FATHERS' PERSPECTIVES ON THEIR LEVEL OF INVOLVEMENT IN THEIR CHILD'S EARLY AUTISM SERVICES

By

Chelsea Burnett Gooden

A thesis submitted to the faculty of
The University of North Carolina at Charlotte
in partial fulfillment of the requirements
for the degree of Master of Education in
Child and Family Studies

Charlotte

2018

Approved by:

____
Dr. JaneDiane Smith

____
Dr. Vivian Correa

____
Mrs. Jamie Brown

ABSTRACT

CHELSEA BURNETT GOODEN. Father's Perspectives on their Level of Involvement in Their Child's Early Autism Services. (Under the direction of Dr. JANEDIANE SMITH)

The aim of this exploratory study was to examine father's perspectives on their level of involvement in early autism services, as well as their feelings regarding how well the service providers are doing to include them in these services. A total of 10 fathers participated in an electronic survey, and 3 fathers participated in 1:1 interviews, recruited through 6 Early Intervention agencies serving families and children with autism. A mixed-methods study was conducted to first get an idea of how easy or difficult fathers found it to be involved with their child whom has autism and, in their services, while the interviews were conducted to give a voice to the fathers' experiences and to see if they align with the results of the study. Findings show while fathers are being included in early intervention services, there is more that service providers can be doing (e.g. using technology, encouraging engagement, understanding fathers' feelings). Possible implications for further research would be including non-English speaking fathers into the study to examine their perspectives, as well as exploring how fathers' perspectives on involvement differ across? various early intervention services (e.g. speech therapy, ABA, early childhood special education programs, etc.

TABLE OF CONTENTS

LIST OF TABLES vi.

CHAPTER 1: INTRODUCTION 1

- 1.1 Statement of the Problem 5
- 1.2 Research Questions 6

CHAPTER 2: REVIEW OF THE LITERATURE 8

- 2.1 Theoretical Background 8
  - Attachment Theory 8
  - Stress and Coping Theory 10
  - Family Systems Theory 12
  - Ecological Theory 12
  - Approaches to Intervention Based on Theories 13
- 2.2 Parental Stress 15
- 2.3 Role of Intervention 17
  - Self-Efficacy 18
- 2.4 Interventions: Not a One Size Fits All 20
  - Fathers’ Interactive Styles 22
    - *Language Acquisition* 22
    - *Play* 23
- 2.5 Where are the Fathers? 27
- 2.6 Including Fathers in Interventions: 31
- 2.7 Summary 33

CHAPTER 3: METHODOLOGY 35

- 3.1 Rationale 35
- 3.2 Participants 36
- 3.3 Setting 37
- 3.4 Procedures 38
- 3.5 Data Collection 40
- 3.6 Measures 42
- 3.7 Data Analysis 46

CHAPTER 4: RESULTS 48

- 4.1 Research Question 1 48
- 4.2 Research Question 2 52

CHAPTER 5: DISCUSSION 61

- 5.1 Limitations 65
- 5.2 Implications for Future Research 67

REFERENCES 69

APPENDIX A: Recruitment Flyer 80

APPENDIX B: Email to Participating Agencies 81

APPENDIX C: Letter of Support Template 82

APPENDIX D: FCDC Questionnaire- *Adapted* 83

APPENDIX E: Interview Protocol 94

APPENDIX F: Consent to Audio Record 96

APPENDIX G: Email Stating Permission to Adapt FCDC Questionnaire 98

LIST OF TABLES

Table 1.1: Demographics of Fathers 37

Table 1.2: Demographics of Children Participating in Services 38

Table 2.1: Fathers’ Involvement with their Child 49

Table 2.2: Fathers’ Involvement in Meetings and Therapies 53

CHAPTER 1: INTRODUCTION

Autism refers to a wide spectrum of complex developmental disorders that typically appear during the first three years of life. It is estimated that 1 in 68 US children has autism; this is a significant increase from the 2003 estimate of 1 in 150 (Centers for Disease Control and Prevention, 2014). Many children with autism have behavior repertoires (e.g., limited verbal communication, deficits in social behavior) that might be expected to have an impact on members of their families (Meadan, Halle, & Ebata, 2010) such as high levels of stress. For many parents, however, one of the most stressful and challenging times can be hearing at diagnosis that their child has an Autism Spectrum Disorder (ASD). This can bring about many questions and uncertainties as families begin to navigate the systems and supports put into place for those facing this journey. There are many resources and interventions available to parents caring for a child with ASD. Unfortunately, many of those resources are not tailored to all parents, nor do they take advantage of those resources. There is a copious amount of research surrounding those interventions and their effectiveness on the outcomes for the child, including improved emotional regulation and cognitive and language development (Shannon, Tamis-LeMonda, London, & Cabrera, 2002; Tamis-LeMonda, Shannon, Cabreera, & Lamb, 2004), as well as the family, such as emotional well-being for parents experiencing stress (Lakey & Cronin, 2008). Research (Flippin & Crais, 2011) has proven time and time again that for many families it is often mothers who are quick to seek out and use resources, but also tend to be the most stressed as they carry the weight of the responsibility of caring for their child with autism. Unfortunately for fathers of children with ASD, they are underrepresented in both early intervention services and research. Fathers also continue to struggle to put into place and/or engage in those supports, which in turn can lead to high levels of stress and unhealthy coping strategies (Hastings, Kovshoff, Brown, Ward, Espinosa, & Remington, 2005; Twoy, Connolly, & Novak, 2007), which can vary from parent to parent.

Stress experienced by fathers and mothers of children with ASD suggests that parents of children with ASD experience greater levels of stress than parents of typically developing children and children with other developmental disabilities (Flippin & Crais, 2011). One way many parents find relief in dealing with their daily stressors is through early intervention services and parent-training programs tailored to meet their needs of living with a child with ASD. Social support and resources directly influence parenting styles and support, health/well-being, and parenting styles directly, and indirectly influence child behavior and development. Research indicates that social support has positive effects on parental well-being, that a parental sense of well-being is directly related to responsive styles of interaction, and that both parental responsiveness and facilitation styles of interaction are related to child development (Trivette & Dunst, 2005).

The amount of time fathers spend caring for and being directly involved in their children’s lives is much different than in the past, with a major shift being made from fathers as breadwinners to taking on co-parenting roles (Pleck & Masciadrelli, 2004). Given the increased evidence of the greater co-parenting role and more direct involvement of fathers with their children, one would expect greater participation of fathers in early intervention for their children with autism (Flippin & Crais, 2011), however this is simply untrue. There has been a major shift in early intervention programs following a more “family friendly” or “family centered” model. The three basic characteristics of family-centered practices are (a) building on family choice by ensuring that families are the primary decision-makers, (b) focusing on families’ strengths, and (c) making the family the unit of services and support (Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2011). Beyond legal mandates, best practice standards suggest that family-centered services, especially for young children, are most effective when parents and professionals work in collaboration (Harry, 1997). This allows a greater participation in key components of early intervention, with mothers continuing to be the primary and often exclusive participants in both autism research and early intervention service delivery (Flippin & Crais, 2011). It is important to note however, that while there is numerous research to back up the involvement of mothers in intervention programs, it does not mean that fathers are not involved, they are just vastly underrepresented in highly individualized interventions and/or research. While early intervention and parent-training programs can be very beneficial in meeting outcomes of the child and family, many are tailored to mothers (Pleck & Masciadrelli, 2004; Flippin & Crais, 2011), with the proportion of participating mothers versus fathers approximately two to one (Dunn, Burbine, Bowers, et al., 2001; Gray, 2006, 2002; Twoy, Connolly & Novak, 2007). This one-parent participation model ignores the growing literature that indicates that mothers and fathers each play an early and integral role in the development of their children, perhaps particularly in their social and communicative skills (Flippin & Crais, 2011).

There is evidence that responsive fathering is a strong indicator of better developmental outcomes for children, including improved emotional regulation and cognitive and language development (Shannon, Tamis-LeMonda, London, & Cabrera, 2002; Tamis-LeMonda, Shannon, Cabreera, & Lamb, 2004). If professionals are not involving fathers in early ASD interventions, they may miss important opportunities to maximize social-communicative gains for these children. This study aims to take a closer look at fathers' perspectives regarding their level of involvement in early intervention services that are tailored to their young child with ASD.

The father-child relationship, as well as the father's relationship with the intervention program, can have a significant impact on how effective a program can be at meeting the needs and outcomes of the family (e.g., improving parental stress and self-efficacy, coping, and resilience and family participation in daily life and routines) (Palm, 2014). Many factors, such as the child's gender, age, and temperament can greatly influence the child's relationship with his/her father. Fathers' interactional styles tend to differ based on the gender of the child, meaning fathers tend to be more stimulating and active as a play partner with their sons, than with their daughters (Lamb 1977a). Another factor, the child's age and maturity can lead to fathers not being as responsive and active to younger infants who are unable to provide clear signals about their needs (Palm, 2014). Finally, the child's temperament and behavior can often affect how the father and child interact and achieve synchrony with each other (Palm, 2014). While the child's characteristics can affect the father-child relationship, there are several paternal characteristics affecting that relationship: extraverted, agreeable, beliefs about their role, and the father's residence status. These characteristics set the stage for more engagement and more enjoyable interactions to foster secure attachments between father and child (Palm, 2014). While the research tends to ignore the residence status of fathers, it is also a major factor that keeps fathers from regular interactions with their child and can lessen their influence on the stability of the family system (Palm, 2014). When fathers are not residing in the same residence as their child this can be a challenge for including them. If fathers perceive that their child favors their mother, they may attempt to exclude themselves and lose confidence in their ability to meet their child's needs for comfort and emotional regulation (Palm, 2014). Also, fathers may not want to use what time they have with their child in early intervention programs, but rather fostering the parent-child relationship, which can be a barrier to including them in programs and services.

1.1 Statement of the Problem

In two-parent family systems, mothers and fathers share parenting roles, but mothers typically assume a larger part of the responsibility of taking care of their families' needs. Most of the research related to families of children with disabilities has focused on mothers (e.g., Bromley, Hare, Davison, & Emerson, 2004; Tomanik, Harris, & Hawkins, 2004), with limited information available about the experiences and roles of fathers of children with disabilities. Carpenter and Towers (2008) noted that researchers have described fathers as 'hard to reach', 'the invisible parent', and the 'shadow'. Turbiville and Marquis (2001) stated, "fathers [are] frequently left out of the family" (p. 223) and most often mothers are the parents who are involved in the decision-making process related to their children with disabilities.

Although most family studies focus on mothers' experiences and needs, a few personal accounts by fathers of children with disabilities (Davis & May, 1991; Hornby, 1992; Meyer, 1995; West, 2000) and research articles related to fathers of children with disabilities exist. Fathers of children with ASD are underrepresented in both early intervention and research. Many studies focusing on autism attempt to recruit both parents, however often, the majority of participants are mothers (Flippin & Crais, 2011; Pleck & Masciadrelli, 2004). Hearing a father's voice provides a more comprehensive picture of the family, as well as the how well early intervention services and parent-training programs are meeting the needs of the families in which they serve. The current study aimed to examine father's perspectives on their level of involvement in early intervention services. Early intervention (EI) services refer to home-visiting programs, parent-training programs, Applied Behavioral Analysis (ABA) therapy, and other services to meet a child's developmental goals (e.g., speech therapy, occupational therapy, developmental play therapy, physical therapy, vision therapy or a combination of these), as well as working to meet the needs and outcomes of families, often tailored to young children, birth to 8, with autism. This study examined those services aimed at serving young children from birth to age 6, or before the child enters a primary educational setting.

1.2 Research Questions

The intent of this research was to explore fathers' perspectives on their involvement in early autism services and to examine how fathers felt on how well service providers are doing when it comes to including them in those services. Due to the limited availability of interventions and studies tailored to fathers, it may be possible to examine if any of the fathers have found higher levels of involvement in certain programs (e.g., local CDSA, private intervention programs, parent-training programs), and why. Through interviews and surveys, this study attempted to answer the following questions: A) What were fathers’ perspectives on their level of involvement with their child’s services and B) What were the fathers’ feelings when it came to how well the service providers were doing to include them in those services?

CHAPTER 2: REVIEW OF THE LITERATURE

To identify relevant literature on father's perspectives regarding lack of involvement in services for their autistic child, the following EBSCOhost research databases were searched: PsychINFO and ERIC. The terms *early intervention, fathers, father's perceptions, special needs child, autism, parental involvement, father's involvement, lack of involvement, level of involvement, involvement* and *measures* were used to identify relevant literature. In addition, the search engines Google Scholar, SAGE Journals, and *Exceptional Children* journal were explored to further locate resources for the literature review.

2.1 Theoretical Background

Historically, fathers have not been viewed as equal partners in parenting children. Freud (cited in Seligman & Darling, 1989) portrayed the mother as the primary influence in the development of the children, while Bowlby (1951) stressed that while the mother was the first and most important object of infant attachment, the father also played an important, yet supporting role. In the past, mothers typically stayed home to raise their children while the fathers worked outside of the home, therefore when a need affecting the children arose, it was the mother who took care of it. The parent-child relationship is the most important relationship that evolves over many years, and that relationship all starts with the role attachment plays on the parent-child relationship.

Attachment Theory.

Attachment theory (Ainsworth, 1967; Bowlby, 1969) has long focused on and examined the evolving parent-child relationship in early childhood with a focus on the mother as the primary attachment figure. It wasn't until the 1970s when the father's role on attachment began to be studied (Palm, 2014). Attachment theory, which grew from Bowlby's (1969) integration of multiple disciplines, continues to rely on multiple perspectives and remains a source of strength by inspiring new studies into father-child attachment dynamics.

The history of fathers and attachment theory has mirrored in many ways the evolving concerns about the changing role of fathers, the importance of father involvement in children's lives, and fathers' influence on child development. For example, in one study by Schaffer and Emerson (1964), they noted that while fathers were emerging as primary attachment figures, they were also selected by children because of their responsiveness versus time spent in caretaking. Children often seek out mothers when they need comfort and fathers when they are looking for a playmate. The changing family structures of the late 1960s and 1970s and the movement of women into the workforce led to new questions about attachment and the role of fathers and child care. By the mid-1970s there was clear evidence that children did form early attachments with their fathers (Lamb & Lewis, 2010). Lamb (1977a; 1977b) noted differences in fathers' and mothers' behavior toward infants and toddlers. While toddlers showed more affiliative behaviors (i.e., smiling, vocalizing, and showing toys) toward fathers (Lamb, 1977), Lamb (1977a) also suggested that mother–infant and father–infant relationships may be experienced in different ways by infants (e.g., mothers are a source of comfort in distress; fathers are desired as stimulating play partners) and that these roles may lead to different impacts on development. For example, fathers have beneficial effects on their children when they have supportive and nurturing relationships with them, as well as their siblings. When they are competent and feel fulfilled as breadwinners, they are successful and supportive partners (Lamb, 2004). Also infants whose fathers are involved in their care are more likely to be securely attached to them, (Cox, Owen, Henderson, & Margand, 1992), be better able to handle strange situations, be more resilient in the face of stressful situations (Kotelchuck, 1976; Parke & Swain, 1975), be more curious and eager to explore the environment, relate more maturely to strangers, react more competently to complex and novel stimuli, and be more trusting in branching out in their explorations (Biller, 1993; Parke & Swain, 1975; Pruett, 1997). The results also document that fathers play an important role in their child's life as attachment figures. This fits with the emerging egalitarian ethic that both mother and father are important for children but their pathways to "secure attachment relationships" may be different (Palm, 2014).

Stress and Coping Theory.

How parents cope with the stress of negotiating needed care and following through with the care varies from parent to parent. For example, family is the first place mothers tend to look for assistance. In an Easter Seals (2009) study, mothers of children with ASD reported that they first look for emotional support, respite, and assistance with family functions from family members (Johnson & Simpson, 2013). Unfortunately, after a search in the literature, it was discovered that while fathers report that their child's externalizing behaviors (e.g., tantrums) were their greatest source of their child related stress (Flippin & Crais, 2011), it was unclear what strategies fathers use to cope with their stress. Stress and coping theory predicts that people individually appraise their own stress and then cope (Lazarus, 1999). Stress can be buffered if one feels supported from social networks because the stressor may seem less threatening or because other people may provide resources useful for coping with stress (Lazarus, 1999). Coping strategies used by parents of children with ASD include social and family supports, support groups, religion, and professional supports and services (Twoy, Connolly, & Novak, 2007). Certain types of coping strategies are more likely to have positive outcomes on parental mood, and others may have a more negative impact (Pottie & Ingram, 2008).

Resilient parents are most able to cope with stress, and social support is a key factor that aids family resiliency (McCubbin, Thompson, & McCubbin, 1996). Social relationships, for example with spouses or partners, may provide the emotional and informational support that help parents cope (Cohen, Underwood, & Gottlieb, 2000). Furthermore, social relationships are thought to influence cognitions, emotions, and biology (Lakey, 2010; Lakey & Cohen, 2000). Therefore, social relationships are positively related to healthy outcomes for parents, such as emotional well-being for parents experiencing stress (Lakey & Cronin, 2008). Parents who are stressed and feel unsupported find themselves at a greater risk for using maladaptive behavior strategies, such as avoidance. For example, mothers experiencing a high level of stress may ignore a child’s behavior and isolate themselves in the home with the child (Gray, 2003). These isolating behaviors may lead to mental health problems.

Despite the importance of coping skills, however, few studies have investigated interventions to improve parental coping specifically in this population, while very few studies have focused on fathers’ coping strategies when faced with a stressor, but rather have focused on how their involvement, or lack thereof, in those supports affects the mothers.

Family Systems Theory.

Each person within a family has their own unique role in interacting with other members of the family unit. Historically within the family system, fathers have been the breadwinner and worked outside of the home to support the family, while the mother was the caretaker overseeing the everyday responsibilities that go into taking care of the family. Family systems approach (Turnbull, Summers, & Brotherson, 1984) described the family system as the sum of its subsystems (e.g., marital, parental, sibling, extended family), which interact with family dynamics or inputs (e.g., family characteristics, family interactions, family lifecycle), to affect family functions or outputs (e.g., affection, spirituality, economics, daily care, socialization, recreation, education). However, as the dynamics or inputs are processed by families, the way in which each family responds are important (Meadan, Stoner & Angell, 2015). Family systems approach (Turnbull, Summers, Brotherson, 1984) would suggest that high levels of parental stress likely have cascading effects on all the relationships in a family. For instance, high levels of parental stress may affect family cohesion, as evidenced by the higher rates of divorce among families with a child with ASD than among comparison groups (Hartley et al., 2010). This is particularly concerning for the families involved but is also important to interventionists and researchers working with these families.

Ecological Theory.

Bronfenbrenner's (1979) ecological theory spotlights the context in which a child develops. Within the ecological theory, a child's early environments (e.g., school, home, community) as well as the interactions within these environments influence the child's development (Bronfenbrenner, 1979). It is made up of five different systems that influence development, Microsystem, Mesosystem, Exosystem, Macrosystem, and Chronosystem, and considers that the person's biology also contributes to this system (Bronfenbrenner, 1979). Both environmental and biological factors are thought to shape child development outcomes. Early environments that children participate in which are small and immediate are known as microsystems (Bronfenbrenner, 1979). Children's microsystems include any immediate relationship they engage in. Environments that are nurturing and encouraging, ensure positive environments the child will grow and develop (e.g., parent-child relationship, early childhood teacher-child relationship). Exosystems are the informal and formal supports and resources that directly or indirectly affect what occurs in different microsystems (e.g., early childhood intervention practices).

Approaches to Intervention Based on Theories.

Early intervention services can be a great support for families affected by having a child with a disability. Traditionally, early intervention services have been directed at the child and the mother. Early intervention approaches have derived from both the ecological approach (Bronfenbrenner, 1979) and family systems theory (Minuchin, 1985) and approach (Turnbull, Summers, & Brotherson, 1984). Like behavioral approaches, human ecology theory emphasizes the interaction and accommodation between the developing child and his or her environment (Dunst, Leet, & Trivette, 1988). Bronfenbrenner's model of individual development is extended to the family as a unit by incorporating family systems theory as an additional aspect of the ecological approach (Murray & McDonald, 1996). Minuchin's (1985) theory and Turnbull et al. (1984) approach to the family system, clearly indicates that the family operates as an interactive unit and that what affects one member affects all members.

These theories allow investigators to understand the parent-child relationship in a natural context. First and foremost, the early parent-child relationship is critical in helping the child develop, as well as foster a sense of trust between the child and his or her parents. When a child feels secure and can trust his or her parents with meeting their needs early on, then it should become easier for the child to trust and feel secure with the parents as they face a crisis within the family. Both the stress and coping theory and family systems theory note the relationship between the family systems and how they may or may not cope with stressors. One coping strategy afforded to families raising a child with a disability is that of early intervention services, which has been built around Bronfenbrenner's (1979) ecological theory, Minuchin's (1985) theory and Turnbull, et al., (1984) approach to the family system. Families operate as an interactive unit and that what affects one member affects all members.

Finally, when it comes to involving parents in early intervention services, Bronfenbrenner (1975) stated,

> Intervention programs that place major emphasis on involving the parent directly in activities fostering the child's development are likely to have constructive impact at any age, but the earlier such activities are begun, and the longer they are continued, the greater the benefit to the child. One major problem remains. [Many] families live under such oppressive circumstances that they are neither willing nor able to participate in the activities required by a parent intervention program. Inadequate health care, poor housing, lack of education, low income and the necessity for full-time work...rob parents of time and energy to spend with their children. (Bronfenbrenner, 1975, p.7)

There are many theories surrounding families and the importance of their involvement in their children's daily activities. For some families being involved is the most important thing, but for others they are not afforded the opportunities, or lack the resources, to be involved. It usually isn't until a family faces some sort of stressor or interruption into their daily lives when they are forced to look outside of their family unit for support in dealing with those stressors. Early intervention is a great resource for families, but if they are unsure of what it is and how it can benefit them for the better, they may be more inclined to decline the services.

2.2 Parental Stress

Over the past 30 years, several researchers have documented higher levels of parental stress in families with a child with ASD compared to parents of children who are typically developing as well as those with other developmental disabilities (Dumas, Wolf, Fisman, & Culligan, 1991; Koegel, Schreibman, Loos, Dirlich-Wilhelm, Dunlap, Robbins, & Plienis, 1992; Sanders & Morgan, 1997). High levels of parental stress have been shown to reduce the effectiveness of early intervention for children with ASD, particularly for those children receiving more time-intensive interventions (e.g. ABA, reinforcement-based, speech and language therapy, parent training programs) (Osborne, McHugh, Saunders, & Reed, 2008).

Johnson & Simpson (2013) wanted to discern if there were differences in maternal stress levels when male spouses/partners did not participate in autism studies compared to married and unmarried mothers whose spouses/partners did participate in the studies. The results concluded that married mothers, whose male spouse/partner did not participate in the study, had lower levels of perceived stress for responding to their child’s tantrums than the other group of mothers. The results also discovered that mothers found it to be stressful when negotiating with the father of their child on how to deal with a child’s challenging behaviors.

To explore parental stress and coping among mothers and fathers, Flippin and Crais (2011) compared studies on father involvement in intervention services. In their meta-analysis they found 17 studies that involved participants (i.e. mothers and fathers of children with ASD 2 to 5 years of age) with the study outcomes geared towards parental stress and coping. In four of those studies (e.g., Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Brobst, Clopton, & Hendrick, 2009; Dabrowska & Pisula, 2010; Epstein, Saltzman-Benaiah, O’Hare, Goll, & Tuck, 2008), both mothers and fathers of children with ASD were found to have elevated levels of stress compared to parents of typically developing children and parents of children with other developmental disabilities. Results comparing levels of stress experienced by mothers versus fathers of children with ASD were mixed. For instance, Flippin and Crais (2011) summarized that mothers and fathers were found to have similar levels of stress in three of the studies (Hastings, 2003; Hastings, Kovshoff, Brown, Ward, Espinosa, & Remington 2005; Hastings, Kovshoff, Ward, Espinosa, Brown, & Remington, 2005; Ornstein Davis & Carter, 2008), however, in eight studies, (Dabrowska & Pisula, 2010; Herring, Gray, Taffe, Tonge, Sweeney, & Einfeld, 2006; Gray, 2003; Little, 2002; Moes, Koegel, Schreibman, & Loos, 1992; Olsson & Hwang, 2001; Sharpley, Bitsika, & Efremidis, 1997; Tehee, Honan, & Hevey, 2009), mothers were found to have greater levels of stress than fathers. In one study (Twoy, Connolly, & Novak, 2007), mothers also reported having lower levels of coping compared to fathers. None of the studies included in this meta-analysis reported that mothers experienced less stress than fathers. Although fathers of children with ASD may have experienced less overall stress than mothers in the majority of included studies, fathers in two studies still demonstrated higher levels of stress compared to fathers of typically developing children and children with other disabilities (Herring et al., 2006; Olsson & Hwang, 2001).

Involving fathers may be especially important, given the negative impact parenting stress has on intervention outcomes for children with ASD (Osborne et al., 2008). The benefits may include developmental gains for the child with ASD, reduced stress levels for parents, and greater cohesion for families.

2.3 Role of Early Intervention

In the 1950s and 1960s, the federal government, with the strong support and advocacy of family associations, such as The Arc, began to develop and validate practices for children with disabilities and their families. These practices, in turn, laid the foundation for implementing effective programs and services of early intervention (EI) and special education in states and localities across the country (U.S. Department of Education, 2007). EI services, authorized by Part C of the Individuals with Disabilities Education Act (IDEA, 2004), are designed to address the developmental needs of eligible infants and toddlers with disabilities, ages birth to three, and their families. Prior to IDEA, the main purpose of EI was very child focused: to enhance the development of young children with disabilities and very specific to the educational setting. Today the primary mission for EI is family support. Public Law 108-446 requires that an Individual Family Service Plan (IFSP) be developed for all children and families receiving EI services (Individuals with Disabilities Education Act, 2004). EI programs should be delivered using a family-centered approach which recognizes the importance of the family in the life of the individual who receives services and must take place in the child’s natural learning environment (e.g. child’s home, school, or any place that is natural and familiar to the child). In the field of EI, this approach builds on the primary nature of family interactions and the implications for children with special needs. Allen and Petr (1998) identified three core elements of family-centered service delivery: (a) the importance of the family as the child's most influential environment and, as such, the unit of attention for services, (b) family members as informed decision makers, and (c) decisions and services built upon and supporting the family's strengths and resources.

Although the special needs of the children are the reason why families receive EI services, experts suggest that family outcomes are just as important as child outcomes in the effort to maximize the potential development of the children (Bailey & Bruder, 2006). Interventions to improve stress, parental self-efficacy, and coping skills are a critical aspect of family-centered care for families of children with ASD (Karst & Van Hecke, 2012). Strong parental self-efficacy may be particularly important for parents of children with ASD because self-efficacy has been found to mediate the relationship between parental mental health and child problem behaviors (Hastings & Brown, 2002). Thus, in theory, robust parental self-efficacy may allow parents to better maintain positive mental health in the face of difficult child behaviors (Kuhaneck, Madonna, Novak, & Pearson, 2015).

Self-Efficacy.

Self-efficacy is defined as one's belief about one's capability to perform or ability to succeed (Bandura, 1994, 1997). Self-efficacy is an important concept to consider in relation to parenting because belief in one's capability as a parent may influence motivation, emotional state, and investment in intervention strategies. Sustaining a positive sense of parenting self-efficacy can be challenging for parents of children with ASD (Kuhn & Carter, 2006), because typical parenting strategies may not work, many child behaviors are extreme, and continually balancing the needs of all family members is demanding (DeGrace, 2004; Kuhaneck, Burroughs, Wright, Lemanczyk, & Darragh, 2010; Larson, 2006; Schaaf et al., 2011). Interventions to improve stress, parental self-efficacy, and coping skills are a critical aspect of family-centered care for families of children with ASD (Karst & Van Hecke, 2012). Strong parental self-efficacy may be particularly important for parents of children with ASD because self-efficacy has been found to mediate the relationship between parental mental health and child problem behaviors (Hastings & Brown, 2002). Self-efficacy is influenced by multiple factors and has the potential to be improved. Studies have demonstrated that parental fatigue and well-being, contextual family factors, and child behaviors all affect self-efficacy (Giallo, Wood, Jellett, & Porter, 2013). In addition, parents' ability to problem solve and use strategies to manage child-related challenges may influence their perceptions of self-efficacy (Foster, Dunn, & Lawson, 2013). Increasing parents' knowledge of ASD may increase self- efficacy because they are better able to understand the child's behaviors and, in turn, infer the child's underlying needs and wants (Kuhn & Carter, 2006).

Kuhaneck, Madonna, Novak, & Pearson (2015) wanted to measure the effectiveness of occupational therapy interventions for children with ASD and their parents to improve parental stress and self-efficacy, coping, and resilience and family participation in daily life and routines. In their meta-analysis 34 articles were selected that matched the inclusion criteria (e.g., peer-reviewed scientific literature published in English, intervention approaches examined were within the scope of practice of occupational therapy, and the literature included in the review was published between January 2006 and April 2013 and included study participants with ASD). Outcomes were categorized into two primary categories: (1) parental self-efficacy, confidence, and competence, and (2) parental decreased stress, improved family coping and resiliency, and quality of life.

The Kuhaneck et al., (2015) review found limited evidence that interventions can improve parental stress levels while some evidence exists to suggest that interventions can in fact increase stress or lead to greater levels of depression. However, stronger evidence is available to support center-based interventions effects with respect to improved parental confidence, competence, and feelings of self-efficacy. Given the inverse relationship found between stress and self-efficacy (Giallo et al., 2013; Raikes & Thompson, 2005), improving self-efficacy may be one method of effectively reducing stress over time (Jones & Prinz, 2005).

2.4 Interventions: Not a One Size Fits All

Interventions should be family-centered, collaborative, and tailored to all learning styles. Many researchers adopt the fact that findings in their studies can be generalized to include fathers (Rodrigue, Morgan, and Geffken, 1992), however this remains to be untrue. According to the Trivette & Dunst (2005), to ensure full collaboration, professionals have a significant responsibility to share all relevant information in a way that matches the family’s style of understanding and how they process that information. It may be beneficial to take into consideration how parents learn new information. As both learners and instructors, gender differences are evident between women and men and, by extension, between mothers and fathers. This is not to say that all women or men follow the differences noted, but research has shown significant differences between several men and women (Flippin & Crais, 2011). For example, as learners, women often prefer receiving support and feedback from instructors and working with others in a cooperative and collaborative environment (Grossman & Grossman, 1994). Women also prefer to receive explanations and directions, and in general, delay decisions until all the available information is gathered. As trainers, women tend to be relationship oriented and provide supportive feedback to students, using an implied teaching style (Brady & Eisler, 1999). This female style of learning and training is reflected throughout the collaborative model of EI and likely has resulted both from the traditional focus on mothers and from EI being a predominately female field.

In contrast, men as learners prefer receiving feedback from peers rather than from an instructor (Grossman & Grossman, 1994). Men also prefer working independently within a competitive environment. As opposed to watching and waiting until all the information is gathered, men are more comfortable jumping in to manipulate materials and problem solve when old solutions no longer apply. It follows that as trainers, men tend to be subject centered and task oriented and to use a direct teaching style (Brady & Eisler, 1999). It may also follow that men typically learn best when instruction is delivered in a way that they have become familiar with in their own lives. Fathers tend to relate to services that are more hands on and in peer-to-peer support (Shannon, Tamis-LeMonda, London, & Cabrera, 2002). However, regarding EI, male learning and training styles are not typically incorporated or even considered. Mothers are presented with the information that best suits their learning style, with the assumption that they will “teach” the fathers what they learned and how to incorporate that into their own interactions with their child. This may be one reason why fathers find it more challenging to become or remain involved, particularly when compared to mothers, in their child's EI services (Flippin & Crais, 2011).

Fathers' Interactive Styles.

Language Acquisition.

While men, particularly fathers, often require a different hands-on learning style, they also differ in their interaction styles with their children, particularly when it comes to their child's social and communication skills (Shannon, Tamis-LeMonda, London, & Cabrera, 2002). For children with communication and social deficits, such as those with ASD, understanding and enhancing the role of fathers may be an important direction in both research and clinical practice. There is evidence that responsive fathering is a strong predictor of better developmental outcomes for children, including improved emotional regulation and cognitive and language development (Shannon et al., 2002; Tamis-LeMonda, Shannon, Cabrera, & Lamb, 2004).

As is the case for children who are typically developing, there is growing evidence that the quality of early parent–child exchanges is particularly important for language acquisition for children with ASD (Siller & Sigman, 2002, 2008). While studies of mother-child interactions (Siller & Sigman, 2002, 2008) have shown that when mothers of preschoolers with ASD use more undemanding utterances, or comments, which reinforce or maintain the child's ongoing activity, their children demonstrate better language abilities throughout adolescence. However, fathers too make important contributions to a child's language and play development. Fathers have interaction and communication styles that are unique from those of mothers (Flippin & Crais, 2011).

Studies of father-child interactions with children who are typically developing have established that fathers offer unique language models, which make important contributions to children’s language development (Clarke-Stewart, 1980; Gleason, 1975). Overall, fathers tend to use a higher-level vocabulary and a more complex language model with their children than do mothers. Fathers are more likely than mothers to direct questions to their children and tend to ask open-ended questions that are more complex than the “yes–no” questions more frequently used by mothers (McLaughlin, Schultz, & White, 1980). This higher -level language model used by fathers has an important role in communicative outcomes for typically developing children. There is some evidence, however, that fathers’ more linguistically challenging style may indeed support child vocabulary development. In fact, fathers’ vocabulary use at 24 months has been shown to predict levels of child expressive language one year later (e.g., 36 months) (Pancsofar & Vernon-Feagans, 2006), whereas mothers’ language did not account for a significant portion of the variance.

Similar to parents of typically developing children and those with other disabilities, differences between mothers’ and fathers’ language models for their children with ASD also have been documented. For example, Wolchik (1983) examined the language patterns of mothers and fathers of 10 children with ASD and 10 typically developing children matched for language, age, sex, and parental education level. Wolchik (1983) revealed few differences between the overall language models of parents of children with ASD versus parents of typically developing children. However, parents of children with ASD used non-language-oriented vocabulary (i.e., language not specifically directed toward eliciting or responding to the child’s language or toward enhancing receptive language) more than parents of typically developing children. In addition, parents of children with ASD tended to use slightly more questions and labels than parents of typically developing children, although the differences were not significant. Moreover, the most striking differences were noted between mothers and fathers. Mothers of children with ASD and children who were typically developing were more active conversationalists than fathers, across all language categories. Mothers used more requests, asked more questions, and labeled objects more often than fathers. Mothers also expanded their child's language more often than fathers and used more non-language-oriented language than fathers. Conversely, fathers engaged in more "other behavior," such as sitting quietly, sighing, talking on the phone, and laughing, than did mothers. These differences in the language models of mothers and fathers of children with ASD were also observed by Konstantareas, Mandel, and Homatidis (1988), who studied 12 children with ASD (40 to 151 months old) and their parents. Compared to mothers, fathers asked an equal percentage of questions but used a greater percentage of directives and a smaller percentage of prompts and statements than did mothers. This suggests that directive language used by fathers may in fact be facilitative for children with ASD, however the reasons for the facilitation are unclear (Flippin & Crais, 2011). It is important to recognize that some aspects of fathers' direct communication styles may indeed play a supportive role in fostering a child's communication development.

Play Skills.

While many fathers are unique in how they communicate with their children, both typically developing and those with ASD, they also are distinct in how they play with their child. Many EI support programs use a play-based therapy approach to foster relationships between parents and their child(ren), peers, and to build on many developmental skills. Play is an important component of not only a child’s development, but of many intervention services. It requires cognitive, social, and emotional skills, and parents have an integral role in the development of their child’s play skills. Play represents an important skill for children to acquire, and higher levels of object play skills have been shown to be strong correlates of language ability for both typically developing children and children with ASD (McCune, 1995; Mundy, Sigman, Ungerer, & Sherman, 1987).

In typical development, object play emerges across four different phases of play which evolve over time: exploratory, relational, functional and symbolic (Flippin & Crais, 2011). The first phase, *exploratory play*, emerges between 2 and 10 months. At this stage, the child begins to investigate properties of a toy through indiscriminate actions and simple manipulations. For example, the child may hold a ball or mouth a toy. At around 10 to 18 months of age, *relational play* emerges. During this stage, the child starts to combine two or more toys in play. For example, the child may stack rings, nest cups, or put toys into a bucket. The third phase, *functional play,* emerges between 12 and 18 months. In this phase, the child begins to use toys and miniatures as intended but without clear evidence of pretense. For example, the child may sweep with a toy broom. Finally, the fourth phase, *symbolic play*, emerges around 18 to 30 months. In this phase, the child starts to substitute one object for another (e.g., a banana for a phone) and begins to engage in more elaborate pretend schemas, imagination, and fantasy play (Casby, 1991; Lifter, Sulzer-Azaroff, Anderson, & Cowdery, 1993;

Ungerer & Sigman, 1984). Symbolic play with objects has been shown to be an important predictor of later language development for typically developing children and those with ASD (Charman, Baron-Cohen, Swettenham, Baird, Drew, & Cox, 2003; Toth, Munson, Meltzoff, & Dawson, 2006).

In contrast to the smooth trajectory for typically developing children, most children with ASD do not follow this same trajectory of developing play skills (Libby, Powell, Messer, & Jordan, 1998). Rather, children with ASD often demonstrate severe deficits in play development. Overall, the play of children with ASD is less elaborate and more repetitive (Williams, Reddy, & Costall, 1996). For instance, children with ASD spend a longer period engaging in exploratory play, past the point at which typically developing children move on to more sophisticated levels of play (Jordan & Libby, 1997). Children with ASD also spend less time than their typically developing peers engaged in the more sophisticated levels of functional or symbolic pretend play (Baranek, Barnett, Adams, Wolcott, Watson, & Crais, 2005; Jarrold, Boucher, & Smith, 1993).

Although both mothers and fathers help their children achieve higher level language and symbolic abilities through play, there are qualitative and quantitative differences between parents in play interactions with their children. For instance, father–child play is more active and rough-and-tumble. Father–child play is also more generative, with fathers being more likely than mothers to engage in play schemas that stretch beyond the physical properties of the toys (Labrell, 1996). Although for most North American families the role of mothers in the family is primarily one of caregiver, the playing role in the family is more frequently associated with fathers (Pleck &

Masciadrelli, 2004). As their child's first and primary play partner, fathers have a distinctive role in supporting their child's development through play. In one study, for example, fathers of children with ASD engaged in less parallel play than mothers while being more directive and less consistently responsive to their child's initiations (Elder, Valcante, Won, & Zylis, 2003). The four fathers in that study also reported being frustrated in not knowing how to play with their children with ASD. From a parental perspective, it may be more difficult to engage in play with a child who continues to play at lower levels than a child who has more complex and perhaps more varied play. However, fathers may be uniquely suited to support the play development of their children with ASD. By enhancing play skills, fathers can not only gain more varied contexts within which to interact with their child but also enhance their child's language and social skills (Flippin & Crais, 2011).

2.5 Where are the Fathers?

We know how fathers can participate in their child's intervention in their own different and unique ways which contribute to their effectiveness, however it is important to understand why their participation and involvement are missing from much of the research and intervention programs. Although the level of father involvement in child care and intervention services is increasing, it continues to be less than mothers (Pleck & Masciadrelli, 2004); the proportion of participating mothers versus fathers is approximately two to one (Dunn, Burbine, Bowers, et al., 2001; Gray, 2006, 2002; Twoy, Connolly & Novak, 2007). Historically within EI services, mothers typically played a primary and a more exclusive participant than fathers because they were more likely at home caring for the children while fathers worked outside of the home and were less available (Murray & McDonald, 1996). It is perhaps a natural extension of their caregiving role that mothers have been the focus of both EI services and research in early ASD interventions, despite the move in our field to more “family-centered” models. For example, within the EI service system, mothers remain the primary participants in child assessments (Crais, Poston, & Free, 2006) and interventions (Able-Boone, 1993; Polmanteer & Turbiville, 2000). This is also the case when it comes to studies that attempt to recruit both parents as participants. Often, most participants in autism studies are mothers (Johnson & Simpson, 2013; Flippin & Crais, 2011). This discrepancy in the number of father participants is similar for other pediatric disabilities (Macfadyen, Swallow, Santacroce & Lambert, 2011).

Although researchers, practitioners, and policy makers alike have advocated for father involvement in EI services for children with disabilities, there are several significant barriers that limit their participation. For example, EI services often fail to target fathers, EI services may not take into consideration the unique parenting needs of fathers, and EI service providers may have limited understanding of effective strategies for engaging fathers (Flippin & Crais, 2011). There are examples of models to engage fathers in early childhood programs (e.g., Early Head Start, Head Start); however, these programs have not specifically targeted fathers of children with disabilities and/or developmental delays specific to EI services. The procedures employed by these programs may be useful in informing efforts to engage fathers in EI services (McBride, Curtiss, Uchima, Lasman, Santos, Weglarz-Ward, Dyer, Jeans & Kern, 2017).

Very little empirical evidence is available that documents the level of involvement exhibited by fathers in EI services, as well as the barriers (both real and perceived) that limit their participation in such activities. For example, a potential barrier is a lack of residential fathers as, according to data from the National Early Intervention Longitudinal Study (NEILS). Only 63% of children entering EI live with their biological father (Hebbeler, Spiker, Baily, Scarborough, Mallik, Simeonsson, & Nelson 2007). Although this is less than the general population (73%), this statistic does not consider that many children do live with their biological father or other men who may step into a father role to fulfill roles and responsibilities. Similarly, work may be a barrier. Most fathers (85.3%) of young children (below 6) work full-time, whereas only 41.8% of mothers of children the same age work full-time (Bureau of Labor Statistics, 2012). This gap may be even wider for parents of children with disabilities and delays as there is some evidence that a child’s disability status has a negative impact on maternal employment but not paternal employment (Parish & Cloud, 2006). Again, these statistics cannot account for within group variations in EI providers’ perceptions of father involvement in EI, nor is it clear how work and residential status play a role in perceptions of involvement (McBride et al., 2017).

Flippin & Crais (2011) compared the participants of different empirical studies related to parent intervention with their child with ASD. Their search was narrowed down to three criteria: (a) participants included at least one child participant with ASD between the ages of 2 and 5 years and their parents, mother and/or father; (b) outcome measures included child social-communicative skills (e.g., verbal or nonverbal communication, imitation, social interaction, joint attention); and (c) parents were the agent of intervention. Studies with outcomes that did not include communication (e.g., problem behaviors, sleep behaviors) and studies in which interventions were primarily delivered by research staff and other professionals with an additional parent component were not included in the review.

A total of 27 articles met criteria for inclusion. Two studies which reported data from the same participants, were considered as a single study for purposes of their review. Of the resulting 26 articles (e.g., 11 controlled group studies and 15 single subject experiments) examining parent intervention in ASD, four group designs and 10 single-subject experiments explicitly stated that participating parents were mothers. Seven group studies and two single-subject experiments did not specifically report whether fathers were included among the parents participating in intervention. Only three studies (Elder et al., 2005; Rocha, Schreibman, & Stahmer, 2007; Symon, 2005) specifically reported the involvement of fathers in parent training for children with ASD. In a study by Rocha and colleagues (2007), one of the three participating parents was the father of a child with ASD. In the study by Symon (2005), one of the three participating mothers trained a father as a secondary therapy provider, although in that study mothers were the primary intervention agents.

While times are changing, so too should services targeted at including families. More fathers are staying home or taking a more active participatory role in their children’s lives. It is evident through research that fathers offer unique ways in which they interact with their children from the way they communicate to the way they play with them. They also have their own unique learning styles as well which should be taken into consideration when implementing EI services. While it is important to understand how far we have come in the research, and even in the overall practice, there is still a gap that exists. One that can only be closed by understanding the obstacles that fathers face in being involved.

2.6 Including Fathers in Interventions: Obstacles, Needs and Supports

According to Cheuk & Lashewicz (2016) fathers' needs are distinct from those of mothers. Researchers found fathers of children with ASD require different supports than mothers (Meadan, Halle & Ebata, 2010) and have distinct ways of interpreting, coping, experiencing, and participating in parenting their child (Flippin & Crais, 2011). Fathers rated the need for in-home support for their child more highly (Benson & Dewey, 2008) and communicated less confidence about responding to their child's challenging behaviors (Sharpley, 1997).

While fathers' involvement is limited in EI services, it is important to explore the thoughts and views of those professionals working with the families to implement family-centered approaches. For example, McBride & colleagues (2017) wanted to explore the gap between service providers' perceptions and practices when it came to father involvement in EI services. Data were gathered from 511 EI service providers to address the following questions:

- How do EI service providers view the role of fathers in influencing the development of their children with disabilities?
- How do EI service providers perceive fathers as being effective targets for EI services?
- At what levels do EI service providers engage fathers in the services being provided?

> What are the major barriers confronting EI service providers to getting fathers more involved in the services provided?

Information gained from the data collected was intended to provide valuable new insight on potential reasons why fathers may play minimal roles in EI services for their children with disabilities. Participants were asked to respond to 12 items on a 5-point Likert scale from 1 (*strongly disagree*) to 5 (*strongly agree*). Examples of questions were: ’Fathers should be encouraged to participate in EI services,” “It is best not to approach a father if you need to find out information about a child for intervention purposes,” and “Every father has some strengths that could be tapped to increase child success.” Findings from McBride & colleagues’ (2017) exploratory study suggested a disconnect exists in providers’ perceptions of fathers’ impact on child development compared with their perceptions of fathers as targets for EI services. For example, a result of the study found that EI services often fail to target fathers, EI services may not take into consideration the unique parenting needs of fathers, and EI service providers may have limited understanding of effective strategies for engaging fathers (Flippin & Crais, 2011). Also, providers reported that they viewed the father as an inappropriate target for services either because of his *Lack of Presence* or because *Men Work and Women Care for Children*, as well as a suggestion from the study that EI services are *Gendered Services*, meaning that providers have difficulty working with fathers, have difficulty working with men, only target mothers, or fail to target fathers (McBride et al., 2017). There were no differences in these perceptions based on the provider’s profession, which may indicate that this is indicative of EI service culture rather than a specific professional group. This project examined only the perceptions of EI providers in terms of father involvement; the voices and perspectives of the fathers themselves were not represented in the data.

2.7 Summary

Parents of children with ASD are at greater risk of increased stress levels and mothers are particularly vulnerable to higher levels of child-related stress. High levels of overall and child-related stress experienced by mothers may be, in part, the result of the greater role they play in their child's primary care and in EI services (Tehee, Honan & Hevey, 2009). Fathers may experience less child-related stress than mothers, however, both mothers and fathers reported relationship stress related to their partner's mental health. This may be particularly important for fathers, given that mothers were shown to experience higher levels of depression in three studies (Little, 2002; Olsson & Hwang, 2001; Sharpley, Bitsika, & Efremidis, 1997).

Not only do fathers play an important role in their child's life as attachment figures, they are also their child's first play partner, and offer their own unique style when it comes to communicating with their child. While many EI services offer a play-based approach in delivering services, involving fathers in early intervention programs is promising on so many levels. While many EI programs claim to be "family-centered" and tailored to meeting the outcomes of both parents, the evidence presented has shown us that this is clearly not the case. While increasing father involvement in intervention services may ease the overall workload for mothers, while reducing maternal stress, it may also enhance the role of fathers in the development of children with communication and social deficits such as ASD. This could be an important direction in realizing optimal “family-centered” services for children with ASD and their families (Flippin & Crais, 2011). Father involvement is more than a purely physical contribution: it is emotional, mental, and spiritual involvement as well (Rump, 2002). This study will explore fathers’ perspectives on their level of involvement in their child’s EI services available to them and explore the fathers’ thoughts on how well the service providers are doing to include them in these services.

CHAPTER 3: METHODOLOGY

To effectively explore father's perspectives on their level of involvement in early autism services, the proposed study was a mixed methods design. The researcher explored fathers' perspectives first through a survey, and then through interviews. The survey was available online and used to gain an understanding about the father's perspectives on their involvement in EI programs, as well as the father's perceived involvement in their child's early autism services. Both the survey and the interviews allowed the researcher to collect authentic data by exploring fathers' perspectives based on their experiences, knowledge, and attitudes with EI services. Many studies have explored father's lack of involvement in EI services (Johnson & Simpson, 2013; Flippin & Crais, 2011) based on mothers' and service providers' feedback and personal experiences working with fathers (McBride et al., 2017). The one-on-one personal interviews allowed the researcher to hear a variety of fathers' voices to provide a more in-depth and comprehensive picture of the family, as well as how well EI services and parent-training programs are meeting the needs of the families in which they serve.

3.1 Rationale

The rationale driving this study was based on the researcher's own personal and professional experience with EI services. While navigating the system with her own son, she discovered that there was very little push by the professionals to include the fathers in services. Along with the providers' own biases, both through personal ties to the autism community and as a researcher, regarding father involvement, it was also discovered that emphasis was being placed on the mothers and making it their responsibility to educate the fathers on what they learned in the sessions. As an early interventionist, the researcher found that while the majority of the home visits included mothers, for the few fathers who were actively involved, they presented a more hands-on approach (i.e., rough and tumble play, play using objects to scaffold language) to learning about how to best address their young child's needs. After an extensive review of the literature and the researcher's own personal and professional experiences and perspectives, the researcher found that EI programs and approaches, tailored to fathers and their learning styles were lacking. Because fathers' involvement has increased in recent years and can be supported by the positive influences of fathers on their children's development (McWayne, Downer, Campos, & Harris, 2013; Palm & Fagan, 2008; Quesenberry, Ostrosky, & Corso, 2007), researchers (e.g. Carpenter & Herbert, 1997; Meadan, Parette, & Doubet, 2013; Parette, Meadan, & Doubet, 2010) have called for more research on fathers' experiences, involvement, and support needs. By conducting a mixed-methods study, these findings will lead to more effective ways in which to incorporate fathers into EI services through various approaches, as well as lead to the discovery of EI programs tailored specifically to fathers of young children with ASD.

3.2 Participants

Participants who completed the survey met the following criteria: (a) must have a child with an ASD diagnosis who received EI services within the past year, or was currently receiving EI services, (b) the child with ASD was between the ages of 2-6 years of age, (c) be a biological, grandparent, foster parent, or adoptive father of a child with ASD, and (d) speak English. The sample was based on convenience. The researcher recruited fathers from various local agencies that served young children and families with autism: an agency that serves individuals with various disabilities from infant through adulthood through early intervention, job training and respite care, an early childhood education center that offers both self-contained and inclusive settings for young children with various disabilities, a Parents as Teachers program, and a local agency that advocates and provides resources for families with a member who has ASD. A total of 19 fathers attempted to take the survey, four were excluded because they did not meet the inclusion criteria, and five were eliminated because they did not complete the survey providing insufficient data, leaving the total participants at 10. Demographics of the fathers who participated in the study are outlined in Table 1.1, while the background of the children involved in those services are outlined in Table 1.2.

Table 1.1 Demographics of Participants

Variable		***n***	**%**
Age	25-34	3	30.0
	35-44	6	60.0
	55-64	1	20.0
	Total	10	100.0
Marital Status	Married	9	90.9
	Divorced	1	10.0
	Total	10	100.0
Race	Caucasian	8	80.0
	Hispanic or Latino	2	20.0
	Total	10	100.0
Education Level	High School graduate, diploma, or equivalent (GED)	3	30.0
	Some college credit, no degree	3	30.0
	Associate Degree	1	10.0
	Bachelor's Degree	3	30.0
	Total	10	100.00
Employment Status	Employed, working 40 or more hours per week	6	60.0
	Employed, working 1-39 hours per week	2	20.0
	Not employed, looking for work	1	10.0
	Disabled, not able to work	1	10.0

	Total	10	100.00
Household Income	$0 – 25,999	1	10
	$26,000 – 49,999	2	20
	$50,000 – 74,999	4	40
	$75,000 – 99,999	1	10
	$200,000 +	1	10
	Prefer Not to Answer	1	10
	Total	10	100

Table 1.2: Demographics of Children Participating in Services

Variable		**Frequency**	**Percent**
Autism Diagnosis	Yes	10	100
Participation in EI	Yes	10	100
Length of Time Child has been receiving EI Services	6-12 months	4	40.0
	12-18 months	1	10.0
	18-24 months	1	10.0
	2-3 years	4	40.0
Is your child currently participating in EI services	Yes	9	90
	No	1	10
Person most responsible for getting your child to and from services.	Mother	7	70
	Father	1	10
	Relative	1	10
	Other	1	10

At the end of the online survey, each participant was asked if they would be willing to participate in the study further by sharing their experiences by participating in a one-on-one interview. If they agreed, then they were prompted to provide their contact information, and were contacted at the conclusion of the online survey to discuss their involvement in the interview process. Pseudonyms were used to identify the participants from the interviews. A total of 3 fathers participated in the follow-up interviews. Of the 3 fathers, 2 were Caucasian (B.C. and A.E., respectively) and 1 was Hispanic (L.P.), and all were between the ages of 35-44 years of age. B.C is a pastor working full-time with 1 child with Autism, diagnosed at 3 years of age; A.E, a sales manager working full time with 1 child with Autism, diagnosed at 2.5 years of age; and L.P. a construction supervisor working full-time with 1 child with Autism diagnosed at 5 years of age.

3.3 Setting

This study was conducted in two parts: a survey and a one-on-one interview. The survey was conducted online using a computer program called Qualtrics. An electronic flyer (Appendix A) with an embedded link to the survey was sent out to each of the agencies that agreed to support the researcher in helping recruit participants prior to the start of the study, using a website called www.smore.com. The agencies were asked to forward a copy of the flyer to the parents. However, for the school, they forwarded it to all the teachers at the school who then forwarded it to their parents in their contact list, as a way of recruiting participants. The interviews were also conducted at a location of the participants' personal choice. The participants chose whether they wanted the interview to be face-to-face, video chat using Google Hangout, by phone or email. Two fathers chose to participate using Google Hangout, while the other father participated via a telephone interview.

3.4 Procedures

Prior to the start of the study, the researcher reached out to various agencies (e.g., early childhood special education programs, early intervention programs, programs providing ABA services, a local Parents as Teachers program, and local autism advocacy agencies) that provided early autism services to families and young children to recruit participants for the study via email using the Email to Agencies Template (Appendix B). Once agency support was established and a letter was received from the agency as evidenced in the Letter of Support Template (Appendix C), the researcher selected one father who has a young child with ASD, not associated with the partnering agencies, to pilot both parts of the study. The purpose of the pilot study was to determine the content validity of the measures Fathers of Children with Developmental Challenges Questionnaire-*Adapted* (Appendix D) and Interview Protocol (Appendix E). Because part of the FCDC Questionnaire-*Adapted* was created by Ly & Goldberg (2013), it was important to make sure it was useful and captured the data that were needed to answer the research questions for this study, while the Interview Protocol allowed the researcher to see if any of the questions or prompts needed to be revised and answer any questions that came from the pilot before preceding to the actual study.

At the conclusion of the pilot, a web link was sent out to the partnering agencies around the beginning of September 2017. Per the agencies' protocols for participating in a research study, they forwarded the flyers with the embedded link to the survey out to the families on their Listservs, as well as posted it to their websites and social media pages. The surveys were active for data collection for one month, wrapping up the middle of October 2017. Reminders to take the survey were sent out to the families and to the participating agencies in which they emailed to their families 15 days from the start of the survey via email, with another sent out 5 days before the survey closed, and a final reminder was sent out the day before the survey closed. The 40-question survey included a combination of multiple choice, fill-in-the blank, matrix tables, and short answer options, and took no more than 20 minutes to complete. When the participants opened the survey, they were given an introduction as well as brief instructions about the survey they were completing. To ensure the participants were consenting to the survey the first question they were asked was: “By clicking "Yes" you will be giving consent to complete the questionnaire.” Should the participant have answered “no” then he was directed to the end of the survey. The participants were also asked two questions to determine eligibility: (1) Do you have a child with an ASD diagnosis, and (2) Has your child participated in an EI service within the last 18 months? Should the participant have answered “no” to either one of those questions, then they were directed to the end of the survey with a thank you screen as they were not eligible to participate in the survey. Due to a low response rate from the first round of survey recruitment, a second round of recruitment took place in January 2018. The researcher again contacted two agencies whom did not respond during the initial recruitment phase in the spring of 2017. Those agencies also went through the same recruitment process and the surveys were available from February to March 2018.

At the end of the survey, the participants were directed to a question asking them if they wished to participate in a focus group as an extension of the current study to further discuss their experiences. If they agreed, the participants were able to provide their contact information (name and email address) so the researcher could contact them. This information was not tied to their survey response questions. Due to the low response rate (n=1) for a focus group, this phase was changed to a one-to-one interview option for any participants responding in the second round of the survey process.

Phase 2 began once phase 1 closed. For those whom agreed to participate in the interviews, they were contacted throughout March 2018 with information regarding the interview, with the interviews concluding by the end of March 2018. The participants participated in the interviews on their own time (usually in the evening), at a location of their personal choices either through a video chat using Google Hangouts or a phone interview. The interviews were between 30 and 45 minutes in length. Prior to the interviews, the researcher emailed the participants the Consent to Audio Record Form (Appendix F), in which the participants printed, signed and then scanned back to the researcher. The researcher used the Interview Protocol (Appendix E) to go over rules of the interview and to help with guiding questions for the participants. Each participant was provided with a $50 Amazon electronic gift card for their participation at the completion of the interviews.

3.5 Data Collection

The study began September 1, 2017 and continued through March 2018. Data collection for both survey windows lasted for 30 days, with reminders sent out to the participants and agencies at days 15, 25 and 29. Using the Interview Protocol (Appendix E), the researcher asked open-ended questions to engage the fathers and collect authentic information. The participants were audio recorded to allow the researcher to go back and transcribe their verbal responses to code for overarching themes and individual experiences discussed to make observations about the fathers' perspectives surrounding their involvement in EI services. These themes are discussed in the results section.

3.6 Measures

Fathers of Children with Developmental Challenges (FCDC) Questionnaire-*Adapted.* (Appendix D) – The original 20-item instrument was created by Ly & Goldberg (2013) as a brief measure to be used to capture the perceptions and experiences of fathers of children with developmental challenges. The purpose of the instrument was to measure two sub-scales: (1) impact on parenting, and (2) involvement with child intervention. To address the construct validity of the FCDC, responses were compared with widely used measures that assessed parenting and personality characteristics of the fathers, and reported child symptomology: *Parenting Stress Index, NEO Five-Factor Inventory, Parenting Commitment Scale* and the *Social Communication Questionnaire.* These measures were selected for their relevance to parenting and fathering literatures and had value for establishing both convergent and divergent validity. The FCDC fills a gap in the literature by offering an easy-to-administer self-report measure of fathers' perceptions of supports for, and barriers to, their involvement with their children with developmental challenges. The FCDC could assist professionals in delivering support services specifically for fathers of children with developmental challenge. When compared with the other instruments used in the study, the author of the study proved FCDC to be valid and demonstrated high reliability ([a=0.89], as did each of the two subscales [a>0.85]) in meeting the goals of the measurement (e.g., measuring impact on parenting and involvement with child intervention) (Ly & Goldberg, 2013).

The 20 items primarily address the psychological and cultural/institutional factors identified as contributors to stress and predictors of involvement among fathers (Lamb *et al*. 1987; Pleck 2012). Further, cognitions about fathering have been increasingly included into research (Pleck 2007), thus items tapping into feelings and thoughts about fatherhood were included in the instrument. Given that the acceptance of the child's developmental challenge has been shown to be uniquely associated with fathers' family experiences (Keller & Honig 2004), seven of the 20 items concerned this topic. The remaining 13 items were distributed among the topics of competence in the parenting role and therapy-related involvement. This instrument allowed participants to indicate their agreement with each item as it generally applies to them on a scale ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). Items will be scored such that higher total scores indicate that fathers experience greater supports to their involvement with their child. For the fathers who are not able to attend at least one educational or therapy-related meeting, a list was compiled of possible reasons why they did not attend.

With the permission of Ly & Goldberg (2013) (Appendix G), the researcher was able to adapt the measure to fit the current study, while also staying true to the conceptual framework intended. The researcher adapted the original measure by including an additional 20 questions at the beginning of the FCDC Questionnaire. The purpose of these additional questions was to collect comprehensive data surrounding the demographic information on the participants completing the electronic survey and their children who are in EI services, and to gather their opinions surrounding their involvement in their child's early autism services. On the form participants were asked about their background and demographics (e.g., marital status, educational background, and occupation), as well as the participants' children's information (e.g., diagnosis, age of child at diagnosis, how many children in family). Other minor adaptations that were made were: a) the researcher changed the term *developmental disabilities* used throughout the matrix questions to autism. This allowed the questions to be more specific to those children with *autism*, whereas *developmental disabilities* were broad and not the intent of the current study. b) for question 27.B, the choice was changed from '*His/her disabilities get in the way of my relationship*" to *"His/her autism gets in the way of my relationship with my child"* to be more specific to the study, c) and for questions 22, 24 and 26, a third answer choice: *When Possible* was provided. Feedback provided during the pilot phase was positive and nothing specific was requested that required revisions to the measure. The adapted questionnaire included a combination of 40 multiple-choice and short answer responses. These questions focused on EI programs and fathers' satisfaction with the programs their children participated in. The electronic survey took approximately 20 minutes to complete.

Consent to Audio Record. (Appendix F)- An audio consent form was emailed to each participant at the beginning of phase 2, the interview. The sessions were audio recorded, which allowed the researcher to go back later to code themes among the participant's responses. By audio recording the participants' responses, it allowed for participant confidentiality in hopes they were more open and honest with their answers, as well as allowed the researcher to gather data more accurately. The form outlined the purpose of the current study, the reason for the interview, how it related to the current study and the reasoning for audio recording the session. The form also stated that participation was voluntary and at any time the participants were able to withdraw from the study, as well as included the researcher's and university's contact information for the participants. The interviews were conducted at various times over the course of a 2-week period, and the date it was held was added to the form with the understanding that the consent would be null and void one year after the date of the session. Participants were asked to sign the emailed copy and then scan it back to the researcher to keep and store away in a locked facility to be destroyed three years after the conclusion of the current study. The consent form asked for the participant's initials and date to allow for confidentiality.

Interview Protocol. (Appendix E)- This form provided the researcher with guiding questions to use during the interviews. The researcher conducted the interviews based on the parent's general responses in the survey to help guide the interview to gain further information. The preliminary prompts used in the interviews came from the researcher's adapted version of Ly and Goldberg's (2013) FCDC Questionnaire. Questions from the FCDC Questionnaire-*Adapted* were selected based on their relevance to the study and reworded to be more inviting to the participants to respond by encouraging them to think about the services, and providers, their child has participated in (e.g., Thinking about the early intervention services your child participated in, how did you go about getting the information that was covered and presented in the sessions? How difficult, or easy, did you find participating and being involved in the sessions and why?). The prompts were revised based on the data from the survey questions to include questions based on McBride & colleagues' (2017) study on providers' perceptions of father involvement (e.g., was there a service that was more beneficial, did you find that your level of involvement in these services added to or reduced your partner's stress level, how satisfied are you with your child's service providers, and asking them to reflect on their relationship with the service providers), as well as adjusted to be used for interviews instead of focus group. By conducting an interview, it allowed the fathers to discuss their perspective, as well as provided the researcher with a deeper understanding on how the fathers view their involvement in their child's early autism services and how their level of involvement has impacted their parenting and being able to care for their child with ASD.

3.7 Data Analysis

Survey. At the conclusion of data collection, the data was downloaded from Qualtrics, an online survey program, into SPSS to organize it and conduct statistical analyses. Data from the surveys allowed the researcher to explore similarities and differences in perspectives based on demographics of the fathers that may have the potential to help early intervention professionals effectively serve and include all members of the family unit in future services. Quantitative methods (e.g., frequencies, means, and standard deviations) were implemented to describe the participant's experiences with EI services, as well as their level of involvement in those services. To explore the fathers' demographic variables, the researcher ran a frequency test on the different demographic variables. Finally, mean and standard deviations were calculated for each of the questions in the survey related to father involvement, as well as calculating the average mean for all the questions under each section to look at how fathers rated their level of involvement. The information was organized in a table to be discussed in the results section of this paper.

Interviews. The study also included an in-depth analysis for themes that emerged throughout the interviews. The researcher transcribed by hand the audio from the interviews to first identify words, phrases and events that appear to be similar and group them into like themes and expand those into like codes. The researcher and an expert in the early intervention field independently conducted thematic analyses on the open-ended responses to the three interviews. The thematic analyses were compared and discussed to ensure trustworthiness and dependability in themes and frequency of the themes within the response with 90% agreement. Participant responses are provided to support the results.

CHAPTER 4: RESULTS

The researcher gained insight into how fathers of young children with autism perceive their involvement in their child's early intervention services and answered the following research questions: 1) What are fathers' perspectives on their level of involvement in their child's services, and 2) What are the fathers' feelings when it comes to how well the service providers are doing to include them in these services? Early intervention was defined as home-visiting programs, parent-training programs, Applied Behavioral Analysis (ABA) therapy, and other services implemented to meet a child's developmental goals (e.g., speech therapy, occupational therapy, developmental play therapy, physical therapy, vision therapy or a combination of these), as well as working to meet the needs and outcomes of families, often tailored to young children with autism. The results will be discussed by exploring the quantitative and thematic analyses of the interview responses separated by the research questions.

4.1 Research Question 1: What are fathers' perspectives on their level of involvement in their child's services?

Father's involvement with their child. Fathers were asked to rate their level of agreement on how easy and difficult they found it to be involved with their child. The researcher used SPSS to run descriptive statistics on the Likert Scales (*M* and *SD*) to explore how easy and difficult they found it to be involved with their child. The results of the surveys are shown in Table 2.1. A lower Likert Scale score suggests that they did not find it difficult to be involved, while a higher Likert Scale score suggests that they did find it difficult to be involved. Overall, fathers disagreed that they found it difficult to be involved with their child (*M* = 2.58), as shown in Table 2.1 Fathers did not find it difficult to avoid caring for their child due to his/her autism diagnosis (*M*=1.50, *SD*=.972), disagreeing with their spouse's belief that the demands of their child's autism would affect their involvement (*M*=1.9, *SD*=.994). However, when it came to them rating their ability to be involved in their child's therapies due to it being too much to handle, the fathers were a bit unsure (*M*=2.90, *SD*=1.449). Additionally, when it came to how easy fathers found it to be involved with their child, a higher Likert Scale rating would show they agreed on its easiness, there was a consistent low-level agreement. The highest level of agreement was related to the fathers' knowledge of getting whatever information he may need about his child's autism diagnosis (M=3.80, SD=.919).

Table 2.1 Fathers' Involvement with their Child

		M	***SD***
It's DIFFICULT to be involved with my child because….	My spouse doesn't believe I can handle the demands of my child's Autism.	1.9	0.99
	Having a child with Autism is more difficult than I expected.	3.60	1.26
	Being involved in his/her therapies is a lot for me to handle.	2.90	1.45
	His/her Autism make me want to avoid caring for my child.	1.50	0.97
	I find myself thinking that the dreams I had for my child will probably not happen.	3.20	1.47
	Having a child with Autism has a large impact on the quality of time that we spend together.	2.70	1.42
	His/her Autism gets in the way of my relationship with my child.	2.30	1.49
	Many ideas about fatherhood have changed because I have a child with Autism.	2.80	1.62

	I do not have the energy to be able to help with my child’s therapies.	2.30	1.25
Average *M*		**2.58**	
It’s EASY to be involved with my child because…	I can handle the difficulties that come with my child’s Autism diagnosis.	3.5	0.85
	I know I am able to get whatever information I need about his/her Autism diagnosis.	3.80	0.92
	I don’t dwell on my child’s Autism diagnosis.	3.40	1.35
Average *M*		**3.57**	

Note. Likert Scale: 1=Strongly Disagree, 2=Disagree, 3=Not Sure, 4=Agree, 5=Strongly Agree

Thematic analysis of interviews. The researcher asked various questions around father’s involvement with his child with autism to better understand their experiences and to see if the information aligned with research question 1. The responses to the open-ended questions from the interviews regarding father’s perspectives to their level of involvement were grouped into two themes and then coded if necessary: *Getting Information* (i.e., mother’s role, organizations and agencies, and internet) and *Father’s Satisfaction with Services on Child’s Progress.*

Getting information. When asked how the fathers in the interviews received the information that was presented in meetings and therapy sessions, three codes emerged: mother’s role, organizations and agencies, and the internet.

Mother’s role. When looking at themes for how fathers gain information, the term *mothers* came up throughout the interviews. When it comes to the mother’s role in early intervention and sharing information, one father (A.E.) stated, *“Of course for the most part [my son] had great therapists who would explain things. Otherwise, my wife would fill me in on what I needed to know.”* Another father (B.C.) noted, *“In regard to his* *school…[mother] is more of the go-to for that because as a school teacher she knows all of the ins and outs and regulations and all of that than I do.”* Finally, a third father (L.P.) shared *“…usually my wife would share the information with me.”* These reflections align with the fact that 70% of fathers surveyed said that their child’s mother is most responsible for getting their child to and from his or her services.

Organizations and agencies. Another common theme was that organizations and agencies shared information with families. A.E. stated they had a representative *“…through the local health alliance and she was always offering us supports, and she was very good at that”*. He and his wife were also referred to a local autism society for additional support and shared *“…the* [local autism support group] *was referred as resource to help answer some of our questions.”* B.C. also shared a similar experience with a local agency saying *“…as far as gathering information, I mean so much of what we did and still do, is gathering our network of people who can advocate, who can advise. The director of Partners for Learning became one of my go-tos.”*

Internet. The internet has become a major source for families in need of information. Two of the fathers (B.C. and L.P.) noted how much they relied on the internet to provide them with information regarding their children:

> *‘The internet is in many ways a kind of support group for those with special needs children” and “So usually my wife would share the information with me, however if there was anything we needed more information on or clarity, we found ourselves by searching on the internet, reading pamphlets or asking the doctor.’*

Father’s satisfaction with services on child’s progress. One way parents rated their satisfaction was based on how much, or little, progress was made when an intervention was put into place. For the three fathers in the study they reflected on whether their child was making any progress in their therapy sessions. The fathers all stated that their child was making progress. For instance, one father (L.P.) stated, "*We are seeing improvements in his speech and of course he is starting to become more independent". Another father (A.E.) shared that they were learning strategies to help their child at home:

> *…getting us down and involved in like play therapies and behavioral therapies. You know just get us down on his level and participate, and if he is playing, watch how he is playing. …then if he gets frustrated, they have shown us different ways to handle his frustration and to cope*."

4.2 Research Question 2: What are the fathers' feelings when it comes to how well the service providers are doing to include them in these services?

Father's involvement in meetings and therapies. Fathers were asked to rate their level of agreement on how easy and difficult they found it to be involved in their child's meetings and therapies. The researcher used SPSS to run descriptive statistics (*M* and *SD*) on the Likert Scale scores to explore how easy and difficult fathers found it to be involved in their child's services. The results of the surveys are described in Table 2.2. A lower Likert Scale score suggests that they did not find it difficult to be involved, while a higher Likert Scale score suggests that they did find it difficult to be involved. When asked to rate how difficult they found it to be involved in meetings about their children, fathers disagreed (Average *M*= 2.5) they found it difficult to find the time to be involved, with a strong disagreement related to fathers feeling like they do not have a say in their child's educational/therapy meetings (*M*=2.00, *SD*=.816). Fathers also reported that they did not have a challenging time understanding the terms and topics at the meetings (*M*=2.20, *SD*=.789) and felt like professionals addressed their comments to their spouse and not to them (*M*=2.70, *SD*=1.418). Fathers in this study did not find it difficult to be involved in their child's educational and therapy meetings, did not have a hard time understanding the terms and topics of the meetings, and felt as though the professionals addressed their comments to include them in those meetings and services.

In contrast, when it came to rating how easy fathers found it to be involved in meetings and therapies about their child, fathers agreed that they found it easy to be active in their child's education (*M*=4.00, *SD*=0.471) and that meetings were arranged at a time that fits with their work schedule (*M*=3.90, *SD*=0.568). However, fathers reported mild disagreement when deciding how easy it was to be involved based on feeling very much included in the discussions (*M*=2.70, *SD*=0.949) and finding it easy to have a say in the meetings (*M*=3.10, *SD*=0.738). It is important to note that 60% of the fathers surveyed reported currently being involved in their child's early intervention services. Finally, when asked whether they attended meetings and therapies as well as a reason for not attending meetings, participants did not provide data.

Table 2.2: Fathers Involvement in Meetings and Therapies

		M	***SD***
It's DIFFICULT to be involved with the meetings about my	There are no other men at the meetings about my child's education.	3.10	1.37
	I feel like I don't have a say in educational/therapy meetings.	2.00	0.82
	I have a hard time understanding all the terms and topics at the education/therapy meetings.	2.20	0.79

child because…	Professionals at the meetings address their comments to my wife and not to me.	2.70	1.42
AVERAGE		**2.5**	
It's EASY to be involved with the meetings about my child because…	During meetings regarding my child's therapies, it is easy for me to have a say.	3.10	0.74
	During meetings regarding my child's therapies, I feel very much included in the discussions.	2.70	0.95
	I find it easy to be active in my child's education.	4.00	0.47
	Meetings with teachers are arranged at a time that fits with my work schedule.	3.90	0.57
Average		**3.42**	

Note. Likert Scale: 1=Strongly Disagree, 2=Disagree, 3=Not Sure, 4=Agree, 5=Strongly Agree

Thematic analysis of father's involvement in meetings and therapies. The responses to the open-ended questions regarding father's perspectives to their level of involvement were grouped into 4 themes and coded: *Participation in Sessions* (i.e., easy vs. difficult), *Satisfaction with Services* (i.e., positive vs. regret), *Father's Work Influences Level of Involvement*, and *Recommendations for Professionals to Include Fathers in Sessions* (i.e., technology, feedback, and encouragement).

Participation in sessions. The fathers were asked to reflect on how easy, or difficult, it was to participate and be involved in the sessions. Of the three fathers interviewed, one father found it to be easy by stating:

> *Oh easy. I am very much a hands-on guy. I want to be involved. Part of me is if there is anything I can replicate at home that is helpful, I want to be. Sometimes*

> *[my son] is difficult enough that you need back up, that one teacher, that one therapist can't do on their own. It doesn't bother me that I very much want to be hands-on. I am giving encouragement on the sidelines or maybe holding a hand out, so he can balance or center himself. Sometimes it's to crack the whip because his attention goes everywhere, and other times I am kind of just standing back to see what the teacher and the therapist is doing, trying to echo, repeating, to try and reinforce.*

In contrast, while two of the fathers interviewed said they found it difficult to participate in sessions, one said that while it was difficult, his son's school is finding ways to include him:

> *…it has been difficult, but they are great there and I really trust them. We have monthly meetings with his team to go over what he is currently working on, what we can work on at home, and just to do a check-in so-to-speak.*

Their experiences on how easy they found it to be involved in services were consistent with the information from the survey of the same question (*M*=4.00, *SD*=0.471).

Satisfaction with services. While the electronic survey asked fathers to rate their level of involvement in early intervention services, the interviews allowed them to expand upon those questions and reflect on their inclusion in services. One father (L.P.) regretted not being included in the sessions as much by saying:

> *Obviously, I definitely wish they would have included me more [in services]. I mean you would think with all of the different types of technology they have now, that they could have found a way to include me, but it is what it is, I guess.*

He also went on to state:

> *I regret it. I wanted to be more involved but couldn't because I work all of the time to be able to provide for my family (*getting emotionally upset). *My wife stays home and has taken on that responsibility, which I am grateful for, but wish I could help out more.…I was able to come for a few sessions if they were on my lunch break or at the end of the day, but that's it. I don't get paid when I am not there. Thinking about this makes me upset, honestly, that is why I am hoping that my experiences can help other people going through the same things*.

However, the other two fathers in the study stated they were satisfied with their inclusion. According to A.E.:

> *I am pretty satisfied. I have been fortunate enough to be involved. I would like to have been involved more. We did have one speech therapist who it seemed like every time we met she would only talk to my wife. Now my wife is a stay-at-home mom, but still. I would try and chime in when I could. That was a bit frustrating, but we eventually moved on from her and his next speech therapist was much better at including me in the sessions and conversations.*

B.C. noted:

> *It doesn't bother me that I very much want to be hands-on. In fact, his occupational therapist has told me specifically "don't interfere, stay out." (laughing) But I don't want to stay out. His teachers are extraordinary. I trust her, but good luck. Yeah, I want to be hands-on as much as possible.*

Father's work influences level of involvement. While all three fathers were vastly different in what they do, a common theme among the fathers in the interviews was how much their work influenced their level of involvement of meetings and therapy sessions and how they managed to make it work.

According to A.E.:

> *Well the job I had before this last one, I was able to be involved. The job I just left, which is why I am home now, I had longer work hours and wasn't able to be involved as much. That is why I am going back to my old job. It has more flexibility and will allow me to be around more.*

B.C. also noted:

> *Tag team as much as we could. Really, I have done more than she [wife] has. Part of it is the scheduling thing. My wife was a school teacher and then a media coordinator whereas her hours are very specific, whereas as a pastor, I am 24/7, my hours are a bit more flexible than hers. So, I took more on of that responsibility than she did and that is just fine, and I had that ability to do so. She has that freedom now. My job here at my new church is twice as busy as it was before, so she does the swim lessons, which I don't do, whereas normally I would do all of the above, but I just don't have time.*

L.P. had a different experience when it came to flexibility of his work:

> *I am the only one working so I was not as available to be at the sessions as I would have liked. My wife mostly took care of that. It came down to feeding my children and paying my bills versus attending meetings. Unfortunately, my work came first since I am the only one working.*

Fathers' recommendations to service providers. Finally, when asked to reflect on some ways service providers could include fathers in the future, some unexpected themes for recommendations came about from the fathers': use of technology, understanding fathers' emotions such as denial, blame and guilt, knowing it is okay to ask for help, use support systems, and encourage their involvement.

Use of technology in sessions. Two of the fathers mentioned that one way that service providers can be inclusive to fathers is by using technology in the sessions. One father stated,

> *I am very much a media guy, so maybe if the therapists can make a recording of some of the therapy sessions and then give that to the dad to show them what they are doing today, or what they have been working on for the last month. Maybe you can try that with your child at home…That may mean more for the therapist to do, but maybe they can hire a media coordinator to put that together.*

While another father suggested doing a phone conference or a video-type meeting to include fathers who are unable to attend the sessions.

Understand emotions like denial, blame, and guilt. A common theme among the fathers when asked about recommendations for future services for both service providers and fathers was to understand the emotions that come with having a child with autism. One father noted that, "*Denial is part of the process, but not a great place to hang out, especially when you know deep down that something is and has always been wrong. I was in denial for too long and I think it kept my son from getting the help he really needed.*" Another father noted that it is important not to play the blame game by reflecting, *"Know that it's not your fault. You didn't cause this. I don't think there is anything else you could do to prevent it. Accept it and move on."* Finally, it is important to know that *"guilt will drown you and we have dealt with that. You can't help but* *wonder. You just have to let that go because…if you are feeling guilty about this you are not going to be able to function.*

Ask for help. Two of the fathers interviewed agreed that asking for help was beneficial in getting through all that having a child with autism can bring. "*I would say don't be afraid to ask for help. We all need it. We can't do this alone. It will only make you stronger.*" While one of the fathers noted that it is important to move past the stereotypes that come with asking for help as a guy.

> *Don't be scared to ask for help. That is very much a guy thing. We don't like to ask for help for anything. Let go of the pride and say I need help. If you do, then you will find that there are people who want to help, and that is what shocked me this whole process is that there are people who want to be involved. When you are dealing with a special child that can be absolutely drive you crazy and stress you out, and you think no one wants to be around that, but in the end the opposite is true, people want to be involved. So, let go of the pride.*

Encourage involvement. One father (A.E.) reflected about how service providers can do more to encourage the fathers to be involved in the sessions.

> *I can imagine some fathers are stand-offish, and yeah, they love their kid, but just have them more encouraged. Hey this is your son. Be involved with what he's got going on, not only to bring him closer to him but for you to understand how he is learning and feeling.*

B.C., however reflected a different perspective based on his satisfaction from being personally involved,

> *I would not have learned these techniques had I not been personally involved in some of his therapies. I think for the dads out there this is a little bit of pride and some shaming, and maybe a cultural thing too that has to be overcome.*

Use support systems. The final recommendation to come out of the interviews was that of using support systems to help navigate the world of early intervention. When it comes to using support systems, B.C. said,

> *"Network, network, raise your army. You cannot fight every battle. Find your advocates, find the professionals, find the people you can call or text any day, whether that is to help you navigate the school system or finding the services you may need.*

CHAPTER 5: DISCUSSION

This study was designed to examine father's perspectives on their level of involvement in early autism services, as well as how they feel service providers are doing to include them in those services. It is important to emphasize that these perspectives of father involvement are from the point of view of the fathers and are based on their own perceptions and experiences. Overall, fathers felt included in those services to a degree, but still had to rely on their spouse, or the mother of their child(ren), to provide information to them. Given technology is a big part of today's lifestyle, the three fathers in the study found the information they were not receiving by doing an internet search. While times are changing, and fathers are beginning to take a more active, hands-on approach to child-rearing and being involved with their children, for the most part, they are still not as involved as mothers are in early intervention services and meetings as illustrated in Dunn, Burbine, Bowers, et al (2001), Gray (2006, 2002) and Twoy, Connolly & Novak (2007). Hearing fathers' experiences through the interviews validates that fathers found it easy to gain information they are seeking, whether it was through their spouse, a local support agency, or the internet. It is important to note that the survey question only reflected their overall easiness in gaining information. It is possible that if the survey questions would have asked more specific questions related to how easy or difficult they found it to receive information through their spouse, local support agency or the internet, the results may have looked differently and been more reflective of the fathers' personal experiences.

Father's Satisfaction with Services and Child's Progress. When fathers were asked about the difficulty for which they found it for them to be involved with their child in his/her interventions based on various factors (i.e., autism gets in the way of relationship, spouse's belief in handling issues, being involved is too much to handle) the majority of the fathers did not find it difficult to be involved with their child in his or her interventions (e.g., fathers find it easy to be active in their child's services, M=4.00, SD=.47), which contradicts Sharpley's (1997) findings that fathers communicate less confidence about responding to their child's challenging behaviors. Fathers noted that they were learning hands-on strategies and *"learning different ways to handle his [son's] frustrations and cope,"* while another father mentioned that he is "*seeing improvements in his speech and of course he is starting to become more independent."* The fathers' experiences on learning strategies to care for their child is consistent with the information from the survey on disagreeing with finding it difficult to care for their child with autism leading to more self-efficacy, as evidenced in Foster, Dunn & Lawson (2013).

Father's Work Influences vs. Father's Employers Influence on Level of Involvement. Several studies have shown that a major barrier to fathers' limited involvement is due to their increased work demands (Flippin & Crais, 2011; McBride et. al., 2016). According to the quantitative analysis of father's involvement, the fathers in this study agreed that they found it easy to be involved in their child's meetings and therapies and that they were scheduled at a time that was convenient for them. The interviews helped bring to light how the father's line of work influenced their level of involvement. One father, a pastor, credited his work as allowing him some flexibility in attending his son's therapy sessions, and even allowed him the chance to *"network to* *figure out the five services that were available [when choosing where to move to]. I consider myself lucky."* Another father, a mechanic, noted that his former place of employment was not very flexible, and he was in the process of going back to a previous place of employment, so he could have the flexibility. Finally, a third father who works in construction, discussed that while his supervisor was supportive in his needing to be at meetings, his position did not allow him the flexibility. He noted, "*He allowed me, and even understood, that sometimes I needed to be there. But again, I didn't get paid when I was there, so I was sacrificing getting paid to what, watch my son in a therapy session.*

The findings of this study suggest that while fathers are aware that their work schedules can prevent them from being involved, it should not be the reason service providers do not attempt to include them in those services, either during or as a follow-up. While the experiences were individual to each father, they did not necessarily reflect the results of the survey data when asked how easy it was to attend meetings arranged at a time that fits with their work schedule. McBride & colleagues (2016) noted that fathers were unavailable due to their work schedules, while noting a disconnect exists between providers and fathers because EI service providers may have limited understanding of effective strategies for engaging fathers. Trivette & Dunst (2006) noted that to ensure full collaboration, professionals have a significant responsibility to share all relevant information in a way that matches the family's style of understanding, while the fathers in this study, however suggested several recommendations for getting service providers to include them in services (e.g., including technology in sessions, being aware of emotions fathers may struggle with, and encouraging engagement).

Trustworthiness. The researcher implemented numerous strategies to enhance the credibility of data obtained through this study by engaging in prolonged engagement with the fathers, triangulating the data, providing thick descriptions, peer debriefing, and finally researcher reflection. Prolonged engagement was done when the researcher spent at least one and a half hours with the fathers (e.g., pre-interview screenings, reminders of the interviews, and getting to know the fathers prior to the interview) which allowed the researcher to check their perspectives and feel comfortable with the researcher. Triangulation was used to design the interview questions through the literature (Flippin & Crais, 2011; Ly and Goldberg, 2013; McBride et. al., 2016) and to create culturally respectful interview questions. It was also established by using the interviews to help interpret the survey results. Peer briefing was established by having the interviews examined and then discussed with a member of the research team. The research team member has a PhD in early childhood special education whose research expertise included families of children with disabilities. Additionally, she has over 35 years of professional experience in the field. Results of the survey research were not disclosed prior to analyzing the transcripts and independently developing codes and themes from the data. Both researchers then discussed the themes and came to a consensus on the most relevant themes reflected in interview data. The researcher provided thick descriptions of the study procedures and used verbatim language to illustrate the father’s experiences. Finally, the researcher was able to use this experience to reflect on her own educational and professional background and personal ties to the autism community and how it can influence the data. The researcher did as much to remove her biases by making sure the fathers involved had no personal ties to the researcher which also allowed her to interpret the data objectively. However, it is believed that the researcher’s personal experience of being parent of a child with autism helped gain the trust of the fathers and allowed them to open up and share their experiences using raw emotion.

5.1 Limitations of Study

This study had a number of limitations which are important to discuss: age of children, non-English speaking families were excluded, low participation rate, this was a sample of convenience and there was no member-checking. The aim of the current study was to explore services that focused on young children with autism between the ages of 2 and 6 years of age. One part of the exclusion criteria was that fathers were asked if their child was diagnosed with autism, and then if their child was between the ages of 2-6. For those fathers who answered “no” they were excluded, however for those fathers who answered “yes” they were then asked to provide what age their child was diagnosed with autism. 50% of the fathers answered that their child was diagnosed earlier than 2 years of age. Therefore, by extending the study to include those children with a diagnosis at 18 months of age, it could have allowed for a higher participation rate in the study.

Currently the autism rate among Hispanic families has increased 110% (Center for Disease Control, 2016). Possible explanations include the fact that Hispanic children are much less likely than non-Hispanic Whites to have health insurance, 3 times as likely to live in households that fall below the poverty line, twice as likely to lack a regular source of medical care, and 1.3 times as likely to experience difficulty accessing specialty care, suggesting that autism could be underdiagnosed in Hispanic children (Palmer, R., Walker, T., Mandell, D., Bayles, B., & Miller, C., 2010). By only gathering data from those fathers who were able to speak English, this tightened the criteria for who could participate. As such, an implication for future research could be to look solely at Hispanic father's as interviewees' perspectives to better understand their experiences.

It was very important to use fathers as the focus for this study. As previously mentioned, the researchers were aware that fathers were going to be a hard to reach group of fathers, and that the response level would be low for this population (Johnson & Simpson, 2013; Flippin & Crais, 2011). Due to the small sample size of this study it is cautionary to generalize findings. While fathers may not be as involved in services and meetings as much as they would like due to work schedules, it is hopeful that their perspectives will provide implications to the field of early intervention and how service providers can do more to include them in those services.

The researcher used a sample of convenience to help recruit fathers from one region of the country where there are multiple resources for a child with ASD. The researcher reached out to several early intervention agencies that served families and young children with autism through her own contacts. This prevented the researcher from hearing perspectives across multiple regions and being able to generalize the findings; instead results reflected the experiences of those fathers in this specific region. While the fathers had to answer several exclusion questions to move forward with the survey, it was impossible to monitor who was answering the questions and if they were authentic, leaving the sampling error high. However, it was important to use this method, given that this is a hard-to-reach population, and we were looking for fathers who met certain criteria.

Finally, even while the fathers' responses were recorded and transcribed verbatim, a limitation to this study was that there was no member-checking done with the fathers to follow up on their responses to the interviews and to make sure their experiences were accurately depicted, due to time constraints. A second-round of data collection was conducted to increase the number of survey respondents. This limited the amount of time between data collection and analysis to participate in a member check of the interviewees. Future studies should provide more time between final data collection and analysis to reconnect with the fathers. Also, the fathers' involvement with member checking could have helped make sure that their thoughts, emotions and experiences were accurately conveyed.

5.2 Implications for Future Studies

There are several implications from the current study to guide future research and practice. Future research should be conducted to study father's involvement across various cultures, especially in the Hispanic culture, where autism is rapidly increasing. Another implication would be to do a comparison among several types of services (e.g. speech therapy, ABA, in-home vs. clinical therapy, etc.) to see where father involvement is higher and look at what strategies and approaches the service providers are using to include fathers. While the recommendations are valuable, they only work if service providers are aware of the needs of fathers and how to best meet those needs. Everyone uses technology in some form today, so it would be helpful to explore how using technology, and which forms of technology can be most helpful, to include fathers when they cannot physically be in attendance and provide them with the resources and information they need.

To summarize the results of this study, fathers' perspectives on their level of involvement were individualized and subjective. While the fathers who completed the electronic survey illustrated less difficulty and more easiness in rating their involvement in early autism services, the interviews, which provided more insight into their experiences, found that for those who had job flexibility, they were able to be more involved. For the father who had to choose between his job and being involved with his child, he found himself regretting not being involved more and wished he had. Overall, the fathers in the interview were satisfied with service providers including them in services and meetings and agreed that they were learning strategies to help their child's overall development. The fathers also reflected that more could be done to include them, such as incorporating technology into the sessions, encouraging involvement, and being aware of fathers' emotions and how that could get in the way of involvement. The insights provided by this study have important implications for what service providers could do to help better support fathers in being more involved in EI.

REFERENCES

References marked with an asterisk (*) indicate studies included in a meta-analysis.

Able-Boone, H. (1993). Family participation in the IFSP process. *Infant-Toddler Intervention*, *3*, 63-71

Ainsworth, M. (1967). *Infancy in Uganda: Infant care and the growth of love*. Baltimore, MD: Johns Hopkins University Press.

Allen, R. & Petr, C. (1998). Rethinking family-centered practice. *American Journal of Orthopsychiatry*, *68,* 4–15. doi:10.1037/h0080265

Bailey, D. B. J., Bruder, M. B., Hebbeler, K., Carta, J., Defosset, M., Greenwood, C., Kahn, L., Barton, L. (2006). Recommended outcomes for families of young children with disabilities. *Journal of Early Intervention, 28*, 4, 227-251

*Baker-Ericzen, M. J., Brookman-Frazee, L., & Stahmer, A. (2005). Stress levels and adaptability in parents of toddlers with and without autism spectrum disorders. *Research & Practice for Persons with Severe Disabilities*, *30*, 194-204

Bandura, A. (1994). Self-efficacy. In V. S. Ramachaudran (Ed.), *Encyclopedia of human behavior*, *4* (pp. 71–81). New York: Academic Press.

Bandura, A. (1997). Self-efficacy: The exercise of control. New York: Freeman

Baranek, G., Barnett, C., Adams, E., Wolcott, N., Watson, L., & Crais, E. (2005). Object play in infants with autism: Methodological issues in retrospective video analysis. *American Journal of Occupational Therapy*, *59*, 20-30

Biller, H.B. (1993). Fathers and families: Paternal factors in child development. Westport, CT: Auborn House.

Bowlby, J. (1951). *Maternal care and mental health*. Geneva: World Health Organization

Brady, K. L., & Eisler, R. M. (1999). Sex and gender in the college classroom: A quantitative analysis of faculty-student interactions and perceptions. *Journal of Educational Psychology*, *91*, 127-145

*Brobst, J. B., Clopton, J. R., & Hendrick, S. S. (2009). Parenting children with autism spectrum disorders: The couple's relationship. *Focus on Autism and Other Developmental Disabilities*, *24*, 38-49.

*Brookman-Frazee, L. (2004). Using parent/clinician partnerships in parent education programs for children with autism. *Journal of Positive Behavior Interventions, 6*, 195-213.

Bronfenbrenner, U. (1975). Is early intervention effective? In B. Z. Friedlander, G. M. Sterritt, & G. E. Kirk (Eds.) *Exceptional infant: Assessment and Intervention, 3,* 449-475 New York: Brunner/Mazel

Bronfenbrenner, U. (1979). *The ecology of human development*. Cambridge, MA: Harvard University Press.

Bruder, M. B. (2000). Family-centered early intervention: Clarifying our values for the new millennium. *Topics in Early Childhood Special Education*, *20*, 105-115.

Bureau of Labor Statistics. (2012). *The economics daily: Happy mother's day from BLS: Working mothers in 2012* (U.S. Department of Labor). Retrieved from http://www.bls.gov/opub/ted/2013/ted_20130510. html

Casby, M. W. (1991). Symbolic play I: A developmental framework. *Infant-Toddler Intervention*, *1*, 219-232.

Charman, T., Baron-Cohen, S., Swettenham, J., Baird, G., Drew, A., & Cox, A. (2003). Predicting language outcome in infants with autism and pervasive developmental disorders. *International Journal of Language and Communication Disorders*, *38,* 265-285.

Cheuk, S., & Lashewicz, B. (2016). How are they doing? Listening as fathers of children with autism spectrum disorder compare themselves to fathers of children who are typically developing. *Autism, 20*(3), 343-352. doi:10.1177/1362361315584464

Clarke-Stewart, K. A. (1980). The father's contribution to children's cognitive and social development in early childhood. In F. A. Pedersen (Ed.), *The father-infant relationship: Observational studies in the family setting* (pp. 111-146). New York, NY: Praeger.

Crais, E., Poston Roy, V., & Free, K. (2006). Parents' and professionals' perceptions of the implementation of family-centered practices in child assessments. *American Journal of Speech-Language Pathology*, *15,* 365377.

Cox, M. J., Owen, M. T., Henderson, V. K., & Margand, N. (1992). The prediction of infant-father and infant-mother attachment. *Developmental Psychology, 28*,474-483.

*Dabrowska, A., & Pisula, E. (2010). Parenting stress and coping styles in mothers and fathers of pre-school children with autism and Down syndrome. *Journal of Intellectual Disability Research, 54*, 266-280.

DeGrace, B. W. (2004). The everyday occupation of families with children with autism. *American Journal of Occupational Therapy, 58,* 543–550. http://dx.doi.org/10.5014/ajot.58.5.543

Dumas, J., Wolf, L., Fisman, S., & Culligan, A. (1991). Parenting stress, child behavior problems, and dysphoria in parents of children with autism, Down syndrome, behavior disorders, and normal development. *Exceptionality, 2*, 97-110.

Dunn, M. E., Burbine, T., Bowers, C., et al. (2001). Moderators of stress in parents of children with autism. *Community Mental Health Journal,* 37(1), 39-52.

Dunst, C., Leet, H., & Trivette, C. (1988). Family resources, personal well-being, and early intervention. *Journal of Special Education*, *22,* 108-116

Easter Seals. (2009). Easter Seals Living with Autism study. Retrieved from http://www.easterseals.com/site/PageServer?pagename=ntlc8 living with autism study home

*Elder, J. H., Valcante, G., Won, D., & Zylis, R. (2003). Effects of in-home training for culturally diverse fathers of children with autism. *Issues in Mental Health Nursing, 24,* 273-295.

*Elder, J. H., Valcante, G., Yarandi, H., White, D., & Elder, T. H. (2005). Evaluating in-home training for fathers of children with autism using single-subject experimentation and group analysis methods. *Nursing Research*, *54*, 22-32.

*Epstein, T., Saltzman-Benaiah, J., O’Hare, A., Goll, J. C., & Tuck, S. (2008). Associated features of Asperger syndrome and their relationship to parenting stress. *Child Care Health & Development*, *34*, 503-511.

Flippin, M., & Crais, E. (2011). The need for more effective father involvement in early autism intervention: A systematic review and recommendations. *Journal of Early Intervention, 33*(1), 24-50. doi:10.1177/1053815111400415

Foster, L., Dunn, W., & Lawson, L. M. (2013). Coaching mothers of children with autism: A qualitative study for occupational therapy practice. *Physical and Occupational Therapy in Pediatrics, 33,* 253–263. http://dx.doi.org/ 10.3109/01942638.2012.747581

*Giallo, R., Wood, C. E., Jellett, R., & Porter, R. (2013). Fatigue, wellbeing and parental self-efficacy in mothers of children with an autism spectrum disorder. *Autism, 17,* 465–480. http://dx.doi.org/10.1177/1362361311416830

Gray, D. E. (2002). Ten years on: a longitudinal study of families of children with autism. *Journal of Intellectual & Developmental Disability,* 27(3): 215-222

*Gray, D. E. (2003). Gender and coping: The parents of children with high functioning autism. *Social Science & Medicine, 56*(3), 631-642

Gray, D. E. (2006). Coping over time: the parents of children with autism. *Journal of Intellectual Disability Research,* 50(12): 970-976

Grossman, H., & Grossman, S. H. (1994). *Gender issues in education*. Needham Heights, MA: Allyn & Bacon.

Harry, B. (1997). Leaning forward or bending over backwards: Cultural reciprocity in working with families. *Journal of Early Intervention, 21,* 62–72.

*Hartley, S. L., Barker, E. T., Seltzer, M. M., Greenberg, J., Bolt, D., Floyd, F., & Orsmond, G. (2010). The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Journal of Family Psychology, 24,* 449-457.

*Hastings, R. P. (2003). Child behavior problems and partner mental health as correlates of stress in mothers and fathers of children with autism. *Journal of Intellectual Disability Research, 47,* 231-237.

Hastings, R. P., & Brown, T. (2002). Behavior problems of children with autism, parental self-efficacy, and mental health. *American Journal of Mental Retardation, 107,* 222–232. http://dx.doi.org/10.1352/08958017(2002)107<0222:BPOCWA>2.0.CO;2

*Hastings, R. P., Kovshoff, H., Brown, T., Ward, N. J., Espinosa, F. D., & Remington, B. (2005). Coping strategies in mothers and fathers of preschool and school-age children with autism. *Autism: The International Journal of Research & Practice, 9*, 377-391.

Hastings, R. P., Kovshoff, H., Ward, N. J., Espinosa, F. D., Brown, T., & Remington, B. (2005). Systems analysis of stress and positive perceptions in mothers and fathers of pre-school children with autism. *Journal of Autism and Developmental Disorders*, *35,* 635-644.

Hebbeler, K., Spiker, D., Baily, D., Scarborough, A., Mallik, S., Simeonsson, R., Nelson, L. (2007). *Early intervention for infants and toddlers with disabilities and their families: Participants, services, and outcomes*. Menlo Park, CA: Stanford Research Institute International.

*Herring, S., Gray, K., Taffe, J., Tonge, B., Sweeney, D., & Einfeld, S. (2006). Behavior and emotional problems in toddlers with pervasive developmental disorders and developmental delay: Associations with parental mental health and family functioning. *Journal of Intellectual Disability Research*, *50,* 874-882.

Jarrold, C., Boucher, J., & Smith, P. K. (1993). Symbolic play in autism: A review. *Journal of Autism and Developmental Disorders*, *23*, 281-387.

Johnson, N., & Simpson, P. (2013). Lack of father involvement in research on children with autism spectrum disorder: Maternal parenting stress and family functioning. *Issues in Mental Health Nursing,* 34, 4, 220-8.

Jones, T. L., & Prinz, R. J. (2005). Potential roles of parental self-efficacy in parent and child adjustment: A review. *Clinical Psychology Review*, *25*, 341–363. http://dx.doi. org/10.1016/j.cpr.2004.12.004

Jordan, R., & Libby, S. (1997). Developing and using play in the curriculum. In S. Powell & R. Jordan (Eds.), *Autism and learning: Guide to good practice* (pp. 28-45). London, UK: David Fulton.

Karst, J. S., & Van Hecke, A. V. (2012). Parent and family impact of autism spectrum disorders: A review and proposed model for intervention evaluation. *Clinical Child and Family Psychology Review*, *15*, 247–277. http://dx.doi.org/10.1007/s10567-012-0119-6

Keller D. & Honig A. S. (2004) Maternal and paternal stress in families with school-aged children with disabilities. *American Journal of Orthopsychiatry, 74***,** 337–48. doi:10.1037/0002-9432.74.3.337.

Koegel, R., Schreibman, L., Loos, L., Dirlich-Wilhelm, H., Dunlap, G., Robbins, F., & Plienis, A. J. (1992). Consistent stress profiles in mothers of children with autism. *Journal of Autism and Developmental Disorders*, *22*, 205-215.

Konstantareas, M. M., Mandel, L., & Homatidis, S. (1988). The language patterns mothers and fathers employ with their autistic boys and girls. *Applied Psycholinguistics*, *9*, 403-414.

Kotelchuck, M. (1976). The infant’s relationship to the father: experimental evidence. In M. E. Lamb (Ed.), *The role of the father in child development* (1st ed., pp. 329-344). New York: Wiley.

Kuhaneck, H. M., Burroughs, T., Wright, J., Lemanczyk, T., & Darragh, A. R. (2010). A qualitative study of coping in mothers of children with an autism spectrum disorder. *Physical and Occupational Therapy in Pediatrics, 30*, 340–350. http://dx.doi.org/10.3109/01942638.2010.481662

Kuhaneck, H. M., Madonna, S., Novak, A., & Pearson, E. (2015). Effectiveness of interventions for children with autism spectrum disorder and their parents: A systematic review of family outcomes. *American Journal of Occupational Therapy*, *69*(5), 1-14. doi:10.5014/ajot.2015.017855

Kuhn, J. C., & Carter, A. S. (2006). Maternal self-efficacy and associated parenting cognitions among mothers of children with autism. *American Journal of Orthopsychiatry*, *76*, 564–575. http://dx.doi.org/10.1037/0002-9432.76.4.564

Lakey, B. (2010). Social support: Basic research and new strategies for intervention. In J.E.Maddux& J.P.Tangney(Eds.), *Social psychological foundations of clinical psychology* (pp. 177–194). New York, NY: Guilford.

Lakey, B., & Cohen, S. (2000). Social support theory and measurement. In S. Cohen, L. Underwood, & B. Gottlieb (Eds.), *Social support measurement and intervention* (pp. 29–52). Oxford, England: Oxford University Press.

Lakey, B., & Cronin. A. (2008). Low social support and major depression: Research, theory and methodological issues. In K.S. Dobson & D. Dozois (Eds.), *Risk factors for depression* (pp 385-408). San Diego, CA: Academic.

Lamb, M. E. (1977a). The development of mother–infant and father–infant interactions in the second year of life. *Developmental Psychology*, *13*, 637–648.

Lamb, M. E. (1977b). Mother–infant and father–infant interaction in the first year of life. *Child Development*, *48*, 167–181.

Lamb M. E., Pleck J. H., Charnov E. L. & Levine J. A. (1987) A biosocial perspective on paternal behavior and involvement. In: *Parenting across the Lifespan: Biosocial Perspectives* (eds J. B. Lancaster, J. Altman, A. Rossi

Lamb, M. E. (Ed.). (2004). *The role of the father in child development*. John Wiley & Sons.

Lamb, M. E., & Lewis, C. (2010). The development and significance of father–child relationships in two parent families. In M. E. Lamb (Ed.), *The role of the father in child development* (5th ed., pp. 94–153). Hoboken, NJ: Wiley.

Larson, E. (2006). Caregiving and autism: How does children’s propensity for routinization influence participation in family activities? *OTJR: Occupation, Participation and Health*, *26*, 69–79. http://dx.doi.org/10.1177/153944920602600205

Lazarus, R. S. (1999). *Stress and emotion: A new synthesis*. New York, NY: Springer

Libby, S., Powell, S., Messer, D., & Jordan, R. (1998). Spontaneous play in children with autism: A reappraisal. *Journal of Autism and Developmental Disorders*, *28*, 487-499.

Lifter, K., Sulzer-Azaroff, B., Anderson, S., & Cowdery, G. E. (1993). Teaching play activities to preschool children with disabilities: The importance of developmental considerations. *Journal of Early Intervention*, *17*, 139-159.

*Little, L. (2002). Differences in stress and coping for mothers and fathers of children with Asperger's syndrome and nonverbal learning disorders. *Pediatric Nursing*, *28*, 565-570.

Ly, A. R., & Goldberg, W. A. (2013). New measure for fathers of children with developmental challenges. *Journal of Intellectual Disability Research, 58*(5), 471-484. doi:10.1111/jir.12044

Macfadyen, A., Swallow, V., Santacroce, S., & Lambert, H. (2011). Involving fathers in research. *Journal for Specialists in Pediatric Nursing*, *16*(3), 216–219.

Mcbride, B. A., Curtiss, S. J., Uchima, K., Laxman, D. J., Santos, R. M., Weglarz-Ward, J., Dyer, J., Jeans, L., Kern, J. (2017). Father involvement in early intervention. *Journal of Early Intervention,* 105381511668611. doi:10.1177/1053815116686118

McCubbin, H. I., Thompson, A., & McCubbin, M. A. (1996). *Family assessment: Resiliency coping and adaptation—inventories for research and practice*. Madison, WI: University of Wisconsin System

McCune, L. (1995). A normative study of representational play at the transition to language. *Developmental Psychology*, *31*, 198-206.

Meadan, H., Halle, J. W., & Ebata, A. T. (2010) Families with children who have autism spectrum disorders: stress and support. *Council for Exceptional Children,* 77(1), 7-36.

Meadan, H., Stoner, J. B., & Angell, M. E. (2015). Fathers of children with autism: perceived roles, responsibilities, and support needs. *Early Child Development and Care, 185*(10), 1678-1694. doi:10.1080/03004430.2015.1019876

Minuchin, P. (1985). Families and individual development: Provocations from the field of family therapy. *Child Development, 56*, 289-302.

*Moes, D., Koegel, R., Schreibman, L., & Loos, L. M. (1992). Stress profiles for mothers and fathers of children with autism. *Psychological Reports, 71*, 1272-1274.

Mundy, P., Sigman, M., Ungerer, J., & Sherman, T. (1987). Nonverbal communication and play correlates of language development in autistic children. *Journal of Autism and Developmental Disorders*, *17,* 349-364.

Murray, J., & McDonald, L., (1996). Father involvement in early intervention programs: Effectiveness, obstacles, and considerations. *Developmental Disabilities Bulletin, 24*(2) 47-57.

*Olsson, M. B., & Hwang, C. P. (2001). Depression in mothers and fathers of children with intellectual disability. *Journal of Intellectual Disability Research*, *45*, 535-543.

*Ornstein Davis, N., & Carter, A. S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations and child characteristics. *Journal of Autism and Developmental Disorders*, *38*, 1278-1291.

Osborne, L. A., McHugh, L., Saunders, J., & Reed, P. (2008). Parenting stress reduces the effectiveness of early teaching interventions for autistic spectrum disorders. *Journal of Autism and Developmental Disorders*, *38*, 1092-1103.

Palm, G. (2014). Attachment theory and fathers: Moving from "being there" to "being with". *Journal of Family Theory and Review, 6*, 282-297. doi:10.1111/jftr.12045

Palmer, R. F., Walker, T., Mandell, D., Bayles, B., & Miller, C. S. (2010). Explaining Low Rates of Autism Among Hispanic Schoolchildren in Texas. *American Journal of Public Health*, *100*(2), 270–272. http://doi.org/10.2105/AJPH.2008.150565

Pancsofar, N., & Vernon-Feagans, L. (2006). Mother and father language input to young children: Contributions to later language development. *Journal of Applied Developmental Psychology, 27,* 571-587.

Paquette, D., & Bigras, M. (2010). The risky situation: A procedure for assessing the father–child activation relationship, *Early Child Development and Care, 180*, 33–50.

Parke, R., & Swain, D. (1975). Infant characteristics and behavior as elicitors of maternal and paternal responsiveness in the newborn period. Paper presented at the meeting of the Society for Research in Child Development, Denver, CO

Parish, S. L., & Cloud, J. M. (2006). Financial well-being of young children with disabilities and their families. *Social Work*, *51*, 223-232. doi:10.1093/sw/51.3.223

Pleck J. H. (2007) Why could father involvement benefit children? Theoretical perspectives. *Applied. Developmental Science 45***,** 1–7. doi: 10.1080/10888690701762068.

Pleck J. H. (2012) Integrating father involvement in parenting research. *Parenting, 12,* 243–53. doi: 10.1080/ 15295192.2012.683365.

*Pleck, J., & Masciadrelli, B. (2004). Paternal involvement in U.S. residential fathers: Levels, sources, and consequences. In M. Lamb (Ed.), *The role of the father in child development* (4th ed., pp. 222-271). New York, NY: John Wiley.

*Polmanteer, K., & Turbiville, V. (2000). Family-responsive individualized family services plans for speech language pathologists. *Language, Speech and Hearing in Schools, 31,* 4-14.

Pruett, K. D. (1997). How men and children affect each other's development. *Zero to Three, 18*(1), 3-11

*Raikes, H. A., & Thompson, R. A. (2005). Efficacy and social support as predictors of parenting stress among families in poverty. *Infant Mental Health Journal, 26,* 177–190. http://dx.doi.org/10.1002/imhj.20044p

*Rocha, M. L., Schreibman, L., & Stahmer, A. C. (2007). Effectiveness of training parents to teach joint attention in children with autism. *Journal of Early Intervention*, *29,* 154-172.

Rodrigue, J., Morgan, S., & Geffken, G. (1992). Psychological adaptation of fathers of children with autism, down syndrome and normal development. *Journal of Autism and Developmental Disorders, 22*, 249-263.

Rump, M. (2002). Involving fathers of young children with special needs. *Young Children*, 57(6), 18-20.

Sanders J. L. & Morgan S. B. (1997) Family stress and adjustment as perceived by parents of children with autism or down syndrome: Implications for intervention. *Child & Family Behavior Therapy 19*, 15–32.

Schaaf, R. C., Toth-Cohen, S., Johnson, S. L., Outten, G., & Benevides, T. W. (2011). The everyday routines of families of children with autism: Examining the impact of sensory processing difficulties on the family. *Autism, 15,* 373–389. http://dx.doi.org/10.1177/1362361310386505

Schaffer, H. R., & Emerson, P. E. (1964). The development of social attachments in infancy. *Monographs of the Society for Research in Child Development, 29,* Ann Arbor, MI: Society for Research in Child Development.

Seligman, M., & Darling, R. (1989). *Ordinary families, special children: A systems approach to childhood disability*. New York: Guilford Press.

Shannon, J. D., Tamis-LeMonda, C. S., London, K., & Cabrera, N. (2002). Beyond rough and tumble: Low-income fathers' interactions and children's cognitive development at 24 months. *Parenting: Science and Practice, 2*, 77-104.

*Sharpley, C. F., Bitsika, V., & Efremidis, B. (1997). Influence of gender, parental health, and perceived expertise of assistance upon stress, anxiety, and depression among parents of children with autism. *Journal of Applied Research in Intellectual Disabilities, 21*: 174-182.

Siller, M., & Sigman, M. (2002). The behaviors of parents of children with autism predict the subsequent development of their children's communication. *Journal of Autism and Developmental Disorders*, *32*, 77-89.

Siller, M., & Sigman, M. (2008). Modeling longitudinal change in the language abilities of children with autism: Parent behaviors and child characteristics as predictors of change. *Developmental Psychology, 44*, 1691-1704.

*Symon, J. B. (2005). Expanding interventions with children with autism: Parents as trainers. *Journal of Positive Behavior Interventions*, *7*, 159-173.

Tamis-LeMonda, C. S., Shannon, J. D., Cabrera, N. J., & Lamb, M. E. (2004). Fathers and mothers at play with their 2 and 3-year-olds: Contributions to language and cognitive development. *Child Development*, *75*, 1806-1820.

*Tehee, E., Honan, R., & Hevey, D. (2009). Factors contributing to stress in parents of individuals with autistic spectrum disorders. *Journal of Applied Research in Intellectual Disabilities, 22*, 34-42.

Toth, K., Munson, J., Meltzoff, A. N., & Dawson, G. (2006). Early predictors of communication development in young children with autism spectrum disorder: Joint attention, imitation, and toy play. *Journal of Autism and Developmental Disorders*, *36*, 993-1005.

Trivette, C., & Dunst, C. (2005). DEC recommended practices: Family-Based Practices. In *DEC Recommended Practices in early intervention/early childhood special education,* (pp. 107-112).

Turnbull, A. P., Summers, J. A., Brotherson, M. J., & University of Kansas. (1984). *Working with families with disabled members: A family systems approach*. Lawrence, Kan.: Research & Training Center on Independent Living, University of Kansas.

Turnbull, A., Turnbull, R., Erwin, E., Soodak, L., & Shogren, K. (2011). *Families, professionals, and exceptionality: Positive outcomes through partnerships and trust* (6th ed.). Upper Saddle River, NJ: Merrill/Prentice Hall.

*Twoy, R., Connolly, P. M., & Novak, J. M. (2007) Coping strategies used by parents of children with autism. *Journal of the American Academy of Nurse Practitioners,* 19(5): 251-260.

Ungerer, J. A., & Sigman, M. (1984). The relation of play and sensorimotor behavior to language in the second year. *Child Development*, *55,* 1448-1455.

U.S. Department of Education. (2007). 25-year history of the IDEA. http://www2.ed.gov/policy/speced/leg/idea/history.html

Williams, E., Reddy, V., & Costall, A. (1996). Taking a closer look at functional play in children with autism. *Journal of Autism and Developmental Disorders*, *31*, 67-77.

Wolchik, S. A. (1983). Language patterns of parents of young autistic and normal children. *Journal of Autism and Developmental Disorders*, *13*, 167-180.

APPENDIX A: RECRUITMENT FLYER

Fathers Wanted for a Research Study!

You are invited to participate in a research study! This two part study is looking to understand fathers' experiences with their level of involvement with their child's early Autism intervention services.

What Will We Do?

You will be asked a series of questions during a 20 minute online survey. You can receive a $50 Amazon gift card by participating in a follow up interview to further discuss your experiences. You can participate in one or both parts of the study. We will ask you about:

- Your child's Autism diagnosis and services
- Your experiences of parenting a child with Autism
- Your level of involvement in your child's therapies

Who Can Participate?

Fathers who:

1. Are at least 18 years of age.
2. Have a child 2-6 year of age with an Autism diagnosis
3. Have a child currently enrolled in an early intervention program or,
4. Have a child who was enrolled in an early intervention program within the past 18 months.

How Can I Participate?

Contact one of the following researchers leading the project:

Mrs. Chelsea Gooden,
University of North Carolina Charlotte
Email: cgooden3@uncc.edu
Phone: 704-402-4631

Dr. JaneDiane Smith,
University of North Carolina Charlotte
Email: jdianesm@uncc.edu
Phone: 704-687-8850

UNC CHARLOTTE
Cato College of Education

APPENDIX B: EMAIL TO PARTICIPATING AGENCIES

Date
Dear [Agency Contact]

I hope this email finds you well. My name is Chelsea Gooden and I am a student at UNC Charlotte. I am currently earning my Master's Degree in Education: Child and Family Studies and am in the ECSEL (Early Childhood Special Education Leaders) Grant program, a grant funded by the US Department of Education geared towards individuals in the field of special education and early intervention. I am beginning the final phase of my graduate program, and I would like to ask for your support completing my study. I am doing my thesis project on father's perspectives on their level of involvement in early autism services. Research shows that fathers are underrepresented in studies, as well as intervention services tailored to their child with autism. Part of my research is to collect data on the perspectives of fathers with respect to their level of involvement, through survey research. I am hoping to use the information from my study to help service providers and Early Interventionists better serve all members in the family in meeting outcomes and goals. The criteria to participate is: (a) fathers (Biological, step-father, grandparent, foster parent, or adoptive) of young children, ages 2-6, with a diagnosis of autism, (b) child is currently enrolled in early autism services, or (c) child was enrolled in early autism services no more than 18 months ago, (d) live in the Charlotte and surrounding areas, and (e) speak English.

I would appreciate the opportunity to speak with you about getting my survey out to some of your families. I will send out a flyer and a link to the online questionnaire via email with the hopes you will email the link out to the families you serve. The questionnaire should take less than 20 minutes to complete. Participation is voluntary, and all data gathered will be confidential. I am happy to share the link to the questionnaire upon request. Please feel free to contact me at cgooden3@uncc.edu, or my committee chair, Dr. JaneDiane Smith at jdianesm@uncc.edu should you have any questions or concerns.

If this is something you would be interested in, please let me know and we can arrange a meeting and/or time to discuss this. My data collection is going to start in September 2017, so there is some time to get it out. Thank you for your time and consideration, and I look forward to hearing from you as soon as possible.

Sincerely,
Chelsea Gooden
M.Ed. Candidate, UNC-Charlotte
Cgooden3@uncc.edu
Dr. JaneDiane Smith
Special Education & Child Development
Associate Professor, UNC-Charlotte

jdianesm@uncc.ed

APPENDIX C: LETTER OF SUPPORT

[Company Letterhead]

[Date]
Dear Mrs. Gooden,

We are happy to support you in your current research project exploring *Father's Perspectives on Their Level of Involvement in Early Autism Services*. We understand that in order to collect data for your research you will need to recruit participants to complete your online survey. We are willing to help you with your recruitment by distributing your surveys to our families via email in accordance with our company's protocol in doing so (for example: providing you with email addresses of families we feel fit your criteria, posting a link to your survey on our website/social media accounts, sharing your flyer and survey link with our staff members to share with the families they serve, and/or a combination of each of these if applicable), in the time frame you have requested for the current study. We also understand that all participants' personal information will be kept confidential and only used for the purpose of this study. It is our hope that the information provides you with sufficient data, and we are able to learn from this study as well.

Please let us know how we can be of further assistance.

Sincerely,

[Agency Contact]

APPENDIX D: Fathers of Children with Developmental Challenges (FCDC) Questionnaire-*Adapted*

Informed Consent

You are invited to participate in a study being conducted by Mrs. Chelsea Gooden, a UNC Charlotte Master of Education Candidate in the Department of Special Education and Child and Family Development. The purpose of the study is to gain insight from fathers like you about your perceptions on your level of involvement in your child's early autism interventions and how you perceive service providers are doing in including you in early intervention services. Many children with an Autism Spectrum Disorder (ASD) may participate in early intervention services to help meet the needs and goals of the child and family. These services are usually lead by a service coordinator, experienced therapist, or early childhood developmental specialist. Early intervention services can be home-visiting programs, parent-training programs, ABA therapy, services to meet your child's developmental goals (i.e. speech, occupational, developmental play therapy, physical therapy, vision or a combination of these). Participation should take approximately 20 minutes to complete.

PARTICIPATION

Your participation in this survey is voluntary. You may refuse to take part in the research or exit the survey at any time without penalty. You may skip any question you do not wish to answer for any reason.

BENEFITS & RISKS

You will receive no direct benefits from participating in this research study. However, your responses may help us learn more about father's experiences when it comes to their involvement in their child's early autism services. There are no foreseeable risks involved in participating in this study other than those encountered in day-to-day life.

CONFIDENTIALITY

Your survey answers will be stored initially with Qualtrics in a password protected electronic format. Data will later be downloaded and stored in SPSS. Responses will be anonymous; however, a numerical identifier will be applied to the responses to help with data analysis. All responses, along with the survey, will be deleted after one (1) year.

At the end of the survey you will be asked if you are interested in participating in an additional focus group, in person. If you choose to provide contact information such as your phone number or email address, your survey responses may no longer be anonymous to the researcher. However, no names or identifying information would be included in any publications or presentations based on these data, and your responses to this survey will remain confidential. Participants whom choose to participate in the follow-up focus group will be provided with a $50 Amazon gift card at the completion of the focus group.

CONTACT

If you have further questions or concerns about your rights as a participant in this study, contact the Office of Research Compliance at (704) 687-1871 or uncc-irb@uncc.edu. If you have questions concerning the study, contact the principal investigator, at (704) 402-4631 or by email at cgooden3@uncc.edu, or my Responsible Faculty Dr. JaneDiane Smith at 704-687-8850 or by email at jdianesm@uncc.edu.

1 **ELECTRONIC CONSENT**:

Please select your choice below. You may print a copy of this consent form for your records. Clicking on the "Agree" button indicates that

- You have read the above information.
- You voluntarily agree to participate.
- You are 18 years of age or older.

○ Agree
○ Do Not Agree

Condition: Do Not Agree Is Selected. Skip To: End of Survey.

Does your child have a diagnosis of Autism Spectrum Disorder?

○ Yes
○ No

Condition: No Is Selected. Skip To: End of Survey.

Did your child participate in an Early Intervention program related to their Autism Diagnosis (e.g. ABA Therapy, Occupational Therapy, Physical Therapy, Speech Therapy, Play Therapy, and Developmental Services (through your local CDSA)?

○ yes
○ No

Condition: No Is Selected. Skip To: End of Survey.

Is your child currently between the ages of 2 and 6 years of age?

○ Yes (1)
○ No (2)

Condition: No Is Selected. Skip To: End of Survey.

The following questions pertain to your child's age, diagnosis and any Early Intervention services or programs he/she may have been involved in to help meet their goals and outcomes.

1. Age of Child at Diagnosis

○ 12-18 months
○ 18-24 months
○ 2-3 years
○ 3-4 years
○ 4-5 years
○ 5-6 years

2. Total number of children with ASD?

○ 1
○ 2
○ 3
○ 4+

3. Total number of children.

○ 1
○ 2
○ 3
○ 4
○ 5+

4. Relationship to child with ASD Diagnosis

○ Biological father
○ Step father
○ Adoptive father
○ Legal father
○ Other (Please Specify)___________
○ Prefer Not to Answer

5. What is your age?

○ 18-24
○ 25-34
○ 35-44
○ 45-54
○ 55-64
○ 65+
○ Prefer not to answer

6. Race (check all that apply)

☐ White
☐ American Indian or Alaska Native
☐ Asian
☐ Native Hawaiian or Pacific Islander
☐ African American
☐ Hispanic or Latino
☐ Other
☐ Prefer not to answer

7. Marital Status

○ Single (Never Married)
○ Married
○ Divorced
○ Separated
○ Widowed
○ Other ____________________
○ Prefer not to answer

8. What is your occupation?
____

9. What is the highest degree or level of school you have completed? If currently enrolled, highest degree received.

○ Some high school, no diploma
○ High School graduate, diploma, or equivalent (GED)
○ Some college credit, no degree
○ Trade/ technical/ vocational training
○ Associate's Degree
○ Bachelor's Degree
○ Master's Degree
○ Doctorate/ Professional Degree
○ Prefer not to answer

10. Which of the following categories best describes your employment status?

○ Employed, working 40 or more hours per week
○ Employed, working 1-39 hours per week
○ Not employed, looking for work
○ Not employed, NOT looking for work
○ Retired
○ Disabled, not able to work
○ Prefer not to answer

11. What is your HOUSEHOLD annual income level?

○ $0 to 25,999
○ $26,000 to 49,999
○ $50,000 to $74,999
○ $75,000 to $99,999
○ $100,000 to $124,999
○ $125,000 to $149,999
○ $150,000 to $174,999
○ $175,000 to $199,999
○ $200,000 and up
○ Prefer not to answer

The focus of this section will be to gain insight into fathers’ perceptions of their level of involvement in early autism services.
Please answer the questions to the best of your knowledge.

12. Did your child participate in an Early Intervention program (ABA, speech therapy, occupational training, developmental services, etc.) within the last 18 months?

- ○ Yes
- ○ No
- ○ Not Sure

13. Is your child currently participating in Early Intervention programs?

- ○ Yes
- ○ No
- ○ Not sure

14. How long has your child been receiving EI Services?

- ○ 0-6 months
- ○ 6-12 months
- ○ 12-18 months
- ○ 18-24 months
- ○ 2-3 years
- ○ 3-4 years
- ○ Other ____________________

15. Thinking about all of the early intervention services your child is/was involved in during the week: What type of services did your child receive, and move the marker to choose what percentage of time you were able to participate in those services?

______ Speech Therapy
______ Occupational Therapy
______ Physical Therapy
______ Vision Therapy
______ Applied Behavioral Analysis Therapy (ABA)
______ Community Based Rehabilitative Services (CBRS)
______ Other

16. Do you know the providers and their roles in working with your family?

- ○ Yes
- ○ No
- ○ Other ____________________

17. Who is most responsible for getting your child to and from services (therapies, school, and doctor appointments)?

☐ Mother
☐ Father
☐ Sibling
☐ Relative (grandparent, aunt, uncle, etc.)
☐ Friend
☐ Other ____________________

18. What are some strengths of the programs in terms of involving and including you in the services? -

____
____
____
____

19. What do you think the intervention programs could do better at in including you in the services?

____
____
____
____

These questions ask about the experiences of parenting a child with Autism. Different fathers have different experiences; there are no right or wrong answers.

How much do you agree with the following statements in terms of how well they describe things that make it easy to be involved with your child? MARK ONE CIRCLE for each item.

20. It's EASY to be involved with my child because…

	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
A. I can handle the difficulties that come with my child's Autism diagnosis.	○	○	○	○	○
B. I know I am able get whatever information I need about his/her Autism diagnosis.	○	○	○	○	○
C. I don't dwell on my child's Autism.	○	○	○	○	○

How much do you agree with the following statements in terms of how well they describe things that limit your involvement with your child? MARK ONE CIRCLE for each item.

21. It is DIFFICULT to be involved with my child because…

	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
D. My spouse doesn't believe I can handle the demands of my child's Autism.	○	○	○	○	○
E. Having a child with Autism is more difficult than I expected.	○	○	○	○	○
F. Being involved in his/her therapies is a lot for me to handle.	○	○	○	○	○
G. His/her Autism make me want to avoid caring for my child.	○	○	○	○	○
H. I find myself thinking that the dreams I had for my child will probably not happen.	○	○	○	○	○
I. Having a child with Autism has a large impact on the quality of time that we spend together.	○	○	○	○	○
J. His/her Autism gets in the way of my relationship with my child.	○	○	○	○	○
K. Many ideas about fatherhood have changed because I have a child with Autism.	○	○	○	○	○
L. I do not have the energy to be able to help with my child's therapies.	○	○	○	○	○

22. Do you attend meetings regarding your child's therapies?

○ Yes
○ No
○ When Possible

Condition: Yes, Is Selected. Skip To: The following questions deal with y....

23. 1. Which of the following reasons explain why you do not attend THERAPY meetings? Check all that apply:

☐ There are no regular therapy meetings
☐ I do not have enough time due to work demands
☐ The therapy meetings conflict with my work hours
☐ I need to be at home to care for the children when therapy meets
☐ I am not really interested in the therapy meetings
☐ My spouse prefers that I not attend the therapy meetings
☐ My input will not make a difference to the meetings
☐ I don’t understand the details of the therapy
☐ My spouse handles and attends the meetings

Display This Question:

If 1.Which of the following reasons explain why you do not attend THERAPY meetings? Check all that apply: “There are no regular therapy meetings” Is Selected

24. Do you attend special meetings that occur from time to time (e.g. IFSP)?

○ Yes
○ No
○ When Possible

Display This Question:

If 1.Which of the following reasons explain why you do not attend EDUCATION meetings?” Check all that apply: “There are no regular education meetings” Is Selected

25. 2. Which of the following reasons explain why you do not attend EDUCATION meetings? Check all that apply:

☐ There are no regular education meetings
☐ I do not have enough time due to work demands
☐ The therapy meetings conflict with my work hours
☐ I need to be at home to care for the children when the education meeting occurs
☐ I am not really interested in the education meetings
☐ My spouse prefers I not attend the education meetings
☐ My input will not make a difference to the meetings
☐ I don’t understand the details of the education meetings
☐ My spouse handles and attends the meetings

Condition: There are no regular education... Is Selected. Skip To: Do you attend special meetings that o....

26. Do you attend special meetings that occur from time to time (e.g., IEP)?

	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
A. During meetings regarding my child's therapies, it is easy for me to have a say.	○	○	○	○	○
B. During meetings regarding my child's therapies, I feel very much included in the discussions.	○	○	○	○	○
C. I find it easy to be active in my child's education.	○	○	○	○	○
D. .Meetings with teachers are arranged at a time that fits with my work schedule.	○	○	○	○	○

○ yes
○ No
○ When Possible

The following questions deal with your involvement in your child's therapies. How much do you agree with the following statements in terms of how well they describe things that limit your involvement with your child? MARK ONE CIRCLE for each item.

27. It is DIFFICULT to be involved with the meetings about my child because…

	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
A. There are no other men at the meetings about my child's education.	○	○	○	○	○
B. I feel like I don't have a say in educational/therapy meetings.	○	○	○	○	○
C. I have a hard time understanding all the terms and topics at the education/therapy meetings.	○	○	○	○	○
D. Professionals at the meetings address their comments to my wife and not to me.	○	○	○	○	○

28. It's EASY to be involved with the meetings about my child because…

STOP AND REVIEW. When you use the bottom right "NEXT" button to click off this screen, you will be exiting the survey. Please take a moment to review your answers.

1. Would you be interested in participating in a follow up focus group? This focus group will take place in late October or early November and will last no more than 90 minutes.

Childcare and food will be provided. You will be provided with a $50 Amazon gift card for your time and appreciation.

○ yes
○ No

Condition: No Is Selected. Skip To: End of Survey2. Name (First Initial, Last Name)

____

3. Please provide the best contact information (phone or email).

____

4. What is the best time to contact you?

○ Morning (8 a.m. to 10 a.m.)
○ Mid-Morning (10 a.m. to 12 p.m.)
○ Early Afternoon (12 pm. to 3 p.m.)
○ Late Afternoon (3 p.m. to 5 p.m.)
○ Evening (5 p.m. to 9 p.m.)

APPENDIX E: Interview Protocol

***Introduction**:* Good afternoon and thank you for agreeing to meet with me to discuss your involvement in your child's early autism services. My name is Chelsea Gooden and I am the researcher who will be interviewing you today. I am with the University of North Carolina Charlotte working on my master's thesis project, under faculty supervision of Dr. JaneDiane Smith, PhD. The purpose of today's interview is to gain insight from fathers such as yourself about your perspectives on your level of involvement in your child's early autism interventions and how you perceive service providers are doing in including you in early intervention services. When I say early intervention services that can be home-visiting programs, parent-training programs, ABA therapy, services to meet your child's developmental goals (e.g., Speech, occupational, developmental play therapy, physical therapy, vision or a combination of these).

You were invited because you have a child with autism who received some sort of early intervention service, participated in the online survey and expressed interest in participating in this study.

Ground Rules: I want to go over some basic guidelines of the interview process:

- If you feel uncomfortable during the session, you have the right to stop the interview or to pass on any question.
- There is no consequence for stopping the interview. Being here is voluntary.
- There are no right or wrong answers.

I will be recording this session, so I do not miss any of your comments. We will be on a first name basis today, and please know your name will not be used in the final report. You may be assured of complete confidentiality, and any data shared or reported will be in aggregate form only and will not identify individual participants.

<Review informed consent form and ask participant to ensure they completed the demographic survey on Qualtrics online survey systems>

Guiding Questions:

1. What services did your child and family receive related to your child's Autism?

2. Was there a service that was more beneficial than others? If so, what?

3. Were the providers female or male?

4. Thinking about the early intervention services your child participated in:

    a. How did you go about getting the information that was covered and presented in the sessions?
    b. How difficult, or easy, did you find it at participating and being involved in the sessions and why?

            i. What made it difficult?
            ii. What made it easy?
    c. In what ways were you involved in the sessions, if any?
    d. Did you find that your level of involvement in these services added to or reduced your partner’s stress level?

5. How do you view the role of the service provider in influencing the development your child with Autism?

6. Looking back at your child’s services, how satisfied are you with your level of involvement in those services?

7. Thinking about your child’s service coordinator and therapists:
    a. Can you tell me about your relationship with this person(s)?
    b. How have these individuals been including you in the services?
    c. Do you wish they had included you more? Less?
    d. How have these individuals been meeting your needs as a parent of a child with ASD?
    e. What do you think are some ways that professionals can do to include fathers in taking an active role in their child’s services?

8. Did your child’s service providers at any point get you in touch with, or mention, services or supports outside of your child’s services?

9. Would you have been comfortable asking for additional supports?

10. What advice would you give going forward to other fathers who are going down the early intervention path?

APPENDIX F: CONSENT TO AUDIO RECORD

UNC CHARLOTTE
Cato College of Education

Department of Special Education and Child Development

9201 University City Blvd, Charlotte, NC 28223-0001
T/ 704.687.8828 f/ 704.687.1625 www.uncc.edu

CONSENT TO AUDIO RECORD AND PARTICIPATE IN A RESEARCH STUDY

"Father's Perspectives on Their Level of Involvement in Early Autism Services"

You are being asked to participate in a research study, *Father's Perspectives on Their Level of Involvement in Early Autism Services*. The purpose of this research study is to explore father's perspectives on their level of involvement in their child's early autism services, and how they feel service providers are doing to include them in the services. At the end, you will be asked to sign this document if you agree to participate in the study.

Chelsea Gooden is a UNC Charlotte Master's in Education candidate in the Department of Child and Family Development and will be conducting this research project under the supervision of Dr. JaneDiane Smith.

You have been contacted about this study because you participated in, and completed, an online questionnaire about your involvement in your child's early autism services. On that questionnaire, you said that you would be willing to participate in a follow-up interview.

You will be interviewed by Chelsea Gooden, the researcher for this study, for approximately 90 minutes. The interview will consist of questions about your involvement in your child's early autism services as well as your relationship with your child's service coordinator or early intervention specialist. The interview will be audio recorded. The audio recordings will be transcribed by Mrs. Gooden.

It is possible that talking about your experiences could make you feel uncomfortable. You are welcome to skip any questions that make you feel uncomfortable, and you may also stop the interview at any time.

Some people find talking about their experiences and participation to be helpful. A possible benefit of this study is that the results may help those professionals serving families and young children with autism better and be more inclusive of all members of the child’s family in those services.

The research team will make every effort to protect your privacy. All your responses to the interview questions will be kept confidential. However, because your voice will be potentially identifiable by anyone who hears the tape/digital recording, your confidentiality for things you say on the tape cannot be guaranteed although the researcher will limit access to the tape/digital recording as described below.

The digital audio recording files will be kept on a password protected computer in a password protected folder and will not be stored on a public network folder. The recordings will be coded by a nickname rather than your name. After the audio recording is transcribed, it will be destroyed. The transcriptions will contain no identifying information. During the study, all transcription materials will be kept in a locked filing cabinet in a locked office. When the results of this study are published, participants will be referred to by nicknames, not names.

The decision to participate in this study is completely up to you. You will not be treated any differently if you decide not to be in this study. If you decide to be in the study, you have the right to withdraw from the study at any time. At the completion of the interview you will be reimbursed for your time with a $50 Amazon gift card.

UNC Charlotte wants to make sure that all research participants are treated in a fair and respectful manner. Contact the Office of Research Compliance at (704)-687-1871 or uncc-irb@uncc.edu if you have questions about your rights as a study participant and reference IRB # 17-0143. If you have any questions about the purpose, procedures, and outcome of this project, contact Dr. JaneDiane Smith (704-687- 8850, jdianesm@uncc.edu).

This form was approved for use on _________________ *for* a period of one (1) year.

I have read the information in this consent form. I have had the chance to ask questions about this study, and those questions have been answered to my satisfaction. I am at least 18 years of age, and I agree to participate in this research project. I understand that I will receive a copy of this form after it has been signed by me and the principal investigator of this research study.

______________________________	______________________	_____________
Initials of Participant	Signature of participant	Date
________________________________	____________________	
Signature of person obtaining consent	Date	

APPENDIX G: EMAIL STATING PERMISSION TO ADAPT FCDC QUESTIONNAIRE

March 19, 2017

Agnes Ly <aly@psych.udel.edu>

to me

Hello Chelsea,

I'm glad to hear that you're interested in the FCDC. A full copy of the measure appears in an appendix at the end of the published article so that people may use it for their research. However, you may be asking for not only the questions but for the version with formatting. If so, attached is the Word .docx version of the FCDC that appears in the article.

Let me know if you have any questions.

All the best,
Agnes

\---
Agnes R. Ly, Ph.D.
(pronouns: she/her/hers)
Assistant Professor
Director of Undergraduate Advising
Department of Psychological and Brain Sciences
University of Delaware

Office: 218 Wolf Hall
Spring 2017 Office Hours: Mondays 2:30pm-4pm; Tuesdays 9am-12pm
Twitter: @ProfessorLy
Facebook: https://www.facebook.com/Dr.AgnesLy