the patterns and connections that emerged, which I later compared and contrasted.

*Selective coding* is the third and final wave of coding. During this process, I was able to develop a single storyline and hone in on the central issue or phenomenon (Charmaz, 2003) (represented in stage 4 of the Diamond approach). When building a theory that is grounded in the raw data, selective coding allows for a single core theme to surface while linking all other emerged categories to that core theme. In other words, selective coding strengthens the theoretical claim in that it allows the researcher to select the core category that helps integrate all other categories, thus propelling the story further (i.e., highlighting the central issue which can lead to new data on parenting children with ASD). I was thus able to create a central theme to which all my data were linked.

### ***Trustworthiness***

In conducting an in-depth, exploratory examination of an understudied phenomenon, qualitative researchers consider the role of trustworthiness. Qualitative research is informed by human perceptions of their realities, thus preconceived judgments or biases can serve to threaten the truthfulness of the data. In order to help establish confidence in the trustworthiness of findings in qualitative research, Dezin & Lincoln (2003) describe the importance of four factors: credibility, transferability, dependability, and confirmability.

Credibility refers to whether the findings of the study are believable and convincing which can be established by several methods. The three methods included in this study to ensure credibility were member checking, triangulation, and peer debriefing. The first method (which was described in detail in a previous section of this chapter) involved returning to the participants once the data had been analyzed to check whether my interpretations of the findings were correct. The latter two methods allowed me to pursue data verification; I used multiple techniques to assess accuracy and truthfulness of the data. When attempting to establish



credibility of the findings in qualitative research, the methods of triangulation and peer debriefing are often used. I used both these methods to increase the credibility of the data that I collected and to ensure that my research on parenting young children with ASD was rigorous.

Of the four different types of triangulation methods outlined by Dezin (1970), I opted to employ the form of *method triangulation*. This approach involved using various procedures to study a phenomenon (i.e., interviews and observations). In the current study, mothers participated in interviews about their parenting experiences and practices, which were verified through direct observations of their parenting interactions with their children. By employing the use of interviews and observations, a deeper understanding of what it is like to parent a child with ASD was obtained.

*Peer debriefing* was done to gather feedback from impartial colleagues about the study with the goal of enhancing the truthfulness or credibility. In addition to discussing the findings with my advisor on a weekly basis, I also consulted with one insider peer (an individual with prior experience with the topic of study) and one outsider peer (an individual with little to no exposure with the topic). According to Lincoln and Guba (1985), peer debriefers serve as “external checkers” of the data collection and analysis process (p.301). In qualitative research, the researcher is an instrument as they are the ones gathering and analyzing the data. Therefore, subjectivity is a threat to the accuracy of the study and must be avoided. By soliciting comments from my two peers, I was able to identify any potential biases that I harbored and to address preconceptions prior to interpreting of the data.

For the current study, I invited two colleagues to serve as external checkers. Both individuals had experience with the qualitative data analysis process. During the peer debriefing sessions, the colleagues examined and coded the transcripts from the interviews and field notes

from different families using a codebook that I had provided based off of the codes generated from reviewing the data. The discrepancies were discussed in a follow-up conference call. Consensus was met regarding the addition or deletion of certain codes and definitions in the codebook in order to make the codes universally understood and to present meaning to the raw data.

A similar process was conducted in my weekly research laboratory meeting. Each lab member was provided a page from a transcribed interview along with the codebook. They were instructed to review the data line-by-line and to utilize the codebook to generate codes. We then discussed their findings as a group which resulted in adjusting the codebook to better reflect the data. In both instances, the peer debriefers also offered feedback on the study, including the strengths and weaknesses of the research. Additionally, suggestions for ways to better detail the stories of mothers raising preschool-aged children with ASD was solicited.

In addition to considering *credibility* through member checking, triangulation, and peer debriefing, qualitative researchers also suggest consideration of transferability, dependability, and confirmability when establishing trustworthiness. *Transferability* refers to the findings being similar to other contextually comparable settings and that other researchers' can apply the findings to their studies. *Dependability* addresses the consistency of the findings over time. Finally, confirmability ensures that the process of data collection, including the findings and interpretations, can be reviewed by others and verified (Bowen,2005; Denzin & Lincoln, 1994). I considered each of these issues as I was analyzing, summarizing and interpreting my data.

### **Ethical Considerations and Reflections**

One way to get a better understanding of the realities of families is to consider epistemology when conducting research. Epistemology is the study of knowledge with the goal

of determining accurate reflections of reality versus assumptions of reality. While conducting this qualitative study, I did not have a clear idea or knowledge about the particular phenomenon of interest, nor did I strictly adhere to a fixed process when gathering and analyzing the data. Rather, I made changes in the gathering and analyzing process as the data evolved. Therefore, I had to be flexible with regard to determining mothers' perceptions about parenting children with ASD. In essence, epistemology encourages investigators to reflect on their assumptions about participants' perceived realities and to consider the integrity of research, which I did throughout the study.

Conducting qualitative research is complex in that there are no set formulas on how to proceed but only guidelines in the literature. Moreover, the researcher is viewed as the "instrument" of data collection and must report on the phenomena under investigation in an objective manner. A goal for the current study was to gather the data while having little to no influence on the participants' accounts of their reality thereby assuming an objectivist position. However, my implicit and sometimes explicit beliefs, biases, and viewpoints may threaten my objective goals. To combat this threat, it was crucial that I was cognizant of my assumptions and how my behavior impacted the inquiry. I reflected on my role as a researcher throughout the data collection and interpretation process. Being aware of the multiple influences I have on the research process is known as reflexivity (Daly, 2007; Glesne, 1999). During the research process, I jotted notes detailing my experiences with the families and reflecting upon how my own values were shaping my thoughts and behavior.

Beyond reflecting on my role, I also considered other ethical obligations when engaging families. Participants' rights, well-being (physical and psychological), and privacy was protected throughout the study. Moreover, when attempting to gain a deeper understanding of

parents' experience when raising a child with ASD through the interview format, I remained cognizant that I may have had to disclose personal information about myself in order for parents to feel at ease with me and open up. Therefore, I did not deceive parents by misrepresenting myself, and my statements to them were always truthful. Additionally, after gaining these mothers' trust, I conducted a follow-up interview to confirm that my interpretations of the findings were correct and that their stories were told in an accurate manner.

I informed the participants of the purposes of the study, the voluntary nature of the study, and received consent prior to conducting the observations and interviews. Additionally, families were given code names as opposed to using their real names to protect their identities. Their data was kept in a locked cabinet and on a password protected computer. Finally, I did not discuss any facts related to the study with other families.

### **Conclusion**

The unique experiences of individuals who are parenting a young child with ASD have received limited attention in the parenting literature. Specific parenting practices and parent-child interactions in families in which there is a child with ASD have not been well studied, thus the voices of these caregivers have been muted. Conducting a qualitative inquiry provided me with a deeper understanding of the realities of these families. The use of interviews allowed mothers to discuss their perceptions of their parenting, and observing the parent-child interactions in-situ allowed me to establish more credibility for the study. Through this approach, I profoundly expanded my knowledge about the practices and behaviors of mothers with preschool aged children who have ASD.

## CHAPTER IV

### Findings

The purpose of this qualitative study was to investigate the parenting practices and behaviors among mothers who have children with Autism Spectrum Disorder (ASD). Additionally, of direct interest was illuminating the unique experiences of mothers raising children with ASD as well as maternal perspectives on the parenting experience. This chapter begins with a description of the participants in the study, and a summary of their narratives. Following these descriptions, I discuss themes and subthemes that emerged based on the data obtained from interviews and observations.

#### **Mother Descriptions and Narratives**

The following section is a brief description about each mother, her description of her child, and how having a child with an ASD influenced who she is overall and as a parent more specifically. To protect their confidentiality, the names of the mothers and their children have been changed. All three interviews per family were conducted in person at their homes. Each mother willingly opened up to share their experiences.

#### ***Anastasia***

Anastasia is a 32-year-old African American unmarried mother of three children. She has a 4-year-old son, Alex, who has been diagnosed with Autistic Disorder. Alex was first diagnosed at the age of two. When asked about her initial reaction to the diagnosis, Anastasia stated:

I kind of already knew. I started noticing differences between his progression and the other kids' progression so I was online trying to figure out what kind of delay I was

dealing with. When we got the diagnosis, it was confirmation for what I already knew. It was a relief but it was hard to digest at the same time because then you have to figure out how to revamp what you're used to doing to accommodate a need that you're not familiar with dealing with. I had mixed feelings. I never really felt sad. It made me more determined to try to find help for him and getting into the world of autism, talking to people, and looking for resources...

Anastasia is a single parent with a full-time job. Her children are active in extracurricular activities which she chauffeurs them to during the week as well as on the weekends. Her mother provides assistance by babysitting the children when her work schedule conflicts with their afterschool schedules (e.g., children walk to grandma's house after school until mother is able to pick them up after work). Although appreciative of her mother's assistance, Anastasia feels as if she is best "equipped" to raise her children, especially Alex given that she spends a significant amount of time with them. This feeling is expressed when she is asked how she currently feels about the diagnosis. She stated:

I have my moments when it's overwhelming because my biggest fear is something happening to me before he or my older children are at age where they can fend for themselves. What happens to him when I'm no longer here? I feel like I'm best equipped to deal with him as compared to everybody else that's in his life. I have a lot of worry and fear about the quality of his life. I feel more fear now than anything else; not knowing what things are going to be like for him. I think about that a lot.

Her feelings of being the "best person for the job" stem from her concerns about the quality of life Alex currently experiences, as well as his future. Although expressing feelings of being overwhelmed, Anastasia views her son Alex in a positive light by describing him as an

affectionate, mellow child who displays his affection through voluntary distribution of hugs and kisses to his mother.

According to Anastasia, the warm interactions stated above, coupled with other more challenging interactions with her son Alex (e.g. getting upset and throwing himself on the ground), have influenced who she is as an individual. She stated:

Having something that came from me and I watched it grow and I'm helping to mold into somebody is most rewarding to me. Having Alex has definitely given me more patience and how to be accepting of other people and situations that they may be going through.

In terms of her parenting, Anastasia expresses that she adopts an ever changing flow of her parenting approach and adjusts given the context of the situation. She stated:

I guess I never really thought about a parenting style for myself. I just kind of do what works for us. It's kind of free flowing...I've had to alter a lot of things since he's received his diagnosis, but I couldn't really give you a particular style. Things flow.

### ***Briana***

Briana is a 41-year-old African American married mother of five children. She has a 5-year-old son, Bobby, who has been diagnosed with PDD-NOS. Bobby was first diagnosed at the age of 4. When asked about her initial reaction to the diagnosis, Briana stated:

It wasn't shocking because we knew something was going on. Anytime a parent finds out information of any sort that's out of the norm, it kind of hurts a little bit. We had to digest the information once we received it, but we weren't the type of parents that were in denial or we had to get a second opinion. We knew off hand based off of having four other children and seeing the way he interacted and the things that he did or didn't do...It

just didn't all add up to me. My husband seconded that and we decided to take the step to have him evaluated.

As a stay-at-home mother, Briana has home-schooled her own children and other non-familial children prior to their official enrollment in preschool and kindergarten. Therefore, she is familiar with children's typical displays of behavior, appropriate time periods for reaching developmental milestones, and young children's cognitive abilities when processing information. Given this knowledge, when asked to explain how she currently feels about the disorder, Briana relates her feelings to what she observed in her son's behavior while assisting him with homework. Briana stated:

It's accurate when you look at Bobby. I recently had a parent say, "Well, he doesn't look like he has autism," and he doesn't. He looks at you when he talks to you. He doesn't show those immediate signs, but when it comes down to doing homework... I couldn't get the information back from him that I would give to him and that brought up a great concern especially when you're spending a great amount of time one-on-one with a child. So now I'm comfortable with it [the diagnosis] because it helps him in the school system. I just didn't want him to go to school and not have the proper tools or equipment to help him in the situation that he's in.

According to Briana, her son is a rambunctious little boy with a soft side who enjoys giving hugs to his mother. When asked about how Bobby has influenced her as an individual, Briana responded by saying:

Oh my goodness. It has humbled me. It has shown my vulnerable sides. It showed a part of me that I didn't know existed. It has shown me some of my greatest fears. Some



of my fears were outside people looking at us a certain way or being judgmental. It opened up all of those doors.

When describing herself as a parent, Briana again mentions the importance of academics. Although steadfast in her belief that academics comes first, Anastasia also reveals the playful relationship that she has with her children which extends to other children (i.e., other family members and neighborhood children). She stated:

As a parent...I'm very active in my children's school career...I teach other kids and sometimes watch some of my friend's children... Summer is the busiest time of year for me because everybody wants to spend the night. It's really hard telling kids no especially in the day and age that we live in when society is really rough out there. This is like a safe haven during the summer time not only for my children but nieces, nephews, and friends. We spend a lot of time together.

### *Cynthia*

Cynthia is a 35-year-old Asian American married mother of two. She has a 4-year-old son, Charles, who has been diagnosed with Asperger's Syndrome. Charles was first diagnosed at the age of 3. When asked about her initial reaction to the diagnosis, Cynthia stated:

It was really hard but when we went in to get the diagnosis, I was pretty sure that he was going to get the diagnosis because I had done so much research online... We went in kind of already knowing but just needing the confirmation. But it was weird because even though they said, "Yes, we think he has this diagnosis," it still was a sinking feeling."

Currently, she feels that the diagnosis is that of a correct one; however, there are times when her trust in the accuracy of the diagnosis wanes. She stated:

I feel like he's on the spectrum...I think I've come to terms with it more but there's kind of a blurred line. He's progressed so much. This past weekend I had one of my best friends from college stay here. She has three kids of her own and she was like, "I really can't tell that he has an ASD." I told her some of the things and she was like, "Well, my brothers were really quirky but they're typical." So, it's gotten to the point where sometimes I feel like maybe he's closer to typical but then other times if he doesn't get enough rest or something happens, I just feel like his behaviors are so autistic [emphasizes the word "autistic"]. I just can't take this...

Cynthia's description of Charles' personality adds to her confusion about his diagnosis. She stated that he is cheerful, inquisitive, and bright but has trouble interacting with peers especially on the playground. "I don't know if that's a spectrum thing or a personality thing." Despite her confusion, Charles' personality and Cynthia's interactions with her son have undoubtedly influenced who she is. They have made her reflect more on her responses to her children's behavior which in turn impacts her parenting of them. According to Cynthia, when describing herself as a parent:

I think that I'm a really hands-on parent...I stay home with him so right now I'm not focused on my career. [Cynthia has a part-time job for which she works remotely from home]. I used to [work full-time]. I am an accountant by training. I'm able to stay home now which is a real blessing because I know not all families can do that. I'm very involved. I consider myself really supportive and loving although I have my faults. I could always use more patience and forbearance. Having children in general is a real test. It really tests your patience in so many ways. I hope I'm doing a good job, [pause] my best.

*Danielle*

Danielle is a 39-year-old Caucasian married mother of two children. She has a 5-year-old son, David, who has been diagnosed with a Asperger's Syndrome. David was first diagnosed at the age of 4. When asked about her initial reaction to the diagnosis, Danielle stated:

Well, it was kind of a gradual thing because we had a bunch of conversations like maybe this is what's going on or we think this is what's going on. At his four year check-up, his doctor said yeah I think he's on the spectrum and she filled out paperwork that then triggered the process through the school. I think there's a part of me that had been holding out hope that that wasn't really it, that there was something else going on. Even though it was a drawn out process it was good to know that the 'thing' had a name but at the same time it was like oh (looks disappointed).

Danielle appears to be adjusting well to the diagnosis. She stated:

In some ways, I feel lucky that we diagnosed it sooner and he got some services. So, that way I feel really grateful because it could have been easy for us not to realize depending on what kind of setting he was in and all that. I feel fairly hopeful because there are times where I get glimpses of how he could connect with peers and really enjoy it and get a lot out of the experience. It's not the kind of gloom and doom scenario that sometimes happen especially when the first diagnosis is given like, "Oh he's never going to connect with a fellow human being," or "He's not going to form relationships and friendships and this is what makes me so happy in my life." At the beginning, I had this gloom and doom thing and I feel more hopeful than I did a year ago

Danielle's positivity about the diagnosis can also be seen in her description of David's personality. "He's an easy-going, funny kid...with a good amount of intellectual curiosity. Danielle openly discusses how her son has influenced who she is. Statements such as, "It's made me more empathetic towards human kind. It's made me better at not reacting immediately but taking a step back and taking a deep breath and saying, "Rather than escalate the situation, I just need to chill out for a moment and be patient" show how interactions with her son have shaped Danielle's feelings about and towards others. Additionally, Danielle has expressed how raising David has given her an "understanding that people are just really different. People have different needs. What makes me happy does not make other people happy. What they need is not what I need." This understanding that people's needs vary and that patience is a virtue is evident in Danielle's description of her parenting. She stated:

I like to be responsive. I try to be nurturing and ask a lot of questions. [I] stay calm and try to connect emotionally and stay relaxed... I parent the way that I am as a human being. I consider myself pretty warm, friendly, interactive, and playful...

### ***Erica***

Erica is a 41-year-old African American married mother with one child. She has a 3-year-old son, Elijah, who has been diagnosed with an Autism Spectrum Disorder. Elijah was first diagnosed at the age of 2. When asked about her initial reaction to the diagnosis, Erica stated:

I didn't accept it. I was upset. I talked to a couple of friends and they were like, "You don't have to accept the diagnosis. Get a second opinion... I didn't know what to do at first. We knew that we had to contact somebody. They suspected that he had autism but...the stuff that they were saying didn't make sense and we brushed it off. We

researched it more and figured out, “Oh, that’s what they mean.” We said, “Maybe he just hasn’t developed yet. He was born so early so maybe things just didn’t come together yet.” Even now, I’m still not sure. I say that maybe when he turns 4-years-old, he’ll be talking fully

Erica still does not believe wholeheartedly in the accuracy of the diagnosis and appeared uncomfortable discussing it with me. At times she appeared to be thinking about the answer before responding. When asked how she feels about the diagnosis today, Erica replied, “Well, I’m still not really sure if that’s what’s wrong sometimes. He hasn’t acted up like that since he was two.”

When asked to describe Elijah’s personality, Erica succinctly stated that he is a happy and observant boy who is a picky eater. The later description has appeared several times throughout the interviews. Elijah’s adverse reactions to novel foods have served as points of contention in the mother-child interactions. According to Erica, “I used to give in to him, but now I just stopped. Sometimes I’ll hide it under something that he already likes and gradually give it to him that way.” Erica’s method of responding to her son’s unwillingness to try new foods is a clear example of her parenting. Having lost two children in the past, Erica is hesitant to bring negativity to the parent-child interaction by coercing her son to do something that he shows a clear adverse reaction to. Erica exerts control when needed, but exhibits great amounts of warmth throughout her interactions with her son.

When asked to describe her parenting, Erica stated, “This is my first child [referring to a viable pregnancy and having had this child survive the perinatal stage]...It was a difficult pregnancy. He was born at 26 weeks and I guess I just make sure I do everything I can for him.” Erica stated that her interactions with her son have also brought her closer to God. Throughout

the interviews, she has mentioned praying every night and taking a step back to take a walk and talk to God when she feels like she is at the brink of losing her cool. “I just pray every night about his condition ever since he was born...sometimes I just need a moment. I take a walk outside, read a scripture, and pray.”

### ***Fatima***

Fatima is a 39-year-old Caucasian married mother of two children on the autism spectrum. She has a 3-year-old son, Fabian, who has been diagnosed with Autism Spectrum Disorder. Fabian was first diagnosed at the age of 2. When asked about her initial reaction to the diagnosis, Fatima stated:

I knew it...It wasn't a big deal. We went into having a second child expecting him to be autistic. If he wasn't, I actually was wondering how am I to parent a neuro-typical child because I don't know. It did not surprise us when we began seeing the behavior pattern at 12 months because we saw it in our first child.

When asked about her current feelings about the diagnosis, Fatima stated:

It's no big deal. It's tiring. A lot of people don't understand. When you talk about everything that goes into an autistic child, it sounds like your life sucks. I had a friend invite us out and I had to tell her that we don't take Fabian to places that aren't baby proof. He gets into things, we're chasing him around, and it's not fun for us.

Although stating, “It's not a big deal,” Fatima continues to discuss the gravity of the effects that the disorder has had on her and her family's lives. Limiting her public exposure is a direct effect of her son's disruptive behavior while in public. When asked how this makes her feel, Fatima replied:

I started doing things on my own. My husband doesn't ever want to go out so he gets stuck watching the baby (referring to Fabian). I go out to lunch with my sister or I go and get my hair done. I can deal with that. I learned that it's hard for me to stay home all of the time so I at least get out once or twice a month.

Fatima's descriptions of Fabian's personality include the more challenging factors that make it difficult to attend a public event with him; however, she also discussed the positive traits that keep her smiling. She stated, "He's quick to anger and strong-willed. He's also affectionate and has a good sense of humor." When asked how Fabian has influenced who she is, Fatima's immediate response was related to her parenting. "It makes me a better parent. I feel like I advocate more for my children with autism more than I would for a neuro-typical child."

Fatima's dedication to parenting is evident in her statement about her description of herself as a parent. When asked to describe herself as a parent Fatima began discussing her boys and their participation in therapies thus centering the conversation on her children. "We do a lot of therapies. Fabian's brother is only doing physical therapy now. Fabian is doing infant-toddler three times a week and speech and physical therapy. He needs to do OT [Occupational Therapy], but there's nothing around here..." She neglected to discuss her parenting behavior until I asked her again to specifically describe herself as a parent. This child-centered response highlights the priorities in Fatima's world (i.e., her children), and discussions about who she is appear to be an afterthought. When bringing this observation to her attention during the interview Fatima stated:

I go straight to my kids. That's your life as an autism parent. It's your kids. So, right now I'm about to go see my back doctor because I'm in so much pain. It's gotten to the point where I don't have a choice. I feel so bad. And the last time I went to the doctor was two years ago; whereas, I am constantly taking the kids to the doctors, specialists,

and therapists. So, I just put my own health to the backburner and that's just my mindset. Once you start the autism journey, that's your mindset.

### **Themes**

Conducting interviews and observations shed light on the realities these mothers face, including factors that play a role in their abilities to adjust to the diagnosis (e.g., child behavior and positive attributes, coping strategies and spiritual support). Each of the mothers in this study spent hours recalling their experiences and detailing their perceptions with respect to parenting their children with ASD. They described the many positive interactions they had with their children, their level of adherence to a schedule or routine, the strategies employed to keep their children focused and cooperative, and their responses to their children's maladaptive behavior (e.g., tantrums). Mother-child interactions including mother responses to their children's behavior during their parent-child interactions were also observed. The purpose of the observations was to allow additional information about the parenting process to be obtained thus documenting the family dynamics.

The data described herein reflect mothers' experiences and behaviors rearing children with ASD. In the following sections, I describe the themes that emerged from mothers' responses to the semi-structured interviews and my observation of their behaviors while interacting with their children. These themes are organized by research question.

#### **Research Question 1: What are the parenting practices and behaviors that mothers use with their preschool aged children with ASD?**

For research question # 1, four major themes emerged from the detailed accounts of mothers' experiences related to parenting preschool aged children with ASD, and observations of



mothers' behaviors with their children. These four themes – positivity, schedules, strategies encouraging child cooperation, and crisis management – along with subthemes that emerged for each of these themes, are discussed in detail below (See table 4).

Table 4

*Relevance of themes in mother-child relationship*

<b><u>Question # 1</u></b> <b>What are the parenting practices and behaviors that mothers use with their preschool aged children with ASD?</b>				
<b>Participant</b>	<b>Theme</b> Positivity within the m-c relationship	<b>Theme</b> Schedules or Routines	<b>Theme</b> Strategies encouraging child cooperation	<b>Theme</b> Crisis Management
<b>1. Anastasia</b>	X	X	X	X
<b>2. Briana</b>	X	X	X	X
<b>3. Cynthia</b>	X	X	X	X
<b>4. Danielle</b>	X	X	X	X
<b>5. Erica</b>	X	X		X
<b>6. Fatima</b>	X	X	X	X

**Theme 1: Positivity within the mother-child relationship**

Parents in the current study asserted that caring for a child with special needs such as ASD can be very demanding. However, they emphasized the positive nature of their experiences with their children with ASD and that there were many rewards they received that are often times overshadowed by discussions of challenges. Mothers in the study discussed several gains that are directly linked to their children with ASD, chief among them being increased patience.

***Increased patience***

When asked about the rewards associated with raising Alex, Anastasia responded:

It's definitely taught me a lot of patience. And I guess how to be accepting of other people and situations that they may be going through...I was that person that would see a child throwing a temper tantrum in a store a be like, "Oh, she needs to tear that butt up," but now that I'm on the other side of it, I realize that that child may not have been throwing what we see as a tantrum, but he may have just been having a hard time processing what's going on in the environment that he's in and that was the only way that he knew to deal with it. So, my patience and my perception of other people's situation have changed tremendously since I have had Alex.

***Increased empathy and understanding***

Other mothers echo Anastasia's sentiments about the positive personal gains linked to raising a child on the autism spectrum. For example, Cynthia described how her understanding of other families of children with special needs and their experiences has broadened:

I do feel like I have gained, I don't know if empathy is the right word, but more understanding definitely of other people who have special needs children. It's really opened up a whole side to me where as now if I hear something like Asperger's or I hear ADHD, or I hear anything about special ed, I totally understand what they're saying.

Similarly, Danielle expressed her increased level of empathy as a result of parenting her 5-year-old son with an ASD:

... it's made me have more empathy towards other human beings in my life too. Parenting is really hard and I'm a lot less "judgey" of different people. I have a lot more empathy. Now if I see a kid acting out I don't automatically think it's the parent's fault. Kids are just kids. Sometimes kids have tantrums and it's nothing you did. It's made me more empathetic towards human kind. It's made me better at not reacting immediately but taking a step back and taking a deep breath and saying, "Rather than escalate the situation, I just need to chill out for a moment. Remember I love this person and they can't control what they're doing."

***Positive parent-child interactions and child characteristics/behavior***

Many of the mothers spoke highly of their children with ASD and shared warm expressions during their descriptions. The following quotations summarize the loving feelings that the mothers have for their children, the benefits associated with raising these youngsters, and the resultant positive interactions they have with them.

Anastasia: The thing that I like about his behavior is that he's a pleasant child. He has his moments where he gets stubborn or fussy but what kid doesn't? I'm blessed because I think his disposition could have been a lot different. I heard that autistic children don't like to be touched, but not my baby. He loves to be hugged. I give him hugs and kisses all of the time. He's very affectionate...that's my cuddle partner. He'll come and lay down and if he wants to watch Mickey Mouse we turn it on and just lay with each other. I enjoy those moments...I enjoy everything about him.

Briana: ...yes, he'll come and get me. He'll say, "I like your hair." If I get a new hairstyle he's coming to touch it. I'm like, "Oh, did you have to touch it?" You know how we are [laughs]. He notices something different about mommy. I had makeup on the other day and he said, "Oh, I like your lips." I love that. I didn't get that out of him before.

Briana also discussed Bobby's impeccable memory and tendency to repeat what was told to him. She was not stating that Bobby was ecolalic (defined as repetition of another person's speech) which is commonly associated with a disorder such as autism, but rather that he was still learning to speak and had yet to master the adult language. Briana stated:

Bobby will repeat stuff to us that we've said to him and it just makes it funny. He made up a word, "You're meaning." That's what he says when he thinks you're mean because you won't let him do something that he wants to do. He's a good kid. His behavior is good.

Bobby's sharp memory and how it served beneficial in his interactions with his mother was observed at the grocery store:

*Bobby reminded his mother to pick up sausages as requested by his father.*

Bobby: Mom, don't forget sausages for daddy.

*Given that Briana was not carrying a list, she was grateful that Bobby reminded her of this item and verbally praised him for his memory.*

Briana: Oh. Thank you so much for reminding mommy. You have such a good memory.

Mothers' responses to interview questions highlight the positive encounters they have with their children. Further, interviews and observations of their interactions with their children revealed frequent displays of positivity across families and contexts. During an interview Briana stated:

He has a soft side of him where he's concerned about little things. He's always giving me a hug. I recently had an operation on my hand and he checks it out every day. He says, "Mommy, it's almost done. It's almost done." There are little things about him that really just make your heart melt...to finally have that love reciprocated back to you because I didn't get that in the beginning. I didn't get the hugs. Even as a baby, I didn't get the cuddle from him because he didn't want me in his space. Now, he hugs me.

This softness in Bobby's demeanor was viewed after school during homework time:

*While in the middle of working on his letters on a child sized table, Bobby, who was sitting beside his mother on a child-sized chair, stopped and placed his head on his mother's shoulder. He then patted her back in a soft manner.*

Briana: Thank you for giving mommy a massage.

*He smiles and proceeds to complete his homework.*

Bobby's friendliness was also discussed by his mom, which was somewhat unexpected for her, given the difficulties that individuals with autism have with their social interactions. According to Briana, "...anybody who walks through that door, he's right there to greet you. He's our host. We love that about him. He wants to say hi. He'll speak to you." During my visits to the home, Briana and Bobby would greet me at the door with a warm "Hello" and a

smile. On one instance, while conducting a general observation in the home, a knock was heard at the front door:

Bobby: Mom, somebody at the door.  
 Briana: Don't answer it.

*Briana did not let Bobby run to the door and open it without her looking through the peep hole and confirming who it was. Her unwillingness for Bobby to answer the door appeared to be more of a safety precaution rather than her attempting to appear as if she is not home in hopes that the visitor would leave. Briana opened the door with Bobby right beside her. They were both excited to see the visitor.*

A glimpse of Bobby's friendliness was also evident during the public observation:

*While at the grocery store, Bobby sat in a child sized toy car that was attached to the grocery cart. As Briana pushed the oversized cart throughout the crowded aisles Bobby waved hello to people as they walked by. The strangers smiled and waved back.*

Bobby: Hi.  
 Briana: You're saying hi to everyone.

Cynthia also delighted in her son's friendly behavior and warm spirit. Charles' kind demeanor allowed his mother to appreciate her daily interactions with him. When asked to describe her son, Cynthia responded:

I think I've come to embrace his quirkiness. He's very smart. Sometimes he'll just say things and it's so amusing and so cute. I just love that about him and he just loves learning so much. He's a very happy and cheerful kid which is really pleasant when everything is going well. I have a friend whose son is really sullen and I realize that that

could be really hard because it could make him a little less lovable. You know what I mean? I think because Charles is so cheerful, it helps me as a mother to love him more. When he's acting up, I remember that he's actually a happy kid.

Danielle too spoke highly of her children, particularly emphasizing the positive attributes of her son with ASD - David. When asked to describe her son David, she stated, "He's very loving and affectionate which I appreciate." David's affectionate nature is not just directed towards his mother but to his father as well:

*During the public observation in a restaurant, David decided to sit next to his father. His dad left the table to use the restroom. Upon his arrival, David asked his dad to come with him to the buffet table.*

David: Dad, can you come with me?

*His father gladly walked with David. After returning to the table David gave his father an unsolicited hug.*

Danielle often discussed David's friendly disposition:

I like doing that kind of stuff with him and I like that he's affectionate. Did you hear him? He was like, "Mom, do you want some hugs and kisses?" He wants me to both chase him 'cause he wants to run around but he wants hugs and kisses and that's really cute. I love that" [said in a soft affectionate voice].

During a lunchtime observation conducted in the home, I witnessed how Danielle and David playfully interact. After taking a walk in the park, Danielle, David, and his infant sister met me at their home to allow me to conduct the observation.

*The father was in the kitchen preparing lunch which included a portion of peas. David walked into the kitchen.*

David: I'm going to steal peas.  
 Father: Stealing isn't good.  
 Danielle: David, you stole my heart.  
 David: No I didn't!  
 Danielle: It's just an expression. It means I love you.

*Danielle kneeled down on the floor to clean up some of the food that the baby spilled from her highchair. While on the floor David got on his mother's back. Danielle gently took him off of her back, sat with her legs crossed and placed him in front of her and gave him hugs and kisses.*

David: Mom, more hugs and kisses.  
*Mom continued to show him affection.*

Danielle: Should we hug for 63 more years?

David: No way!  
*Danielle turned her attention to his baby sister. David walked up to Danielle.*

David: Can I have more hugs and kisses now?  
 Danielle: As long as your dad keeps an eye on your sister.

*Danielle began to hug and kiss David while sitting at the table.*

Similar to Danielle's fondness of her son as observed and described throughout the interviews, Erica also described the types of behavior exhibited by her son that makes her smile.

She stated:



I like when he brings me a book and he'll say, "This." Sometimes he speaks very clearly.  
 Or even certain things that he does like take the wash cloth and throw it into the tub.  
 He sees me do it so it's a routine.

Throughout my observations of Erica interacting with her son, Elijah, I have only heard him say one word, "Yeah." Despite his communication delays, his desire to be in close proximity to his mother was evident. He often would walk up to his mother unsolicited.

*During a general observation in the home Elijah walked up to Erica while she prepared dinner. He leaned on to his mother and wrapped his arms around her leg. He followed her as she walked from room to room.*

This gesture of warmth (i.e., the gentle wrapping of his arms around her) coupled with his desire to be in close proximity to his mother are signs of positive interactions between the two. A similarly affectionate moment was seen between Fatima and her son Fabian. According to Fatima, the family does not like eating dinner at the table and prefers to "do their own thing" once dinner has been prepared.

*During the dinner time observation in the home Fabian and his mother were sitting on the couch watching television. Fatima brought Fabian his plate and sat next to him.*

Fabian: Hug.  
 Fatima: You want a hug?

*She placed Fabian in her lap, gave him a hug and continued watching television.*

Unsolicited moments of affectionate gestures were observed within each family. Children's expressions of love within their interactions with their caregivers have undoubtedly

influenced these mothers' behaviors in and perspectives of their parent-child relationship. For example, participants expressed how their interactions with their children have initiated a transformation in them to become greater, more caring human beings. When asked to reflect upon her experiences as a mother with a child on the autism spectrum, Anastasia stated:

It's a journey, it is, but to be honest with you, I don't think that I would change anything. The person that he is, is making me into the person that I am now and I don't think that if he was a typically functioning child that I would have made the revelations about myself and other people. You know, having him has actually made me remove some people from my life. If you don't have patience with my child, you're not the kind of person I want to be around. I wouldn't change it.

Similarly, Fatima spoke of what her life would possibly be like if her children were typically developing:

I would be a different person I'd think if I didn't have them. I'd be happier, but at the same time I wouldn't be so passionate, I probably would be bored, I don't know if I'd be such a good parent...it grounded me.

### ***Maternal provisions for stimulation***

Many of the mothers described ways in which they intellectually stimulate their children which included labeling items on flashcards and taping them to the actual object, providing a large clock to help child determine time, reading to children, encouraging fine motor skills through assistance with lacing and tying shoes, and purchasing developmentally appropriate toys. Statements like, "We have different things to stimulate him in the house like toys, play

dough, books, paint...and we have a rabbit to help him be gentle” show Briana’s efforts in ensuring that her son thrives in his environment. After a dinner time observation:

*Briana was viewed selecting two books from shelves that contained at least 50 books and began reading to her younger sons. Shortly thereafter, the roles switched as Bobby voluntarily took over and began reading to his mother and brother.*

Briana: Very good. Let’s go back and look at the pictures as we read so that we can understand the story.

*Throughout the reading, Briana posed several questions to her sons that encouraged higher order thinking (e.g., Why is the boy happy)? Additionally, she had the boys play a more interactive role by asking them to mimic the actions of the characters in the book.*

Briana: Where’s Sam? What is Sam?

Bobby: Ummm, Sam is a cat.

Briana: Good! What does a cat say?

Bobby: Meow.

Briana: Good. The cat hid from the children. Can you go hide behind the couch for mommy?” Briana emphasized the word ‘behind’ so as to teach her sons positioning in space. Bobby retreats behind the couch and hides.

Briana: Bobby is hiding behind the couch. I can’t see him.

*After completing the story, Bobby and his mother reviewed flashcards where he verbally labeled the pictures that were on each card. Bobby seemed familiar with this part of the evening as if it were a routine for him. Briana did not have to explain the rules to him or the purpose of the cards. Additionally, she engaged in parallel talk with Bobby where she talked about her*

*actions while performing them and her statements were not perfunctory in nature.*

This example highlights mothers' desire to provide an enriched environment to their children with ASD. Briana also created opportunities for stimulation in environments that may otherwise seem mundane. For example, while strolling down the aisles of a grocery store, Briana kept her son focused and engaged by allowing him to take items off of the shelves for her as she labeled them.

Briana: This is an onion.

Bobby: Onion.

Briana: Put it in the bag. Mom emphasizes the word "in" as Bobby follows her directions.

Briana: Alright. Are you ready to go? The store is finished. The store is over.

Bobby: The store is finished.

*Bobby was well behaved throughout the shopping experience. At the register, Briana allowed Bobby to scan the coupons and assist in putting the cash in the checkout machine. Bobby smiled and appeared very pleased.*

It is evident that positive parenting and positive mother-child interactions exist among these families who have children with ASD, from the affection and warmth displayed as well as parents' efforts to promote their children's development through stimulation. The interactive behavior of mothers during some more challenging times (i.e., a child's strict adherence to a schedule or routine) surfaced during both interviews and observations with mothers adopting varied approaches to their children's idiosyncrasies regarding scheduling.

## **Theme 2: Schedules and Routines**

Many of the participating mothers discussed the rigidity hallmark sign of ASD and provided their method of overcoming any possible issues that may arise from children's strict adherence to routines. The *Schedules and Routines* theme encompasses this issue, and the multiple strategies mothers undertook to address children's behavior in this arena.

### ***Flexibility***

Many of the mothers discussed their unwillingness to abide by routines and instead embrace flexibility of their schedules in hopes that their child with ASD would be less inclined to develop unhealthy habits. These mothers' refusal to adhere to a routine in some ways serves as a protective factor for these children's emotional well-being and ultimately, the quality of the parent-child relationship. Anastasia, a mother of a 5-year-old boy with ASD described her reluctance to abide by a routine. When asked to describe a typical day in her life with Alex (her son), Anastasia replied:

Every day is different. I purposely don't keep him on a routine. That's one of my methods of dealing with autism. I know so many autistic children are so set on routines that if something goes on outside of that then they'll have a hard time processing it. I purposely do things different every day to get him adjusted to having to deal with different situation. The only thing that's the same is to come home and take his coat and shoes off. He can do whatever he wants after that.

Anastasia also noted how research suggests that children on the autism spectrum thrive when given routines, but this is not the case for her family. Because she is a single mother of three active children, the entire family must remain open to last minute schedule changes:

We don't really have routines. In all of the research and everything that I've been doing, it says routines are kind of crucial for autistic children, but for me, us not having a routine works better because there is nothing to break. There is nothing to set him off because things can be this way one day and different tomorrow. Because we do a lot, my daughter cheers, my son is in an afterschool program, I never know what my schedule is going to be like. So not having a routine actually works for us. It's not like that in our house because it's just me and the kids. So if one of the other kids has an emergency, we kind of all have to get up and go. So not having a routine in that respect works for us.

Another mother agreed with Anastasia's assertion that having a routine can hinder rather than smooth the process. For example, Briana, a mother of five children, highlighted the importance of flexibility in her family's schedule. She stated:

That's the thing, with my life it's never a routine. He's the fifth child so I have to accommodate every child...I don't have a routine day... I don't want him to get stuck in this one way of doing things...I got to go with the flow. Nothing is set according to a handbook. Things change every morning.

Briana's belief in flexibility was evident through her discussion of her driving directions while Bobby, her son, was in the car. According to Briana:

A lot of times we try to do things differently so that he can see things in a different light so he won't get stuck on one way of doing things. Sometimes it's the way we go home. Last night I didn't make the left turn that we normally make off of the exit. So when I made the right he was like, "Mommy, where are we going." So sometimes we do things

differently on purpose just so that he won't get stuck in that regiment... some things are routinely done for him but we try to switch things up as much as we can so he can adapt to change and transitioning much easier and it has helped a great deal.

### ***Rigidity***

Not all families, however, exercised flexibility in their interactions with their children, particularly because their children appeared to thrive on routines. For Cynthia, a mother of a 4-year-old child with Asperger's syndrome, this resonated with her. Cynthia stated, "Our days are very routine...to provide structure, we just try to be consistent...we just stick to the schedule."

Many of the mothers shared stories about the rigidity in their children's behavior and methods used to address such inflexibility. For example, although Briana refused to abide by a strict schedule given the size of her family (5 children) and their varying needs, Bobby's rigidity at times compelled her to respond to his behavior in ways that she would typically not have with her other four children. Briana's response to a question regarding flexibility served as an example:

Melissa: Is he flexible?

Briana: Bobby likes super heroes. My mom bought him a little short sleeve spider man shirt. Well he wanted to wear that thing every day! I was like, "Lord, I can't wash this thing every day. What are we going to do?" So...went to TJ Maxx. I went to the kids' department and they had a whole rack of super hero shirts for \$5. I took them in every color...this is for my son and he has to have one of these for every day of the week. It's okay to turn things around to make his world a little better.

Several of the other mothers discussed their appreciation of the routines and repetition that best serve their children. Cynthia described Charles' anticipation of an event occurring, however, his lack of understanding of time has him constantly inquiring about when the event

will take place. This frequent probing might influence the mother's interactive behavior with her son as these questions can lead to irritation. She stated:

...because of the resistance to change, he likes to know what's on the schedule. Let's say if we had a trip to the Baltimore aquarium planned, in that case I wouldn't tell him too far in advance because they have no concept of time. So he's like, "Are we going, are we going today?" So let's say we were going next week, I would have to be like, "No, no" for a week. So in that instance, just learning the best way to tell him something is hard.

Charles' resistance to change is also evident in Cynthia's recall of a conversation that she had with his teacher regarding her son's behavior:

I talked to the teacher one day and she said, "Oh, today we did something different and I could tell it affected Chris." I was like, "Really, like what?" So, they typically do their morning carpet, circle time, and snack or something, but instead she said it was a beautiful day so they went for a class walk and that was not in the schedule. So I said, "Did he act out" and she said, "No, but he looked completely lost."

Charles' confusion and reaction to the change in schedule was minor as compared to Erica's experience with her son. Erica, the mother of 3-year-old Elijah, shared her experience with her son's ability to adjust to change. She stated, "He's a happy child and if his routine is disrupted then he's not... If his routine was disrupted then he would lay on the floor and just kick, cry, and scream."



Mothers' discussions of their children's ability, willingness, and responses to change are expressed in the above statements as being challenging at times. Additionally, transitions can also be difficult to manage for both children with ASD and their mothers.

### ***Transitions***

Whereas some children in the study adjust well to their evolving schedules, others do not. Based on the differing child behavioral responses to change, it is clear that mothers employ varying strategies to alleviate the potential negative outcomes associated with rigidity. According to data from interviews and observations, the ways in which mothers introduce change to their children with ASD are crucial. Danielle is the mother of David, a 5-year-old boy with Asperger's syndrome. Although she described her son as adjusting well to transitions, the onset of her child's meltdowns as triggered by a transition is difficult to predict:

...everything is new to him. He transitions well with that sort of thing...it was never a huge struggle when he had to go to school or even change school. But, he went to a Tuesday one hour drop-off tumbling class two years ago and that was an epic struggle. The one hour tumbling class was a lot harder to get him to go versus going to school every day.

During Danielle's discussion of her inability to predict her son's meltdowns, she vividly recalled when she was pregnant with David's younger sister and was highly concerned about the labor process. The thought of leaving David with a relative for a couple of days without providing him sufficient advanced notice weighed heavily on her.

That was the hardest thing when we knew we were going to be gone for a day or two for his sister's birth. We couldn't prepare him for that transition. We talked about it a lot but couldn't tell him it was happening on a Monday. That was really hard about being

pregnant; we couldn't say one week from today we're going to be gone for a couple of weeks. We couldn't do that. We had to flag that it was going to happen but we didn't know when it was going to happen. We didn't know when the labor was going to start. He did better than I thought he would.

Danielle's desire for overall smoother transitions was shared by Fatima, a mother of two children on the autism spectrum. When discussing her 3-year-old son's ability and willingness to transition, she addressed her concerns not just for herself and her son, but for anyone that spends a significant amount of time interacting with him.

I want him to work on transitioning. I want it to be smoother for me, my husband, the teachers, my dad, or for anyone that's caring for him... he's not dumb, he just doesn't want to do it. He knows it's coming. It happens every day.

Transitions were discussed by some participating mothers as being challenging at times. To address these and other issues related to child behavior, mothers described strategies to encourage cooperation from their children during their interactions. These strategies are discussed below.

### **Theme 3: Maternal strategies linked to child cooperation**

As aforementioned, mothers' adherence to a strict schedule varies and, according to the data, so does their approach to addressing child misbehavior and inattentiveness. As seen in multiple contexts within the mother-child relationship, strategies employed to encourage appropriate and acceptable behavior include, but were not limited to, disciplining the child (e.g., placing him in timeout), redirecting the behavior, offering incentives, using a timer, and coaching. Many parents highlighted the behavior that they wished to change along with the typical outcomes associated with each strategy.

## *Discipline*

When discussing a typical day in her life, Cynthia mentioned her almost daily struggles to get Charles ready for school. She described in detail the micromanaging that occurs while her son is getting dressed due to his inability to stay focused:

Okay, Honey, get dressed. No, no, put your underwear on, now your pants.”

There’s just so much prompting. “Put on your pants.” I turn around and he’s off doing something else, “Have you put on your pants yet?” So there’s a lot of follow through which gets kind of old, fast!

A behavior chart was introduced at school to which Charles seemed to adjust well. Given the success of the chart, Cynthia decided to implement it in the home as well. She stated:

We have a behavior chart which they started at school and he likes it. If you’re doing a great job then you’re just on blue but if you misbehave or don’t listen, you get a warning. If you continue not to listen then the teacher will move your name down to yellow. It’s kind of a visual indicator to show you, “Uh oh, you need to make better choices.” He’s so fearful of getting on a different color and wanting to stay in my good graces, all I have to say is, “Mom is going to have to move your name to yellow,” even though I can’t even find the chart. I just have to say that. He’s like, “Noooooo” and then he’ll get dressed. It’s usually just motivating by the behavior chart.

Although the behavior chart appears to be successful, Cynthia admits that her employment of the chart is inconsistent and is typically used after a maladaptive behavior has been displayed:

I don't use it often, just really to discipline him, which is really sad. I should probably reinforce like, "Oh, you're on blue. You're doing a great job!" I forget that. I usually just use it when it's time to discipline.

Unlike Cynthia, Fatima opts for a time out method to correct her son's misbehavior. She stated:

I tell him, "You can't kick or bite." If he has his toys or Ipad or whatever it is that he wants, that gets taken away. It doesn't really work when I take it away because he starts screaming and then there's nothing else to take away. He gets time outs sometimes, but I don't know if they're working. He doesn't like them.

Fatima's employment of a disciplinary action was seen during the dinner time observation:

*Fabian, Fatima's son, stand on a child-sized table while dinner was being prepared.*

Fatima: Hey, get down. I don't want you climbing on this.

*Fatima removed her son from the table and repositioned the table to another location in the room. Fabian proceeded to make the sound as if he was crying, however, tears were not forming and he began to bite his mother.*

Fatima: No, biting!

*She then walked away from her son and continued preparing lunch in the kitchen.*

During an interview, Fatima expressed how she responded when her son misbehaved (e.g., bites her). According to Fatima:

I put him in timeout and I will hold his butt there. I'm trying to teach him that there are consequences. So I use a lot of "now this is a consequence because..." We'll stand behind him because otherwise he'll dart and it probably is about three minutes of him trying to get around us, break away, and crawl in between our legs. Finally, he starts

crying and gives up. I only keep him there for 30 seconds. Once it actually starts, I don't say a word. I tell him that time out will start once he actually stands. He faces the door and I'm behind him. Afterwards, he wants a hug and I tell him why he got time out.

One example of Fatima disciplining Fabian was seen after a trip to the mall:

*Prior to exiting the mall, Fabian wanted to continue riding a motorized helicopter. Fatima decided that he had been on the helicopter long enough and that it was time to go. Fabian began crying hysterically and Fatima carried him out of the mall and to the car. Upon arriving at the vehicle, Fatima withheld giving Fabian his Ipad.*

Fatima: You can have your Ipad when you calm down.

*After two minutes of disruption, Fabian eventually stopped crying and Fatima passed his Ipad to him in the backseat.*

### ***Talks to child/Redirection***

Anastasia and Briana are two mothers who decided to address their children's maladaptive behavior by talking to their sons and explaining why their behavior was unacceptable. For example, Anastasia discussed how she managed Alex's desire to jump up and down on the couch. She stated:

I'll take him down and place him on the floor. Typically he'll get right back on the couch. A lot of times he'll just leave it alone eventually, not because I told him to but because he's just wants to... I try to explain it to him the best way that I know how in a way that I think that he will understand it. Most of the time I'll just redirect it...Alex, it's a little bit different...because his brain works differently than theirs (referring to her other children). I can say to the older kids, go sit down and don't get back up...but Alex doesn't understand that so I...try to make sure I am making eye contact with him so that

he understands what I'm trying to ask him to do...and help him understand what's right and what's wrong.

Anastasia's typical response to Alex jumping on the couch was viewed in-situ towards the end of a home observation:

*While gathering my belongings and saying my goodbyes, Alex began standing on the couch.*

Anastasia: Alex, get down.

*Alex continued standing on the couch while fixated on the cartoon show playing on the television. His mother proceeded to walk over to him and physically remove him from the couch. She gently placed him on the floor to continue watching the show.*

Anastasia: You can't stand on the couch because you'll fall and hurt yourself.

*Alex complied and remained on the floor.*

In this particular example, Anastasia opted to explain to her son the potential danger of standing on the couch. Redirection was also evident during her interactions with Alex. In a separate example, Anastasia was observed redirecting her son's behavior:

*While Anastasia was bathing her son he began crying.*

Anastasia: He's crying because he thinks I'm going to wash his hair. He hates getting his hair wet.

Melissa: Okay.

*She began singing Alex's favorite songs to him to halt the crying as she gave him his nightly bath. His fear of having his hair washed disappeared and his mother's solo quickly turned to a duet.*

During an in-home interview, Briana also discussed how she typically responds to her son's maladaptive behaviors. In the following quote, she explained Bobby's tendency to run away from her:

It's a tedious task, but you stop what you're doing and handle it right away with Bobby ...so that he understands what's going on...whereas any other five year old, you sometimes can deal with it later. One of his big deals was running out to the street. I would have to stop what I'm doing and take him to the end of the driveway and tell him, "We do not run out to the street." I would have to give him my 'Mommy' look and use my 'Mommy' tone. I have to just drop what I'm doing. Forget the groceries right now because this is very important. He needs to know that this is a life or death situation...When he first started running out to the street he would laugh when I would talk to him about it. I guess he wanted it to be a game; he wanted you to chase him. In the beginning my kids would chase him. Everybody would say, "Bobby is going to be a track star." We thought it was cute but after a while, when it got real serious, we could no longer play with him. Now I do a lot of talking to him about it and that seems to work. If it takes five minutes to talk to him about it and we're in the middle of the parking lot at the grocery store then five minutes it's going to be; because if it's a matter of life and death...

This very issue was seen during my public observation with Bobby and his mother:

*After completing the observation in the grocery store, we walked out to the parking lot to load the groceries into the car. Bobby was standing next to his mother and suddenly ran away in the middle of a crowded parking lot on a Saturday afternoon. Briana and I quickly ran after*

*him and safely brought him back to the car.  
His mother stated in a stern voice,*

Briana: You don't run away from mommy. That's dangerous! I'm not happy with your actions. You can't watch the DVD in the car now. You have to listen to mommy. You scared me.

Although visibly disturbed by her son's actions, Briana kept her composure and explained to Bobby why his tendency to run away from her is that of a dangerous one. Bobby appeared saddened by his mother's scolding, whimpered a bit, and then sat quietly in his car seat.

### ***Incentives/Rewards***

Yet another approach employed by some participating mothers included offering incentives to their children for displays of positive behavior. For example, Briana used the fun-filled kid zone known as Chuck E. Cheese to encourage her son Bobby to: (1) stay focused while doing his homework, (2) increase his willingness to consume a variety of foods given his very limited palette, and (3) keep her son calm while in the dentist chair, among other topics discussed in the interviews and viewed during the observations.

A glimpse of reward offering from another participating mother, Cynthia, was observed when she wanted her children to eat carrots as a snack while dinner was being prepared.

*The children were in the living room watching a show on the Ipad. Cynthia walked up to them, handed them a carrot and stated:*

Cynthia: If you want to continue watching the show then you need to eat the whole thing.

*She walked away and the children complied without uttering a single word of resistance.*



This interaction serves as an example of how the Ipad was used as a strong incentive for healthy eating. During an interview with Cynthia, she discussed how her parenting of her children including providing rewards:

We're not very harsh discipliners, I think what we do is... a lot of incentivizing with rewards or taking things away if they don't do it. That's one of our main things with Charles is we have the chart and the stickers and if you try new food you can get this. So [we do] a lot of motivating.

### ***Employment of timer***

Setting a timer was also discussed as a means for Cynthia to encourage cooperation from Charles specifically during bedtime. When discussing how Cynthia manages the bedtime routine, she stated:

...typically he will always go but there's the resistant—"Oh, I want to keep drawing," so I usually set the timer when I'm trying to get the kids off to bed. I'll say, "Okay, kids you've got five minutes. I'm going to set the timer." I use that a lot.

Briana also employed a timer at times when interacting with her son Bobby. She stated, "I use the timer often. I tell him to give mommy five minutes. It may not be five minutes but he knows he needs to wait and come back later and ask again." While observing the homework process:

*Brian allowed Bobby to take a break halfway through to watch a few minutes of a movie as a reward.*

Briana: You get to watch your movie until 4:45pm. After that you have to come back to finish your homework.  
Bobby: Mom, it's 4:06pm.

*He then ran to the family room and began watching the movie.*

This specific occurrence is an example that combines the current topic, (i.e., use of a timer), as well as the previous topic of rewards and incentives. Interestingly, Briana did not set an actual timer, but rather kept track of the time in her head. Despite not presenting a tangible timer to Bobby, the intent remained the same. That is, she rewarded Bobby for the work already completed and provided him with a tool to hopefully facilitate a smooth transition back to homework time.

Cynthia's and Briana's use of the timer are just two examples of how some mothers choose to decrease the potential occurrence of disruptive behavior from their children during their interactions. Instead, employment of tools that aid in these transitions is just one of many strategies used by mothers of children with ASD to encourage cooperation within the parent-child relationship.

### ***Coaching***

Coaching was a strategy employed by mothers to increase displays of acceptable behavior. Danielle used coaching with her son David in hopes of fostering more positive peer interactions and more appropriate social behavior. According to Danielle:

...there's definitely some coaching and some things I try to do as a parent in the home or out. I do a lot of- "We're going over to so and so house, what can you say to them?" I prep him on conversational norms. I don't have to do that as much now as I did a year ago. "What can you say if somebody is playing with that toy and you want to play with it?" It's not as much about me wanting him to be polite but I want to give him as much coaching about what to do in those social interactions...

Danielle's concerns about David's lack of social skills and her coaching techniques surfaced during a dinner observation:

*Danielle was busy holding her 6-month-old baby and David wanted to play with his mother.*

David:        Want to play this with me?  
 Danielle:     I can't play right now because I'm holding your sister.  
 David:        Mom, don't hold my sister.  
 Danielle:     What's the polite way to say that?  
 David:        Mom, can you please not hold my sister?  
 Danielle:     Okay, I'll hand your sister to your dad.

This exchange, although seemingly simple, is an example of David's ability to initiate an interaction with his mother. This is especially important given Danielle's concerns about David's difficulties initiating social interactions with his peers. Hopes of David being able to transfer his social skills from the home setting into the school environment were expressed by his mother. This is not to say that David is completely socially astute at home, but rather, he appears more comfortable in a familial situation as opposed to a peer context according to his mother.

It is important to note that Danielle's coaching interactions with her son have evolved over the years. Instead of focusing her attention on the "how to," Danielle's strategy is now geared toward discussing the value of friendships with her son. She stated:

A year or two ago, I was doing more of the social interaction coaching. I don't do as much anymore. I more so talk about the value of friendships or remind him of those times where I could see that he was getting enjoyment out of interacting with peers. I more try to instill the values rather than talk about the techniques of it.

The coaching technique employed by Danielle was initially intended to assist her son in social settings, but has also been beneficial in preventing and/or discontinuing child behavior problems.

#### **Theme 4: Crisis management**

During the semi-structured interviews, mothers explained the behaviors exhibited by their children that make it challenging to parent them. For example, externalizing problem behaviors along with impairments classic to this disorder (i.e., social-communication deficits and restricted and repetitive behaviors) emerged as influential factors in the parenting of children with ASD.

##### *Child emotion expression*

One way that some mothers address these problem behaviors (e.g., kicking and biting), is to allow the child to express and attempt to regulate his own emotions. For example, Erica discussed her son's meltdowns and factors that might trigger such aggressive behavior. She stated:

With him, I have to always be aware that he can have a meltdown... he can have a meltdown because his environment has changed. Or it could be that his routine was disrupted or he has to transition and do something different that he's not use to doing and he doesn't know how to deal with that... He may not react well to some things. I let him express himself.

Anastasia echoed Erica's statements regarding how her child adapts to changes in his environment as she expanded on the issue in her interview. According to Anastasia, her son's willingness to obey is not always guaranteed; during moments of disruption, allowance for space and freedom for Alex to express himself is granted. According to Anastasia, "He doesn't

conform to what you need him to do once he has it in his head that he doesn't want to be involved in an activity. I let him get his emotions out.”

Similarly, Fatima regularly allows her son Fabian to express himself physically, at home and in public, albeit stressful, time-consuming, and embarrassing at times:

He'll kick, bite, scratch, and pinch you. He'll bite the handle bar (referring to the cart at Target). He'll sit sideways [in the cart]. I just let him know that when he's done having his meltdown, we'll leave or he'll get his Ipad back. Once he's done, he's like, "Okay mom. Can I have my Ipad?" His meltdowns aren't that bad anymore. His longest meltdown was about seven minutes. That's not that bad but at the time it seems like it's three hours especially when you're out and about and people are looking at you. They're not really that long anymore; before they used to be 20 minutes.

### *Halting the tantrum in its track*

Unlike the mothers stated above, Briana's responds to her son's tantrums by halting the tantrum the moment it occurs. When discussing Bobby's behavior during church, his mother described how he would physically drop to the floor when he was ready to leave despite church still being in service:

We didn't want that to be a crutch for Bobby. We didn't want him to think that whenever he hit the floor that we would take him out of the room. So, after a while we stopped it. "Sit in the chair and get it together.”

Briana went on to discuss how Bobby's aberrant behavior of dropping himself to the ground was initially ignored but eventually the family began to address his behavior by explaining to him that they "were staying until the service ended and that he had no choice in the matter.”

According to Briana, Bobby quickly deleted this action from his repertoire of behaviors, but has recently added another to increase the likelihood that he will get what he wants. For example, his mother described how Bobby woke up one day claiming stomach pains. Being a concerned parent, she opted to keep him home from school. After monitoring his behavior for a couple of hours, she noticed that he appeared to be fine and had a great time watching television. To prevent Bobby from believing that his course of action was acceptable (i.e., claiming illness when in fact he was not), and to deter him from recycling this strategy in the future, Briana got him dressed and drove him to school, hence exhibiting a “no nonsense” parenting behavior. “If you give an inch then they’ll take a mile,” she stated.

***“Overwhelm him with love and affection”***

Danielle discussed how she addressed her son’s aberrant behavior, such as banging his head on a surface when upset. Providing large amounts of affection is typically how she manages David’s exhibitions of aggressive behavior. When asked about her response to his tantrums, she explained:

He’ll throw himself on the ground. But he used to bang his head on the concrete sidewalk outside. I worry mostly about him hurting himself. Even if he’s acting out or doing things where he might try to hurt himself, I hug him and tell him I love him. I’m restraining him with force but try to do it in a loving, nurturing way. I try to get him to be goofy and kind of do it through play.

***Ignore the behavior***

While David’s acts of aggressive, self-injurious behavior commands his mother’s full attention, Fatima conversely adopted a practice that included ignoring her son Fabian’s tantrums. At times when this action did not appear to alter Fabian’s behavior, his mother resorted to

physically removing him from the situation. She described her parenting behavior when Fabian's tantrums occur in a public setting:

If he's in the middle of the aisle having a meltdown, I just stand there and watch him.

People just look at me like I'm crazy and I'm like, "Sorry he's in the way. He'll get up when he's done. Sometimes I just pick him up and carry him.

An example of this parental response to Fabian's tantrum was viewed while walking through the mall. Upon completion of the public observation, Fabian, his mother, and I were headed towards the exit of the mall. A large ride-on motorized toy helicopter and fire truck captured Fabian's attention. After Fatima paid for her son to ride on both, he refused to exit once the rides finished. He began crying, whining, and dropping himself on the floor. Disappointed in his actions and tired of his misbehavior, Fatima physically picked him up and carried him to the car.

Fatima also mentioned that at times, just to maintain her sanity, she gives into her child's requests despite Fabian's inappropriate displays of behavior. She stated,

I've seen people on websites complain that mothers just give children what they want whether they're autistic or not autistic. As a parent with an autistic child, sometimes you just have to do that in that moment just to get by.

### ***Probing***

Inquiries regarding the child's concerns have also been used as a means of managing crises within mother-child interactions. A salient description of her interaction with her son was discussed by Cynthia. She had inadvertently eaten Charles' french fries at the zoo and his reaction to the mishap was filled with anger. She explained:

...we went to go see the zoo lights and he was really tired. We walked by the food court and he smelled the French Fries and chicken tenders and he was like, "I want to go to the restaurant, I want to go!" So, we were like let's just make this as peaceful as possible and let's just go buy him some fries and chicken tenders. We ate them and he was eating them and he was fine and then he stopped eating them. We thought he was done so we finished off the fries. He turned back and the fries were gone—melt down! Oh, he started screaming and crying. The way he talks is very interesting. He talks around it. He'll be like, "You're not allowed to have your favorite thing!" So, he's basically saying, "You hurt me so you can't have your favorite thing." "Nobody is allowed to have french fries." We knew he wasn't going to be consolable because he was so tired and it was getting late so we just left. I think he was upset until we reached home. That had to be about 30 minutes. But he was kind of beside himself, still upset and still crying. So the whole time that he was throwing that tantrum, you can't reason with him when he's that far gone. We just got him home, he calmed down, and he just went to bed. We talked about it that night or the next day but I said, "Do you remember what happened with the french fries?" He was like, "Yeah, you ate them all." [Mother laughs]. We tried to teach him in that moment and said, "If that happens again you need to tell us when you're not done eating and we won't eat anymore. You have to tell us what you want." It was just a misunderstanding. We thought he was done so we ate them all. I think we learned from it.



**Research Question 2: What are the beliefs and experiences of mothers relative to raising preschool aged children with ASD?**

For research question # 2, four major themes emerged from the detailed accounts of mothers' experiences related to parenting preschool aged children with ASD. When asked about their perspectives on and experiences with their children, they tended to focus on: 1) the children's maladaptive behavior; 2) the children's abilities; 3) interfacing with the public while having a child with ASD; and 4) the stress they experience having a child with ASD. These four themes are discussed in detail below (See table 5).

Table 5

*Relevance of themes in mother-child relationship*

<p align="center"><b>Question # 2</b>  <b>What are the beliefs and experiences of mothers relative to raising preschool aged children with ASD?</b></p>				
<b>Participant</b>	<b>Theme</b> Perspectives on child's maladaptive behavior	<b>Theme</b> Perspectives on child's abilities	<b>Theme</b> Perceptions and experiences around Public interfacing	<b>Theme</b> Stress associated with caring for a child with an ASD
<b>1. Anastasia</b>	X	X	X	X
<b>2. Briana</b>			X	X
<b>3. Cynthia</b>	X	X		X
<b>4. Danielle</b>	X	X	X	X
<b>5. Erica</b>		X		
<b>6. Fatima</b>		X	X	X

**Theme 1: Perspectives on maladaptive behavior**

This particular theme focuses on mothers' beliefs about the reasons for their children's displays of inappropriate behavior. Several mothers expressed their confusion about whether or not her child was intentionally being non-compliant or if the maladaptive behavior exhibited was

a direct result of the disorder. Perspectives about their children's behavior and etiology were expressed by mothers and captured in both their interviews and observations.

***Willfully non-compliant?***

During early childhood, challenging child behaviors are evident across families with neurotypical children and those with special needs. Parents may possess feelings of confusion as the timing of these displays are not always predictable nor is the intent behind the behavior easily understood. Statements expressed by Cynthia such as, "He can't help it sometimes and sometimes he can, I'm sure" reflect mothers' confusion. Anastasia also provided insight into her bewilderment regarding her son's maladaptive behavior:

He's stubborn. It's hard to determine if he's being stubborn or if it's a result of how his brain works because of the autism. Sometimes it may seem like he's ignoring you but he's just tuned in to what he's doing that he can't break his concentration to pay attention to what you're doing. He's still ignoring you but it's not deliberate.

An example of Anastasia talking to her son and Alex seemingly ignoring her was observed during dinner time:

Anastasia: Are you hungry?

*While Anastasia was in the kitchen she shouted to her son who was sitting around the corner in the living room,*

*Alex, who was stationed 6-7 steps away from his mother in the living room, did not respond. Despite the lack of reciprocal conversation between the two, they both continued on with their original actions prior to her query as if a conversation was not initiated by the mother. Anastasia continued to prepare dinner while Alex*

*watched television without uttering a single word.*

Danielle added to mothers' collective pool of confusion as she described her son's unwillingness to take medicine:

I second guess myself because I don't know. A classic example is that he doesn't want to take medicine even though he's in pain. Is that because he's on the autism spectrum? I don't know. Every time there's something that I don't understand why he's doing it, it might not have anything to do with being on the autism spectrum but I don't know what is and what isn't. If he wasn't on the spectrum then I would just say, "That's just what a kid his age does." I'm generally not a worrier, but I don't know whether to put it in the pocket. Is this because my kid is on the autism spectrum or it's because I have a kid who is 5 years old?

In the above statements, it is clear that mothers' beliefs about the causes of their children's displays of maladaptive behavior are questionable. Their understanding about the reason behind a child's behavior seems to be connected to their responses to the child's behavior itself. For example, Anastasia expressed her dislike of having to repeat herself more than once to her children with the exception of Alex:

I am not big on repeating myself in general so it definitely does get frustrating, but I also have to keep in mind that he's...just isn't processing what I'm saying to him. My approach with him is different than my approach with the older kids. By the second time I've said it to my older kids, I'm already irritated. Alex has about five or six times before I start to feel frustrated...

## Theme 2: Perspectives on child's abilities

This theme centered on mothers' beliefs about their children's abilities to succeed in all that they attempt in the present and for them to ultimately become productive members of society in the future. Despite the differing acceptance levels from the mothers regarding their children's diagnoses, it was evident through their interviews and observations that the mothers: (1) had high expectations for their children despite their diagnoses, and (2) acknowledged the many improvements that their children exhibited over time, although several expressed their uncertainty of whether it is a result of therapy or general human maturation.

Erica showed her high expectations for her son Elijah as she played on the driveway with him:

*Erica was seen dribbling an adult sized basketball around her son as he attempted to retrieve it from her. Once in his possession, he struggled to hold the ball given that his hands were too small to secure it. As the ball occasionally fell out of his hands, Erica would exclaim,*

Erica:        You can do it!

This playful exchange between a mother and child highlights Erica's desire for her son to try even despite his physical limitations.

Fantasia's like-mindedness with Erica was revealed during one of her interviews. Despite having two sons on the autism spectrum, Fantasia's expectations of her boys' behavior would be the same if they were typically developing. She stated,

I've always told my older son and I'm beginning to start this with Fabian although he's a little too young. I want to start building that idea that just because you're autistic doesn't

mean you have to have inappropriate behavior. Mommy still expects you to behave. I still expect certain things from you.

### ***Hopeful for the future***

Many of the mothers expressed how hopeful they were for their children's future. This optimism stemmed from the progress made by their children from the moment of initial diagnosis to their current level of functioning across contexts. The following are examples of statements made per mother regarding their child's progress:

- Cynthia: I really feel like he's come a long way.
- Danielle: I see him trying to initiate and a year or two ago, I didn't see that.
- Erica: It's going to take a lot of patience and with time things will get better. Things have gotten better and it can only get better.
- Fatima: We look at where he was 24 months ago and where he is now. It's huge, huge, progress. Early intervention matters no matter which way you slice it; whether you have a typically developing child or a child with special needs, it's always beneficial...Probably in the next year, Fabian will be better.

These statements, although brief, summarize mothers' optimistic spirit as it relates to the development of their children with ASD.

### ***Maternal concerns regarding child's ability to adapt***

Whereas some mothers expressed high levels of optimism regarding their children's future, other mothers articulated their uncertainty about their children's ability to adapt in the world especially when the mothers are deceased. According to Anastasia:

I have my moments when it's overwhelming because my biggest fear is something happening to me before he or my older children are at age where they can fend for themselves and even after that. What happens to him when I'm no longer here? I feel

like I'm best equipped to deal with him as compared to everybody else that's in his life. I have a lot of worry and fear about the quality of his life. I feel more fear now than anything else; not knowing what things are going to be like for him. I think about that a lot.

For Briana, the diagnosis was difficult to accept due in part to her worries about the limitations that are associated with the disorder (e.g., impaired cognitive abilities and lack of interpersonal relationships). The thought of someone attempting to take advantage of her child and him not having the cognitive wherewithal to discern individuals with good intentions from those without, keeps Briana up at night. In the response below, she explained her thought process:

I cried because how is this going to affect him growing up. When he gets into adulthood, we're not going to be there all of the time. What happens if we pass away? Will he be able to function? Will he be able to make it? We're blessed to have four other kids so I know one of my kids will step up to the plate and look in on him but what will happen to him? Will he be able to hold a job, go to college, have a family, function like a normal person or what we consider to be normal in society... How will this affect him in the long run? That's where a lot of my tears came from. Forget what people thought, it was more so about my child and how he's going to make it. Will he learn? Yeah, he could memorize things but will he comprehend what's going on? I don't want anybody to mishandle my baby when I'm not around. People play a lot of mind games on us normal folk and we fall into craziness. Just think about an adult, or a child, or an adolescent who doesn't comprehend on that level and people get them to do things that they really shouldn't do...

### **Theme 3: Perceptions and experiences around public interfacing**

Having a child with special needs does not halt the lives of mothers but rather becomes an extension of their experiences. Specifically related to mothers' social relationships, they must continue interacting with members within and outside of their social networks while simultaneously caring for her child with ASD. In this section, mothers discussed issues related to their interfacing with the public and how having a child with ASD affects these interactions.

#### ***Judgment from strangers***

Many mothers discussed their concerns, be it past or current, about the public's reactions to their children's behavior. The stares received from strangers during children's tantrums, the unsolicited advice passersby provide as children cry uncontrollably, or the glances due to an occasional sound effect that some children with ASD make that are common to their mothers, but unusual for strangers, have influenced mothers' self-consciousness while being out in public with their children with ASD. According to Briana:

In the beginning, 10% of me was worried about what I needed to do to help him and the other 90% was worried about everybody else... I was so worried about how other folk would perceive him and interact with him...having normal kids and then having a child with autism, it just felt like a handicap. I didn't want other people to think all of my other kids are smart, but something is wrong with Bobby...I think that's what bothered me the most to the point where I didn't want to take him out too often. If I took him out then I would make sure that he's right by my side...

Fatima echoed Briana's concern about the public's opinion and elaborated on how many individuals make assumptions about her child given his appearance. She stated:

Everyone is staring at you and thinks that you're just not disciplining your child or that he's a spoiled brat. Because people don't know its autism and they don't physically see anything wrong with him, they just assume that it's the parent and that I need to learn how to discipline him. They don't realize that discipline doesn't work for an autistic child, at least not at this age. It depends on the child's level of functioning. Sometimes discipline won't work at all if they're lower functioning. Also, if they're having a meltdown because of sensory issues, then you can't punish them for that.

Danielle also shared Briana's and Fatima's concerns regarding public scrutiny; however, she regularly attempted to ignore the stares, and choose to concentrate more on her son's needs at the time. According to Danielle:

Sometimes, if he throws himself on the ground, I'm embarrassed but then screw that. It's about how he's doing. I need to not care if I'm embarrassed about how this interaction is going. I just need to care about what's best for him. I'm certainly self-conscious about it though.

### ***Limit family outings***

During the many interviews conducted with the families, public scrutiny emerged as one of the major reasons behind families' limited outings. Other factors surfaced regarding mothers' hesitation in making public family appearances. These discussions included, but were not limited to, the financial strain associated with taking family vacations and the unfairness to the other children that an activity had to end due to the uncooperative behavior exhibited by the child with ASD. While discussing Alex's behavior, Anastasia suddenly became aware mid-sentence of how limited her family outings are:



I'm noticing that I don't do as many outside activities as a group as I did when it was just my older two children and that's all on me... I really tailor the activities that we all do together because I don't want him to be uncomfortable and I don't want it to be a situation where the older kids are really enjoying themselves and we have to go because he's getting overwhelmed with the situation that we're in. We don't do as much as a group outside of the house.

### ***Public disclosure of child's disorder***

Several mothers discussed the topic of privacy, specifically, their past, and for some, current struggles in determining: (1) whether they should allow the disorder to be a private family matter; or (2) whether it would be helpful to let others know about their child's disorder, especially during those public tantrum moments. Some mothers expressed the possibility that the public scrutiny would be less intense and strangers' perceptions of their children with ASD would be more positive if they possessed knowledge of the diagnosis. Despite this confusion, it remained clear that the process of acceptance allowed for mothers to receive more insight and introspection on the matter. In Briana's explanation of her feelings about the disorder, she described her initial discomfort with the disability and her now very vocal advocate voice.

I've learned that it's okay to have the feelings that I have...sometimes I would beat myself up for feeling ashamed or feeling nervous...especially when I first found out but now I feel a little bit more comfortable... it's opened up a door for me to say, "Hey Autism Speaks, let's rock and roll! Give me a bull horn!" I'm at that phase now, so it's made me really comfortable with who I am, with who my son is and it's made my whole family comfortable.

Similarly, Danielle struggled with the privacy issue, but unlike Briana, Danielle hesitated to disclose her son's personal information to the public, specifically his diagnosis. She stated:

This is about me, but it's also about him and respecting his privacy. For instance, I will tell people in person that my son is on the autism spectrum, but I've never once posted it on my Facebook wall. I tweet sometimes about kids on the autism spectrum or new research but we only have like four followers on Twitter... I'll tweet things that I think will help them understand our child better.

Although many of the mothers have accepted or have resigned themselves to the fact that their children indeed are on the autism spectrum, as the above data indicate, these mothers differ in how they interface with the public. The issue of privacy appears to be a complex matter as mothers remain prudent about the information that they provide the public.

#### **Theme # 4: Stress**

All of the mothers in this study discussed the stress that they endure due to various factors associated with parenting a child with ASD. Below is a discussion of those factors.

##### ***Funding for therapy***

Therapeutic services, although very much needed and helpful in fostering more positive outcomes for special needs children and their families, have been discussed as a source of stress for some participating mothers. Specifically, the cost of obtaining these services coupled with the families' ongoing battles to have their insurance companies pay for the care has emerged as major stressors. For Fatima in particular, this strain has not only impacted the very essence of who she is at the core, but also the family's livelihood. In a very candid interview, she explained:

You're constantly fighting the insurance company...and the school system...for services...there's no money. No one can help. There's no respite care that's free. You're constantly on guard. Anytime something happens with insurance or school, I'm ready to fight... I know that I come across as bitchy...everything that has to do with insurance or the school system and therapies, you're automatically defensive. It's a lot easier to start that way than to get the turn around. If I didn't have to deal with this, I'd probably be more fun and loving. I'd have more time for myself. Having financial stress is really, really devastating. I'm fighting for Applied Behavior Analysis (ABA). I'm not paying my mortgage for ABA. I'm fighting my butt off for this.

For Fatima, it is clear in her speech that having two children on the autism spectrum and paying out-of-pocket for her children's therapy is frustrating and stressful given her financial need. Notably, all participating families in this study were of middle-to-lower socioeconomic status. Furthermore, her experience sheds light on an external stressor, specifically the fight for services.

### ***Maternal concerns regarding children's social deficits***

Although there is variability in the social skills of children with ASD, several participating mothers have expressed social impairments as being a major concern for their children with ASD. Cynthia described her son's hesitation in engaging in play with his peers:

At age 2.5, he could not talk to any of his peers. He did not play with other kids so he was socially very behind. He had a lot of anxiety when we would go to the playground and he used to never want to leave the house. Now looking back, the playground was stressful for him... if kids were there he knew they were going to talk to him and he doesn't know how to play with them. He has decreased motor planning skills so if they

want to play some game, he doesn't know what the steps are...and conversing is very hard for him and it still is... I think he's aware. He actually voiced it in his own way... we would go to the playground and then we'd be the only ones there for a while and so if another family was walking towards the playground, I remember distinctly, he got up on the playground structure and said, "No share playground!" I remember laughing ...I thought it was a sharing thing, but now looking back I think it was his way of saying, "I don't want to have to talk to any other kids." And then he used to say, "It makes me anxious." He realized that's what it meant. That's how I figured out it was making him anxious to be with kids.

This description serves as a poignant example of Charles' feelings of anxiety while interacting with his peers. Additionally, Danielle's description of her son David's awkward behavior while among peers serves as another example of challenges that children on the autism spectrum face.

He likes to be near kids. He wants to be on the outside of where they are. He doesn't want to be in the middle of a social interaction necessarily, but he likes the energy of being near a social interaction...especially if kids are on a playground playing tag, he'll literally run around them but not try to get in the game of tag.

I was able to view Erica's son, Elijah, among peers at a playground in the mall. Similar to the behavior that was described by David's mother, Elijah played around the children but not with them.

*On one instance, a child pushed Elijah off of a stationary car and her father had her apologize. The little girl stood right in front of him and expressed her apology repeatedly.*

Girl: Sorry. Sorry.

*Elijah continued sitting on the car, all the while never making eye contact with her or uttering a word. In fact, he continued fidgeting on the car and adjusting his body position because the girl was “in his way.” It was almost as if he perceived himself as being the only child on the playground despite having a little girl directing in front of him and approximately 20 more children in the play area.*

Importantly, Danielle was one of two participating mothers who expressed her son’s ability to connect with his peers in her recollection of a family trip. She described her delight in seeing her son enjoying his interactions with his peers. She explained:

We took a vacation to visit some good friends of ours who have a son that is five months older than David and he really connected with that kid by the end. I don’t know if it was because it was more intense meaning we stayed with them and was together with them 24 hours a day for a couple of days but in some ways it was the first time I’ve seen that he really connected with a kid his own age and really enjoyed that and was initiated and going back and forth. It was nice to see that he can do this. He can become friends and connect with other kids and really enjoy it and be happy.

Although describing David’s ability to engage his peers and initiate play in this example, Danielle repeatedly expressed her concerns regarding her son’s lack of social skills in other settings, thus highlighting the commonalities in mothers’ perceptions of their children’s social abilities.

The skills I want him to have in terms of functioning independently are the skills of connecting with other people...I want to wave a magic wand and make him want to be

friends with other kids. That's something that I didn't think that I would actively want from my child because I thought that children would innately want that. I was a kid that wanted that...connecting with others, forming relationships, and getting value and joy out of that...I wouldn't have thought that I would have to have conversations like, "Being friends with other kids is great and I love being friends." I'll talk to him about how important friends are in my life. I didn't think that I would have to explicitly have those conversations with my child. All of the social skills problems keep me up at night sometimes.

Danielle goes on to provide an example of a specific problem area for her son David:

He can't read social cues. I like that he's a jokester. It's funny. Every once in awhile it's either annoying—I hate to say annoying. But, sometimes he'll crack a joke and it will be funny and he loves that we laugh so much that he'll keep on doing it and get more and more ridiculous. He has trouble picking up my social cues and I'm sure it's that way for his peers too.

Anastasia and Cynthia shared similar concerns with Danielle regarding their son's impaired social skills. According to Anastasia:

I would like him to engage other children in play. Since we got the dog, he engages her. He'll stand next to her and try to have her chase him. So, he is developing those skills with the dog. He even comes to grab our hand and take us to where he wants to go but he's not doing that with other children... He'll try to play with older kids but he's not quite interested in children his own age. My oldest son is nine years older than Alex and my daughter is seven years older than Alex so he's use to being around older kids.

Cynthia echoes Anastasia's concerns and recounts a specific example that limits her son's ability to connect with his peers. According to Cynthia:

I would like him to be able to play with kids. If we go to the playground, I sometimes see him eyeing the other kids and he gets excited when they're around but he still needs help with social interaction. Sometimes what he says is not appropriate or it's just super goofy and doesn't make any sense. He's very repetitive and he loves drawing. He's so into it and it kind of drives how I interact with him because he's always talking about it. So, I end up having to just talk about what he's doing. Right now he's into drawing these three little cartoon characters which are a bird, a mouse, and an elk. I have no idea why. He loves them and he talks about them. ..It kind of directs how I interact with him because I have to talk about it. It's hard for him to be interested in other things that say his sister wants to talk about or that I want to talk about so it's kind of all about him [laughs]. That makes it difficult and it also makes it difficult for other kids, which is why he has a hard time because he doesn't want to talk about Teenage Mutant Ninja Turtles or Star Wars. He wants to talk about his elk or his mouse [laughs]. One good thing is that because he's with kids all day, he started talking about Spiderman. I want him to be able to talk about what the kids are talking about.

After describing her son's behavior that may make it difficult to engage his peers, Anastasia also recalled an example of a social skill exhibited by her son that is pivotal to establishing and maintaining social relationships.

One thing that happened recently is that he reacted to other kids, whether they get hurt or if they act up in class, I know he's told me before that it disturbs him. It's hard for him

to handle because it makes him so uncomfortable. So, if a kid in the class is crying or throwing a tantrum or something, he told me he feels like he's crying inside. That's so cute.

Charles' concern for his classmate's feelings varies from Fatima's description of her son's interaction with his peers. According to Fatima:

I worry about the social skills of both my kid. He pushes other kids and parents tend to give me that look because they don't understand. But I see neuro-typical kids pushing other kids. He's not good at sharing yet, but he's 3 years old. I don't think most 3 year olds like to share anyways.

### ***Maternal concerns regarding children's communication deficits***

Although there is variability in the communicative skills of children with ASD, several mothers in this study have expressed communication problems as being a major concern for their children with ASD. For example, Erica described her son's form of communication prior to receiving therapeutic intervention. She stated, "The only way he knew how to communicate was to cry or scream. They taught him other ways to communicate." When asked about how Elijah's limited verbal communication made her feel, Erica replied:

It's frustrating sometimes because I see how other 3 year olds talk. A lot of 3 year olds communicate very well. Sometimes I think he knows what we're saying to him, but he doesn't say it. Sometimes he says things very clearly. I'll say, "Bath time," and he'll say, "Bath time," and other times he doesn't say it...It doesn't impact [how I interact with him], it's just I wish he would verbalize more...It may be hard to process everything because he was a premature baby. Maybe it affected him when he was born...I know



that he's smart; it's just a matter of getting him to verbalize consistently. It doesn't change how I feel. It's just sometimes it's frustrating. I'm like, "What are you thinking or why did you act that way?"

Similarly, Cynthia discussed her son's early communication deficits, specifically, differences in Charles' receptive and expressive skills.

In his speech, he was slightly delayed... You could ask him questions and he totally understood you. But I noticed that compared to kids his age, he wasn't expressing himself. There was a bit of an expressive speech delay which we found out later was a pragmatic speech delay. He also echoed a lot which is echolalia. A lot!

Anastasia also highlighted her son's limited ability to communicate and her desires for him talk. She explained, "Communicate his needs [is important]... Let me know how his day went. Let me know if someone has hurt him or is mean to him... That's the main thing for me." In her explanation of his speech, Anastasia goes on to provide examples of how Alex's speech is impaired.

A lot of his communication is just repeating what you said to him. He doesn't do a lot of spontaneous conversation. If you say, "Alex, how was your day," he'll just say, "Day." He typically just repeats the last few words that you're saying to him. He doesn't really tell you his needs outside of drinking and a lot of times he'll see a cup and just say drink because he saw that cup... I just wish that he could communicate those needs to me without having to be prompted... it doesn't make me feel any way towards him. It's just one of those things that makes me feel sad. It feels like it's unfortunate that he can't do that.

Despite her son's delayed communication skills, Anastasia explained how her communication with her son during their interactions is similar to how she would talk to other children without a disorder. According to Anastasia:

I still talk to him as if he would be answering every question that I asked and I don't let up because I feel like at some point, he'll get there. He may not, but in my mind he will so I still communicate with him the same way that I communicate with my older two kids. I just don't get the same responses from him that I would from them. I encourage communication. I was opposed to the pictures and signing because I felt like he had the ability to communicate verbally with me so that's what I'm pushing for.

During the data collection process, Anastasia's form of communication was observed in the home as well as in a public setting. While she prepared dinner, Anastasia was viewed talking to her son from the kitchen as he watched television:

Anastasia: Alex, are you hungry? We're having homemade hamburgers today.

*Alex did not respond to his mother and continued staring at the television. His mother walked over to the living room and stood in front of the television to get his attention.*

Anastasia: Dinner is almost ready. Are you hungry?

Alex: Hungry.

Anastasia: Alright. You'll have to go wash your hands in five minutes to eat.

Alex: Eat.

*Anastasia walked away to continue prepping dinner and Alex proceeded to stare at the cartoon that was projecting on the television screen.*

In the above example, Alex's limited communication skills and his mother's response of standing in front of the television did not appear to generate any conflict within the mother-child relationship. However, Fatima described how her son's language delays can ignite conflict within their relationship. When asked about the most important skill that she wanted her son to work on, Fatima stated, "Communication." She further elaborated how the delays in child's ability to use language have created conflict within her interactions with her son. For example, Fatima shared how although she is more familiar with her son's speech than a stranger might be, there are times when his language is difficult for her to comprehend thus resulting in frustration on his part. She further explained how people in his environment underestimated his cognitive abilities due to his delayed language. She stated:

He's so smart, but his communication inhibits a lot. People don't realize how smart and observant he is because he doesn't speak a lot. When he does speak, it's hard to understand. The lack of communication he has can be very difficult because he gets so frustrated. I'm like, "I'm sorry, I don't understand." He gets so frustrated that he bites and scratches himself all because I don't understand him. I understand more than someone who isn't use to him.

Fatima also described how her son's communication impairments have hindered him in the social and academic arenas. Fatima stated, "Communication...articulation and pragmatics...really inhibits him at school..." Similarly, Anastasia also briefly mentioned academics; however, her reason for discussing this topic slightly differed from Fatima's. Anastasia stated, "If he's never a straight A student, that doesn't matter to me. I just want to know that when he's not around me that his needs will be met...I want him to be able to communicate his needs."

Fatima discussed her efforts to facilitate language development through her parenting practices during those moments of frustration and the progress made by her son. She explained:

I usually tell him to show me what he wants and that seems to work. I tell him, “I don’t understand,” and he knows what that means. He then starts screaming and I’ll say, “You need to use your words.” He tries to talk. Typically if we’re not in the car then he’ll take my hand and he’ll show me. The act of showing me makes him realize that I’m trying to understand and once that happens then he’ll calm down. It was really bad before he started speech therapy and he could not speak. Now that he’s talking more, it’s not as bad as it use to be. Once he gets better at speaking then I think that that will really help. It really inhibits him at school and I think at some of the evaluations...

### ***Worries about child’s well-being***

Concerns shared by mothers of children with ASD were identified across families. For example, Anastasia worried about leaving Alex in the care of others. Her apprehension stems from a fear that he will not eat all day given her observance that, at times, he will not vocalize his hunger pains. She stated:

It worries me because he will be with somebody and not eat all day. That’s probably why I don’t let him go with many people because most people are used to a four year old telling them when they’re ready to eat. Because he can’t do that, I only let him go with a very small group of people and I let them know that he’s not going to tell you when he’s ready to eat so it’s up to you to make sure my child eats at least three times a day. I don’t worry about him at daycare because they have a schedule that they follow so I know he’s going to eat at daycare. But outside of that, that is something that’s worrisome to me...

Overall, a major underlining theme of discussions with mothers is their desire to provide for children so that the quality of life is positive. Fear and worry are natural feelings that surface as a result of this all-consuming goal. Briana said it best, “My greatest fear is not getting him everything that he needs to get him to where he needs to be. I don’t want to slight him in that area.”

### ***Psychotherapy and pharmaceutical need***

Although only one mother discussed her participation in therapy and the use of medication to alleviate stress, it is still important to highlight as her experiences may be similar to other mothers not participated in this small scale study. Fatima provided an account of her state of mind prior to receiving therapy:

My life included just yelling at everybody, even at the cat. I was so stressed that I finally went, about 6 months ago, to a psychiatrist and was put on depression and anxiety medication. He says that I’m showing similar symptoms of PTSD.

The data presented above highlight the stress mothers feel in their parenting role. They expressed concerns regarding their children’s social and communication deficits and the impact that these impairments have on their parenting behavior during their interactions with their children. Additionally, their concerns about money and to a lesser extent their concern about their own mental health surfaced in interviews with these mothers.

### **Research Question 3: What facilitates or hinders mothers’ parenting of their preschool aged children with ASD?**

The third and final research question addresses factors that play a role in mothers’ ability to successfully parent their children as well as those that may make rearing more challenging.

For research question # 3, three major themes emerged from the semi-structured interviews and observations. These three themes – maternal resources, interpersonal supports, and ecological support – along with subthemes that emerged for each of these themes, are discussed in detail below (See table 6).

Table 6

*Relevance of themes in mother-child relationship*

<b>Question # 3</b>			
<b>What facilitates or hinders mothers' parenting of their preschool aged children with ASD?</b>			
<b>Participant</b>	<b>Theme Maternal resources</b>	<b>Theme Interpersonal supports</b>	<b>Theme Ecological support</b>
<b>1. Anastasia</b>		X	X
<b>2. Briana</b>	X	X	X
<b>3. Cynthia</b>	X	X	X
<b>4. Danielle</b>	X	X	X
<b>5. Erica</b>	X	X	X
<b>6. Fatima</b>	X	X	

**Theme 1: Maternal resources**

Mothers must navigate through certain challenges associated with rearing children on the autism spectrum in hopes of preserving positive mother-child interactions and ultimately the quality of their relationship. As a result, mothers have created coping mechanisms that promote more positive interactions with their youngsters.

***Maternal regulation in the parenting context***

Many of the mothers' discussed their coping mechanisms that help promote more positive interactions with their youngsters. For example, Cynthia described her need to remove herself from her son, at times, when engaging in everyday routines:

... he's very, very picky so it's hard. I just want to pick my battles so I'm not going to fight about breakfast right before school... I have to kind of take a step back and be calm myself because I've noticed if I get angry really fast then it just escalates the whole situation.

Her unwillingness to coerce Charles to eat the entire meal was evident during a dinner observation:

*Charles chose only to eat the breading of the corn dog and refused to consume the actual hotdog portion. His mother relented to his wishes without any further attempts to exert her authority.*

Charles: Just want a regular popsicle.  
 Cynthia: It's not a popsicle. It's a corn dog.  
 Charles: I'm just going to eat the skin.  
 Cynthia: It's up to you. That's fine. You can eat it however you want.

Fatima employed a similar style of parenting during dinner time. She expressed, "We've tried to do the whole eating dinner as a family thing and nobody likes it. Fabian isn't going to sit in a chair. I give him his plate and he'll eat it when he's ready." Given these mothers' responses, it appears that the adversities experienced within the parent-child relationship allow for prioritizing to occur regarding the level of importance placed on the actual conflict itself.

### ***Religiosity***

Several mothers participating in this study stated that turning to a higher power afforded them strength during post ASD diagnosis. Both Briana and Erica discussed their submission to God and letting his will be done in regards to their children with ASD. According to Briana, "Bobby is going to do whatever God has intended for him. Our faith and our religion keeps us

afloat.” Erica described her daily devotion time with God and how she prayed to him for guidance in all areas of her life, including her son’s diagnosis and his very limited vocabulary:

Well, I need some time with the Lord daily. I’ll journal and talk to the Lord about what’s going on in my life. I try to get some perspective of what’s coming next. I pray every night. I’m trusting and believing that he [Elijah] will talk...definitely the power of prayer affects my decision making. I just pray every night about his condition ever since he was born.

### *Parenting capacities*

A shared feeling among participating mothers, with the exception of Fatima, was that raising a child on the autism spectrum and the behaviors linked with the disorder are foreign. Although many of the mothers already had older children, the specific experiences associated with rearing a child with ASD are unique. Hence, several of the mothers questioned their parenting abilities. Interestingly, despite having to raise two children on the autism spectrum, Fatima expressed a stronger belief in her parenting abilities than all other participating mothers. For example, when asked to describe how her children with ASD have impacted her family, she responded:

It’s no big deal...I keep telling my husband we survived this with my older son, we’ll survive this with Fabian. Around four is when our older son started to listen to rules so I assume Fabian is going to be the same, so we have another year. He just doesn’t listen, that’s the big thing that really irritates us. He never stops, even if it’s dangerous. He never stops.



## **Theme # 2: Interpersonal supports**

According to mothers of children with ASD, the support provided by both familial and non-familial groups have aided in attenuating some of the stress experienced by these parents.

### ***Non-familial support***

Several of the mothers have expressed how discussions with other families who have children with special needs have aided them in coping with the disorder. For example, when asked about factors that help facilitate her interactions with her son, Briana stated:

I talk to other families. When I bring him to speech therapy class, I hear the other parents talking about difficulties with eating. I'm like, "Wow, I'm having that same problem." It makes me feel better being able to hear someone share their story and make me realize that I am not the only one.

Similarly Erica described how she seeks out support groups online. She explained, "Although I don't have any friends that have special needs kids, I've met some on Facebook..." The searching for support is critical in that several mothers of children with ASD expressed a desire to converse with families who have similar circumstances as they may be better equipped to understand mothers' feelings and experiences.

### ***Family support***

Through interviews and observations, it is evident that family members serve as an integral source of support for families raising children on the autism spectrum. For example, Anastasia's mother babysits her grandchildren when there are conflicting schedules that do not allow for Anastasia to get off of work. Additionally, David's father cares for the children as co-parenting is displayed in their household. Statements such as the following highlight Danielle's acknowledgement of the support that she receives from her husband and the quality of the

relationship that her son David has with his father, “I feel like he is fairly connected and at times even more connected with my husband who is the one who has spent more time with him overall since he’s been born.”

Unfortunately, not every mother’s experience includes unwavering support from family members. For example, Anastasia, Cynthia, and Briana discussed the disbelief of and disagreement with the diagnosis that some of their family members have expressed. A salient quote from Cynthia illuminates such feelings:

I think we have some family members that may not even believe us. “Oh you guys were just making it up. He’s so smart...” That actually is a little bit stressful... we have two sets of grandparents. My parents are on board with it...my mom worked in childcare for 25 years...she has seen hundreds and thousands of kids so she kind of knows. When we told her she was very supportive. The other set of grandparents, we love them to death, but I think it’s harder for them to swallow...it’s tiresome because I don’t think it’s my job to convince them that there’s something wrong with my child... I wish everyone could be on the same page...

### ***Ecological support***

Mothers’ many obligations to the family, coupled with their determination to serve as advocates for their children when it comes to receiving services, can all play a role in how much they are able to enhance the development of children and to promote their relationships with others. For example, as a full-time worker, Danielle acknowledges the challenges faced maintaining her relationships with her children, husband, and friends as she has little time to interact with them given her demanding schedule. She stated:

It's overwhelming to be working a full-time demanding job that's more than 40 hours of week. I still want to have a social life and maintain some of my friendships and other relationships that I have. Sometimes I don't have the space or the capacity to do what I probably need to do for him [her son David] but I also have to take care of myself too, otherwise I'm not as good of a parent. I would say the top thing that I do deliberately is maintain close emotional connections.

Conversely, Erica quit her job to spend more time with her family; however, this decision resulted in more of a financial strain being placed on her husband. Despite this added layer of stress, Erica is satisfied with her decision as she has seen progress being made in her son Elijah. She stated, "...that time period that he turned two, I was working and then I had to stop work so I could be home with him. Me being home with him everyday made a difference."

### ***Advocacy and research on Autism Spectrum Disorder***

A topic of discussion that emerged across families was mothers serving as advocates for their children with ASD. Many of the mothers conducted research on the web and in libraries to uncover the intricacies of the disability including etiology, services, and interventions. Anastasia described herself as a researcher in the following statement, "...I've become a little research fanatic. I'm always on Google looking up things...my main goal is to find as much resources as I can for him."

Likewise, Briana and Cynthia were constantly reading and stayed informed on the latest news regarding ASD. Briana stated, "I'm always reading up on autism to try to understand it a little bit more. I think it's an ongoing process."

The third research question allowed for mothers to describe salient factors in their lives that both aid and hinder their interactions with their children with ASD. Generally speaking,

support, be it familial, non-familial, therapeutic, or ecological, serve as valuable resources that families of children on the autism spectrum recognize and need.

### Summary

Six mothers participated in semi-structured interviews and allowed both in-home and public observations to be conducted. The questions explored in this study addressed the behaviors that mothers of preschool aged children with ASD exhibit in their interactions with their youngsters, mothers' beliefs pertaining to their experiences with their children and finally, factors that play a role in aiding or impeding raising a child on the autism spectrum. Several themes emerged and were discussed in detail throughout this chapter as they relate to the research questions.

For research question 1, four themes were presented. In the *positivity theme*, mothers of children with ASD described characteristics of their children and parenting experiences that make their interactions with their children rewarding. The *schedules and routines theme* included mothers descriptions of their children's and their own willingness to deviate from schedules and routines along with methods employed to overcome any possible issues that may arise from this rigidity. The *maternal strategies linked to child cooperation theme* addressed mothers' approaches to child misbehavior and inattentiveness. Finally, the *crisis management theme* detailed mothers' explanations of the behaviors exhibited by their children that make it challenging to parent them and their responses to such behaviors.

For research question 2, a description of four themes and the associated data were presented. In the *perspectives on maladaptive behavior theme*, mothers' beliefs about the reason behind their children's displays of inappropriate behavior were outlined. The *perspectives on children's abilities theme* highlighted mothers' beliefs about their children's abilities to be

successful in their efforts and to become future productive members of society. The *public interfacing theme* addressed mothers' direct interactions with or thoughts pertaining to individuals in society about how they perceive the child with ASD. Finally, the *stress theme* detailed the perceived stress endured by mothers due to various factors associated with parenting a child with ASD.

For research question 3, two themes were presented. In the *maternal resources theme*, the coping mechanisms that mothers employ to promote more positive interactions with their children were outlined. Finally, the *interpersonal supports theme* addressed the factors within the families' immediate surroundings (e.g., people, groups, and research) that enhance the parent-child relationship.

In the following chapter, a discussion will be presented on how these themes relate to the existing literature and how this study will contribute to researchers' and practitioners' understanding of mothers' experiences raising children with ASD.

## CHAPTER V

### Discussion

In this study, the experiences of mothers raising preschool aged children with Autism Spectrum Disorder were explored. Specifically, the parenting practices and behaviors that mothers exhibit during their interactions with their children were of key interest. Little attention has been devoted to parenting practices in families in which there is a child with ASD. Factors such as mother-child engagement in daily routines and activities, mother's perceptions about their rewarding and challenging parenting experiences, and the role that child characteristics play in mothers' perceived competencies and psychological functioning have all been studied in this population to varying extents. However, the literature on the contributions of these factors to the everyday lives and experiences of mothers of children with ASD, particularly with respect to parenting these children, is scant.

The mothers in this study shared rich and detailed narratives of their parenting experiences thus allowing this study to make a unique contribution to the parenting literature. The emerging data from their stories resulted in the creation of various themes that were both consistent and inconsistent with the literature on parenting children with ASD. Interestingly, although mothers' experiences of raising children on the autism spectrum may be similar at times, the parenting behavior that mothers exhibit in their interactions with their children varied.

Given this finding, a proposed theory of *differential parenting responses* was generated. In other words, mothers' parenting behavior was designed to meet the needs of their children with ASD, but it varied based on the child and the context. Child characteristics (i.e., the severity of the disorder, child behavior problems, and social and communication impairments) were found to be contributing factors in mothers' varied employment of parenting practices and their displays of parenting behavior during their interactions with their children. Further, the context

in which the parenting occurs (e.g., public place vs. home; academic vs. social tasks) also influenced the type of parenting mothers employed. The contribution of child functioning to parenting has been documented in the literature (Belsky, 1984), as has the influence of the context (Bornstein, 1995). However, consideration of parenting in the context of these characteristics of children with ASD and their contexts has been limited.

Findings from this dissertation further highlight the contribution of child characteristics on parenting, an issue which both Belsky's and Bardley's conceptualizations of parenting emphasized. The data from the interviews and mother-child observations in the current study suggest that parenting of this unique population may be distinct from that of typically developing children. For example, whereas the concerns of mothers raising typically developing preschool aged children may center around daily care giving routines (e.g., addressing food aversions, providing sufficient amounts of stimulation, and allocating time for naps), mothers of children with ASD must address these similar concerns in addition to factors that are associated with the diagnosis. Participating mothers also discussed worrying about their children's ability to live independent lives after they were deceased. Additionally, several of the mothers lowered their expectations of their children after the diagnosis. Moreover, mothers expressed confusion regarding the cause of their children's displays of maladaptive behavior. These mothers questioned whether the disorder caused their child to exhibit maladaptive behavior or if these displays were typical of preschool age child in general. Such findings suggest that maternal parenting of children with ASD may be distinct from that of typically developing children in myriad ways.

Further, the findings from this study support the theoretical framework utilized herein. Bradley (2002) asserts that parents perform specific tasks to help children adapt to their

environments and become functioning adults in society. These five tasks are (1) sustenance (includes providing nutrients and shelter to their children), (2) stimulation (ensuring that their children are receiving sufficient sensory and meaningful information in their environment), (3) support (responding to the needs of the child to optimize their development), (4) structure (ensuring that their children are receiving sufficient amounts of the above and considering the child's specific needs as it relates to the above factors), and (5) surveillance (being aware of their children's whereabouts and keeping them safe). Data collected from the interviews and observations allowed for these parenting tasks to be discussed and seen in-situ.

Regarding *sustenance*, all mothers described their children's aversions to certain foods and the various strategies devised to encourage children to eat (e.g., providing incentives or hiding the unwanted food in spoonfuls of the desired food). Food challenges required mothers to be creative in the parenting of their children with ASD. Mothers also discussed how they ensured that their children were receiving sufficient *stimulation* in their environments. Supplying their children with books, developmentally appropriate toys, placing labels on items in the household, and performing therapeutic techniques in the home all surfaced as ways to provide sufficient child stimulation. Mothers *supported* their children with ASD by responding to their children's inquiries and needs in a timely fashion, and having warm, nurturing interactions with them. Additionally, these mothers considered their children's individual needs when providing input, thus employing *structure* in their children's environments. For example, whereas some children exhibited more independence in their interactions with their mothers, others required more assistance from mothers in their activities of daily living (e.g., feeding themselves). Finally, regarding *surveillance*, all mothers were aware of their children's



whereabouts throughout the observations and made efforts to ensure the safety of their children (e.g., standing in front of a store exit to block a child from running away).

The conclusions about the results of this dissertation study are discussed in four sections below. First the consideration of themes in the context of extant literature is discussed by category. Second, the limitations of this study are provided. Third, the implications for the findings, ethical considerations, and personal reflections are offered. Finally, recommendations for future research are outlined.

### **Category # 1: Parenting Practices and Behaviors**

This category contained themes that explored positivity within the mother-child relationship, children's and their families' adherence to schedules and routines, strategies employed by mothers to encourage child cooperation, and finally mothers' management of child crises (i.e., behavior problems).

#### ***Positivity within the mother-child relationship***

Numerous research studies have found that caring for a child with ASD is demanding (Dabrowska & Pisula, 2010; Griffith et al., 2010). However, all mothers in this study revealed, through their words in the interviews and actions in the observations, a positive approach to parenting their children. Specifically, mothers displayed warmth, responsiveness, and sensitivity, and an overall positive quality of their relationships with their children. According to Bradley (2002), maternal provisions of support, as defined as responses to the expressed and unexpressed needs of the child, can benefit children in the social milieu. Recent research has documented that factors such as parental warmth, sensitivity, communication, and opportunities for cognitive stimulation, which mothers in the current study display, are influential in shaping the cognitive and social skills of individuals with ASD (Conti, 2015; Smith, Greenberg, Seltzer, & Hong,

2008). These positive parenting behaviors have been linked to more positive parent-child relationships, a decrease in children's problem behavior (Smith, Greenberg, Selzer, & Hong, 2008), and more optimal child developmental outcomes (Capps, Sigman, & Mundy, 1994; Lambrechets et al., 2011). Additionally, this finding expands on the findings of Sharpley, Bitsikia, & Efremidis (1997), in which 20% of their sample of 219 parents of children with ASD reported their lives as being manageable. In fact, many mothers in this study consistently reported feeling very positive about their lives and their interactions with their children with ASD.

Congruent with mothers' perception of positive relationships with their children, all six mothers revealed positive perceptions of their children's interactions with others. They discussed their delight when their children expressed signs of wanting to engage with either them or others in the environment (e.g., making statements that refer to missing their friends or willingly engaging in play with the mother or others, including their peers, without any prompting from mother). It is likely that maternal support (i.e., being sensitive to their children's needs), warmth, and nurturance played a role in these children's varying levels of engagement with their mothers and peers.

These mothers also reported benefits to themselves from parenting their children with ASD, including increased patience and enhanced spiritual growth (Ekas, Whitman, Shivers, 2009; Hastings, Allen, McDermott, & Still, 2002; Stainton & Besser, 1998). While reflecting upon their experiences, half of the participating mothers explicitly expressed how caring for a child on the autism spectrum and the challenges associated with parenting these children has expanded their level of patience. These findings are similar to Hastings et al.'s (2002) results on families of children with intellectual disabilities. Moreover, this increased patience has allowed

them to be more aware of their children's needs, desires, and behaviors, both adaptive and maladaptive. For example, whereas mothers may have originally viewed their children's "meltdowns" as misbehavior, patience has now afforded them the ability to probe more into the child's feelings and possible triggering factors. Employing patience in their interactions with their youngsters is important in that it has been linked to parents' coping strategies and mental well-being (Smith et al., 2008). These findings of positivity are consistent with DePape & Lindsay's (2014) review of the literature on parental experiences associated with caring for a child with ASD. Specifically, families emphasized the need to reflect upon the positive factors within the parent-child relationship.

It is important to note, however, that not all parent-child interactions and mothers' overall experiences raising children with ASD were positive in nature. The vast majority of literature on the social skills of children with ASD contradicts my findings of unsolicited displays of warmth from the child towards others in the environment. In fact, many researchers have found impairments in the social skills of children on the autism spectrum (e.g., attachment difficulties) (Rutgers, et al., 2007). Interestingly, although all of the mothers discussed experiences within the parent-child relationship that paint a more positive picture on the parenting of these children, they also did not hesitate to highlight some of the stressors that make parenting children with ASD more challenging (e.g., child problem behaviors). This finding is in line with other studies that examine both negative and positive outcomes for families that have children with disabilities (Blacher, Neece, & Paczkowski, 2005; Hastings, Allen, McDermott, & Still, 2002).

### *Schedules and routines*

The schedules that children with ASD and their families abide by and the routines that children engage in have also surfaced as influences on parenting in this study. Many individuals

with ASD exhibit restrictive, repetitive, and stereotyped patterns of behavior often characterized by narrow or inflexible interests (APA, 2015). Notably, although a desire for repetition is common among children across developmental functioning in early childhood, children with ASD have been found to exhibit restricted and repetitive behaviors that are more extreme than children with other disorders and typically developing children (Richler, Bishop, Kleinke, & Lord, 2007). There is, however, limited evidence showing that high-functioning children (HFC) with ASD share similar numbers of interest as their typically developing peers. In the referenced study (Richler et al., 2007), the intensity of HFC's interest was found to be greater and more object oriented as compared to the interest of neurotypical children.

Despite such findings, the data that emerged from mother interviews and parent-child observations are consistent with the vast majority of literature on the preferences of children with ASD. Specifically, some of the children in the study had difficulty deviating from routines or transitioning from one location or event to another. Nearly half of the mothers candidly discussed their children's atypical behavior (e.g., obsessions with placement of items, preferences for specific character prints on t-shirts, or trouble transitioning) and the impact it has on the family dynamics. In response to their children's difficulty with flexibility, including trouble transitioning from one task/location to another, several of the mothers employed strategies to help provide structure to the child's life and ultimately to create calmness in the parent-child interactions. For example, obliging and refraining from taking the child to summer camp or purchasing several shirts with super hero prints were strategies employed by some participating mothers to facilitate more positive parenting experiences. Consistent with the data, changes in children's routines can trigger problem behaviors from children with ASD which lead to difficulty adjusting in families of these children (DePape & Lindsay, 2014).

As Bradley (2002) suggests, parental provisions of structure within the parent-child relationship, which includes ensuring that the child receives sufficient support and environmental input specific to his or her needs, can lead to better child adjustment. Therefore, mothers' willingness to cater to their children's rigid adherence to schedules and routines may serve to be beneficial to the child (i.e., provides him an opportunity to regulate his emotions after receiving the super hero printed shirt) as well as to the mother (i.e., her interactions with her child becomes more pleasant after producing the shirt with the Superman logo). The theme of schedules and routines is also important because mothers in this study expressed concerns about their children's strict adherence to schedules or routines. The behaviors exhibited by their children when disruption occurs in their routines can negatively impact mothers' mental health (i.e., produce anxiety) and perceptions of their parenting competencies which in turn may affect parent behaviors and parent-child interactions. These issues were salient in the current study and were consistent with Boyd et al.'s (2014) review of the literature in families of children with ASD. Specifically, children's strict adherence to routines has been found to impact families' spontaneity and engagement in activities. Ultimately, these parents desire 'shared experiences' in that both the child and other members of the family can enjoy participating in activities as a unit without triggering problem behaviors from the child with ASD as a result of a disruptive routine.

The literature suggests routines can serve as a form of structure for children on the autism spectrum and that individuals with ASD show a preference for routines and sameness (Szatmari et al. 2006; Lam et al., 2008), with deviations from the norm resulting in mood and behavior problems (Lam et al., 2005; Gabriels et al., 2005). However, half of the mothers in this study vehemently opposed adherence to a strict routine. This unwillingness to accept children's

ritualistic behavior, including strict adherence to a schedule or routine, was found in Fariugia's (2009) study. After interviewing 16 mothers and fathers of individuals with ASD, Fariugia (2009) found that parents disliked their children's restricted behavior and argued that it limited their activities outside of the house. This finding of limited engagement in public activities is especially important for mothers with other children.

The participating mothers in my dissertation study had to remain cognizant of their varying schedules and expressed the need to embrace fluidity due, in part, to their other children's involvement in extracurricular activities. For these mothers, adherence to a routine was secondary to balancing their parenting roles and ensuring equity within their parent-child interactions. Additionally, mothers' described in great detail their decisions to limit their support of their children's repetitive, ritualistic behaviors or interests. This decision was influenced by mothers' fears that their children with ASD will rigidly adhere to one rule or become too reliant on one way of participating in daily activities. One mother's response to this fear was to purposefully take various routes home in hopes of introducing fluidity to her son with ASD. This finding again supports Bradley's (2002) framework which underscores the importance of structure within the parent-child relationship.

The results of this study shed light on the varying beliefs about adhering to a schedule or routine that mothers raising children with ASD possess. These findings are important for the literature on parenting children with ASD, because the beliefs that mothers have about their day-to-day priorities and concerns enable them and their families to adapt to their life situations and have more positive interactions with their children (Hastings & Taunt, 2002).

### *Strategies encouraging child cooperation*

Similar to mothers' varied responses to their children's restricted and repetitive patterns of behavior as it relates to their daily activities, maternal approaches to addressing their children's misbehavior and inattentiveness were also found to vary in this study. One way to encourage child cooperation as found in the literature is to implement routines for children with ASD which several of the participating mothers did. Children with ASD experience significantly more behavioral problems than typically developing children and children with other disabilities (Brereton, Tonge, & Einfeld, 2006). Challenging behaviors exhibited by some individuals with ASD, such as a need for consistency and sameness and impairments in communication and social interactions, may make parenting more of a challenge for some mothers and thus can create significant problems in the parent-child relationship. Additionally, mothers' responses to their children's behavior can greatly impact their overall development (Sameroff, 2004). Given these findings, it is important for parents to possess the tools to establish and maintain those parent-child transactions that decrease problem behaviors in their children, such as increasing their cooperation with tasks and parental demands.

In regard to employing strategies that increase child cooperation, all of the mothers in this study endorsed some form of disciplinary tactic geared towards extinguishing children's displays of maladaptive behavior (e.g., use of timer, redirection, incentivizing, and coaching). Consistent with the literature (Armstrong & Kimonis, 2013), these parenting strategies have been found to decrease the displays of undesirable behavior in children. For example, mindful parenting, which is described as the caregiver having a clear, nonjudgmental, internally reflective mind in situations, including disruptive encounters with their children, allows parents to be more aware of how they perceive and respond to their children. Importantly, mindful parenting has been

found to decrease aggression, non-compliance, and self-injurious behavior in children with ASD (Singh et al., 2006).

When addressing children's maladaptive behavior, mothers' employment of disciplinary tactics requires her to be mindful of the situation at hand and the role that child characteristics (e.g., the severity of the disorder) plays in children's displays of such behaviors. For example, two of the mothers discussed their parenting practices with their child with ASD versus those employed with their typically developing children. These mothers described their increased willingness to repeat themselves more than twice during moments of misbehavior from the child with the disorder; however, their typically developing children were not granted such leeway. In this example, mothers remained cognizant of their children's cognitive deficiencies and their difficulties processing social information in the environment (e.g., impaired theory of mind) as compared to the cognitive abilities of their typically developing siblings.

This finding of differential parenting behavior, generally favoring the child with the disorder, has been reported for families that have both children with disabilities and typically developing children, although the evidence is limited (Quitter & Opipare, 1994; Meirsschaut, Wareyn, & Roeyers, 2011). Interestingly, one participating mother did describe employing the same parenting practices with both her son on the autism spectrum and her typically developing younger daughter. She expressed how the parenting behaviors that were successful in decreasing the frequency of maladaptive behavior in her son with ASD had also proven effective with her typically developing daughter. This resultant positive child behavior was likely to have contributed to her use of identical disciplinary measures across children. Additionally, it is likely that birth order played a role in her decision-making given that the child with ASD was the eldest.



While the strategies employed by the participating mothers may not be representative of all parents raising children with ASD, especially for those children that are older and or more cognitively advanced, this finding contributes to the current literature in that various parenting strategies can be employed with preschool aged children with ASD to decrease the displays of problem behaviors. Additionally, as aforementioned, child behavior problems have been found to be one of the primary contributors to parent psychological functioning (e.g., parental stress) (Baker et. al, 2003; Hastings et al., 2005; Richdale et al. 2000). The maladjusted behavior exhibited by children with ASD coupled with their severe impairments in communication and social interactions can have considerable impact on mothers' perceptions of their children and their experiences, thus negatively influencing their interactive behavior. These mothers' adaptation of child-centered strategies to foster child cooperation seemed to have a positive influence on their well-being.

Finally, this theme of the various strategies employed by mothers to encourage child cooperation is important because it highlights mothers' differential parenting with their children with ASD and their typically developing siblings. Although exploring differences in mothers' parenting behaviors within families was not a goal of this study, the emerging data draw attention to how ASD impacts the family unit as a whole (i.e., transferability of autism-adapted parenting strategies across children within the same family).

### ***Crisis management***

The mothers in the current study often had to engage in parenting that resembled crisis management. A recurring challenge discussed among mothers of children with ASD was child problem behaviors (e.g., tantrums, whining, running away in a public place, and children's social-communication difficulties). In this study, mothers openly described the behaviors

exhibited by their children that make it difficult to parent them (e.g., noncompliance and aggression) and their typical parenting practices when such behaviors are presented.

Additionally, mothers described elements in the environment that might serve as triggers for their children's maladaptive behavior. DePape and Lindsay (2014) reviewed the literature that addressed these issues and found that parents of children with ASD reported confusion about how to manage problem behaviors.

In terms of mother responses to child misbehavior in this study, two of the six mothers described allowing their children to regulate their own behavior by providing them time to express their feelings mainly through physical acts (i.e., screaming, yelling, and crying). Once the child had calmed down, these mothers then continued to engage the child. Unfortunately, the empirical evidence regarding parent responses to the maladaptive behavior displayed by children with ASD is scant. However, findings from the literature on typically developing children have shown that children's abilities to regulate their emotions (i.e., anger) which often result in child problem behaviors, is associated with parents' abilities to modulate their own emotions and the negative responses to their children's behavior (Snyder, Stoolmiller, Wilson, & Yamamoto, 2003).

Mothers' varied responses to their children's behavior further supports how the process of parenting involves distinct and multiple exchanges between the parent and the child across contexts. Other parental responses found in this study included providing hugs and kisses to the child during moments of externalizing problem behaviors as well as probing to uncover the child's concerns as a means of managing crises within mother-child interactions. According to participating mothers, these parent responses were helpful in mitigating child externalizing problems. As aforementioned, child behavior problems have been found to contribute to

parents' psychological functioning (Baker et. al, 2003; Hastings et al., 2005). Taken together, the findings in this dissertation as well as in the parenting literature are pivotal because they highlight the bidirectional role that parent and child displays of emotions and behavior have on social relationships (e.g., mother-child relationships).

This bidirectional link between the behavior of children with ASD and parents' behavioral responses represents an important component of mothers' early experiences raising children with ASD. Importantly, Bradley (2002) asserts that both parent and child actively construct their environments as well as respond to what the environment presents, therefore are co-creators of their experiences. Although findings from this dissertation study support this assertion, it is again important to highlight the varied responses of mothers in their interactions with their children with ASD. Notably, not all participating mothers adopted an approach that relinquished some level of control over the duration of the exhibited problem behavior (i.e., allowed the child to be in charge of regulating his own emotions). For example, two of the participating mothers in this dissertation study took on a less diplomatic approach to responding to their children's displays of maladaptive behavior which included verbally reprimanding the child or ignoring the behavior all together. Mothers' varying responses to their children's maladaptive behavior is congruent with the literature on parenting children across different levels of developmental functioning that highlights the variability in parenting processes (Maljaars et al, 2014).

Although behavior problems (e.g., temper tantrums) are frequent and prevalent in early childhood, young children with ASD have been found to have increased levels of behavioral and emotional problems than their typically developing counterparts (Mahan & Matson, 2011). The problem behaviors manifested in children with ASD can negatively influence mothers'

perceptions of parenting their children (Sanders & Morgan, 1997) as well as their interactive behavior (Kasari & Sigman, 1997), thus supporting the bidirectional nature of parent-child relationships discussed in the literature (Bradley, 2002). This investigation of the bidirectional relationship between child and parent factors can help researchers garner a better understanding of parents' early experiences with their children with ASD, and how their parenting is affected by their children's behavior.

### **Category # 2- Beliefs and experiences of mothers**

This category contained themes that relate to mothers' perceptions, feelings, and experiences with respect to parenting a child with ASD. The following themes emerged within this category: maternal perspectives on child's maladaptive behavior, maternal perspectives on children's abilities, public interfacing, and perceived stress associated with caring for a child with ASD. Mothers' perspectives on their experiences with their children are important in that these perceptions can influence parental practices which ultimately shape children's developmental outcomes (Hastings et al., 2007).

#### ***Perspectives on child's maladaptive behavior***

To garner a better understanding of mothers' experiences, it is important to explore their beliefs about the underlying reason for their children's displays of maladaptive behavior. Research consistently shows that parents of children with ASD have difficulties with adjustment. For example, Lee (2009) found that these parents reported experiencing more stress and feeling less optimistic than parents with typically developing children. These negative feelings related to caring for a child with special needs may shape parents' perceptions about their children, particularly in reference to their maladaptive behavior.

The impairments associated with this specific disorder (i.e., restricted and repetitive behavior and social-communication difficulties) coupled with the ubiquitous challenges experienced by all parents of preschool aged children regardless of where they are developmentally, can lead to confusion on the part of the caregiver. Mothers' perspectives about the etiology of their children's behavior were captured in both their interviews and observations. In fact, several of the participating mothers expressed their confusion about whether or not their children were intentionally being non-compliant or if the maladaptive behavior exhibited was a direct result of the disorder.

Although mothers' feelings of confusion about the possible causes behind their children's displays of problem behavior have been documented on websites of ASD-relevant organizations (e.g., Autism Speaks), little research is available which directly explores parents' perspectives about the disorder as it relates to the causes of child misbehavior. Hartley, Schaidle, Burnson (2013) found that mothers and fathers tended to attribute the problem behaviors exhibited by their children and adolescents with ASD to characteristics that were internal to the child and that could be controlled by the child. Notably, parents of younger children (between 3-5 years of age) were more likely to attribute child internal characteristics to their children's displays of maladaptive behavior as compared to parents with older children. These findings suggest that parents of children with ASD tend to attribute child behavior problems to the disability itself and not necessarily the child. These findings also suggest parents of children with ASD perceive their children as being able to control the behavior problem. These findings are important in that they support the idea that behavior problems may be amenable to change through behavioral interventions.

In an interesting study related to medical causes and children's behavior, Dale, Jahoda, & Knott (2006) explored mothers' beliefs about ASD and the meaning that they ascribe to the diagnosis as they attempt to make sense of the disorder. These researchers explored locus of cause which relates to mothers' perceptions of whether or not an event was internally caused (i.e., genetics) or due to external causes (i.e., vaccination). Difficulties related to ASD (e.g., child regression) were found to influence mothers' diverse range of attributions. Although this study does not directly capture mothers' confusion regarding children's behavior problems, it serves as an example of mothers' complex thinking regarding their attributions of the causes of the disorder.

The theme of mothers' perspectives on their children's displays of problem behavior is important to highlight because mothers' attributions have been found to predict their emotional and behavioral responses to their children (Hartley, Schaidle, Burnson (2013). Additionally, children's disruptive behavior has been found to be connected to mothers' negative emotional responses (Snyder, Stoolmiller, Wilson, & Yamamoto, 2003). Importantly, as previously mentioned, mothers' emotional and behavioral responses to their children's behavior can exacerbate children's problem behavior. This bidirectional pathway was revealed in Lecavalier, Leone, & Wiltz's (2006) study, in which they found that children's problem behavior and parents' stress exacerbated each other over time. These dissertation findings and evidence from the literature support the notion that the moment-to-moment exchanges within the mother-child relationship can profoundly influence parenting practice, behaviors, and perspectives as well as the frequency of children's behavior problems.

### *Perspectives on child's abilities*

According to Bradley (2002), parents have the responsibility of guiding their children to reach their goals with the hopes of them becoming productive members of society. For participating mothers, several described present and future goals for child independence and social relationship building. Despite their children's impairments in a variety of developmental areas, many of the mothers acknowledged their children's progress over the months and years and remained hopeful. This view of hopefulness in parents' short term and long term expectations of their children's development was consistent with Fleischmann's (2005) grounded theory study on websites for parents of children with ASD. While examining the narratives of parents from 33 self-published websites, Fleischmann found that parents lowered their expectations of the abilities of their children with ASD while continuing to hope for future progress. Importantly, mothers acknowledged that their children's progress was dependent on parents' efforts to help them succeed, thus supporting Bradley's (2002) multiple foci on parental behavior.

Mothers' desires for their children to strive to succeed despite their diagnosis emerged during the interviews. Half of the mothers in this study discussed their beliefs in their children's abilities to be successful at acquiring certain skills that would allow them to live more independent lives (e.g., being potty trained). Explanations were also given regarding their desires for their children not to be treated differently from other children. Half of the participating mothers viewed extreme concessions made for their children with ASD as negative and as potentially handicapping their children. The other half of participating mothers highlighted their children's deficiencies, particularly in the social milieu, and discussed their daily preoccupation with and concerns for how these impairments hinder their children's abilities

to acquire certain skills (e.g., obtaining and maintain social relationships). Notably, some mothers' unwillingness to adjust their interactions with their children with ASD to accommodate their children's deficiencies is inconsistent with the literature on parenting children with ASD. In fact, many researchers have found that parents of children with ASD lower their expectations of their children with ASD (Fleischmann, 2005) and alter their interaction patterns to better support their children's areas of difficulty (Werner DeGrace, 2004). Despite the variation in mothers' perspectives on their children's abilities, it remained clear that all six participating mothers were hopeful for the future. The statements shared by mothers highlight their optimistic spirit as it relates to the development of and interactions with their children with ASD.

### ***Perceptions and experiences around public interfacing***

In regard to mother-child relationships, it was important to explore extensions of mothers' experiences including the role that society plays in shaping mothers' interactions with their children. In DePape's and Lindsay's (2014) review of the literature on the experiences associated with caring for a child with ASD, many parents reported receiving criticism from strangers in public. Consistent with these findings, all of the participating mothers described their level of discomfort when their children exhibited socially inappropriate behavior in a public setting and the scrutiny that followed. This finding is consistent with the parenting literature with families of children with ASD, which suggests that the challenges of parenting (e.g., child displays of maladaptive behavior while in public) have resulted in feelings of shame and humiliation in mothers of children with ASD (Gray, 2002). Additionally, these parents also reported dealing with social exclusion from certain activities and losing some of their friends in their social networks. For example, one mother described how her son's tendency to run away from her and bump into things in the process has prevented her from attending social events at



her friends' homes. Notably, it is not clear whether her friends intentionally ostracize her or if this mother isolates herself from the group due to her child's problem behavior. Many of the parents also described restricting their daily activities to avoid public situations with their children. This finding is particularly important because the stigmatizing from others in the environment can shape how mothers respond to their children's behavior while in a public setting (Farrugia, 2009).

The majority of the mothers in this dissertation study even discussed limiting public family appearances due, in part, to the disruptive behavior exhibited by the child with ASD (i.e., yelling, crying, kicking, screaming, etc.), which is consistent with the parenting literature on mothers' perceptions of people's reactions to their children with special needs in public places (Boyd, McCarty & Sethi, 2014; Ryan, 2005; 2008). In his 2009 study on public stigmatizing of parents of children with ASD, Farrugia interviewed 11 mothers and 5 fathers of children with ASD and found that many families limited their public outings to avoid public situations with their children. Although limiting family outings may be beneficial to the parent and the child with ASD in that the home environment allows family members to be themselves and provides a certain layer of comfort, these limitations can be harmful to the overall dynamics of the family unit.

Five out of six of the participating mothers had other children who, more often than not, had to cater to the desires of the child with ASD during times of disruption. Mothers in this study discussed feelings of guilt, specifically related to slighting the other children in the family from engaging in outside activities. Restricting family activities has been found to create feelings of resentment towards the child with ASD from their siblings (Gray, 1998).

Additionally, Howlin (1998) found that siblings of children with ASD often felt that they were

not receiving the same amount of attention from their parents that the child with ASD was receiving and that parents' behavioral expectations were lower for children with ASD. These findings are important in that rearing a child with ASD has not only been found to impact the parents, but siblings as well (White, 2013).

While discussing their families' limited engagement in public activities, some mothers explained their responses to the public scrutiny they faced. Whereas some mothers were willing to share the child's diagnosis with onlookers, others refrained from disclosing such information with the goal of protecting their children's privacy as it relates to their medical needs. Farrugia (2009) reported that some parents of children with ASD wanted to put shirts on their children that read, 'I have autism' to disclose to the world that the child's display of maladaptive behavior was due to a disorder. Additionally, parents in the Farrugia study reported that children's appearance (i.e., lack of physical abnormalities) played a role in how the public perceived their children during moments of disruption. The findings in the literature as well as in this dissertation study are important in that (1) they highlight mothers' need to balance their responsibilities between the child with ASD and other members of the family and (2) they shed light on mothers' internal struggles regarding their decisions to inform the public of private and sensitive child matters (i.e., the diagnosis of the child). Finally, children's behavior while in public directly reflects parents' perceived competence which may add an extra layer of stress on parents raising children with ASD, thus making their parenting experiences more difficult. Findings of limited family outings are consistent with DePape and Lindsay's (2014) review of the literature on parenting children with ASD.

### *Stress associated with caring for a child with an ASD*

Another central factor related to parenting children with ASD was the stress stemming from a variety of sources (e.g., funding for therapeutic services, employment status, provisions for sufficient child stimulation, child social impairments, and concerns related to children's daily well-being). In regard to perceived stressors, all six participating mothers discussed factors that make parenting children with ASD more difficult. Importantly, the demands associated with caring for a child on the autism spectrum has been linked to parents' psychological distress (Glasberg, Martins, & Harris, 2006; Hastings, 2008), which has the potential to negatively impact mother-child interactions and ultimately child outcomes.

During mothers' discussions of the factors related to raising children with ASD that contributed to their perceived stress, several of the mothers reported occasional feelings of "moodiness" while interacting with people in the environment, including their children. Some of these negative feelings experienced by mothers resulted from work demands outside of the home and the financial burdens associated with having a child with ASD (e.g., out-of-pocket costs for therapeutic services). For example, four of the participating mothers discussed the economic necessity of being employed either full-time or part-time. Full-time employed mothers expressed how the demands placed on them at work can overwhelm and exhaust them to the point that it negatively impacts their interactions with their children after arriving home. These mothers also discussed their efforts to "make up" for their physical and emotional absence during the week by engaging in more frequent high quality interactions over the weekend (e.g., making breakfast together or going on nature walks in the park with their children).

Although the demands of mother employment can have an indirect negative effect on parent-child interactions, unemployment as an alternative can be detrimental to mothers'

psychological functioning (i.e., lead to stress) which too can impact parents' interactive behavior with their children. Specific to employment in families with children with disabilities, Gordon, Roesnman, & Cuskelly, (2007) found lower levels of employment among mothers of children with disabilities versus those without. Consistent with the employment literature on families with children with disabilities (Warfield, 2001), three of the participating mothers discussed having financial difficulty as a result of having to either stop working or refraining from applying for a job and focusing their energy on the daily demands associated with caring for a child on the spectrum.

For these mothers, although finding employment outside of the home may (1) serve as a reprieve from the everyday stress associated with caring for a child with ASD and (2) provide supplemental income, sacrificing employment for the betterment of the child (e.g., being able to provide structure and an enriched environment to the child while home) was a sacrifice that they were willing to make. This finding is consistent with the literature on employment statuses of mothers with children with ASD (McCabe, 2009). Specifically, mothers' decisions to be unemployed have been found to be a direct result of their desire to play a more active role in the promotion of optimal development in their children with ASD (McCabe, 2009). Notably, in the parenting literature of part time employed mothers with typically developing children, findings of more sensitive parenting in their interactions with their youngsters is evident (Beuhler & O'Brien, 2011). These findings support Bradley's (2002) descriptions of the parenting actions carried out by caregivers to help their children adapt to their environments and ultimately improve the quality of mother-child interactions.

Another source of stress as discussed by participating mothers stemmed from their constant need to address issues such as advocating for child services in the county and school

setting. Specifically, all six of the mothers discussed to some degree their level of advocacy in obtaining services for their children, and highlighted the complexity in negotiating for their children on the spectrum. Often times, mothers felt that their concerns about their children receiving insufficient therapy hours were falling on deaf ears. Moreover, county criteria for receiving additional free services made several of these mothers ineligible despite already experiencing the financial strain of caring for a child with special needs. This finding is consistent with the literature that addresses parental concerns about the services their children received. For example, Woodgate, Ateah, & Secco (2008) found that many of the 16 mothers and fathers of 3-9 year old children with ASD in their study were dissatisfied with the services offered to their children. Notably, parents who made changes to their existing circumstances related to lack of services were found to cope better than parents who accepted the system as is.

Although much is known about the fundamental importance of supporting families with children with special needs, results from mothers' interviews shed light on their frustrations resulting from lack of support from their counties and school systems. These factors, along with others, motivated mothers in their quest for knowledge pertaining to child and family services and support. Many of these mothers reported not only serving in the capacity of advocate for their children with ASD, but also that they became researchers - scouring the internet and library shelves to increase their knowledge on parenting this unique group of children. This mobilization of resources coupled with parents' desires to advocate for their children may benefit the parents themselves. Therapeutic services received by children with ASD can help decrease the frequency of children's displays of problem behavior, which in turn, can alleviate some of the stress experienced by these parents (Dunn et al., 2012).

Indeed, parents of children with ASD report more elevated levels of stress when compared to parents of typically developing children and parents of children with other disabilities (Blancher & McIntyre, 2006; Estes et al., 2009; Montes & Halterman, 2007). Factors discussed in the interviews (i.e., funding for therapeutic services, mother's employment status, provisions for sufficient child stimulation, children's difficulties in the social arena and concerns regarding children's daily well-being) are likely to contribute to the level of stress perceived by parents of children with ASD. These findings are important because the stress levels experienced by these mothers can negatively impact parenting behaviors, practices, and interactions with children.

### **Category # 3- Factors that facilitate or hinder parenting**

Mothers in this study disclosed and demonstrated many factors that may facilitate or hinder their parenting of their children with ASD. This category contained themes related to the resources (i.e., the coping mechanisms that promote more positive interactions with their children with ASD), and the supports provided by both familial and non-familial groups that aid in their abilities to adapt to the experiences associated with raising this unique population.

#### ***Maternal resources***

The literature on the challenges associated with rearing children on the autism spectrum is robust. DePape & Lindsay (2014) review of the parenting literature on the experiences of parents of children with ASD show that these caregivers are overwhelmed by family demands. Importantly, the coping mechanisms that caregivers possess can mitigate the potential negative impact these challenges may have on mother-child interactions and mothers' psychological functioning. For example, Higgins, Bailey, & Pearce (2005) found parent coping strategies to buffer the effects of caregiving burden on stress, anxiety, and depression. Surprisingly, although

all mothers discussed moments of difficulty within the parent-child relationship, only two of the mothers described specific maternal coping responses to mitigate feelings of irritation or frustration (i.e., stepping away from her child). Coping strategies are critical because they can assist mothers in addressing the demands related to parenting children with ASD (Folkman & Moskowitz, 2004). Thus, some mothers experience fewer difficulties in their interactions with their children if they have more coping strategies and psychological resources (Hastings & Taunt, 2002).

Enhanced spirituality was also discussed as a resource that aids mothers during their interactions with their children with ASD. Half of the mothers in the study discussed the role of religion after receiving the child's diagnosis and seeking guidance from God throughout their interactions with their children. Previous literature on the increased spiritual growth of parents raising children with special needs is consistent with the dissertation findings related to religiosity (Ekas, Whitman, & Shivers, 2009).

It is also important to note that mothers' coping during their interactions with their children as well as their emotional adjustment has been found to be related to their perceptions of their parenting abilities (Sanders & Morgan, 1997). Consistent with the literature on the perceived competencies of parents of children with ASD (Fleischmann, 2005), several of the participating mothers questioned their parenting competencies. For five of the six mothers, raising a child on the autism spectrum and the behaviors linked with the disorder were foreign concepts given that their other children were typically developing. As a result, these mothers worried about their capacities as parents of these unique children.

This feeling of unease is supported by a study in which ASD was found to be a stressor that challenged parents' self-efficacy and psychological well-being (Meirsschaut et al., 2010). It

is likely that the characteristics of the child (i.e., severity of the disorder) may play a role in mothers' perceptions of their parenting abilities. Whereas some children with ASD require some degree of support in addressing social communication impairments and restricted, repetitive behavior problems, others' impairments are more severe thus requiring significant aid (APA, 2014). Children's ability to function independently may influence parents' psychological functioning which in turn impacts their parenting behavior.

As found in the literature on parenting children with ASD, parents who feel competent about their parenting abilities tend to be more active in their children's lives and experience more positive interactions with their children than parents who have lower perceptions of their parenting abilities (Kuhn, & Carter, 2006; Meirsschaut et al., 2010). Therefore, it is imperative that mothers of children with ASD possess the psychological and social resources that aid in their interactions with their youngsters.

### ***Interpersonal supports***

Mothers in this study described the support received from both familial and non-familial groups, as well as the role that support played in mitigating some of the challenges associated with raising a child with ASD. All participating mothers acknowledged the assistance received from individuals in their immediate environment (e.g., spouse and child's grandparents). Spousal support emerged as a topic of discussion during the interviews and was seen during the home and public observations. For example, David's father cooked lunch which allowed Danielle to address her child's solicitations for play and rigidity in the type of play he wanted to engage in with his mother. This finding of spousal support is consistent with early studies on the interactions between parents and their children with disabilities. Specifically, parents who perceived the support in their marriages as being sufficient tended to cope better with the



challenges associated with parenting children with special needs, than did parents who were dissatisfied with their spousal support (Beckman, 1983; Friedrich, 1979). Importantly, conflict between co-parents has been found to be negatively associated with the social skills of typically developing children (Cabrera et al., 2012), which highlights the importance of congruence between spousal parenting approaches and mothers' perception of support from their spouses for child outcomes.

For participating families in this dissertation study, social support in the marriage proved to be an invaluable factor. For example, in families where the father was present, parents shared the daily care giving responsibilities including cooking, paying bills, and chauffeuring the children to their schools, therapy sessions, and extracurricular activities. Findings of daily father engagement in their interactions with their preschool age children are consistent with the literature (Leavell, 2012). For the mother who was a single parent, these daily caregiving responsibilities, coupled with her full-time employment status and her advocate and researcher roles, made parenting more challenging. In this isolated case, and in the case of other mothers in this study, the grandparents of the children served as a great source of supplemental support. Regardless of the grandparents' geographical location (e.g., some resided within a 30 minute drive from the participating families while others lived out-of-the-state), parents were grateful for the level of support received from their families. These findings of familial support are important because individuals that provide the support can serve as protective agents to the family unit (i.e., mitigate some of the stress associated with caring for children on the autism spectrum) (Boyd, 2002; Ekas, Lickenbrock, & Whitman, 2010; Weiss, 2002). Moreover, the families' ability to adapt to the challenges associated with parenting this unique population has

been found to be linked to parents' perceptions of the support that they receive from their networks (Boyd, 2002; Meadan, Halle, & Ebata, 2010).

Overall, participating mothers discussed the critical role that informal support (i.e., familial) played on their perspectives and experiences of their everyday realities. Discussions of formal support (i.e., therapeutic services) were discussed albeit to a limited extent. The mothers' perspectives on their parenting abilities were found to be linked to the level of perceived support received especially from their families. Notably, in their review of the parenting literature on families with children with ASD, DePape & Lindsay (2014) found that many families removed people from their lives who were unsupportive of their children thus highlighting parents' desires for support.

### ***Psychotherapy and pharmaceutical needs***

Although only one mother disclosed her participation in therapy and utilizing pharmaceuticals to aid in her ability to adapt to parenting challenges, this issue is still important to highlight. As previously discussed, mothers of children with ASD report elevated levels of stress in comparison to mothers of children with other developmental delays and mothers of typically developing children (Blancher & McIntyre, 2006). Additionally, these mothers are at increased risk of depression (Olsson & Hwang, 2001). It is likely that child characteristics (e.g., severity of the disorder) contribute to mothers' compromised psychological functioning. Interestingly and importantly, the mother who described her need to address her mental health concerns had two children on the autism spectrum. She also speculated that her husband too exhibited classic hallmark signs for this disorder (e.g., deficits in social interactions). Thus, this mother's unique experiences may explain her disclosure of the need for psychotherapeutic services.

Importantly, mothers' mental health can make the family more vulnerable to risk in a number of ways. For example, mothers might be more stressed and depressed if they have multiple children to whom they have to attend, particularly if they are young. Additionally, the psychological well-being of mothers may be more compromised if more than one of her children are on the autism spectrum as is the case with Fatima. This unique experience of having multiple children diagnosed with ASD may shape mothers' interactive behavior while parenting her children, affect her overall mental health, and thus increase the other risks that the family may encounter (Lovejoy, Graczyk, O'Hare, & Neuman, 2000).

In sum, caring for a child with ASD can be demanding and has been linked to elevated levels of stress in these parents (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005). Parental stress associated with rearing children with disabilities places parents at higher risk of depression (Gray, 2003). Although the literature on the psychological functioning of parents of children with ASD as it relates to child characteristics is robust (Glasberg, Martins, & Harris, 2006; Hastings, 2008), the literature directed at understanding the parenting experiences of these parents is in its early stages.

This dissertation study sheds light on the parenting processes found in families in which there is a child with ASD. Specifically, this study identified the following factors as critical to the consideration of parenting processes within this population: (1) positive parenting experiences with children with ASD; (2) parental responses to children's displays of maladaptive behavior; (3) the impact of stress on mothers' psychological well-being and interactive behavior with their children; and (4) resources that facilitate mothers' interactions with their children with ASD (i.e., coping strategies and ecological supports).

### **Limitations of the study**

This study is not exempt from having limitations, which I discuss herein. First, the small sample size of six is not representative of the population of parents of children with ASD. The goal of qualitative methodology is to obtain a better understanding of an understudied phenomenon in a context-specific setting (i.e., real-world setting) without manipulation from the researcher. This study therefore aligned with the goals of qualitative research and highlighted the parenting experiences of mothers of children with ASD. While external validity is of great concern in other studies, the goal of this dissertation study was to uncover the experiences of mothers raising preschool-aged children with ASD, not to generalize their experiences.

Of the mothers who participated in this study, it is possible that their experiences may be different from those mothers with children with ASD who did not participate. All of the participating mothers were recruited from Children's National Medical Center (CNMC) through a listserv of individuals who were either currently receiving services from CNMC or who had received services in the past and wanted to receive notification of research opportunities. Allowing continued contact through research opportunities suggests that these mothers were more likely to be involved in the medical progress of their children and therefore would be more likely to volunteer for this study. Notably, volunteers received a monetary compensation of \$150. Mothers who may not have normally responded to the recruitment flyer may have opted to participate to receive the compensation. Mothers of very low socioeconomic status and mothers contending with more risks in their lives not necessarily associated with their children who have ASD may also not have been reached through this recruitment method. Despite this possibility, the findings of the study shed light on the personal experiences of mothers raising

preschool aged children with ASD, particularly parenting practices and behaviors employed in their interactions with their youngsters.

The second limitation of this study is that the data collection process entailed interviewing mothers of children with ASD. Participants may have withheld certain information for fear of judgment from the interviewer or it is possible that they did not feel comfortable disclosing personal information that may have further aided in the discovery of mothers' parenting practices and behaviors. Participating mothers were informed of the efforts made to keep their information confidential (e.g., use of pseudonyms to protect their identity) to increase the participants' level of comfort. I also carefully and strategically disclosed appropriate personal information about myself to make the participant feel at ease. Additionally, I observed parenting behaviors in-situ to corroborate what mothers revealed during the interview.

A third limitation of the study is that I served as the analysis tool. Unlike quantitative methodology that employs psychometrically sound measures and software programs to statistically generate output of the research findings, in qualitative research, the experimenter is that tool. My task was to select the salient quotes from the mother interviews and field notes that best describe and explain mother-child interactions. Due to the nature of the methodology, experimenter bias is a possible concern. To mitigate the likelihood of my biases shaping the interpretation of the data, I enlisted peer debriefers to ensure that the findings of the study were valid. An inside peer debriefer (someone who has knowledge of the topic) and an outside peer debriefer (someone who has little to no knowledge of the topic) reviewed transcripts and observation notes throughout the data collecting process. I used their feedback to better define my codes and select quotes which best exemplified the emerging codes. This process led to the creation of themes and subthemes.

A fourth limitation of this study is that it only included mothers. Fathers as well as other family members (e.g., grandparents) play an integral role in children's development, including participating in the daily caregiving of children. Making adjustments in possible future studies to include fathers and other family members would enrich the data gleaned from parenting studies.

Finally, another limitation of this study is that families with girls who were on the autism spectrum did not participate. An inclusion criterion for this particular study did not limit the involvement of families to only those who had 3-5 year old boys with ASD. Although boys are 4-5 times more likely to suffer from this disorder, gathering information on the parenting experiences of mothers raising girls with ASD would further shed light on the similarities and differences associated with caring for a child on the autism spectrum across gender.

### **Implications**

Despite the limitations presented above, results from this study can have practical implications for professionals working with children with ASD (i.e., clinicians and other practitioners) and their families. The findings presented herein can inform professionals of the factors that contribute to the everyday realities and experiences associated with parenting children on the autism spectrum. Specifically, the findings from this study bring forth implications for the development of policy and practice to enhance the parenting that children with ASD receive.

Overall, this study highlights the need for additional supports for mothers around parenting their children with ASD. Schools and teachers can assist in engaging and supporting mothers of children with ASD. Teachers spend a significant amount of time during the day addressing the needs of the children who are enrolled in their classrooms. During these hours,

both positive and challenging interactions may unfold. For the more challenging experiences, teachers must implement techniques to mitigate some of the maladaptive behaviors exhibited by their students (e.g., temper tantrums). The teaching techniques that appear more effective in decreasing the frequency of behavior problems in children with ASD can be taught to mothers of these children and transferred to the home setting. In this manner, teachers can more effectively engage mothers of children with ASD and include them in the many educational and therapeutic processes that are implemented for this population.

According to the participants' perspectives, caring for a child with ASD includes both positive and negative interactions. Parenting interventions which build on the strengths that parents display in their interactions with their children may enhance their capacities to address the negative aspects of the interactions. Based on this study's findings, parenting interventions that focus on helping parents be "mindful" of and responsive to their children's individual needs and aim to improve parenting skills in an interactive manner may be particularly useful for families in which there is a child with ASD (e.g., Brookman-Frazee, Stahmer, Baker-Ericzen, & Tsai, 2006).

Government and insurance policies can ensure funding for therapy and intervention services that assist parents in improving their interactions and relationships with their children with ASD around specific challenging experiences (e.g., behavior problems and social-communication deficits). Additionally, development of programs that address mothers' mental health, specifically as it relates to stress and depression, can be beneficial as mothers navigate through their everyday experiences with their children with ASD. Finally, interventions that help mothers to access informal and formal resources may be critical for decreasing stress and enhancing parenting.

Researchers may capitalize on the findings from this dissertation to generate hypotheses specifically related to mother-child relationships. For example, future studies could examine whether children with ASD who receive therapeutic interventions in the school setting that help them adapt to their environments may exhibit more positive behavior during their interactions with their mothers at home. A second hypothesis that may be generated considers the communication level of the child. Specifically, studies could examine to what extent children with ASD who are more emotionally expressive possess skills that may allow for more positive mother-child exchanges to occur. A third hypothesis to be tested could entail to what extent cumulative risks for both the mother and the child are detrimental to the quality of the parent-child relationship. A final hypothesis involves the specific parenting practices that mothers employ with their children with ASD. Future studies could examine whether parenting of a child with ASD is distinct from the parenting of a typically developing child. For example, mothers' concerns regarding children's ability to function independently as he develops or when she is deceased, coupled with her current and future expectations for her child based on the functioning level of the child could be compared for mothers of typically developing children and those with ASD.

### **Ethical Considerations**

As with any study, ethical issues must be considered and addressed. Two main challenges inherent in the study included ensuring participant confidentiality and acknowledging the families' need of support. Mothers disclosed sensitive information about themselves and their children with ASD, including medical and family histories. To ensure protection of this information, families were provided with a university approved HIPPA form detailing the researcher's acknowledgment of the private nature of their documents (children's IEP and/or



evaluation forms from a licensed clinician). Additionally, participants' information was stored in locked cabinets to which only I had access.

Additionally, to address the support needs discussed by participating mothers, I provided resources to all families at the conclusion of the data collection phase. These resources included a list of support groups in the greater Washington, DC area as well as organizations dedicated to increasing awareness of ASD, advocating for the needs of individuals with ASD and their families, and researching causes of and treatments for this particular disorder.

### **Personal Reflections**

Reflexivity in qualitative analysis is when the researcher engages in being self-aware regarding their role in the creation of knowledge. The main goals of participating in the reflection process are to ensure (1) that the data are valid, and (2) to be as transparent as possible about your findings and the data analysis process (Finlay, 2002). During the data collection phase, I was aware of my positioning as a researcher. In qualitative research, the experimenter serves in the capacity of the instrument of data collection as well as the data analyzer. Therefore, I was a central figure who influenced not just how the data were collected, but the interpretation of mothers' personal experiences as well. Given this methodological approach, subjectivity can play a role insofar as my ability to be impartial could have been at risk (Bodgan & Biklen, 1998).

My experiences working and interacting with families with children with ASD were beneficial in that they afforded me the ability to be clear on my population of interest for this dissertation. However, it may have jeopardized my view of this disorder and the individuals affected by it. Therefore, I had to remain cognizant of how my past and current relationships with families of children with ASD may have played a role in how I perceived the information that mothers shared in their interviews and my interpretations of the parenting behaviors

displayed in the mother-child observations. During the data analysis process, I remained aware of my potential biases and made every effort to remain neutral as to not misinterpret the data. My peer reviewers also helped in this regard.

While considering my position as a data collector and the issues of subjectivity that may arise, I also had to remain aware of my participation level during the observations. My goal was to serve as a passive participant which involved being present in the milieu in which the parent-child interaction is occurring but remaining as a bystander, while taking detailed notes on mothers' behaviors with their children. For the majority of the observations, I was able to serve in this capacity. However, there were two salient events when I had to take an active position, both times due to safety issues. For example, I had to assist in running after a child in a grocery store parking lot on a busy Saturday afternoon. On a separate occasion with a different mother, I assisted in stopping a child from running out of a store in the mall. Therefore, my approach of remaining as a spectator was not possible in these moments.

These isolated situations were reminders of how critical reflexivity is throughout the data collection process as my active participatory role may have altered what would have happened naturally within the mother-child relationship if I was not present. Therefore, the personal reflection process that occurred throughout the data collection and analyzing process allowed for the integrity of the research to be upheld.

### **Research directions**

The results of this study help to inform researchers about the experiences of mothers raising preschool aged children with ASD. An interesting finding in this study is that although all of the mothers expressed hope in their children's abilities to function in society (be it independently or with assistance), differences in how mothers interacted with their children were

discussed and observed (e.g., various strategies employed to address child problem behaviors). Further research needs to be conducted which specifically looks at parent responses to children's behavior and the linkages to the quality of the parent-child relationship over time and across child developmental functioning.

Additionally, given that child behavior problems have been identified as one of the contributing factors to parents' psychological health, studies should aim for a better understanding of parents' behaviors while interacting with a child around specific challenging behaviors. Such research could lead to more interventions that focus directly on parental response to the behavioral abnormalities of children with ASD. Further, future researchers should consider the environment in which the research is being conducted. The current study underscores the importance of more exploration on the daily experiences of parents and how parenting practices are employed in a less contrived space, (i.e., the home or in a public setting).

Another recommendation for future research is to examine the parenting experiences of mothers with children on varying levels of severity. As delineated in the DSM-V, children's diagnosis of ASD is based on the severity of their deficiencies with level 1 representing the limited *support needed (least severe)*, level 2 representing the *substantial support required* and level 3 representing *very substantial support (most severe)* needed in addressing social communication impairments and restricted repetitive behavior problems. The parenting experiences of mothers interacting with a child classified as level 3 versus a child on level one may vary, thereby, eliciting differences in parenting behavior. This information would help researchers garner a better understanding of the type of parenting practices employed with children with more severe symptoms versus less severe symptoms. Although this study included children across the autism spectrum, conducting a study with inclusion criteria that considered

the severity levels of the children can shed light on mothers' experiences of parenting children with ASD who share or differ on severity classifications.

It would also be beneficial to recruit a larger sample size in future studies. Obtaining knowledge from a larger pool of mothers raising preschool aged children with ASD can inform interventions that address the needs of families of children with ASD. A quantitative study would also contribute to the literature on parenting children with ASD. Specifically, employing measurement tools across a larger sample of participants and the various statistical analyses that can be conducted could elucidate moderating and mediating factors that may better facilitate or hinder parenting of this group of children.

Additionally, studies focusing on the determinants of parenting, (i.e., parents' psychological resources and personality, characteristics of the child, and the broader social contexts that impact the parent-child relationship) would further contribute to the parenting literature of this unique population. Given that fathers and other family members are contributors to children's development, observing and interviewing them regarding the rearing of children with ASD is important.

Specific to parenting, mothers and fathers have traditionally been viewed as having the responsibility for the quality of interactions within the parent-child relationship. However, future studies should consider a transactional model where the emphasis on directionality is placed on both the child and factors within the child's immediate environment that can affect the course of development. For example, the child's functioning level and the family environment, including parenting and the influence of other family members, can play a role in children's ability to adapt overtime.

Finally, this study was unique in that half of the participating families were African American, thus the experiences of mothers across various ethnic groups were documented. Future research should be conducted that explores the parenting of children with a more diverse sample, including African American and Latino families. Given the findings of this study (i.e., differential parenting practices), it would behoove researchers to examine factors that play a role in influencing the parenting behavior of mothers raising children with ASD across ethnicities (e.g., social support and religiosity).

### **Summary and Conclusions**

The purpose of the present study was to explore the experiences of six mothers raising preschool aged children with Autism Spectrum Disorder. Of particular interest were the parenting practices and behaviors that mothers employ during their interactions with their children. Findings from semi-structured interviews and mother-child observations yielded 32 categories clustered under 11 themes. Despite discussing similar positive and challenging experiences related to parenting children on the autism spectrum, the mothers varied in their responses to their children's behavior. Although mothers reported and displayed many positive interactions with their children, they devised specific strategies to promote cooperation and to manage crises with their children based on their own characteristics and backgrounds.

The characteristics of these children have been found to influence mothers' parenting. It is likely that the parenting of children with ASD is distinct from that of typically developing children. For example, mothers' concerns regarding the ability of their preschool aged children with ASD to live independent lives when the parents are deceased may not be shared with mothers raising typically developing children. Additionally, the expectations that mothers have for their typically developing children may vary from those expectations that mothers of children

with ASD possess. Given the diagnosis of ASD, mothers' developmental expectations of this unique population may be lowered as compared to children without disabilities, a factor which may affect their parenting across multiple situations and contexts.

Child characteristics (e.g., social and communication skills) and behavior problems were found to be major contributors to mothers' psychological well-being, and also influenced mothers' parenting practices and behaviors. Additionally, mother responses to child behavior problems extended to other children in the family in that it limited the entire family's engagement in public activities. Mothers' informal and formal supports were also influential in the ways they approached parenting. These findings illuminate the uniqueness in parent-child interactions and resulting effects on maternal and family factors. Although the time spent with these families was limited, the rich data collected allowed for a theory of differential parenting responses to be proposed.

In conclusion, given the paucity of research on the parenting practices and behaviors of this unique population, the present study contributes to the literature by providing researchers with an enhanced understanding of the experiences of mothers raising preschool aged children with ASD. The stories told by mothers and their first-hand accounts of their interactions with their children, along with the observations of parent-child interactions, highlight the complexities of this relationship in the social context. Moreover, the findings in this study can help support the needs of the children with ASD and their families given that ASD is now considered a health risk. Finally, it would benefit families of children with ASD if researchers built on the methodology and findings of this dissertation study to increase the scope of the empirical and intervention literature on parenting practices, parent-child interactions, and child-specific influences on parenting with this population.

## Appendices

### Appendix A

#### *Recruitment Flyer*

## Parents of 3-5 year old children with autism in the Metropolitan Washington, DC area

*-Are you a mother of a preschool child with autism?*

*-Do you want to tell your story?*

If so, please consider participating in a study about parenting children with autism. We will be conducting interviews and in-home observations with participants, who will receive up to \$150.

If you have questions, please call me, Melissa Duchene,  
at (301) 405-5210 and leave a message.



## Appendix B

### *Telephone Screening Interview*

Hi, my name is Melissa Duchene and I am calling to thank you for your interest in the parenting children with autism study. The purpose of this study is to get a better understanding of mothers' experiences raising children with autism. The study procedures include two in-home observations and one observation in a public setting, for example, a grocery store or park. Each observation will last 1-2 hours. Additionally, I will conduct three separate interviews in the home with each lasting 1-2 hours in length. Now that you have a more information about the requirements of the study, are you willing to participate?

**If no**, thank mother again for her initial interest.

**If yes**, continue below.

Prior to participating in the study, I must first ask a couple of questions to determine your eligibility.

1. How old is your child? \_\_\_\_\_
2. Are you the mother and primary caregiver of the child with autism? \_\_\_\_\_
3. Are you willing to allow me to conduct two observations in the home and one in a public setting (e.g., a grocery store)? \_\_\_\_\_
4. Are you willing to have the interviews audiotaped? \_\_\_\_\_
5. Are you willing to allow me to view documentation from a professional regarding the confirmed diagnosis of autism and IQ of your child? \_\_\_\_\_

**If yes to the above five questions then proceed to schedule an appointment for home visit #**

**1 and get remaining contact information and end screening.**



## Appendix C

### *Consent Form*

Page 1 of 3

Initials \_\_\_\_\_ Date \_\_\_\_\_

Maternal Experiences of Parenting Preschool Aged Children with Autism: A Qualitative Analysis

### Informed Consent Form

This is a research project being conducted by Melissa Duchene and Brenda Jones Harden at the University of Maryland, College Park. I am inviting you to participate in this research project because you are a mother of a child who has been diagnosed with autism. The purpose of this research is to examine how mothers parent their children, including their perceptions and experiences of parenting, and parent-child interactions. This research project involves audiotaping my interviews with you. Three 1-2 hour audio-recorded interviews will be conducted during which you will be asked a series of questions regarding your experiences parenting your child. Sample questions from the interview include, “How has having a child with autism affected your family, and “What about your child’s behavior influences how you interact with him/her?” Three 1-2 hour long observations of you interacting with your child will also be conducted in the home and in a public setting (e.g., park). The researcher will be taking notes during these mother-child observations.

There may be some risks from participating in this research study. You may experience emotionally charged feelings when recalling your experiences. You will receive a list of resources if you wish to pursue counseling. There are no direct benefits from participating in this research. However, a possible benefit includes having an opportunity to tell your story about your experiences raising a child with autism. We hope that, in the future, other people might benefit from this study as the results may help researchers learn more about parents’ well-being and the parent-child relationship in families in which there is a child with autism.

Any potential loss of confidentiality will be minimized by storing all information in a secure locked cabinet. The researcher will be the only one with access to this cabinet. Codes (e.g., A1) will be used when referring to any member of your family including yourself and your child.

I agree to be audiotaped during my participation in this study.

I do not agree to be audiotaped during my participation in this study. Unfortunately, mothers who decline to be audiotape cannot participate in this study.

If we write a report or article about this research project, your identity will be protected to the maximum extent possible. Your information may be shared with representatives of the University of Maryland, College Park or governmental authorities if you or someone else is in danger or if we are required to do so by law.

Your child's information may be shared with representatives of the University of Maryland or governmental authorities if your child or someone else is in danger or if we are required to do so by law.

You will receive \$150 for your complete participation in the study. This study will be conducted in parts. Compensation for each completed part of the study is below:

- Screening interview- Mothers will receive \$10 after completing the screening interview
- Home visits # 1-3 Mothers will receive \$70 after completing one in-home interview and two in-home observations
- Visits # 4-6- Mothers will receive \$70 after completing two in-home interviews and one observation in a public setting (e.g., park)

You will be responsible for any taxes assessed on the compensation.

Check here if you expect to earn \$600 or more as a research participant in UMCP studies in this calendar year. You must provide your name, address and SSN to receive compensation.

Check here if you do not expect to earn \$600 or more as a research participant in UMCP studies in this calendar year. Your name, address, and SSN will not be collected to receive compensation.

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

If you decide to stop taking part in the study, if you have questions, concerns, or complaints, or if you need to report an injury related to the research, please contact the investigator:

**Brenda Jones Harden, Ph.D.**

Department of Human Development and Quantitative Methodology  
 3304 Benjamin Building  
 University of Maryland  
 College Park, MD 20742  
 (301) 405-2580  
 bjharden@umd.edu

**Melissa Duchene**

Department of Human Development and Quantitative Methodology  
 3304 Benjamin Building  
 University of Maryland  
 College Park, MD 20742  
 (301) 405-5210  
 mduchene@umd.edu

*If you have questions about your rights as a research participant or wish to report a research- related injury, please contact:*

**University of Maryland College Park  
 Institutional Review Board Office  
 1204 Marie Mount Hall  
 College Park, Maryland, 20742  
 E-mail: irb@umd.edu  
 Telephone: 301-405-0678**

*This research has been reviewed according to the University of Maryland, College Park IRB procedures for research involving human subjects.*

*Your signature indicates that you are at least 18 years of age; you have read this consent form or have had it read to you; your questions have been answered to your satisfaction and you voluntarily agree to participate in this research study. You will receive a copy of this signed consent form.*

*If you agree to participate, please sign your name below.*

Name of Participant: \_\_\_\_\_

**Please Print**

Signature of Participant: \_\_\_\_\_

Child's Name: \_\_\_\_\_

**Please Print**

Date: \_\_\_\_\_

## Appendix D

Participant ID # \_\_\_\_\_

*Demographics Questionnaire*

Today's Date: \_\_\_\_\_

**A. INFORMATION ABOUT PARENTS****Mother's Date of Birth:** \_\_\_\_\_

1. How would you describe your racial/ethnic background?

Asian or Pacific Islander

Black (African American; non-Hispanic

Caribbean (Please Specify) \_\_\_\_\_

White (Caucasian; non-Hispanic)

Hispanic/Latino (Please Specify) \_\_\_\_\_

Native American or American Indian

Mixed (Please Specify) \_\_\_\_\_

Other (Please Specify) \_\_\_\_\_

2. Highest grade or year of regular school completed/GED:

Grade 1 2 3 4 5 6 7 8 9 10 11 12

13 Some College

14 College Degree

15. Post graduate degree (Ph.D., M.A., M.D.)

16. GED

3. What is your employment status?

Full-time

Part-time

Unemployed

**Father's Date of Birth:** \_\_\_\_\_

1. How would you describe your racial/ethnic background?

Asian or Pacific Islander

Black (African American; non-Hispanic

Caribbean (Please Specify) \_\_\_\_\_

White (Caucasian; non-Hispanic)

Hispanic/Latino (Please Specify) \_\_\_\_\_

Native American or American Indian

Mixed (Please Specify) \_\_\_\_\_

Other (Please Specify) \_\_\_\_\_

2. Highest grade or year of regular school completed/GED:

Grade 1 2 3 4 5 6 7 8 9 10 11 12

13 Some College

14 College Degree

15. Post graduate degree (Ph.D., M.A., M.D.)

16. GED

3. What is your employment status?

Full-time

Part-time

Unemployed

4. What is the status of your relationship with (CHILD)'s biological mother/father now? (Circle one) Is s/he

- Unmarried
- X-wife/husband/separated
- Live-in Partner
- Girlfriend/Boyfriend, Non-resident
- Friend
- Deceased
- Something else(specify) \_\_\_\_\_

5. Does child's biological mother/father currently live with child? (Circle one)

- Yes

6. In the past month, did mother/father spend time with child?

- Yes
- No

7. In the past month, how often have mother/father spent one or more hours a day with (CHILD)? Was it

Every day

Almost every day

A few times a week

A few times a month

Once or twice, or

Never?

8. How many children does mother/father have with you? \_\_\_\_\_
9. Thinking of the coming years, how much do YOU want mother/father to be involved in raising (CHILD)? Would you say

A LOT

A LITTLE

NOT VERY MUCH

NOT AT ALL?

10. And, how much do you think mother/father wants to be involved in raising (CHILD)? Would you say

A LOT

A LITTLE

NOT VERY MUCH

NOT AT ALL?

**B. INFORMATION ABOUT “ \_\_\_\_\_ ” (CHILD)**

1. What is CHILD’S date of birth? \_\_\_\_\_
2. Is CHILD a boy or girl? \_\_\_\_\_
3. What is CHILD’S racial or ethnic background?

Asian or Pacific Islander

Black (African American; non-Hispanic)

Caribbean (Please Specify) \_\_\_\_\_

White (Caucasian; non-Hispanic)

Hispanic/Latino (Please Specify) \_\_\_\_\_

Native American or American Indian

Mixed (Please Specify) \_\_\_\_\_

Other (Please Specify) \_\_\_\_\_

**C. INFORMATION ABOUT OUR FAMILY**

1. How many people are living in your home? \_\_\_\_\_

2. How many by each age group?

0-5..... \_\_\_\_\_ children

6-12..... \_\_\_\_\_ children

13-18..... \_\_\_\_\_ children

Adults..... \_\_\_\_\_ adults

<b>Relationship of Household Member to YOU e.g. husband, brother, etc.</b>	<b>Age</b>
1.	
2.	
3.	
4.	
5.	
6.	
7.	



8.	
9.	
10	
11.	
12.	

4. Is a language other than English spoken in your home?

Yes

No

If yes, what? \_\_\_\_\_

## Appendix E

### *Interview Questions*

#### **First Interview Questions**

1. Tell me about yourself as a parent.
2. Tell me about your child [INSERT CHILD'S NAME] and your family?
3. How would you describe (your child with autism) [INSERT CHILD'S NAME]?
4. How has having (a child with autism) [INSERT CHILD'S NAME] influenced who you are?
5. How would you describe yourself as a parent of (a child with autism) [INSERT CHILD'S NAME]?

#### **Second Interview Questions**

1. How old was (your child) [INSERT CHILD'S NAME] when he/she was diagnosed?
  - i. What was it like for you when (your child) [INSERT CHILD'S NAME] was diagnosed?
  - ii. How do you currently feel about the diagnosis?
2. What is (your child's) [INSERT CHILD'S NAME] personality like?
  - i. How does (your child's) [INSERT CHILD'S NAME] personality affect your daily interactions with him/her?
3. How has having a child with autism affected your family?
4. Tell me about a typical day in your life with your child.
  - i. What do you do with (your child) [INSERT CHILD'S NAME]?
  - ii. What kinds of routines and activities do you engage in with (your child) [INSERT CHILD'S NAME]?
  - iii. Tell me about leisure activities that you engage in with (your child) [INSERT CHILD'S NAME].

- iv. Tell me about any therapeutic routines that you engage in with (your child) [INSERT CHILD'S NAME].
5. What do you do to ensure that your child is healthy and develops optimally?
- i. Do you bring (your child) [INSERT CHILD'S NAME] to see a physician on a regular basis?
  - ii. What do you do to provide an enriched environment for (your child) [INSERT CHILD'S NAME] to develop in?
6. How is mealtime handled?
- i. What is (your child) [INSERT CHILD'S NAME] doing while dinner is being prepared?
  - ii. What do you do to ensure that dinner time runs smoothly?
  - iii. How do you handle any potential disturbances during dinner time?
7. How is bedtime handled?
- i. What do you do to prepare (your child) [INSERT CHILD'S NAME] for bed?
  - ii. What do you do if (your child) [INSERT CHILD'S NAME] does not want to go to bed?
8. How do you provide structure to (your child)? [INSERT CHILD'S NAME]?
9. What are some skills that you would like your child to have in order to function independently?
10. How do you monitor (your child's) [INSERT CHILD'S NAME] whereabouts?
11. What about (your child's) [INSERT CHILD'S NAME] behavior influences how you interact with him/her?
- i. What about (your child's) [INSERT CHILD'S NAME] behavior do you enjoy?
  - ii. Is there anything in particular that is difficult? Why?
  - iii. How do you feel about your interactions with (your child) [CHILD'S NAME]?

12. Describe your role as a parent of (a child with autism) [INSERT CHILD'S NAME]?

- i. What differences are there between how you would parent a child with autism vs. one without?
- ii. What do you think are the most important things you do as a parent for (your child with autism) [INSERT CHILD'S NAME]?
- iii. What supports do you provide your child [INSERT CHILD'S NAME].
  - a. Tell me about any therapeutic interventions outside of the home that (your child) [INSERT NAME] participates in.
  - b. What do you do in the home to help (your child) [INSERT CHILD'S NAME] get through the day?
    - i. Do you modify the home in any way?
  - c. What kind of stimulation do you provide your child?
    - i. Tell me about the pictures and equipment that your child has access to in his environment.

13. Tell me about your perceptions of being a parent of (a child with autism) [INSERT CHILD'S NAME].

- i. What factors play a role in your parenting abilities?
- ii. What factors play a role in being able to provide an enriched environment for (your child) [INSERT CHILD'S NAME]?
- iii. How has your well-being affected how you parent your child?

14. What has it been like raising your child?

- i. What are some of the rewarding experiences?
- ii. What are some of the challenging experiences?

### **Third Interview Questions**

1. What do your experiences of having a child with autism mean to you?
2. How has your role as a parent of a child with autism changed who you are?
3. How has your experience with this study affected you and your perceptions of your parenting role?
4. Do you have anything else to share?

### **Generic Probing Questions**

1. “You mentioned \_\_\_\_\_, tell me about that.”
2. “You mentioned \_\_\_\_\_, what was that like for you?”
3. “You talked about \_\_\_\_\_, describe that experience in as much detail as possible.”
4. “What were your feelings about that?”
5. “It sounds as though you had a pretty strong reaction.”
6. “It sounds like you’re saying.....”

## Appendix F

*Resources for Families with Children with Autism Spectrum Disorders*

1. The Autism Society of America  
[www.autism-society.org](http://www.autism-society.org)  
[www.autismsource.org](http://www.autismsource.org)
2. Organization for Autism Research (OAR)  
[www.researchautism.com](http://www.researchautism.com)
3. National Institute of Mental Health (NIMH)  
[www.nimh.nih.gov/publicat/autism.com](http://www.nimh.nih.gov/publicat/autism.com)
4. US Autism and Asperger Association (USAAA)  
[www.usautism.org/](http://www.usautism.org/)
5. DC Autism Parents (DCAP)  
[www.dcautismparents.org/](http://www.dcautismparents.org/)  
(202) 271-9262
6. The One World Center for Autism  
[www.worldforautism.info/](http://www.worldforautism.info/)  
1400 Nalley Terrace  
Hyattsville, MD 20785  
(301) 618-8395
7. National Federation of Families for Children's Mental Health  
<http://ffcmh.org/>  
9605 Medical Center Drive  
Rockville, MD 20850  
(240) 403-1901

## Appendix G

**Examples of codable factors in qualitative research**

(Lewins, Taylor &amp; Gibbs, 2005)

	<b>What can be coded</b>	<b>Examples</b>
1	<b>Behaviors</b> , specific acts	Seeking reassurance, Bragging
2	<b>Events</b> – short once in a lifetime events or things people have done that are often told as a story.	Wedding day, day moved out of home for university, starting first job
3	<b>Activities</b> – these are of a longer duration, involve other people within a particular setting	Going clubbing, attending a night course, conservation Work
4	<b>Strategies</b> , practice or tactics	Being nasty to get dumped, Staying late at work to get Promotion
5	<b>States</b> – general conditions experienced by people or found in organizations	Hopelessness “I’ll never meet anyone better at my age” settling for someone who is not really suitable
6	<b>Meanings</b> – A wide range of phenomena at the core of much qualitative analysis. Meanings and interpretations are important parts of what directs participants actions.	
	a. What concepts do participants use to understand their world? What norms, values, and rules guide their actions	The term „chilling out“ is used by young people to mean relaxing and not doing very Much
	b. What meaning or significance it has for participants, how do they construe events, what are the feelings	Jealousy “ I just felt why did she get him”
	c. What symbols do people use to understand their situation? What names do they use for objects, events, persons, roles, setting and equipment?	A PhD is referred to as „a test of endurance“ (because finishing a PhD is a challenge)
7	<b>Participation</b> – adaptation to a new setting or involvement	About new neighbors “In my new house I have to keep my

## Appendix H

### *Definition of Themes*

#### **Question # 1: What are the parenting practices and behaviors that mothers use with their preschool aged children with ASD?**

##### *Theme 1- Positivity within the m-c relationship*

- **Definition** -Mothers' positive parent child interactions and descriptions of positivity related to child characteristics and behavior as well as rewards/gains associated with raising a child with ASD

##### *Theme 2- Schedules or routines*

- **Definition** -Mothers' descriptions of children's strict adherence to routines/schedules and method of overcoming any possible issues that may arise from this rigidity; mothers' willingness to adhere to a strict routine/schedule

##### *Theme 3- Strategies encouraging child cooperation*

- **Definition** -Mothers' approach to addressing child misbehavior and inattentiveness

##### *Theme 4- Crisis management*

- **Definition** -Mothers' explanations of the behaviors exhibited by their children that make it challenging to parent them & their responses to such behaviors

#### **Question 2: What are the beliefs and experiences of mothers relative to raising preschool aged children with ASD?**

##### *Theme 1- Perspectives on child's maladaptive behavior*

- **Definition** -Mothers' beliefs about the reason behind her child's displays of inappropriate behavior

##### *Theme 2- Perspectives on child's abilities*



- **Definition** -Mothers' beliefs about her child's abilities to succeed in all that he attempts in the present and for son to ultimately become a productive member of society in the future

*Theme 3- Perceptions and experiences around public interfacing*

- **Definition** -Mothers' direct interactions with or thoughts pertaining to individuals in society about how they perceive the child with ASD

*Theme 4- Stress associated with caring for a child with an ASD*

- **Definition** -Stress endured due to various factors associated with the disorder

**Question 3: What facilitates or hinders mothers' parenting of their preschool aged children with ASD?**

*Theme 1- Maternal resources*

- **Definition** -Mothers' self coping mechanisms that promote more positive interactions with their youngsters

*Theme 2- Interpersonal supports*

- **Definition** -The support provided by both familial and non-familial individuals/groups

*Theme 3- Ecological factors*

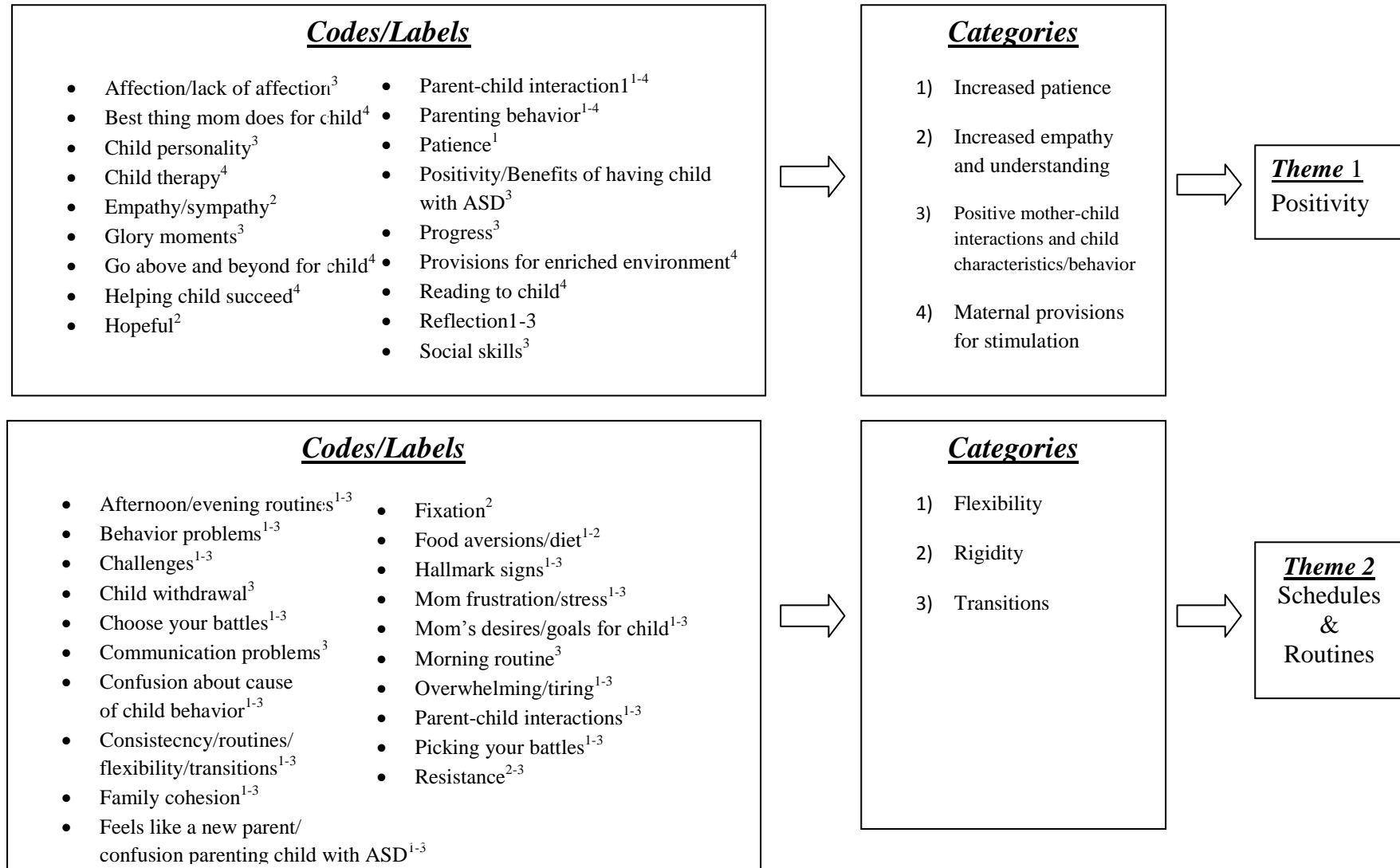
- **Definition** -Family's limited funding and mothers' determination to serve as advocates for their children

## Appendix I

## Codes, categories, and themes

**Research Question 1:** What are the parent practices and behaviors that mothers use with preschool aged children with ASD?

Note: Superscript numbers correspond with category



### Codes/Labels

- Behavior problems<sup>1-3</sup>
- Challenges<sup>1-5</sup>
- Choose your battles<sup>1</sup>
- Coaching<sup>3</sup>
- Differences between child with ASD and typically developing child<sup>1-5</sup>
- Discipline<sup>1</sup>
- Discussions with other families<sup>1-5</sup>
- Educating siblings about ASD<sup>1-3</sup>
- Feels like a new parent<sup>1-5</sup>
- Food aversion/diet<sup>2-3</sup>
- Meal time<sup>3</sup>
- Mom frustration/stress<sup>1-5</sup>
- Overwhelming/tiring<sup>1-5</sup>
- Parent-child interactions<sup>1-5</sup>
- Picking your battles<sup>1-5</sup>
- Potty training issues<sup>3-4</sup>
- Redirection<sup>2</sup>
- Resistance<sup>1-3</sup>
- Social skills<sup>5</sup>
- Talk it over<sup>2</sup>
- Use of timer<sup>4</sup>

### Categories

- 1) Discipline
- 2) Talks to child/redirection
- 3) Incentives/rewards
- 4) Employment of timer
- 5) Coaching

**Theme 3**  
Maternal strategies & child cooperation

### Codes/Labels

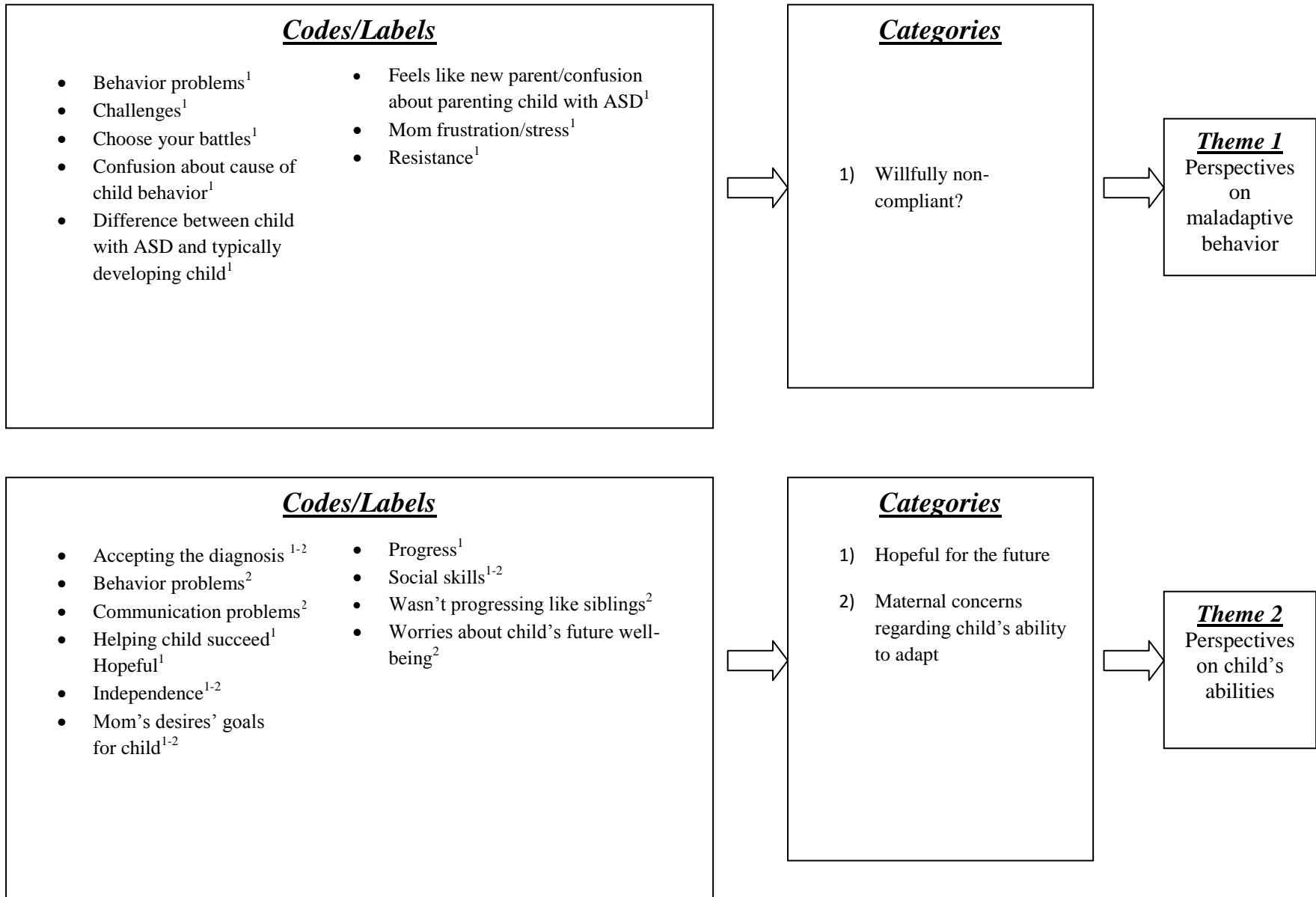
- Behavior problems<sup>1-5</sup>
- Challenges<sup>1-5</sup>
- Choose your battles<sup>1-5</sup>
- Communication problems<sup>1</sup>
- Confusion about cause of child behavior<sup>1</sup>
- Difference between child with ASD and typically developing child<sup>1-5</sup>
- Discipline<sup>1-5</sup>
- Discussions with other families<sup>1-5</sup>
- Fear of judgment<sup>1-4</sup>
- Feels like new parent/confusion about parenting child with ASD<sup>1-5</sup>
- Meal time<sup>3</sup>
- Indifference regarding p-c interactions<sup>1-5</sup>
- Mom frustration/stress<sup>1-5</sup>
- Overwhelming/tiring<sup>1-5</sup>
- Parent-child interactions<sup>1-5</sup>
- Parenting behavior<sup>2-5</sup>
- Patience<sup>1</sup>
- Resistance<sup>1-3</sup>

### Categories

- 1) Child emotion expression
- 2) Halting the tantrum in its track
- 3) “Overwhelm him with love and affection”
- 4) Ignore the behavior
- 5) Probing

**Theme 4**  
Crisis management

**Research Question 2:** What are the beliefs and experiences of mothers relative to raising preschool aged children with ASD?



### Codes/Labels

- Behavior problems<sup>1-3</sup>
- Challenges<sup>1-3</sup>
- Choose your battles<sup>1-3</sup>
- Communication problems<sup>1</sup>
- Discipline<sup>1</sup>
- Family cohesion<sup>2</sup>
- Fear of judgment<sup>1</sup>
- Parent-child interactions<sup>1-2</sup>
- Social skills<sup>2</sup>



### Categories

- 1) Judgment from others
- 2) Limited family outings
- 3) Public disclosure of child's disorder



**Theme 3**  
Public  
interfacing

### Codes/Labels

- Behavior problems<sup>2</sup>
- Challenges<sup>2</sup>
- Child therapy<sup>1</sup>
- Coaching<sup>2</sup>
- Communication problems<sup>2</sup>
- Doctor's appointments<sup>4</sup>
- Limited funds<sup>1</sup>
- Mom's desires/goals for child<sup>2</sup>
- Mom's health is secondary<sup>4</sup>
- Parent-child interactions<sup>3</sup>
- Social skills<sup>2</sup>
- Worries about child's future well-being<sup>3</sup>



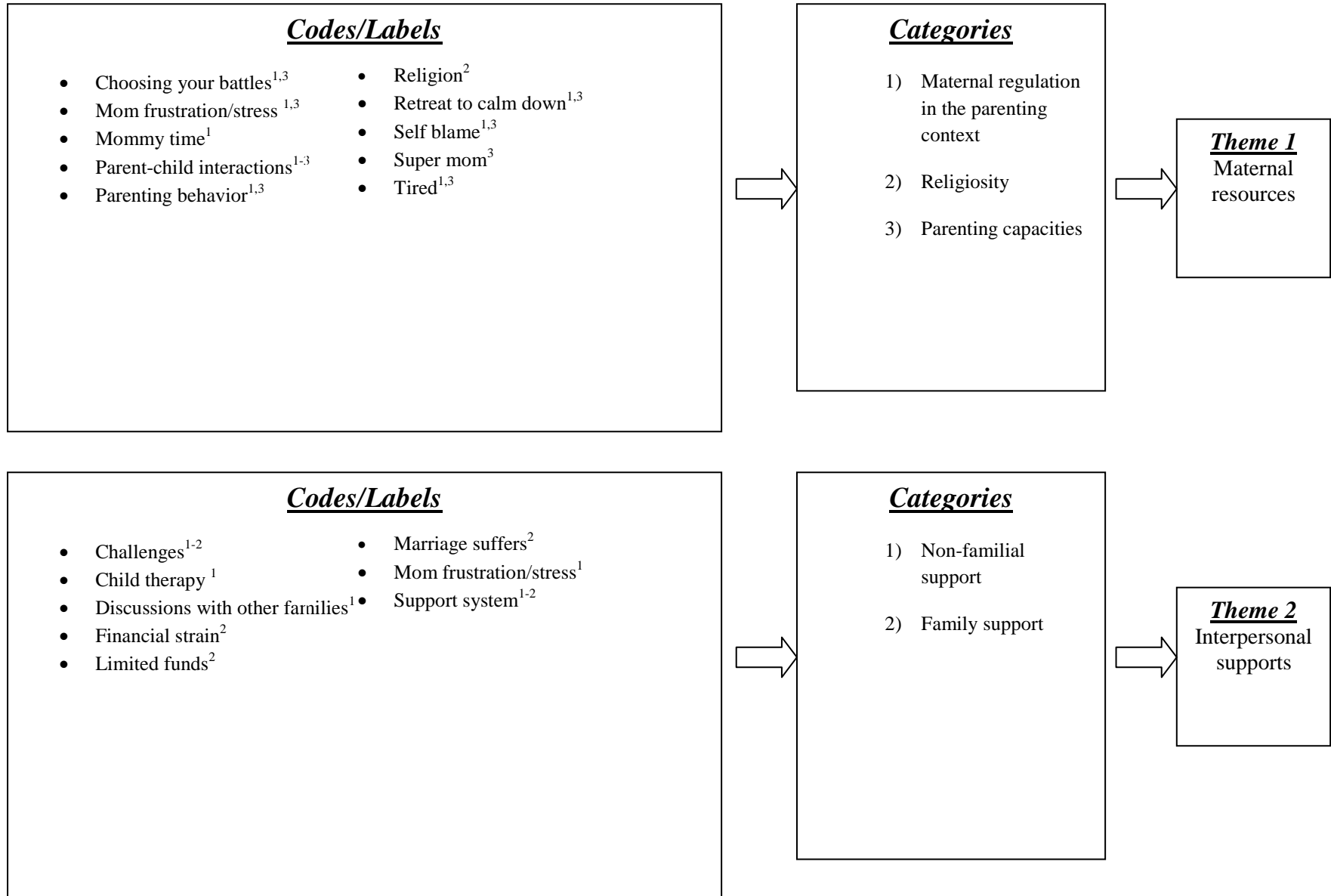
### Categories

- 1) Funding for therapy
- 2) Maternal concerns regarding children's social deficits
- 3) Worries about child's well-being
- 4) Psychotherapy and pharmaceutical need



**Theme 4**  
Stress

**Research Question 3:** What facilitates or hinders mothers' parenting of their preschool aged children with ASD?



**Codes/Labels**

- Active in autism community<sup>1</sup>
- Advocate<sup>1</sup>
- Challenges<sup>1</sup>
- Child therapy<sup>1-2</sup>
- Confusion about ASD<sup>2</sup>
- Fight to get social services<sup>1</sup>
- Let the world know<sup>1</sup>
- Mom frustration/stress<sup>1</sup>
- Overwhelming/tiring<sup>1</sup>
- Protective mom<sup>1</sup>
- Research on ASD<sup>2</sup>
- Resources for ASD<sup>2</sup>
- Support system<sup>1-2</sup>



**Categories**

- 1) Advocacy
- 2) Research on ASD



**Theme 3**  
Ecological  
factors

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