

2019

# African American Fathers Raising An Autistic Child

Shannon Latoya Burns-Darden  
*Walden University*

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# Walden University

College of Social and Behavioral Sciences

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Shannon Burns-Darden

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## Review Committee

Dr. Susana Verdinelli, Committee Chairperson, Psychology Faculty  
Dr. Nina Nabors, Committee Member, Psychology Faculty  
Dr. Penny McNatt Devine, University Reviewer, Psychology Faculty

Chief Academic Officer  
Eric Riedel, Ph.D.

Walden University  
2018

Abstract

African American Fathers Raising an Autistic Child

by

Shannon Burns-Darden

MS, Walden University, 2015

MS, Albany State University, 2008

BS, Albany State University, 2004

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Clinical Psychology

Walden University

December 2018

## Abstract

Parents of a child diagnosed with autism have a high risk for physical and emotional stress with mental health difficulties. Little research exists regarding fathers with an autistic child, and less information exists on African American fathers who struggle with coping and finding appropriate interventions and resources for raising an autistic child. The purpose of this interpretative, phenomenological study was to analyze the lived experiences of 12 African American fathers raising their child diagnosed with autism spectrum disorder. This study's theoretical lens was Bowen's family systems theory. The data from this study consisted of 12 interviews with African American fathers using an open-ended and semistructured format. Data were analyzed using thematic analysis. The fathers' descriptions of their lived experiences yielded 4 themes: father's interaction with the child, emotional reactions, discipline of the child, and awareness support of autism spectrum disorder. African American fathers indicated positive results caring for their child with autism and desired effective interventions to increase the child's continued success for the future. Findings supported the father's presence as significant as the mothers when caring for a child diagnosed with autism. Implications for positive social change include professionals understanding the lived experiences of the African American father, such as increased community supports, resources, advocates, education, and awareness in the African American community.

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## Dedication

First, I dedicate this dissertation to God, as I would not have completed this degree without him. I also dedicate this research to all those diagnosed with autism. I pray my research provides awareness and education to all communities. To my husband (Reynard Darden) and best friend; you have sacrificed so much during this trying time as I have never heard you complain about the mistress we call “the dissertation”. Many times you have watched the tears fall as I have questioned the ability to sustain such pressure of succeeding. You continued to have a listening ear during the late nights as your words were always motivating and encouraging. I thank God for you and appreciate your patience as I traveled along this road of knowledge. To my cubs, my children, my reason for breathing air; London and Logan. You two I have always called my Ph.D. babies as I sat in the hospital bed while completing this dissertation. As I think of the strength it took to complete this degree, without you two I question how much I could have endured. You two will continue to be my reason for wanting better, and I pray you are better than me when you too travel this road of knowledge. To my mother and father (Janet & Dr. Columbus Burns III); without you there would be no me! I thank the two of you for the drive and wisdom I possess. You two have always pushed education for Courtney and me, and we thank you for it!!

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## Chapter 1: Introduction to the Study

### **Introduction**

Parents of children who have incurable illnesses can experience stress.

Researchers have shown that parents of a child diagnosed with autism have a high risk for physical and emotional stress and mental health difficulties (Benson, 2006; Gau et al., 2012; Gra, 2002; Hamlyn-Wright, Draghi-Lorenz, & Ellis, 2007; Lecavalier, Leone, & Wiltz, 2006; Little, 2002; Sivberg, 2002; Woodgate, Ateah, & Secco, 2008). Although many researchers have examined the needs of mothers who have autistic children, fathers also require and seek support for raising an autistic child. Men as caregivers play a role in the development of the child (Cabrera, Tamis-LeMonda, Bradley, Hofferth, & Lamb, 2000; Ramchandani & McConachie, 2005). However, few scholars have examined the mental health needs of fathers who have autistic children (Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010). In addition, researchers have not explored the experiences of African American fathers who are raising an autistic child. More research is needed on fathers and autism to provide them with the support that they need in their role as caregivers (Meadan, Halle, & Ebata, 2010; Papageorgiou & Kalyva, 2010).

The purpose of the study was to examine the lived experiences of African American fathers who are raising an autistic child. I explored the emotions of fathers who have an autistic child, their challenges in parenting the child, their ways of coping, and their overall lived experience raising a child diagnosed with autism. In Chapter 1, I provide an overview of the background of the study, prevalence and consequences of autism. The study, key terms, research questions, assumptions and delimitations,

theoretical framework, and research design are also presented. The chapter closes with the potential for establishing social change and implications for an increase of awareness and support for African American fathers raising an autistic child.

### **Background of the Study**

Autism is now one of the fastest growing developmental disorders in the United States (Levere, 2013). The autism spectrum disorder (ASD) is a neurological condition that can affect any ethnicity, race, and socioeconomic status (Centers for Disease Control and Prevention [CDC], 2010). According to the American Psychological Association (APA, 2013), autism is described as a persistent deficit in social communication and social interaction across multiple contexts, as manifested by the individual displaying a deficit in social and emotional reciprocity. Signs of autism can be seen in children aged 18 to 24 months. Children who are diagnosed late in age are known to have more negative symptoms, such as lack of eye contact, attention behaviors, lack of pretend play, and a deficit in language development (APA, 2013). According to Maino, Viola, and Donati (2009), there are several factors that may contribute to a diagnosis of autism, such as brain injuries, constitutional vulnerabilities, or structural cerebellum deficiencies. However, at present, the etiology of autism is not fully understood.

The CDC (2012) reported that the average number of children in the United States diagnosed with ASD is 1 in 88. The (CDC, 2014) now reported the number of children diagnosed with autism is one in 68, which is an increase from 2 years ago. The CDC (2014) indicated that European American children were 1.2 times more likely than African American children to receive autism diagnosis. African American children were

1.3 times more likely than Hispanic Americans to be diagnosed with the autism disorder (CDC, 2014). Given the prevalence of autism, research concerning autism in all ethnic groups should be conducted. According to the CDC (2014), the percentage of African American children diagnosed with autism is 13.2 to 1,000. There is a gap in literature on fathers and their experiences with raising a child with autism (Vacca, 2013), and there is even less information on African American fathers' experiences of caring for children with autism (Carr & Lord, 2013; Simon, 2013). Researchers have concentrated on mothers, as they are more likely viewed as the primary caregiver (Ryan & Runswick, 2009).

Many African American parents seek help in caring for their autistic child because they fear that their child may be removed from their homes (Tape, 2011). However, parents might encounter barriers to seeking advice for their child diagnosed with autism. Mandell, Novak, and Zubritsky (2005) stated that providers often have a poor understanding of the symptoms, prognosis, and treatment options for autism, as parents often receive conflicting information regarding treatment. Medical professionals should also take into consideration the parents' culture and socioeconomic status when offering services. Santarelli, Koegel, Casas, and Koegel (2001) reported that if there is a discrepancy between the provider and client, it can result in cultural dissonance, which can affect the success of the program.

African American children are often diagnosed with autism at a later age than European American children. African Americans are 2.6 times less likely to receive an autism diagnosis during their first visit (Mandell, Ittenbach, Levy, & Pinto-Martin, 2007).



African American children were 5.1 times more likely than European American children to receive a diagnosis of adjustment disorder than attention deficit hyperactivity disorder (ADHD). African American children were also 2.4 times more likely than European American children to have a diagnosis of conduct disorder than ADHD. According to these numbers, ethnicity may influence the parents' descriptions of the symptoms of autism and the clinicians' interpretations, expectations, and symptom presentation of autism (Mandell et al., 2007). According to the CDC (2014), the prevalence among European American children (15.5 per 1,000) was significantly higher than it was among African American children (13.2 per 1,000), Asian American children (11.3 per 1,000), and Hispanic American children (10.1 per 1,000; CDC, 2014).

According to Liebman and Abell (2000), the father is often the forgotten parent due to noninvolvement in the care of the child and the secondary role within the family unit. For many years, the mother's role was in the home while the father worked and provided financial stability. Over the past 30 years, the roles of the mother and father have now changed. Currently, it is not uncommon for the mother to work and the father to act as the caregiver for the children (Cabrera, Tamis-LeMonda, Bradley, Hofferth, & Lamb, 2000; Flippin & Crais, 2011; Towers, 2009).

There are current qualitative studies that have showed the benefit of the father playing a more active role in their children lives (Honig, 2008). Carpenter and Towers (2008) reported that fathers felt any support person helped their spouse more than themselves as they were perceived as "hard to reach," "invisible," or a "shadow." Medical professionals also have a tendency to neglect the father as they often inform the

mother of the child's medical condition rather than the father (Lamb & Lauman-Billings, 1997). For decades, mothers have been perceived as the primary caregiver and not until recent years have fathers had the chance to play a more active role in the care of the child with economic and societal changes (Garfield & Isacco, 2006; Towers, 2009). According to DePape and Lindsay (2015), studies on maternal caregivers are overrepresented as mothers account for three quarters of the respondents. This may be the result of a stronger aspiration to target only the primary caregiver, even though fathers have begun to act in this role more frequently (Ellison et al., 2009). More scholars should target fathers and their roles in the home raising an autistic child.

There is limited research on African American caregivers raising an autistic child due to the underrepresentation of the diagnosis. Knowledge of African American families caring for a child diagnosed with autism is limited due to the scarcity of research specific to the autism disorder as it compares to African American families (Dyches et al., 2004).

### **Fathers and Autism**

According to Nease and Austin (2010), fathers often feel that their life has new meaning when finding out they are going to become a father. The new father experiences thoughts of being the protector, provider, and decision maker (Habib, 2012). However, when the father learns that his child has a disability, the feeling is often diminished. Fathers who raise a child with autism report higher levels of stress, parenting issues, and less life satisfaction than a father raising a child without the autism disorder (Benjak, Vuletic, & Kolaric, 2011; Darling, Senatore, & Strachan, 2012; Hayes & Watson, 2013). According to Baker, Blacher, and Olsson (2005), fathers who have a child with a

developmental delay (such as autism) report experiencing more stress as they often must work overtime or take on extra jobs to pay for medical expenses or to supplement the mother's income as she often stops working to care for the child. This causes stress for the father as he is not able to engage in family activities or outside extracurricular activities for himself (MacDonald & Hastings, 2010).

### **Mothers and Autism**

According to Irely and Silver (1996), stay-at-home mothers who act as the primary caretaker are more stressed emotionally and physically than fathers. Mothers who are raising a child with autism report high levels of stress as they struggle with their child's lack of affection. The mother feels stress or anxiety when their child does not smile at them, hold their hand, look them in the eye, or interact with their siblings (Seung, Ashwell, Elder, & Valcante, 2006). Mothers often sacrifice careers and extracurricular activities to care for their child with autism (Harper, Dyches, Harper, Roper, & South, 2013; Myers, Mackintosh, & Goin-Kochel, 2009). Mothers also become the child's primary caregiver and teacher; she makes sure that bills are paid while caring for siblings and being a wife (Hock, Timm, & Ramisch, 2012). Mothers may have unrealistic expectations for the child diagnosed with autism, which also leads to frustration and stress.

### **Parents and Autism**

Cowan (2010) reported that parents of a child diagnosed with autism suffer from higher levels of stress because they are uncertain of the child's future, and they have often isolated themselves from family and friends. Parents also reported experiencing

financial stress as the child's medical expenses are high, with the mother having to stay home to support the child. According to Featherstone (1980), parents reported negative emotions, guilt, anger, and frustration. Couples often report marital dissatisfaction that leads to higher divorce rates.

### **Financial Cost and Autism**

There are several stressors that parents raising an autistic child may experience. Parents report financial stress as one of the most challenging factors of raising a child with autism. According to Lavelle et al. (2014), in 2011, the total cost of caring for a child diagnosed with autism was more than \$11 billion dollars. The cost per child equaled over \$17, 000 per child (author, year). Although a child with autism is often provided insurance to cover medical needs, most insurance companies have a certain limit that each child may receive (Lavelle et al., 2014). Parents report feeling overwhelmed as medical expenses force them to find alternate ways to pay for medical services, pay out of pocket, or eliminate the services for the child (Hock et al., 2012; Lutz, Patterson, & Klein, 2012). As the prevalence of autism continues to rise, the financial burden for parents will also continue to increase.

### **Autism and Education**

Education plays a role in a child's long-term treatment and success. Children who are diagnosed with autism are still afforded the same educational opportunities as a child without autism (Artiles, Klingner, & Tate, 2006). However, parents of a child with autism report disparities in the child's education. Parents of African American child report inequalities that often go unnoticed in the education system. According to Losen and

Orfield (2002), minority children may receive poor instruction, isolation from those without a disability, and little curriculum instructions from teachers. Since 1970, researchers have advocated for individualized treatment programs for children diagnosed with autism in the school system.

### **Statement of the Problem**

This study was needed because there have been few studies that included fathers when examining being a caregiver to a child diagnosed with autism. Little research exists regarding fathers with an autistic child, with the majority of the research targeting mothers' experiences (Hornby, 1992; Sawyer et al, 2010). Research targeting fathers acting as the caregiver is significant as scholars have shown fathers can have a positive influence on children by acting as their caregiver, educator, and advocate (Honig, 2008). Due to the prevalence of autism, the father's perspective of the disorder is vital for future studies.

### **Nature of the Study**

The purpose of this qualitative, interpretative phenomenological study was to explore the lived experiences of African American fathers who were raising a child diagnosed with autism. There is little research on autism and the African American culture (Simon, 2013; Vacca, 2013). There are also few studies on autism and caregivers in general. As the number of children diagnosed with autism increases, there is a need for more information about raising autistic children in the African American community.

In this study, I used a phenomenological, qualitative method. This method was the most appropriate way to gather the lived experiences of individuals (Barbour, 2008;

Bryman, 2008; Denzin & Lincoln, 2008; Dickson, Swift, James, & Liamputtong, 2008; Leedy & Ormrod, 2010; Liamputtong, 2007). More studies about African American fathers and their experiences of raising a child with autism could increase awareness of the autistic disorder within the African American community.

### **Research Questions**

I addressed the following questions:

1. What are the experiences of African American fathers raising an autistic child?
2. What are the emotional reactions of African American fathers after they have learned of their child's diagnosis?
3. How do African American fathers describe their parenting experiences with their autistic children?
4. What are the challenges that African American fathers experience when raising an autistic child?

### **Rationale, Relevance, and Significance for the Study**

In this study, I targeted the lived experiences of African American fathers who were raising an autistic child. The study was limited to African American fathers who were raising a biological child diagnosed with autism between 18 months and 18-years-old with or without their spouse. The study of African American fathers' experiences in caring for an autistic child was significant due to the prevalence of children diagnosed with autism and the lack information about autism in general in the African American community.

In this study, I expanded on the work of previous research through an exploration of a small group of fathers who have a child with autism. An increased understanding of their lived experience has the potential to facilitate positive social change in terms of more effective interventions, earlier diagnosis, resources for psychological stressors, community support, education, and overall awareness for parents of children with autism. This study may provide insights for researchers, clinicians, and others who work with African American fathers who have children with autism.

### **Theoretical Framework**

The theoretical framework for this study was based on Bowen's (1978) family systems theory (BFST). The BFST stated, "the human family is a multigenerational, natural, living system and that the emotional functioning of each member of the system affects the functioning of the other members in predictable ways" (Comella, Bader, Ball, Wiseman, & Sagar, 1995, p. 5). According to Bowen, family systems theory relates to the autistic child within the family in several ways. The autistic child has an influence on family functioning and interactions between family members, which includes parents, siblings, and the family as a whole. Broderick (1993) described the family system as a way people fit together and that each individual must "maintain its shape so the system can maintain its' shape" (p. 8). How parents of the child diagnosed with autism copes with anger, despair, grief, guilt and stress affects every member of the family, including the child diagnosed with autism. Support and resources are significant in assisting the family, especially fathers, with ways to cope.

### **Definition of Terms**

The terms that were used in my study appear below.

*Autism:* A host of conditions that affects an individual's way of reciprocating with others, and it may include a behavior of routine (APA, 2000; Dworzynski, Happe, Bolton, & Ronald, 2009; Leekam, Prior, & Mirko, 2011).

*African American:* African Americans are individuals who were born in and/or residing within the United States whose ethnicity was that of African origin (U.S. Census Bureau, 2010).

*Fatherhood:* The male role within the family structure who assumes not only the identity of provider, nurturer, and disciplinarian, but also teacher, protector, and caregiver (Olmstead, Futris, & Pasley, 2009).

*Family systems theory:* A theory that the family is a structure and events affecting any one person essentially affect everyone associated with the unit (Wehman, 1998).

*Phenomenological theory:* A perspective of research where the goal is to gain knowledge about how individuals experience things (Creswell, 2007).

### **Assumptions**

While conducting a phenomenological study, the aim was to remain truthful so that the participants' words are accurately reflected. The goal of this research was to bring awareness to the African American father who too raises an autistic child. It was my assumption that all responses from the participants were honest and valid. I ensured that the participants felt comfortable and all responses were confidential. I assumed that all participants read well, and their comprehension was normal. I assumed all participants



had experienced the same or similar phenomenon. I also assumed that participants had a sincere interest in participating in the research and did not have any other motives.

### **Scope and Delimitations**

In this study, I planned to interview African American fathers who had a biological autistic child between the ages of 18 months to 18-years-old. Their child had to have been diagnosed with autism and not any other developmental disorder. The father had to be living with their child. Consequently, other ethnic groups, mothers, or other caretakers were excluded. Additionally, children with other developmental delays and children younger than 18 months or older than 18 were excluded from the study.

### **Limitations**

A potential limitation associated with this investigation was based that the data in my study solely depended on the narrated voices and experiences of a group of individuals who shared the same phenomenon. To refine the essence of the experience of African American fathers raising an autistic child, the data were based on the subjective and conscious recollection of such experiences during the interview. I relied on the accuracy of the self-reporting structure that characterized the interview. Participants possessed the ability to engage in such narrative and displayed a willingness to provide rich details as they were guided by the open-ended and semistructured format of the interviewing process. If there was an inability to do so, this resulted in a limitation of the study. Concerns about privacy and confidentiality could have been other limitations during research. There was the possibility that a participant experienced discomfort while sharing his experience due to the sensitive nature of the topic of the interview. The

participants could have been reluctant to share personal information associated with their experiences. There is a common theme among the African American culture which states, “family business is family business.” The participants could have held certain information. It was imperative to inform all participants prior to the interview about the strict adherence to ethical standards and the IRB protocols endorsed by the dissertation committee and myself.

Another potential limitation was my limited experience conducting one-on-one interviews. Such limited experience could have affected the necessary rapport and the dynamics of the interview. Also, during the research interviews, I asked for clarification to the provided responses and/or asked additional questions if the information obtained by the participant was not clear. Throughout the interview process, I maintained objectivity and avoided imposing personal biases, ideas, and opinions that could have negatively impacted the outcome of the interview.

### **Significance**

The research served as a catalyst to promote social change by expanding the knowledge based on the lack of information about fathers of autistic children and by identifying the obstacles that these fathers faced. The results from this study provided insight into the world of African American fathers and autism and how it affected various aspects of their life. The significance of an early diagnosis is vital, as once the disorder is known, resources for the child can be put in place (Keenan et al., 2010). The findings from this study have the potential to help medical professionals understand how African American fathers are affected in their daily lives and to provide resources and support.

The results from this research could lead to resources for psychological stressors, community support, education, and overall awareness for all parents of an autistic child. This study can provide positive social change and a voice to the African American father as he continues to provide data to possible interventions to aid in the awareness and road to success raising an autistic child.

### **Summary**

In this chapter, I described background information regarding African American fathers raising an autistic child. I presented the research questions for this study. The theoretical frameworks for this study were identified, and the family systems theory and social support theory were described. In Chapter 2, I present the literature review of autism and its impact on the African American father.

## Chapter 2: Literature Review

### **Introduction**

The purpose of this study was to fill the research gap regarding African American fathers and their lived experiences of having a child with autism. A parent who knows that his or her child has an illness that has no cure experiences stress. Parents of a child diagnosed with autism have a high risk for physical and emotional stress with mental health difficulties (Benson, 2006; Gra, 2002; Gau et al., 2012; Hamlyn-Wright et al., 2007; Lecavalier et al., 2006; Little, 2002; Sivberg, 2002; Woodgate et al., 2008). Few scholars have examined the experiences and needs of fathers of children with autism. Additional research is needed about fathers and autism to provide them with the support that they need in their role as caregivers. Medical professionals and researchers can use the results of this study to create more community resources and raise awareness of autism.

In this literature review, I describe autism. I discuss the symptoms of a child who has been diagnosed with autism, as well as assessments or screening tools used to diagnose a child with autism. I then explain how the autism disorder can affect the family with an emphasis on the father. I outline ways that African American fathers identify challenges and cope with having a child with autism. I identify the importance of research about African American fathers raising an autistic child. Finally, I present the theoretical framework for the study.

### **Search Strategy**

Literature searches were conducted using the following Walden library databases: PsycINFO; Google Scholar; PsycARTICLES; PsycCRITIQUES; PsycEXTRA; SocINDEX; ProQUEST Dissertations at Walden; and ERIC-Educational Resource Information Center, Health Sciences, and Nursing Collection. There were several key words used to access the literature, such as *autism, father, African American fathers, diagnosis, stress, fatherhood, motherhood, family system theory, etiology, interventions, and community.*

### **Theoretical Framework**

The theoretical framework of this phenomenological study was Bowen's (1978) family systems theory. According to Wehman (1998), family events affect everyone in the family system. I used the family systems theory because it includes a description of the family traits, life cycles, and relationships within the family (Pang, 2010); fathers are an integral part of this dynamic. A child diagnosed with any disability will affect the entire family in some way. The disability of the child could lead to marital issues between parents, and siblings may feel a sense of resentment (Ross & Cuskelly, 2006; Seligman & Darling, 2007).

According to Seligman and Darling (2007), by using the family systems theory, the entire family can be studied as each individual plays a role in the family unit. According to Pang (2010), children with autism benefit from early intervention strategies on topics such as family characteristics and their interactions among each other. Baker,

Mailick-Seltzer, and Greenberg (2011) claimed that children diagnosed with autism, like any other child, will respond to their family environment rather than acting upon it.

Parents do not anticipate having a child with a disability (Duis, Summers, & Summers, 1997; Freeman et al., 1991; Hutton & Caron, 2005, Moses et al., 1992). There are parents who report feeling grief when thinking about the many dreams, hopes, and promises for their child they envisioned (Moses, 2004). There are fathers who report blaming their wives for their child being diagnosed with autism (Goin-Kochel, Mackintosh, & Myers, 2009). Both parents have blamed themselves for the child having the diagnosis (Neely-Barnes, Hall, Robert, & Graff, 2011). Siblings report feeling proud as their sibling with autism accomplishes a certain task. However, the sibling also reports feeling an urgency of responsibility that comes with frustration and at times embarrassment (Angell, Meadan, & Stoner, 2012). The entire family dynamic can be affected as families adjust to the diagnosis and needs of child with autism (Wall, 2010). For professionals to understand a child, they must understand the needs of a family as a whole (Turnbull et al., 2006).

There are studies that also used the family system's theory that described having a child with a disability and the result it had on the caretaker and other family members. The studies described how the family life cycle has distinct stages, and depending on family events, family members may experience a shift in family roles. The family life cycle is a view of a developing family spanning from adulthood to death, and common transitional challenges often are encountered by predicted changes in the family system (Carter & McGoldrick, 1999, Nichols & Schwartz, 2004).

According to Troster (2001), a group of mothers who had a child with a disability described the life of the mother as stressful. The mothers in the study reported extreme stress due to behavioral competencies, such as limited adaptability; hyperactivity; temperaments; and parental functioning, such as health, partnership, and social relations (Troster, 2001). Parents of a child with a disability often report lower scores of wellbeing and an increase in feelings of depression than parents of children with no disability (Oelofsen & Richardson, 2006). Most of the stress that has been reported by mothers of children diagnosed with a disability is due to increased responsibilities of the mother that consists of raising, caring for, and providing for the child with the disability (Horton & Wallander, 2001; Tröster, 2001). Most families that had a child with a disability experience discontinuity in the various stages of the life cycle that may force the family system to change (DeMarle & Le Roux, 2001).

Social support is one positive coping strategy that is common in reducing stress in a family system. Support is described as “resources provided by individuals outside the family” and it includes informational, instrumental, emotional/psychological, and physical/maternal support (Keller & Honig, 2004, p. 338). According to Hodapp, Findler, and Smith (1998), several studies have researched the relationship between the size of the family’s social support network and stress in the family. Social supports have been shown to offer relief for families with a child diagnosed with a disability (Boyd, 2002; Dunst, Trivette, & Cross, 1986; Tröster, 2001). Although there are some families that display negative coping skills, there are some that report positive coping skills. Positive coping skills may include accepting the child’s disability and feelings towards the child,

providing support and much needed education for the family, ensuring a consistent and active social support system, using community resources, and having faith (Kuster & Merkle, 2004).

### **Literature Review**

Autism is described as a host of conditions that affect an individual's ability to reciprocate to another person and may include a behavior of routine (APA, 2000; Dworzynski et al., 2009; Leekam et al., 2011). As of 2012, one in every 88 children have the autism disorder (Ramisch, 2012; Solomon & Chung, 2012). Individuals of any ethnicity can be diagnosed with autism. According to the CDC (2014), the prevalence of autism among European American children (15.5 per 1,000) was significantly higher than it was among African American children (13.2 per 1,000), Asian American children (11.3 per 1,000), and Hispanic American children (10.1 per 1,000). Boys are four to five times more likely to have this disorder (Baron-Cohen et al., 2011; Rice, 2011). According to the CDC (2014), autism has been diagnosed in boys (1 in 89) while girls are 1 in 42.

The first sign of autism was described in the literature in 1938 when Asperger described a population in a hospital; these patients were called autistic psychopaths. Kanner is also identified as a pioneer of autism (Lyons & Fitzgerald, 2007). Kanner (1944) studied a group of 11 young boys and identified distinct symptoms of autism. Kanner identified the boys as "having a sense of loneliness as they were all occupied with the preservation of sameness" (Kanner, 19744, p. 100). While studying the boys, Kanner noticed that the parents of the children were cold, obsessive, and detached. Despite the parents' behaviors, they could not account for the cause of the behaviors observed in their



children. Kanner then requested information regarding the biological, psychological, and social characteristics of autism. Kanner claimed that the cause of autism was due to environmental and biological factors.

There is no known cause for autism. Some researchers have suggested that autism comes from the environment or genetics. Other scholars claimed that the cause of autism is based on the mother's or father's age at the time that the mother conceives. Some researchers have suggested that autism is due to pollutants and chemical exposure (Adams et al., 2009; Dietert, Dietert, & Dewitt, 2011; Grandjean & Landrigan, 2006; Kern et al., 2011). However, there has not been any confirmed autism diagnoses linked to genetic or environment factors.

The etiology of autism is confusing as scholars have suggested that heterogeneity plays a role in the genetic transmission of autism, such as rare recessive or de novo mutations, inherited mutations, and common alleles (Constantino, Zhang, Frazier, Abbacchi, & Law, 2010), as well as chromosomal anomalies found in 7.4% of ASD cases (Marshall et al., 2008). Individuals diagnosed with autism are more like to have Chromosomes 2, 7, and 15. Individuals with certain syndrome are also at a higher risk of being diagnosed with autism such as Fragile X syndrome (FXS). This is a gene that results in the absence of fragile X mental retardation protein (Nolin et al., 2003). Despite past and present research, there is no known cause for autism.

The APA (2013) described autism as a persistent deficit in social communication and social interaction across multiple contexts, as manifested in the individual displaying a deficit in social and emotional reciprocity, either currently or historically. Examples of

deficits in social and emotional reciprocity include uncommon or abnormal back and forth communication with another individual, a lack of interests or emotions, or a delay or elimination of response to social interaction. Autism disorder affects the way in which the child interacts with others, and autistic individuals demonstrate repetitive motions or patterns. These impairments could be severe or mild, and early detection of autism is vital to the future success of the child (APA, 2013).

Children can exhibit signs of autism as early as 18 to 24 months. Children who are diagnosed later on in life are more likely to exhibit additional symptoms, such as poor eye contact, attention behaviors, pretend play, and a deficit in language development. There is debate as to the most effective age for screening a child for autism. For example, Cohen et al. (2000) stated that if a child is screened for autism before the age of 16 months, the diagnosis may not be valid because at that age, normal infants may have the same behaviors as a child with autism. This is known as a false-positive diagnosis (Cohen et al., 2000).

There have been several theories on why a child is born with autism (Folstein & Sheidley, 2001). A single etiology of the autism disorder has yet to be determined. According to Maino et al. (2009), there are theories on the potential causes of autism disorders, such as parentally induced autism, brain injuries, constitutional vulnerabilities, structural cerebellum deficiencies, viral infections, and certain vaccines. Parentally induced autism is one of the first etiologies of autism. Parentally induced autism is defined as mothers who are cold and have no feeling, which causes their children to have autistic symptoms and signs. Historically, the only treatment for the disorder was the

recommendation of psychotherapy for parents and play therapy for the child. Some practitioners would recommend that the child be removed from the parent's home and admitted into a mental institution (Schopler & Mesibov, 1986; Schreibman, 1988). However, scholars have recently not supported this theory. Autism is among the few disorders that have no known concrete cause.

In the early 1950s and 1960s, researchers suggested that autism was due to stress levels among family members. Researchers suggested that if parents separated, the stress would result in a tragedy to the child, which was a traumatic event during the ego developmental stage (Cantwell & Baker, 1984). In the 1970s and 1980s, researchers began to look at biological factors as the cause of autism (Cantwell & Baker, 1984; Schopler, 1994). Researchers encouraged parents to help their child in the home and enter them in individualized and behavioral treatment programs (Schopler & Mesibov, 1986).

According to Cannell (2010), the cause of autism is associated with a Vitamin D deficiency either during pregnancy or early childhood. Cannell (2008) believed that the autism epidemic could be eliminated with the increase of Vitamin D supplementation. Cannell (2008) stated that many people have become afraid of the sun due to the skin cancer, which may limit their exposure to Vitamin D in the sun. Cannell (year) also asserted that many pregnant women are taking a small percentage of prenatal vitamins orally, but are not receiving Vitamin D exposure on their skin. The majority of Vitamin D comes from the skin, not from oral intake. Cannell (year) argued that sun exposure has decreased during the past 20 years, which was the timeframe in which the rate of autism

has increased. According to Park (2012), the increase of autism is the result of more awareness by parents, school administrators, and doctors.

The etiology of autism is complex as it surpasses multiple developmental anomalies (Maino et al., 2002). Autism is not based on a cultural relative condition (Berry, Poortinga, Segall, & Dasen, 1992), but rather a universal cultural psychiatric condition which is now an epidemic worldwide. To date, there is no cure for autism. However, early intervention and identification of autism are used to ensure positive outcomes for the child and family (Wetherby, Watt, Morgan, & Shumway, 2006; Wetherby & Woods, 2003, 2006; Wetherby et al., 2004).

### **Screening Tools Used for Diagnosing**

According to Bilszta and Bilszta (2013), there are several screening tools that can be used to confirm a diagnosis of autism. CHAT is a parent and health practitioner questionnaire that is comprised of 14 questions divided into two sections (Bilszta & Bilszta, 2013). The health practitioner asks parents a series of questions concerning their child's play to determine whether it is normal or impaired. The first nine questions are used to determine if the child pretend plays, has normal development, and/or has social interests. The last five questions are answered by the health professional and focus on gazing, social interaction, pretend play, and protodeclarative pointing. The screening is commonly used because it does not take long to administer (Bilszta & Bilszta, 2013). Children who fail this screening are at a high risk of having autism disorder. However, if the child passes the gazing assessment but fails the other components of the assessment, they are at a high risk of having some developmental delay.

M-CHAT is an expanded screen for autism disorder, with 23 questions that are answered by the parents. This assessment includes a focus on sensory and motor abnormalities, social interactions, joint attention, playing ability, early language, and communication abilities (Bilszta & Bilszta, 2013). Although the M-CHAT is an early detection screening tool, it has some limitations to its validity. The M-CHAT is based on behavioral observations of the child; however, if the child has some developmental delays due to the lack of interactions with others, the child may be misdiagnosed with autism (Bilszta & Bilszta, 2013). The assessments may be used to determine if a child may not need to be assessed until he or she has had some interaction with others, such as preschool (Bilszta & Bilszta, 2013).

Scholars have also used the Vineland Adaptive Behavior Scales (Sparrow, Balla, & Cicchetti, 1984), which is a known norm-referenced tool to measure the dysfunction within the autistic child (Carter, Davis, Klin, & Volkmar, 2005). The most effective programs and assessment measures in most schools for autism include the Treatment and Education of Autistic and Communication Handicapped Children (TEACCH), Applied Behavior Analysis (ABA), and the Observation Scale (BOS).

Raising a child with autism is stressful because it is difficult to obtain a correct diagnosis (O'Brien, 2007). Behaviors are difficult to manage (Brobst, Clopton, & Hendrick, 2009; Davis & Carter 2008; Higgins, Bailey, & Pearce, 2005), and the child's behaviors may cause parents to isolate themselves from others in the community (Hock, 2012; Myers, 2009). The parents of a child with autism have stated that they feel stressed out, exhausted, and burned out because of they are caring for an autistic child (Doig,

McLennan, & Urichuk, 2009). Parents of an autistic child have more burdens and less time to enjoy activities in the community, and they are more likely to quit their jobs due to issues with childcare than parents of children diagnosed with any other disability (Lee et al., 2008).

### **Sensory Deficit**

One of the most significant components associated with a child with autism may be sensory integration (Aylott, 2011; Lane, Dennis, & Geraghty, 2011; Mays, Beal-Alvarez, & Jolivette, 2011; Wiggins, Robins, Bakeman, & Adamson, 2009). For an autistic child, a soft wind may hurt his or her ears; yet, he or she may show no signs of pain standing in an ant bed being bitten by several ants. A simple shower may seem as though the water pierces the child's skin, or the sounds of construction may cause an extreme reaction because the sounds may seem damaging to the child's ears. A child with autism may suffer from several sensory impairments, such ways as auditory, gustatory, visual, tactile, olfactory, vestibular, and proprioceptive. Myler, Fantacone, and Merritt (2003) found that a child with autism may have issues with light, which could lead to extreme reactions such as seizures. A child with autism may also experience a sensitive reaction to sound (Hitoglau, Veveri, Antoniadis, & Zafeiriou, 2010; Menzinger & Jackson, 2009; Myck-Wayne, Robinson, & Henson, 2011). Parents often describe their child diagnosed with autism as being unusual eaters (Nadon, Ehrmann Feldmann, Dunn, & Gisel, 2011; Paterson & Peck, 2011). Autistic children may also be affected by a disorder called pica, the sensation for or a desire to eat items such as dirt, clay, paint, or

hair (Corsini, 2002). I stopped reviewing here. Please go through the rest of your chapter and look for the patterns I pointed out to you. I will now look at Chapter 3.

### **Autism and Social Development**

Kanner (1944) first introduced the term early infantile autism in 1943 when observing 11 children who seemed to lack the ability to socialize and accept affection. Kanner believed that such children did not have the ability to understand the social world; Kanner used the term autism to describe the self-contained behaviors that were observed in such children (as cited in Volkmar & Klin, 2005, p. 6). Kanner also observed children who had issues with change, isolation, and disordered communication. These characteristics remain prevalent in current autism diagnoses. During observations, Kanner noticed that three of the 11 children did not speak and displayed language impairments of echolalia, literalness, and difficulty with pronouns as they often described themselves in the third person (as cited in Volkmar & Klin, 2005, p. 6).

Approximately 50% of children diagnosed with autism are mute, while the rest display some language deficit. These children lack the ability to hold a normal conversation with their peers that often results in isolation and social withdrawal (Charlop-Christy & Kelso, 2003). Approximately 30% of individuals with autism lack the ability to communicate well into adulthood (Anderson et al., 2007; Hus, Pickles, Cook, Risi, & Lord, 2007). Those who remain minimally verbal are at an increased risk for a decreased quality of life (Howlin & Rutter, 1989). Those with autism may rely on visual aids and pictures to assist them with communication (Cafiero & Meyer, 2008).

Autism is characterized by social and communication deficiencies and the way in which information is shared with others. Autism is defined by social deficits that are seen as unique deficits to autism (Tager-Flusberg, 1999). Children with autism received their diagnosis before the age of 4. Younger children diagnosed with autism may have difficulty responding to their name, unlike other children of the same age group. Children with autism may not respond to their mother's voice, are delayed in expression, and also lack receptive skills (Klin, 1991; Lord, 1995; Lord, Pickles, DiLavore, & Shulman as cited in Tager-Flusberg et al., 2005).

Herbert et al. (2005) used MRI technology to study brain patterns and electrochemical functions of children with a developmental language order and high functioning autism. Herbert et al. found that the cerebral patterns were the same. However, the control groups were different as cerebral symmetry was examined. Herbert et al. found that the gray and white areas of the cortical lobes were similar; the brain areas were different as the parcellation units were divided. Herbert et al. concluded that the cortical asymmetry for both experimental groups were suggestive of pervasive anatomical changes that have the ability to affect connectivity within hemispheres in the cortex regions.

Although children with autism often present with communication and language deficits, interventions, such as the use of nonverbal cues along with imitation and joint attention may be beneficial for the child (Charman et al., 2003). In addition, scholars have recommended assistance with the child's comprehension ability during the child's early years (Paul, Cohen, & Caparulo, as cited in Tager-Flusberg et al., 2005). Joint



attention is an early developing social gesture skill typically between an adult and a child that consists of gazing with respect to an object or event (Jones & Carr, 2004). Children with autism may lack the ability to initiate conversations, repeat behaviors and language, and maintain a normal pitch and tone (APA, 2000). According to Hancock and Kaiser (2002), if a child with autism improves his or her language skills, then the child's way of behaving, way of learning academically, and way of interacting with its peers will increase reciprocally.

According to the APA (2000), repetitive and restrictive behaviors are common behaviors in autistic individuals. For example, an autistic child may play with the same toy daily while refraining from playing with another toy. The child may also become obsessed with routine so that any change may result in extreme behavior. A child with autism may repeat the same body movement, such as rocking backwards and forward, hand movements, and pacing in the same direction for an extended period of time (Koegel & Koegel, 1995; Scott et al., 2000).

Richler, Bishop, Kleinke, and Lord, (2007) observed repetitive and restricted behaviors in 165 children with autism and 49 with a nonspectrum developmental disorder, and 65 normally developing children at the age of 2. A nonspectrum disorder is also referred to as non-other-specified for individuals who fail to meet the criteria for autism or any other defined developmental disorder, but may have deficits in communication, social interactions with others, reciprocal communication, and stereotypical behavioral (APA, 2013). Scholars have found that autistic children have similar sensorimotor behaviors and sameness factors. Richler et al. (2007) found that

autistic children displayed finger and hand motions, the repetitive use of the same object, unusual sensory awareness, compulsions, rituals, issues with change, and environmental changes.

A child with autism may seem as though he or she would rather be alone than with his or her peers. Children with autism have social interaction deficits that cause them to struggle with nonverbal behaviors, such as facial expressions, inappropriate peer relationships, interests with peers, a lack of affection, failure to respond to verbal cues, and a lack of social and emotional reciprocity.

### **African American Autistic Children and Education**

African American children are overrepresented in special education (Artiles et al., 2006; Blanchette 2009; Blanchette, Klingner et al., 2009; Connor & Ferri 2005; Donovan & Cross 2002; Harry, Klingner, & Hart, 2006; Reid & Knight 2006). African American students are twice as likely, compared to other ethnicities, to be diagnosed as intellectually disabled, twice as likely to be emotional disturbed, and almost two times as likely to have the label of developmentally delayed (Blanchette, Klingner et al., 2009; Connor & Ferri, 2005). Although there are disparities regarding African American children and special education, many families do not know how to address these disparities. Harry et al. (2006) reported that families often lack the knowledge or rapport with the right supporters to dispute any decisions made by the school system. According to Harry et al., once African American children are in the system, parents report experiences of educators making them feel guilty if their child has a disability as children are blamed for their uncontrollable behaviors. Parents report that educators make them

feel as though their parenting skills precipitated the child's behaviors (Alameda-Lawson, & Lawson, 2004; Brandon, Higgins, Pierce, Tandy, & Silieo, 2010; Zionts, Zionts, Harrison, & Bellinger, 2003).

Schools must provide modifications for children with ASD because children diagnosed with autism benefit from educational services and mastering subject matters (Simpson, de Boer-Ott, & Smith-Myles, 2003). Losen and Orfield (2002) stated that minority children with disabilities experience inadequate educational care, isolation from students without a disability, and low curriculum instruction. Consideration to flexible schedules, the amount of time the student is being mainstreamed and exposed to general students, and effective support must be considered when educating a child with autism (Autism Research Institute, 2007). Children with autism should receive combinations of educational interventions to meet the students' needs (Mesibov, 1994). Educational programs should be individualized to assist the autistic child with social skills and daily functioning skills (Huang & Wheeler, 2006).

### **Family Relationships and Autism**

Parents of an autistic child experience higher levels of stress as they struggle to get the child to interact with them. The child lacks the ability to look the parents in the eye, hold their hands while walking, respond with a smile, and or have a conversation with them (Rodrigue, Morgan, & Geffken, 1992; Seung, Ashwell, Elder, & Valcante, 2006). A parent who has a child with an illness that has no cure may experience stress. Parents of a child diagnosed with autism have a high risk for physical and emotional stress that may result in mental health difficulties (Benson, 2006; Gau et al., 2012; Gra,

2002; Hamlyn-Wright et al., 2007; Lecavalier et al., 2006; Little, 2002; Sivberg, 2002; Woodgate et al., 2008). According to Al-Kandari (2007), caring for a child with a physical or developmental disorder could lead to parental feelings of dissatisfaction. Such stress may be due to unrealistic expectations, a lack of respite support, a lack of resources in the community and schools, or their inability to meet the child's needs. Raising a child with autism is more stressful than raising a child without a disability.

There has been extensive research on autism and how it affects mothers (Baker & Drapela, 2010; Meirsschaut, Roeyers, & Warreyn, 2010; Ogston, Mackintosh, & Myers 2011; Watson, 1998). However, there is little research on the father, stress, and how he copes with raising a child with autism (Altiere & Kluge, 2009). The automaticity of the mother and her relationship with her child has outweighed the impact of fathers and how they affect their autistic child's development (De Falco, Esposito, Venuti, & Bornstein, 2008; Flippin & Crais, 2011; Grossman et al., 2002). The mother and her relationship with the autistic child is often targeted more than fathers and their relationship with the autistic child.

Researchers have claimed that mothers of autistic children experience more stress than fathers (Baker-Ericzen, Brookman-Fraze, & Stahmer, 2005; Dabrowska & Pisula, 2010; Merkaj, Kika, & Simaku, 2013). However, fathers with an autistic child experience comparable levels of stress (Davis & Carter, 2008) or greater levels than mothers (Rivard, Terroux, Parent-Boursier, & Mercier, 2014). According to Baker et al. (2005), fathers who have a child with a developmental delay report more negative impacts on the family than fathers with a child without a disability. More research about fathers and their

autistic child is needed to provide fathers with the support needed to help them care for their autistic child. Because autism is one of the most commonly diagnosed developmental disability in the United States, there is a need for mental health programs to help fathers cope with the daily stressors of a child diagnosed with autism.

Stress can be leveled out if the individual feels supported. There could be resources implemented to help the parent with stress (Lazarus, 1999). Parents cope with the stress via social supports are more likely to be resilient (McCubbin, Thompson, & McCubbin, 1996). Parents of a child with autism often seek outside resources in the community if there are no immediate family members to help them deal with stress (Lazarus, 1999).

Family members are also affected by the child's diagnosis. According to researchers (Baker et al., 2005; Johnson, Frenn, Feetham, & Simpson, 2011; Phetrasuwan & Miles, 2009), family members often experience feelings such as being overwhelmed, which can affect the family members' mental health. The severity of the autism, marital quality, how angry the parent becomes, and the number of children the parent has also affects how the family copes with a child with autism.

### **Marital Satisfaction**

According to Dumas, Margolin, and John (2003), marital satisfaction is comprised of the couple's interaction with each other and how they feel about each other. Marriage is viewed as a system where both individuals react to one another's behaviors. Children who have been diagnosed with a developmental disorder are 3% to 6% more likely to be the product of divorced parents (Risdal & Singer, 2004). Floyd and Zmich

(1991) compared the level of marital satisfaction between parents with and without a child with a developmental disorder. Floyd and Zmich indicated that there was lower marital satisfaction with the married couple with a child with a developmental disorder. According to Dyson (1997), both parents raising a child with autism report stress with regards to parenting, but at different levels. Couples are more likely to experience resilience compared to single parents. For example, parents of a child with a developmental disorder are more likely to stay together as (Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001; Urbano & Hodapp, 2007).

### **Siblings**

For many families, the brother and sister relationship are the most important bond they will have with another individual in their life. From birth, siblings begin to learn from one another as they begin to become one another's best friend, companion, enemy, protector, and role model. Older siblings begin to act as the teacher as the younger sibling begins to imitate their actions and behaviors (Azmitia & Hesser, 1993). Richmond, Stocker, and Rienks (2005) found that the quality of the sibling relationship in the middle childhood years predicts the child's life during adolescence. The sibling relationship is a connection of biological and affective ties (Tsao, 2013).

The sibling of an autistic child may internalize or externalize their problems, have issues with peers around them, and demonstrate delinquent behaviors as well as an increase in hyperactivity and withdrawal behaviors (Benson & Karlof 2008; Gau et al., 2010; Verte, Roeyers, & Buysse, 2003). The autistic child may cause the sibling to

experience anxiety, which may negatively affect the sibling relationship (Hastings, 2007; Orsmond, Kuo, & Seltzer, 2009).

Cook (2006) estimated that there are 7 million children with a sibling who has been diagnosed with a disability. As the normally developing child is introduced to the disability, he or she may have difficulties maintaining and building positive relationships in the future (Crnic & Leconte, 1986). The sibling of a child with a disability usually assumes an increased level of responsibility, which could potentially become a problem (Marks, Matson, & Barraza, 2005). The sibling may experience anxiety with concerns of the disabled child's future and well-being. However, if a sibling is educated about the diagnosis, they are less likely to experience stress and anxiety.

The Simons Foundation Autism Research Initiative Simplex Collection (SSC) explored whether siblings of an autistic child suffered from anxiety (as cited in Shivers, Diesenroth, & Taylor, 2013). The SSC predicted that female siblings would experience more anxiety than boys (as cited in Shivers et al., 2013). It was postulated that the more behavioral problems that the autistic child exhibited, the higher the anxiety of the sibling affected (SSC as cited in Shivers et al., 2013). The SSC concluded that siblings of an autistic child do not have an increased rate of anxiety (as cited in Shivers et al., 2013). The SSC suggested that females might be at a greater risk of increased anxiety (as cited in Shivers et al., 2013). However, male siblings may be more likely to seek professional help (SSC as cited in Shivers et al., 2013).

### **Autism and Cost Expenses**

Being the caregiver to a child diagnosed with autism could be a financial burden. The average medical expense for a child diagnosed with autism in 2011 was about \$3,020 (Lavelle et al., 2014). This cost was 18% higher than a child without a diagnosis of autism (Lavelle et al., 2014). The caregiver of a child with autism may experience costly prescriptions, ER visits, physician office visits, occupational, speech, and physical therapy (Lavelle et al., 2014). In 2011, the cost for a child with autism was \$11.5 billion, which equaled to \$17, 081 per child (Lavelle et al., 2014).

Most insurance companies have a cap that each child may receive, which often results in caregivers paying themselves for care or eliminating services once they have received the limited amount of service offered (Hock, Timm, & Ramish, 2012; Lutz, Patterson, & Klein, 2012). Approximately 43% of parents with a child diagnosed with autism reported financial burdens due to cost for multiple therapies (Child and Adolescent Health Measurement Initiative [CAHMI], 2013). However, the Affordable Care Act helps families with payment for behavioral health treatment and assists the caregiver until the child reaches the age of 26 (U. S. Department of Health & Human Services [HHS], 2013). A child under the age of 3 is eligible to receive state and government funds to assist parents with expenses (Montes, Halterman, & Magyar, 2009; Texas Department of Assistive & Rehabilitative Services [DARS], 2013).

### **Fatherhood and Child Development**

Fathers raising a child with autism experience more stress than raising a child without a disability (Herring et al., 2006). Fathers raising a child with autism reported



stress and marital dissatisfaction and difficulty finding support (Brobst et al., 2009).

According to Pleck (2010), a father is the male figure of the two biological parents. The father could be identified as an uncle, grandfather, or step or adoptive father. Pleck explained that fatherhood is measured by the male's interaction in the child's life, warmth responsiveness, and the decision making for the child. Pleck (2010) acknowledged the significance of the father's role in the development of a child. Pleck stated that fathers uniquely contribute to child development, as outlined in the fatherhood-masculinity model. The fatherhood-masculinity model has six components: gender differences in parenting, father presence resulting in childhood outcomes, frequency and paternal presence, a father's sense of maleness, child outcomes, paternal involvement, and father presence. A new father must adjust to new responsibilities.

Fathers provide many several roles throughout their lifetime, such as a protector, provider, and decision maker (Habib, 2012). According to Nease and Austin (2010), first-time fathers describe fatherhood as providing meaning in the meaning of their lives. However, their expectations as fathers may decrease if they learn that their child is born with a disability. According to Cowan (2010), fathers have a strong emotional reaction to their child being diagnosed with autism, which causes high levels of stress. Having a child diagnosed with autism can place a strain on the fathers and change the meaning of fatherhood for the father (DePape & Lindsey, 2015).

There are few studies on fathers of autistic children and stress, stigma, and coping skills for the father. Fathers of children diagnosed with autism reported higher levels of stress, parenting issues, and lower life satisfaction than fathers of a child without a

disability (Benjak et al., 2011; Darling et al., 2012; Hayes & Watson, 2013). Heam (1995) noted that mothers are concerned about support while fathers are focused on appropriate health insurance, the child's health, and marital satisfaction. Seligman and Darling (2007) claimed that fathers usually focus on the long-term outcome of the child where mothers focus on ways to understand and cope with the disorder. Fathers also focus on how society will accept the child, especially the family as a whole.

According to Rosenbaugh (2009) a report of fathers caring for a child diagnosed with Down Syndrome was examined. In the research, it was revealed there were few negative reports of fathers of the child diagnosed with Down Syndrome. However, a few fathers did report a lack of information in the beginning and feeling alone. Fathers reported the need for emotional support, religious support and support from other fathers.

Fathers of children diagnosed with Down Syndrome reported a large amount of positive aspects when caring for the child. According to Rosenbaugh (2009) fathers of a child with Down Syndrome reported they received a large amount of help from their communities. Fathers reported they received a large amount of information from their healthcare provider and it was very helpful. Fathers were immediately offered respite care as well as professional psychological help. Fathers of the child diagnosed with Down Syndrome wanted to sit down with other fathers to hear their experiences. Fathers reported there was more than enough literature regarding the diagnosis; especially on the internet. Fathers reported once they learned of the diagnosis, they were offered occupational and physical therapy. Fathers reported they could cope with the diagnosis

better due to the amount of services they were offered. Fathers encouraged other dads to attend conferences regarding the child's diagnosis.

### **African American Fathers and Autism**

While searching other dissertations targeting African American fathers raising an Autistic child, there was only one dissertation that appeared and few targeted African American families. Results of dissertations and thesis studies are described in this section. One study in particular was that of (Hannon, 2013). In this study, the father which was the researcher was also the father of an autistic child. Similar to my study, the researcher reported he also experienced various emotions and challenges caring for his child diagnosed with autism. Similarity, fathers in his study also reported a lack of awareness and never knew what autism was. Fathers in the study also described parenting a child with autism as rewarding. Hannon's study also reported fathers found the lack of awareness in the community regarding autism as a challenge; also in the school environment. Fathers in Hannon's study also displayed optimism for the child's future success.

According to Schrader (2013), there are few studies on fathers acting as the caregiver for an autistic child. Most scholars focused on mothers and their lived experiences (Hornby, 1992; Sawyer et al., 2010). Schrader (2013) conducted a study to address the gap in research on fathers and their lived experience with autistic child. The fathers reported experiencing high levels of frustration and anxiety after doctor appointments, tests, and evaluations before they understood that their child was diagnosed with autism (Schrader, 2013). The fathers also reported that doctors behaved

as though they had no knowledge of autism and provided the father with a referral to seek specialists (Schrader, 2013). Four out of seven of the fathers reported that they have increased coping skills to maintain a normal life to the best of their ability (Schrader, 2013). All seven fathers reported that there is a need for more social supports for fathers raising a child with autism.

Simon (2013) investigated African American families and their lived experience raising a child diagnosed with autism. Overall, African American parents experienced feelings of being overwhelmed as well as feelings of empowerment. Similar to my study, the parents in the study reported that not only did they receive the autism diagnosis at a later age, they also dealt with their child being diagnosed with several disorders, such as mental retardation, developmental delay, oppositional defiant disorder, obsessive compulsive disorder, and socially emotionally disturbed. These findings were aligned with reports from other researchers (Mandell et al., 2007; Mandell et al., 2005).

Another study conducted by Parks (2017) focused on African American families raising an autistic child. In this study, parents reported there was a lack of awareness within their communities and family members. She reported her family questioned why they allowed their child to be labeled by “those White doctors”? However, her study also speaks about the African American community labeling “their own kind” because they have a disability. She reports she and other families raising an autistic child, engage with other ethnicities as Blacks “just don’t get it.”

A study by Bethel (2016) also described the parenting experiences from an African American’s perspective. In the study, parents reported raising a child with autism

has its challenges. The study described the lack of awareness among the Black community has a barrier. The report described parents attempting to explain autism and its symptoms to their parents as one parent reported “she’ll be fine, you didn’t talk until later either”. This is an indication the family members were not aware the communication deficit with autistic children. Parents in the study also reported the late diagnosis of autism for their child. Parents in the study reported never knowing what autism was until Black celebrities began to speak out about their children diagnosed with autism such as; Holly Robinson-Pete and Toni Braxton.

Due to the lack of resources and awareness in the African American community, African American parents are forced to educate themselves regarding their child’s diagnosis and available resources as there is little help from outside agencies. The parents learn to navigate the Internet, network with other parents with children of autism, read, and form support groups for parents (Simon, 2013). African American families lack social support with early intervention, interventions that focus on cultural beliefs, and ways to cope with their child being diagnosed with autism (Simon, 2013). This research provided information regarding early intervention assistance in the home and community, medical professionals having a clearer understanding of belief systems from the African Americans perspective, and coping skills used to cope with demands of caring for a child with autism disorder.

In addition to Hannon’s study, he outlined the richness, uniqueness, complexities, and nuances of the African American father and his narratives raising a child with autism. The fathers in the study all reported that they experienced frustration as there was little

information regarding autism (Hannon, 2013). The fathers reported that they wanted to make sure their families were aware of the disorder as well. The fathers in this study reported that they maintained hope, although the child being diagnosed with autism was challenging (Hannon, 2013). The fathers experienced negative racial interactions in various contexts (Hannon, 2013). The fathers reported that it may be difficult to compare his situation to that of a non-African American father as they may not experience issues of disparities of within the schools and difficulty finding services (Hannon, 2013). African American fathers in this study engaged in various coping mechanisms to deal with the stressors of raising a child with autism (Hannon, 2013). The fathers in this study were all a part of a social organization that helped secure adequate services by using their capital (Hannon, 2013). Hannon identified several suggestions for future implications such as a wider participant pool from gay fathers, single fathers, racially diverse fathers, and those with various educational backgrounds. My study differs from Hannon (2013) as his theoretical framework targets the family life cycle theory.

However, this researcher will target the family systems theory. The family life cycle theory explains this framework as family members being affected when an event occurs within the family circle. The life cycle is comprised of several transitional stages throughout the family such as; the coming and going of family members, marriages, births, deaths and retirement. When a family member is diagnosed with an illness, the family takes on a shift. Each family member has a role and function, but the main value within the family is support and nature. Hannon (2012) also used a case study method as this researcher used the interpretative phenomenological analysis (IPA) method.

Santos (2014) conducted a study to explore four fathers' share experiences of having a child with the autism disorder. The fathers in the study reported that there were challenges in raising a child with autism, but they each displayed courage while taking steps to make sure that the child had a bright future (Santos, 2014). The fathers in this study reported involvement with their child (Santos, 2014). Santos reported limitations to the study, such as there not being enough time to conduct research and choosing to ask sensitive questions regarding the father's autistic child.

### **Summary**

This literature review included a description of several characteristics of autism. For many, raising a child means two parents are working together to improve the success of the child. However, as a father takes on this significant role, he is faced with many barriers. Researchers have explored mothers and their perspectives on raising an autistic child. However, there are fathers in the same communities playing the same roles.

Men, as caregivers, play a role in the developmental of the child (Cabrera et al., 2000; Ramchandani & McConachie, 2005). Even though there is little research regarding fathers and their autistic children, there are only few dissertation studies addressing the complexities of African American fathers and their autistic child and more research in this area is warranted. Men are underrepresented in the research as most of the recent studies focus on the mother (Flippin & Crais, 2011). However, fathers require ways to decrease stress, increase positive family dynamics, and increase resources in the school. In Chapter 3, I described the methodology used in the study.

## Chapter 3: Research Method

### **Introduction**

The purpose of this interpretative phenomenological analysis (IPA) was to examine the lived experiences of African American fathers who are raising an autistic child. The emotions of fathers who have an autistic child, their challenges in parenting the child, and their ways of coping were also explored. In this chapter, I review this study's research design and rationale. I also discuss the role of the researcher, participants, sample, data collection, data analysis, and conclusion.

### **Research Design and Rationale**

Researchers use the IPA design to gather the lived experience of several individuals (Smith, Flowers, & Larkin, 2009). Smith and Osborn (2003) reported that an IPA is a fitting approach when the researcher's goal is to discover how participants perceive the experiences they endure. According to Eglander (2012), a phenomenological approach begins with knowing that there is a need to understand a phenomenon from the lived experiences of the participants to discover the true meaning of it. According to Moustakas (1994), phenomenological researchers attempt to find the essences of the participants' experiences. During the IPA, the researcher interviews participants according to their interest in the cause or purpose of the phenomenon. According to Creswell (2013), the scholars should highlight the essence of the experience from more than one person.

I chose a qualitative approach versus a quantitative approach because I desired to explore the participants' lived experience rather than interpret statistical data. According



to Creswell (2013), a qualitative study will allow the researcher to gain a new understanding about a phenomenon, gather and develop new ideas, hypothesize viewpoints about facts, and discover issues that are present within the participants' lived experience. I chose a qualitative versus quantitative study because numerical measurements lack the sensitivity of the participant's race, gender, economic status, and individual differences (Creswell, 2007). The qualitative methodology was more appropriate to respond to the research questions in this study. Qualitative research was best suited for this study as it allows the participants to speak for themselves (Gillian, 2002). Qualitative researchers use in-depth words to provide rich meaning to the given phenomenon (Munhall, 2012). I used the IPA approach to capture the lived experiences of African American fathers raising an autistic child.

I targeted African American fathers raising an autistic child. The research consisted of 12 participants ages 18 and older. According to Creswell (2013), it is recommended that the researcher use five to 25 interviews and participants. By using more than one participant, it is possible the information may be similar or different (Baxter & Jack, 2008; Yin, 2003a, 2003b).

I addressed the following questions:

1. What are the experiences of African American fathers raising an autistic child?
2. What are the emotional reactions of African American fathers after they have learned of their child's diagnosis?
3. How do African American fathers describe their parenting experiences

with their autistic children?

4. What are the challenges that African American fathers experience when raising an autistic child?

### **Role of the Researcher**

According to Merriam (2002), the researcher's role is the most significant as the researcher is the primary instrument for data collection and analysis in qualitative research. Qualitative researchers are viewed as the main instrument of the collection and data analysis (Greenbank, 2003; Page, 1997). According to Creswell (2013) and Leedy and Ormrod (2010), there are several significant characteristics in the collection of data when using a qualitative method:

- The researcher is the main tool as data are collected
- The researcher uses open-ended questions during interviewing
- The researcher uses themes that are collected after the participants are interviewed
- Data collected during interviews are only focused on the participant and not the researcher
- The research design has the ability to change
- During research, the information provided is used by allowing the participant to view the lived experience through a wide lens
- The researcher conducts this research in a natural setting while observing, recording, interpreting, and reporting the described picture of the phenomenon, setting, and meaning to the participants (Stake, 2006).

In this study, I designed this project, conducted interviews, transcribed the interviews, conducted the analysis, and wrote up results.

## **Methodology**

### **Participant Selection Criteria**

Smith and Osborn (2003) claimed that IPA researchers strive to achieve a homogenous sample during the study. Researchers use purposeful sampling. During IPA studies, the researcher uses an inductive approach generating coding that emerges from data collected rather than testing a theory.

The lack of information on the study population made this research significant as there was a gap in the literature. According to Carr and Lord (2013), there is little research on the experiences of African American families with autistic children. In this study, I focused on adult African American males ages 18 and older who spoke English and who had a biological child diagnosed on the ASD. The participants' socioeconomic status, background, and educational levels differed. I targeted African American fathers who resided in the home with an autistic child. Although some fathers were married, I focused only on the father and not the mother or other caregivers in the home. If scholars learn how these processes interact in one person or organization, they will know more about how these processes apply to other similar persons or organizations (McNabb, 2008).

### **Sampling**

When conducting research, the sample size is important (Creswell, 2013). According to Mason (2010), there are guidelines regarding the number of participants

needed for a qualitative study. Sample size for an IPA consists of five to 25 participants with a minimum of six. According to Lodico, Spaulding, and Voegtle (2010), qualitative research generally involves a “small number of individuals to study with “no tables of minimum size samples” (pp. 163-164). The sample size of this study consisted of 12 participants until saturation occurred. Saturation occurs when there are no new data to be observed by the researcher (Dworkin, 2012; Guest, Bunce, & John, 2006), or “when gathering fresh data no longer has the ability to provide new theoretical insights, or theoretical categories” (Charmaz 2006, p. 113). Guests et al. (2006) conducted 60 in-depth interviews which resulted in saturation occurring within the first 12 interviews.

Patton (1996) stated that the meaningfulness and depth that comes from information-rich cases is the aim of qualitative studies, with the skill and knowledge of the researcher as the primary tool for eliciting this data. According to Creswell (2013), a criterion sampling consists of participants who experience the same or similar lived experiences. The sample consisted of fathers who were African American, over the age of 18, were fluent in English, had a biological child diagnosed with autism, and who lived with the child.

### **Purposeful Sampling**

For this study, participants were selected through a purposeful sampling method. According to Lodico et al. (2010), purposeful sampling is the selection of those participants who have key knowledge or information related to the purpose of the study. Purposeful sampling also consisted of selecting participants who provided the most in-depth information. To assist with the recruitment process, I used the technique identified

as snowballing sampling. Snowballing sampling, or chain sampling, is a recruitment technique that facilitates the identification of potential participants by other research participants who may be aware of other individuals who meet the research eligibility criteria because they share the phenomenon under investigation (Creswell, 2013). I used the snowballing method as information regarding the study spread within the community as a result from giving participants a flyer of the study from the outpatient clinic (Appendix D).

### **Setting**

During this study, I gathered the lived experiences of fathers who were raising an autistic child. I interviewed the participants in selected confidential environments to ensure that each participant felt free of any biases that might affect validity. According to Creswell (2007), Leedy and Ormrod (2010), and Phelps, Hodgson, McCammon, and Lamson (2009), it is vital that the interview is given in a natural setting where the participants can relive their lived experiences. The interviews took place in a natural setting at the library. However, I was sure to make the setting safe and comfortable to conduct the interview. I allowed the participants to choose the time of the interview to decrease the likelihood of any distractions that may have interfered with responses. It is expected that using the participants' selected setting will also increase the participant's level of confidentiality.

### **Recruitment and Participation**

I obtained access to a local outpatient center that treated autistic children and helped their families as well. The clinical psychologist allowed me to post flyers

(Appendix D) on the bulletin boards in the outpatient clinic regarding the research.

Participants who were interested contacted me with a time and place for the interview. I sought fathers in the community to participate in the study who met these criteria as well. Next, fathers who responded to the letter of invitation were contacted and made aware of the title of the study, qualifications needed to participate, participant expectations, and my information. The fathers were provided research guidelines that explained that participation in the study is voluntary (Appendix A). Following these steps, a face-to-face interview was scheduled with the participants. Fathers who selected were African American, at least 18 years of age, had a biological child diagnosed with autism, and spoke English fluently. Participants were informed they could stop participation at any time. The participants' names were changed to ensure confidentiality.

All interviews except one, lasted no longer than 30-60 minutes and included open-ended questions. Those who were not African American fathers, who did not have a biological child diagnosed with autism, and who were under the age of 18 were excluded from the sample. Finally, to facilitate the recruitment, I used snowball sampling. Snowball sampling or chain sampling is a recruitment strategy that can facilitate the identification of potential participants by other research participants who might know individuals who fit the research eligibility criteria because they share the phenomenon under investigation (Creswell, 2013).

### **Screening Procedures**

Screening took place as the fathers were contacted regarding their participation with the study. The screening criteria included African American fathers at least 18 years

of age and older who were raising a biological child diagnosed with autism between 18 months and 18-years-old with or without their spouse and had a willingness to participate. Fathers who were most willing to participate in the study were selected. There were a total of 12 fathers selected for research.

### **Instrumentation**

According to Yin (1994), the interview is the most vital source of qualitative data collection methods. The interview consisted of open-ended, semistructured questions that allowed the participant to express themselves freely. The research questions were developed due for the qualitative study. I created the questions with the participants in mind. The research questions were designed from previous studies, the literature review/conceptual issues, and from the theoretical framework. The research questions were created with the intent to help the lives of the participants. The interview was an in-depth conversation. Once the information was shared with me, the information was immediately transcribed for manual coding to eliminate any flaws.

### **Data Collection**

Data collection within qualitative research consists of documented analysis, observations, and interviews. The researcher can use more than one method for collecting data to create more credible findings (Lodico et al., 2010). I listed the data collection methods below.

**Demographic questionnaire.** Participants were asked to complete some basic demographic questions: age of the child, age of the father, number of children in the home, and the gender of the child.

**Semistructured interview.** The primary method for data collection was the use of semistructured interviews, in which an interview protocol made of a list of topics to be explored was the focus point discussed with the participants. “Semi structured interviews are controlled and organized” (Lodico et al., 2010). During the interviews, I asked fathers questions from a list of interview questions (Appendix C). I had the ability to change the order of the questions from a guiding interview list of questions depending on emerging topics (Lodico et al., 2010).

I used the purposeful sampling method. I recorded this information from the participants. The information collected was held in a secure location. The interview questions allowed fathers to speak openly of their thoughts as they learned of the child’s diagnosis, emotional reactions, and challenges of being a father of a child diagnosed with autism. I also asked questions to address respite supports and the lack of and recommendations to other fathers raising an autistic child. Observation and field notes were a part of the data collection used in the research. I referred to notes created during qualitative fieldwork to remember and record the behaviors, activities, events, and other features of an observation. I used the field notes to produce meaning and an understanding of the culture, social situation, or phenomenon being studied.

### **Data Analysis Plan**

In phenomenology, there are several layers involved in the process of data analysis. According to Creswell (2013), data analysis requires questions that help facilitate the interpretation of the data while documenting observations during and following the interview. Data analysis is comprised of investigation, classification,



organization, checking, and the reincorporation of documentation or evidence that allows the researcher to arrive at conclusions or inferences that possess empirical support (Yin, 2014). Miles, Huberman, and Saldana (2014) suggested that data analysis should not be a separate activity from the data collection. In qualitative research, data collection and data analysis are conducted simultaneously. This process allows the researcher to analyze data collected that may reveal new information to help with future research. The researcher then analyzes the data collected for themes or significant statements (Creswell, 2009). The search for meaningful statements relates to the research questions that allow the researcher to develop a greater understanding of the participants' experience as they relate to the phenomenon under investigation.

I analyzed the detailed lived experiences of African American fathers raising an autistic child. During this step, I uncovered recurrent themes and or perspectives. According to Rogers (1957), the researcher interprets the data to help expose the father's personal meaning of their lived experiences. Rogers (1949) believed that the clinician's goals should be to "perceive as sensitively and accurately as possible all of the perceptual field as it is being experienced by the individual " by indicating to the individual the extent to which he is experiencing the issue through the individual's eyes (p.87). The data allowed me to identify areas of concern quoted from the fathers raising a child diagnosed with autism. Data found during this phase contributed to the conclusion of recurring themes.

I used an Olympic recorder to audio tape the interviews with each individual father. I listened to the audio recordings several times to confirm the validity of the

father's statements. I transcribed and organized the information collected from the fathers. I focused on the method that consisted on the selection of codes. A code is used to concisely summarize. Miles et al. (2014) described coding as a "chunk of information" based on the collected data. A codebook was used to guide the analysis from the interviews. A codebook consists of a record of the emerging codes to facilitate the organization or reorganization of data into categories (Saldana, 2015).

Using a codebook allowed the researcher to stay organized as data quickly changed and data analysis progressed. The researcher recorded the themes with paper and pencil on hardcopies of the transcribed data. A significant part of the coding method is the condensation of information that allows the researcher to extract the most significant information. During this process, salient codes were used to eliminate the possibility of duplicate themes. However, if a code is assigned to a data chunk the purpose is to screen for reoccurring patterns of data (Miles, Huberman & Saldana, 2015). Codes have the ability to change during the data analysis process (Miles, Huberman & Saldana, 2015).

Thematic analysis is a technique that recognizes, scrutinizes, evaluates, describes and informs others about pattern and themes that have been noted within the data; ergo, Yin's pattern matching data analysis technique is closely related to thematic analysis (Braun & Clark, 2006). The purpose of thematic analysis is to recapitulate the data into themes (Ryan & Bernard, 2000). Thematic analysis is rich in its usefulness as it can be an essentialist or realist tool. Thematic analysis describes the reality and meanings of the participants in the everyday lives; or acts as a constructionist's method targeting the lived experiences and realities are the outcome of discourses operating within the walls of a

society. As I compiled all data, I then identified emerging themes associated with the lived experiences of African American fathers raising an autistic child that were coded.

### **Issues of Trustworthiness**

Trustworthiness during qualitative research refers to the process of being compliant with research protocol and upholding integrity during the study's findings. Trustworthiness involves the research process and design, data analysis, and reporting of findings (Hays & Singh, 2012). According to Creswell (2007), qualitative studies entail verification whereas, quantitative studies have validity and reliability measures. Thomas and Magilvy (2011) reported that in qualitative research, the goal is to develop an understanding of the lived experience. However, during quantitative research, the focus is based upon data that builds theory and knowledge.

I was sure to confirm the study findings were accurate and valid so that this research can be used for future implications in the field of psychology. I used several characteristics, such as accuracy, credibility, transferability, dependability and confirmability (Denzin & Lincoln, 1994; Lincoln & Guba, 1984).

### **Accuracy**

I allowed the participants to review each document that included information derived from their lived experience. Each participant was asked to make any corrections to any errors found within the manuscript. All participants confirmed their information was accurate. I also used the method of triangulation. This method consisted of cross-referencing for verification.

### **Triangulation**

As themes emerge as the researcher manipulates multiple resources, triangulation evolves (Creswell, 2013). According to Barusch, Gringeri, and George (2011), triangulation is the use of multiple data sources about the same topic, which that adds richness to multiple perspectives. When conducting qualitative research, researchers use triangulation to pin-point effects, create a common point of view, and establish and maintain rigor. Triangulation of data gives the researcher the ability to uncover imminent data and to provide richer and truer reflections (Casey & Murphy, 2009).

### **Credibility**

According to Patton (2002) credibility is an assessment that detects the information provided by the participants is correct. An example is the accuracy of representation of the participants lived experiences and actions. I maintained contact with the participant's over a period of time to produce a credible foundation. I confirmed there were no repetitious statements from the participants which helped confirm the credibility of the data provided. I confirmed the data are credible by performing saturation of the themes resulted from interviews.

### **Transferability**

Transferability in this study refers to how closely the findings of this research might be compared to studies researched along the same lines, involving a similar number of participants. Although qualitative research is argued not to be generalizable, basic qualitative research transferability, meaning the research site may be similar to other sites and settings. To improve transferability, the study gathered detailed descriptions and background and context information (Lodico, et al., 2010). The focus to

thick descriptions and detail can better allow the reader to decide the usefulness of the study to their own situations.

### **Confirmability**

The coding methods were clearly in the results section of this study for future implications. A chronological audit was stated in the researcher's log which described every research activity, from when IRB approval was granted, to the last step in data analyses process. The researcher's log documented the researcher's mode of thinking, decisions made during the research process, and reflexivity.

### **Ethical Procedures**

Approval to conduct this research was provided by the institutional review board (IRB) before the researcher began the experimental process. I confirmed confidentiality by refraining from the use of the participants' names. The participants were identified by Participant #1, Participant #2, Participant #3 etc. A password was used for the security of the raw data collected from the participants during the research. I provided informed consent forms to confirm the participant's' approval to be a part of the research. However, the participants were informed that they have the right to discontinue the process at any time.

The informed consent provided the participant with the purpose of the study they were involved in, my role as well as their role, and the risks and benefits of the research. The risks of the study may have resulted in fathers becoming emotionally involved as past events may have resurfaced. The benefits of the research may have resulted in an increased awareness of the disorder. The researcher could have provided resources to the

fathers to eliminate stress. The data collected from the research, such as notes, recordings, and personal information, was locked in a safe to maintain security and confidentiality. The information saved on audio tapes, notes, and the hard drive is saved and will for 5 years before it is then shredded (Creswell, 2013).

### **Summary**

The purpose of this study was to explore African American fathers' lived experience of raising an autistic child. An interpretative phenomenological analysis was conducted during this research. The researcher used open-ended, semi-structured questions during the interview. The participants were African American, married and single, had a biological child diagnosed with autism, be 18 or older, and resided in the state of Georgia. I used audio tapes and direct observation for data collection during this study. Information from these data produced themes that were transcribed. The goal of this study was to provide a greater awareness of autism and to provide the African American father hope for support and resources in the future.

In Chapter 4, I discussed the findings of this study about African American fathers lived experience of raising a child with autism. The results of the study indicated African American fathers appeared more hopeful rather than depressed, but did report being angry and sadness about their child being diagnosed with autism. African American fathers did not report signs of anxiety or depression when discussing the effects of raising their child diagnosed with autism.

## Chapter 4: Results

### **Introduction**

The purpose of this qualitative, interpretative phenomenological study was to explore the lived experiences of African American fathers who are raising a child diagnosed with autism. The interviews focused on four main questions: RQ 1. What are the experiences of African American fathers raising an autistic child? RQ2. What are the emotional reactions of African American fathers after they have learned of their child's diagnosis? RQ3. How do African American fathers describe their parenting experiences with their autistic child? RQ4. What are the challenges that African American fathers experience when raising an autistic child?

The data have the ability to identify the ways to appropriately prepare and support African American fathers in raising their child diagnosed with autism. This study can contribute to social change through understanding and raising awareness regarding the psychological and emotional needs of African American fathers in their task of raising their child diagnosed with autism. This understanding and awareness will help those African American fathers who struggle with accepting their child's diagnoses and who may be reluctant to seek help. This chapter presents the findings of this interpretative phenomenological qualitative study of African American fathers raising an autistic child. Sample characteristics, data analysis, codes grouped by themes, participant quotes supporting the findings, evidence of trustworthiness, and chapter summary are included in the chapter.

This chapter begins with a general description of the demographics of the participants as a group. Data collection methods are explained. Next, the data analysis procedures are outlined, and emergent themes are discussed. Evidence of trustworthiness are presented. Finally, the results are presented, and themes are discussed in greater detail.

### **Setting**

I obtained access to a local outpatient center that treats autistic children and helps their families as well. The clinical psychologist allowed me to post flyers (Appendix D) on the bulletin boards in the outpatient clinic regarding the research. Participants who were interested contacted me with a time and place for the interview. I also sought out fathers in the community to participate in the study who met these criteria as well. Fathers who responded to the letter of invitation were contacted and made aware of the title of the study, qualifications needed to participate, participant expectations, and my information.

The fathers were provided with research guidelines that explained participation in the study is voluntary (Appendix A). A face-to-face interview was scheduled with three father participants (in a local library) as the remaining 12 were conducted over the phone. Fathers selected were African American, at least 18 years of age, had a biological child diagnosed with autism, and spoke English fluently.

Participants were informed that they had the right to stop the interview at any time. However, none of the participants did so and completed the interview process



successfully. Participants' names were changed to ensure confidentiality. Interviews did not last longer than 30-60 minutes and included open-ended questions.

### **Demographics**

The descriptive data explores and summarizes how African American fathers raising an autistic child describes their lived experiences. All fathers were African American, at least 18 years of age, residing in the home with the child diagnosed with autism, and spoke fluent English. All fathers except one had other siblings in the home. One father reported his son was the only child. All fathers confirmed that their child was diagnosed with autism. All of the fathers except one was married to the child's mother.

For the purpose of this research, none of the father's real names were used, and participants were identified by fictitious names. All participants were identified as "fathers" or "participants" to protect their identities. Interviews took place over the phone or at a local library, which was chosen as it is a public setting. All fathers were connected by being the African American father raising an autistic child. All participants were provided a \$25.00 Starbuck's gift card for their participation. A sample of the father's demographics can be found in Tables 1.

Table 1

*Participant Demographics*

	Father's Age	Child's Age	# of Children at Home	Gender of Child
Father 1	42	12	2	Male
Father 2	40	12	2	Female
Father 3	40	9	2	Male
Father 4	40	11	1	Male
Father 5	30	8	2	Male
Father 6	27	7	3	Male
Father 7	39	13	1	Male
Father 8	48	10	3	Female
Father 9	30	6	3	Male
Father 10	42	13	4	Male
Father 11	41	16	3	Male
Father 12	42	9	4	Female

### **Data Collection**

I collected the data for 6 weeks from 12 African American fathers raising a child diagnosed with autism. All data were collected through semistructured interviews using the interview protocol (Appendix C). I followed my procedures for recruitment and data collection, and all interviews were completed successfully. I desired to interview more fathers face-to-face; but, only three of the 12 fathers were able to do so. The remaining nine fathers completed the interviews over the phone successfully.

To maintain privacy, each face-to-face interview was conducted at a local library that consisted of a natural setting. The length of the interviews ranged between 45-60 minutes. One father's interview lasted longer than 60 minutes. I used an Olympus digital voice recorder to record the responses during the open-ended interviews. The recordings were then stored onto a separate USB flash drive. I then transferred the recorded responses from the fathers to a separate Word document that was hand-written. I listened to the responses carefully as I hand wrote the open-ended responses. I listened to the responses several times for validity for accuracy.

Copies of the transcriptions were placed on a USB flash drive and stored in a locked cabinet in my home. I called each participant to schedule a date and time to e-mail the responses following the interview to confirm validity and accuracy. All fathers confirmed the accuracy of their transcripts over the phone as I read their responses aloud. All fathers shared their lived experiences. There were a few fathers who shared more than others.

### **Data Analysis**

The process of coding data, according to the IPA qualitative research tradition, is flexible and led by the goal of uncovering the ways in which participants make sense of their lived experiences (Braun & Clarke, 2006; Smith et al., 2009). Upon the completion of data collection, I became the transcriber, a role I took to be sure I experienced every step of this phase of the study. Although it took time to transcribe each interview, I was able to internalize the participants' thoughts.

While transcribing the data, the goal was not only to familiarize myself with participants' self-reports, but also to develop a deeper understanding about participants' lived experiences with regard to the phenomenological research questions under exploration (Moustakas, 1994). Rogers (1949) believed that the clinician's goals should be to perceive as sensitively and accurately as possible all of the perceptual field as it is being experienced by the individual. This is accomplished by explaining to the individual the extent to which he or she is experiencing the issue through the individual's eyes. The data allowed me to identify areas of concern quoted from the fathers raising a child diagnosed with autism.

Each father was numbered 1 to 12 as this helped with identifying each father. I identified each father by his number and removed any names. Once the interviews were transcribed, each father read and confirmed his transcript was accurate. None of the fathers requested any changes of their documented statements. Once accuracy was confirmed, I began the process of coding. I was able to keep my data organized by creating a coding template that I used to code each transcript. Each code was saved from

the father's transcript as "Father 1 Coding" The coding consisted of three individual columns as the first consisted of raw data, the second consisted of the line-by-line coding, and the third was identified as focused coding. A sample of this line-by-line and focused coding can be found in Tables 2 and 3.

Table 2

*Sample of Interview Excerpt Line-by-Line and Focused Coding*

Raw data	Line-by-line coding	Focused coding
<p>Q. Tell me about your child diagnosed with autism. How would you describe him?</p> <p>My child with autism is high on the spectrum a lot of times non-verbal, he's a lot of times slow moving, he is nonsociable, he doesn't like to go a lot of places; especially around a lot of people and he just really wants a lot of attention.</p>	<p>High spectrum autism Aware of her diagnosis</p> <p>Autism symptoms may not be noticed initially May appear to be a "normal" child</p>	<p>Characteristic of autism Awareness of autism Awareness of autism</p>

Table 3

*Sample of Interview Excerpt Line-by-Line and Focused Coding*

Raw data	Line-by-line coding	Focused coding
Q. Tell me about your child diagnosed with autism. How would you describe him?		
My child, you have to tell him things over and over and I have to re-direct him with that. He also says things over and over and I have to tell him, “son I don’t want to hear that again”. He’s the same as other little kids, but he’s just a little different	Forgetfulness Teacher of his child Repetition of words Teacher of his child/blunt with child Father feels child is normal	Symptom of autism Disorder Father Interaction With son of Autism Disorder Father normalizing behaviors

As Smith and Dunworth (2003) discussed, engaging in the process of coding each interview separately assists in gaining the necessary insight about each participant’s lived experiences. The line-by-line coding was important in guiding the data analysis as it helped clarify my decision regarding the kind of data needed to focus to begin to distill the qualitative inquiry. The focused coding process was necessary in narrowing my inquiry on data that were relevant and meaningful in conceptualizing emerging themes (Charmaz, 2004). The coding process, including the line-by-line coding and focused coding, was an essential aspect of data analysis as it assisted with identifying emerging trends or themes from all 12 interviews (Dcuir-Gunby, Marshall, & McCulloch, 2011). At

the end of each father's coding, I created a section titled: memo. The memo allowed me to insert my overall opinion of the father's interview. A sample memo is below.

MEMO: This father made me feel as though learning his child was diagnosed was scary as he felt lost as a parent. The father made me feel as though with a lack of information, he never gave up on his child as he identified himself as being his son's "go-to" person for anything. The father painted the picture of having a close bond with his son. The father increased his knowledge of the diagnosis and shared this with other parents with similar experiences. The father made it seem as though raising a child diagnosed with autism isn't easy, but possible.

Following creating the memo, I then created definitions of data located in the focused coding column. The definitions consisted of the father's exact words to name and define such definitions. For example for "activities father shares with child," the definition consisted of activities the father engages in with the son such as playing video games and play basketball. Once all codes for the interview were listed and defined, I began the process of abstraction. In abstraction, codes are grouped together in terms of the similar themes that they express (Smith et al., 2009).

One of the themes that was identified in each father's interview was "father's emotional reaction." I defined this theme as the father reported feeling sadness, crying, and being distraught when he found out details of the diagnosis. After this theme was created, I then went through the interview and found all codes that related to the overarching theme. In comparing each interview and the participant's shared and unique experiences, I reverted back to my first transcriptions to edit and refine themes that were

previously identified in earlier transcripts. I was sure to minimize themes that fit in the category of previously recorded themes. For example, if a theme stated, “father felt unsure of how others would treat his son at the family reunion,” I went back to the transcript and broke this statement down to fit into two overarching themes. I targeted themes focused on the father’s emotional reaction and the lack of awareness of autism disorder.

Finally, once all transcripts had been coded and the family of themes created for each individual form of data, I then created one large document to capture the themes from all fathers’ interviews. A codebook was used to guide the analysis from the interviews. A codebook consists of a record of the emerging codes to facilitate the organization or reorganization of data into categories (Saldana, 2015). Using a codebook allowed me to stay organized as data quickly changed and data analysis progressed. The left column listed the theme and its definition. The middle column considered the numeration of each code, and the third column represented how many times it appeared in each interview throughout the data (Smith et al., 2009).

Table 4

*Sample Codebook*

Theme	Number of Times It Appears	Number of Interviews I Appears In
The overarching theme refers to fathers identifying such descriptions as sadness, anger, guilt, blessed and optimism.	47	Interviews 1-12



Following the creation of my large codebook, I identified codes that presented the most significant to the fathers and how these codes and themes related to the research questions. My goal was to identify reoccurring patterns and or experiences. Data collected from the fathers' responses were compared, consolidated, coded, and compiled at the end to confirm the consistency and accuracy of the data interpretation. There were no instrumentation changes, alterations, or modifications to data strategies. I stopped reviewing here. Please go through the rest of your chapter and look for the patterns I pointed out to you. I will now look at Chapter 5.

### **Evidence of Trustworthiness**

The data from this study resulted from open-ended interviews of the 12 participants. The interviews were audio-taped, and I manually transcribed them. I checked each transcript for accuracy and validity. Each participant received a copy of the transcript of his interview via e-mail to provide the participants the opportunity to confirm accuracy and also to correct responses to interview responses if necessary.

All participants confirmed their responses to the interviews were correct. Safeguards were discussed to minimize potential bias from influencing results obtained in this study. Merriam (2009) described this step as essential to the internal validity process of qualitative research. I became familiar with standards of quality for the specific type of qualitative investigation that was utilized in this study; but, I also worked to demonstrate credibility, transferability, dependability, and confirmability in this study.

**Credibility**

As discussed in Chapter 3, the accuracy of the data was based on verbatim transcripts of the recorded interviews. One digital recording device was utilized for each interview to ensure accuracy of the narrated accounts provided by each participant during the interview process. All of the collected data was transcribed from the recording device and typed into a Word document to ensure the integrity of the content of all provided responses. After the initial transcript was created the researcher re-played each interview to ensure that the transcribed data was accurately captured word by word based on the content of the interview. This extra step helped detect any potential omissions that could compromise the integrity of the data and the responses provided by the participants. Credibility was attained as a result of an accurate description of the lived experience of African American fathers raising a child diagnosed with autism.

**Transferability**

According to Yin (2011) transferability can be established by ascertaining if the findings of one study can be applied and generalized to another study. According to Patton (2002), findings are considered to have a transferable quality when researchers conduct a similar inquiry in a new or different setting and obtain an outcome consistent with the original study. It was significant for me to identify and describe each father's unique experience so this study can increase data researched and collected by other African American father's raisins an autistic child. Information about each participant was collected in the interview process, and information was also explained both in words and in figures so readers can comprehend other fathers who have shared these lived

experiences. Throughout the data collection process, I paid careful attention to the context of the participant's experiences. Through these efforts, I was able to obtain a thick description of the participant's experiences and promote the transferability of this study (Mills, Durepos, & Wiebe, 2010).

### **Dependability**

Dependability relates to the degree at which findings from the research are consistent and valid and could also be repeated in yet another study. Dependability was confirmed through the use of quotes from the transcripts, which included textural and structural descriptions. In this way, congruence between the data and the report were maintained. I was sure to include quotes from participants within the context. The issue of dependability involves the attempt to examine and ensure the process of the qualitative inquiry in the way in which there is consistency overtime under different conditions (Lincoln & Guba, 1985). To increase the research dependability, each step of this research was described in detail, and evidence of empirical support and researcher decision making was thoroughly documented. Throughout the process of data collection, a detailed audit trail was maintained to confirm all processes for this study were organized and accessible during analysis (Nowell et al., 2017). Full disclosure was important in ensuring that the data was dependable and presented without bias or exclusion. The duration of the study and the content quality contribute to dependable results. It is very likely if this research were conducted in this same manner, the same results would exist.

## **Confirmability**

Confirmability is the extent in which the researcher maintains neutrality so that participants' responses dictate the outcome of the study (Bloomberg & Volpe, 2008). Confirmability involves steps taken to ensure the minimization of personal bias diluting the quality of the study include ongoing self-reflection or checking throughout the inquiry. The other step utilized to address concerns of confirmability involved documenting data collection and steps of analysis. To confirm the results from this study, I minimized the possibility of personal bias by diluting the quality of the study by ongoing self-reflection and checking data throughout the inquiry. The other step utilized to address concerns of confirmability involved myself documenting data collection and steps of analysis throughout the study. I, also read and re-read, listened carefully and analyzed all data. Member checking will ensure credibility by allowing the participant to review the transcript for accuracy (Creswell, 2013). To address member checking, I used probes as needed, for participants to clarify or expand on their information. I also sent each participant through shared e-mail addresses, a summary of their interview transcript to review, correct as needed, and e-mail back to me (if needed). Member checking took place during the interview process and the conclusion of the study where participants reviewed their responses which increased credibility.

The next section will include four major themes of the study: father's interaction with the child, father's emotional reactions, discipline of the child, awareness of autism and supports for autism. Table 5 contains the various themes that emerged from the data, including a description from the themes.

Table 5

*Emergent Themes and Subthemes*

Emergent Themes	Subthemes
Theme 1: Father interaction with the child	Playing video games Interacting in Outside Activities Taking the child to their appt's (Therapy)
Theme 2: Emotional Reactions	Sadness, Guilt, Anger, Blessed, Relieved, & Optimistic
Theme 3: Discipline of the Child	Child manipulates father Does child understand discipline and punishment Father often unsure of ways to discipline
Theme 4: Awareness & Support of Autism	Father lack of awareness of autism Society's lack of knowledge of autism Resources

**Findings**

All of the fathers in the study reported this was the first time they participated in a study regarding the father's experience raising their child diagnosed with autism. The fathers reported it made them feel as though they had a voice and that it also felt great to give advice to other fathers who also have a child diagnosed with autism. The fathers reported that if they had participated in a study as this earlier, they would have been better prepared to raise a child diagnosed with autism. Fathers reported that before their child was diagnosed with autism, they never knew much about the diagnosis. A few of the fathers became emotional during the interview feeling happiness, guilt, and sadness. Most of the tears occurred as fathers spoke about how proud they are of the child and about being their father.

## **Research Question 1**

The first research question of the study was: What are the experiences of African American fathers raising an autistic child? One theme reflected a response to this research question, father's interaction with the child. The following subthemes were related to the main theme and they represent the many ways in which fathers interacted with their children: Playing video games, interacting with the child in outside activities, and taking the child to their appointments.

**Theme 1: Father's interaction with the child.** The first organizing theme to emerge in these data was present in all 12 interviews with participants. This theme referred to how fathers interacted with their child diagnosed with autism. Across all participants accounts, father's interaction with the child and codes related to this theme appeared consistently throughout the data. Fathers saw themselves as being more involved with their children than their spouses. Three subthemes were identified to make the meaning of the ways in which fathers interacted with their children. The first subtheme involved playing video games as an activity in which fathers interacted with the child. The second subtheme identified the father interacting with the child with outside activities. The third subtheme consisted of taking the child to their appointments as means of interacting with the child.

**Playing video games.** The subtheme playing video games was consistent with most fathers in the study. Fathers described playing video games as a way of establishing rapport and increasing communication with the child. Participant 1 shared, "the pediatrician told me I have to find a way to get into his world and only then would I

notice a breakthrough.” Participants shared that the purpose of playing video games together was to increase interaction and contact with their children. Participants disclosed that their child’s doctor encouraged them to try to find things their child enjoys doing and also increasing more hands-on activities to build rapport with their child.

Several fathers mentioned Mind Craft as a very popular video game among children diagnosed with autism. Fathers described that while playing the video game, they realized their child began to communicate more. Participants shared in the eyes of the child it was just a game; but, to the father it was a great communication tool. Participants described playing video games began to be a daily interaction following homework.

Participant 1 said:

I noticed he was watching a lot of video games and I kind of asked him do you want to play it or you just like to watch it? He said he likes to play it, I got it, and he's been playing it a lot; you know I play it with him.

One father shared that when he and his son play the video game Mind Craft, they talked and laughed a lot. Participant 9 said, “Before me and my son started playing video games together, he would walk pass me like I wasn’t there because he lacked communication skills.” Participant 10 disclosed, “When we play the game, my son talks a little. However, he doesn’t like to talk much and gets easily irritated.” The father disclosed he allows his son to lead the conversation, and it is still an enjoyable interaction among them.

**Interacting in outside activities.** The second subtheme was identified as fathers providing examples of interaction with outside activities. Fathers explained this activity as a sign of progress as most children diagnosed with autism may display a dislike for interacting outside of the home. Fathers described ways in which they interact with their children in public, and also stated the difficulties of doing this. One father reported his son will go out to eat in public; but, they really have to monitor the length of the activity as the child began feeling very uncomfortable.

Participant 1 said:

He is nonsociable, he doesn't like to go a lot of places; especially around a lot of people. I have to really think about where we're going, how long we will be there, how many people are there; even where the table is located in the restaurant. My son with autism got to the point he would not eat in public. My son has to learn how to overcome challenges and taking him out to eat in a public place helps.

Other father reported similar experiences with their child diagnosed with autism.

Fathers appeared to express happiness when describing the activities that they engaged in with their child; despite the diagnosis of autism. Participant 2 shared activities he and his daughter enjoy although she would rather be alone and inside of the home.

My daughter enjoys the movies, but she has a sensory deficit. However, I don't allow this to stop us from enjoying the movies and I take her out of the movie if I notice her covering her ears. But um she's not very, I don't want to say outgoing; she would much rather be inside, if it's up to her. She has no issues being to herself.



Other participants expressed similar experiences regarding taking their child diagnosed with autism to outside activities despite challenges. Participant 4 disclosed, “My son doesn’t like going out of the house much, but we go to the playground, movies and to restaurants together a lot”.

Participant 9 said:

Although, church is not her favorite place to go and she tells me the choir hurts her ears sometimes. I can tell she is getting aggravated and myself or my wife will take her outside until the song is over. I think the people in church look at us crazy sometimes when we leave as soon as the song starts, we still get up like it’s nothing. They may be looking, but back in the days she uses to have meltdown when the choir sang, now we just step outside when she covers her ears.

Participant 3 said, “Me and my son like to attend football games; he loves Alabama games.” Participant 4 said “If there is one activity me and my son do the most, it would be going to the movies, going to the playground and restaurants.”

Participant 6 reported, “Me and my son run a lot, this is a skill we have in common. My son wants to be an Olympic runner one day.” Participant 7 said:

Me and my son go to the playground a lot. However, our number one activity to do outside of the home is swimming. As a child I never liked to swim, but now it’s something I actually look forward to. We also like to hang out in my mancave together.

Participant 9 shared he and his son enjoy going to the playground, swimming and bowling. Fathers described engaging in outside activities with their child, and they appeared to look forward to the experience just as much as the child.

**Taking child to appointments.** The third overarching subtheme was identified as fathers taking the child to their appointments which increased the father and child's interaction. None of the fathers described taking their child to their appointments as a burden or hassle. The fathers desired to take on this task, even changing work shifts to be able to do so. Participant 1 said:

I am always the parent that takes my son to his appointments. This is a time when we bond in the car and we sing and talk along the way". "I'm normally the one that takes him to his appointments, counseling sessions, speech sessions, um and you know I think it's very important for him to learn more. I'm normally the one that attends the field trips and those activities and I'm normally the only father there, or parent there.

Participant 9 disclosed:

I had been laid off from my job, but this allows me more time to interact with my son. I also wanted to take him to his appointments so I can bond and know my son like his mother does.

Participant 11 said:

I take my son to his appointment so my wife doesn't have to. My son only likes being out with me most of the time and my wife hate this. I know she's jealous,

but she said she aint, I know she lying though. He really doesn't like being out with his mama and he said she takes too long.

Most of the fathers also saw the task as relieving their spouse of being concerned with taking the child to the appointments. The fathers appeared to have a desire to ease the load off of the mother by taking on such a task. None of the fathers described this task as a burden and enjoyed this time with their child.

### **Research Question 2**

The second research question of the study was: What are the emotional reactions of African American fathers after they have learned of their child's diagnosis? One theme reflected a response to this research question, fathers' reaction after learning their child was diagnosed with autism. The following subthemes were related to the main theme and they represent the many ways in which fathers emotionally reacted to the autism disorder, that is, sadness, guilt, anger, blessed, relief, and optimistic.

**Theme 2: Fathers' reaction to autism.** The first organizing theme to emerge in this data was present in all 12 interviews with participants. This theme referred to how fathers reacted after learning their child was diagnosed with autism. Across all participants accounts, father's emotional reaction after learning of the disorder and codes related to this theme appeared consistently in the data. The father's description of their reactions resulted in five subthemes. The subthemes were sadness, guilt, anger, blessed, relief, and optimism.

**Sadness.** While describing emotional reactions after learning their child was diagnosed with autism, fathers reported feeling a sense of sadness. However, fathers did

not report sadness for themselves, but for their child. Fathers thought of all the challenges the child would endure as a result of the autism disorder. Fathers described their times of sadness following learning their child was diagnosed with autism.

Participant 11 said, “I would sometimes pull over on the side of the road and cry before going home. I cried a lot of nights.” Participants described experiencing several emotions and questioning their manhood. Participant 4 shared, “When they told us my son had autism, I felt sad at first because like I um said, I really didn’t know what it was.”

Participant 9 said:

Man, you talking about a man with his emotions all over the place. I use to think a man shouldn’t feel that way, but I did. Hell, one time I thought I needed to be in therapy and looking back I probably should have been.

**Guilt.** Fathers reported feeling guilty for several reasons following learning their child was diagnosed with autism. Fathers described guilt for past mistakes, for being old, for not testing the child earlier, and for drinking beer while the mother was pregnant with the child.

Participant 1 disclosed:

I felt guilty after learning my son was diagnosed with autism because we should have had him tested for autism earlier. I think there were many challenges that could have been avoided. You know it tough having one child with autism and one without it.

Another father reported feeling guilty because he thought his daughter had autism because he was old. The father stated he was distraught when he found out this was not

the case. A second father reported feeling guilt after finding out his son was diagnosed with autism and began blaming himself. The father cited to how quiet he was a child and did not speak or socialize much.

The father reported he too, began to blame himself following the autism diagnosis. The father admitted he did not know exactly what he did wrong, but for some reason he felt it was his fault as a father. Fathers felt guilt due to unhealthy habits engaged in while the mother was pregnant. Participant 10 cited, "Shit, I thought it was my fault for drinking beer when she was pregnant."

One father blamed his incarceration stating, as he found out his son was diagnosed with autism, he instantly felt guilty as he was in and out of jail growing up. The father reported he felt it was his bad luck as he was not the nicest person in the past. Fathers continued to experience blame as one father reported he felt guilty and told his wife they had to have missed something when he was a baby. Fathers appeared to experience more self-blame following their child being diagnosed with autism. None of the fathers reported blaming their wives for their child being diagnosed with autism

**Anger.** There were not many fathers that identified anger as an emotion following finding out their child was diagnosed with autism. However, two fathers experienced the emotion of anger for several reasons. Fathers reported they felt angry for not knowing about the diagnosis to being angry at God. One father reported experiencing selfishness after learning his son was diagnosed with autism.

Participant 6 reported:

I immediately thought of all the father and son things we would not be able to do together. What father doesn't dream of playing sports, getting dirty in the mud and climbing trees like I use to, liking fast cars like me and taking him to all kinds of games. But I came to realize my son does like sports, just not the one's I use to enjoy as child.

One father disclosed during the interview he asked God why would he give him a son that has autism. However, the father quickly stated he knows he cannot play God and there is nothing he can do to make his son not have autism. One father reported, after his wife suspected his son showed signs of autism, he immediately became angry with her for thinking something was wrong with his son. Participant 2 stated, "I won't lie and say I wasn't upset by it because it wasn't about myself, but about the challenges she would have."

**Blessed.** Following the fathers providing accounts of emotional reactions such as sadness, guilt and anger, fathers also reported feeling blessed. Participant 1 stated, "Following the sadness and hurt, I began to realize I was blessed to be my son's father." Participant 2 disclosed, "There were challenges early on, but we got over them. She is a testament to that and I am blessed to have her and be her dad."

Another father reported during the interview, he felt even more blessed to be his son's father following learning of his son was diagnosed with autism. Participant 4, "I feel really blessed to be my son's father." Participant 6 reported, "Although my son gets on my nerves, I am blessed and thankful for my son." Fathers continued to report feeling

blessed following finding out about the autism diagnosis. Participant 8 stated, “I know my baby was a gift from him you know, she’s my little angel and blessing.”

**Relief.** Father’s also expressed a sense of relief following learning their child was diagnosed with autism. Participant #1 shared, “I was relieved when we received the news, but thankful to receive answers. I mean, my son is my best friend.” Fathers reported their wives also felt a sense of relief as well after finding out about the autism diagnosis. Participant # 9 expressed “My wife admitted she felt relieved about the diagnosis and I told her I couldn’t lie because I was too.”. Fathers expressed though they didn’t want anything to be wrong with their child, they were relieved to finally get answers. One father reported he immediately jumped into finding out ways to help his son.

Participant #2 said: But, all and all there was something different about her and when she was diagnosed it was a relief and about getting her right and the proper diagnosis, getting the right therapy and I can say she is far beyond what I feared when she was diagnosed at this point.

Although, fathers felt many emotions regarding autism, they experienced similar emotions after learning their child was diagnosed with autism. Participant 11 reported, “I felt so much relief when I found out I was not the cause of his autism and the damn doctors don’t even know where it come from.”

**Optimistic.** Although fathers identified feelings of sadness, anger and guilt, there were also positive feelings such as optimism. Fathers described a sense of optimism despite their child being diagnosed with autism and continued to focus on the things the child could do, rather than their diagnosis. Fathers appeared to continuously set goals for

their child as they refused to allow the autism diagnosis to define or hinder their child's future.

Participant 1 shared, "When I first heard about the diagnosis I thought it is something that he may not overcome, but I believe that he can. I will do whatever it takes for him to succeed." He went on to say, "I look at the progress that she has made as far as her being extremely intelligent and it's evident she is. I have faith in what I've seen and what I believe in."

Participant 2 stated, "I see myself as serving a great purpose in her life and showing her ways to, you know just showing her rights and wrongs. Participant 4 said, "Even though my son has autism, I try to see him the same as I see other kids."

Participant 8 disclosed, "My baby may have autism, but I know her future is bright just like other girls her age. You know this is what was given to me and so I really did not see it as something to get down about." Participant 11 shared his optimism about his son stating, "I know my son has a lot of potential and I'm just waiting to see what hurdles he will jump."

Participant 1 stated:

The more I learned the more I wanted to be involved, the more I wanted to be supportive and the main thing is to provide for him, to show him, you know going forward that he can be independent that you know it's a condition that I had to learn.



Fathers reported feeling optimistic about their child's future despite the autism disorder and its challenges. Participant 1 could not have given a clearer picture as evidence by this statement:

I like to do affirmations with him to let him know that he is loved, he is strong, that he is brilliant and he can do anything he sets his mind to do. And, just show him that we really love him and that um, that you know the things you're having issues with are the things you have to be successful with in this life.

Fathers did not report the autism diagnosis as a barrier for success, but a reason to succeed even further in life.

### **Research Question 3**

The third research question of the study was: How do African American fathers describe their parenting experience raising a child diagnosed with autism? One theme reflected a response to this research question, discipline of the child. The following subthemes were related to the main theme and they represent the many ways in which fathers describe their parenting experience: child manipulation of the father, father being unsure of ways to discipline, and the child's awareness of discipline and punishment.

**Theme 3: Discipline of the child.** The first organizing theme to emerge in these data was present consistently throughout the participants interviews. This theme referred to how fathers described the discipline of a child diagnosed with autism. Fathers disclosed focusing more on when and how to discipline their child diagnosed with autism. Across all participants accounts, father's discipline of the child and codes related to this theme appeared several times in the data. The father's description of the discipline

of the child resulted in three subthemes. The first subtheme involved child manipulation of the father, the second subtheme consisted of fathers being unsure of ways to discipline their child, and the third was identified as the child's understanding of discipline and punishment.

**Manipulation of the father.** Fathers in this study described ways their child displayed manipulation by using their autism diagnosis to their advantage. Fathers reported the disciplining of a child diagnosed with autism could be very challenging. Participant 2 reported, "My daughter is manipulative at times and I really have to think if her actions are justly; only because of the difficulties that comes with the autism disorder. I would allow her to get away with certain things and I take the blame for that."

However, there are times when fathers reported there was no doubt the child was being manipulative and was aware of what he or she was doing. Fathers reported certain techniques used to assess if the child was aware of their actions. One father reported he asked questions and listened to his son's response to figure out if he was being manipulative with the father. Another reported when his son misbehaves, he attempts to act as though is not aware of his behaviors.

However, the father reported he continued with the consequence of taking his favorite items from him. Fathers appeared to know their child was aware of the manipulative behaviors. Participant 4 stated, "When he gets in trouble it's mostly because I have asked him to something he may not want to do and he ignores me (on purpose)." Participant # reported "My daughter is my kryptonite and I think she plays on this gift."

**Father unsure of ways to discipline.** Most fathers reported struggling with ways to discipline their child diagnosed with autism. Fathers were unsure if they should verbally talk to the child, put them in the corner, take their favorite items, spank, or ignore behaviors because of the autism diagnosis. There were some fathers that were more aware of their child's autism symptoms which helped decipher if the child was aware of his or her behavior. This topic appeared to be one of the most challenging among fathers.

Participant 1 disclosed:

When my son misbehaves, I take his video game away and it changes his behavior. I also increase his homework assignment as well at times. I sit him down and allow him to figure out what he did wrong. I have to make sure the punishment is within whatever he did to be reprimanded.

However, the fathers reported discipline at times still remains a challenge. Participant 2 shared, "I find balance between discipline because of her age and her disorder can be extremely challenging. You know I try to identify what's right." Several fathers experienced similar struggles with the follow through of discipline which causes conflict in the home. One father expressed marital conflict in reference to the disagreements experienced in his home about the discipline of his son.

Participant 10 stated, "Me and my wife argue about some of the things and off the wall decisions he'll make sometimes." Another father shared at times it is hard to discipline his son because they are so close to one another. However, the father reported when he does discipline him, he only takes things away from him.

Another father reported he never spans his child; but, he does take items away from him. The father reported his son does not get in much trouble and follows directions most of the time. The father reported this is an area he has to really improve in. However, one father reported he has no problem disciplining his child.

During the phone interview, the father's son began to have a temper tantrum and it caused the researcher and father to stop the interview. However, within a couple of minutes, the father had placed the child in time-out and spoke to him about his behavior. The child appeared calm and his behavior had ceased. The father reported his son responds to him well and he is the disciplinarian in the home.

Participant 7 shared, "I learned more information about his diagnosis and learned ways to work with him which has made me a stronger man." Several fathers disclosed having a lack of discipline with their children. One father admitted he allows his daughter to get away with many things and refuse to allow anyone to discipline her. One father reported his wife has told him several times he does not discipline his son enough.

However, the father reported he thinks he does and they just have different ways to discipline. The father stated he is the calm one of the two. The father did admit to the lack of follow through as he described taking an item away from him for a short period of time and returning it right back to him. Participant 10 stated, "I learned a long time ago spanking does not work."

However, the father reported he takes things away from him. Just as other fathers in this study, another father also admitted he takes his son paint away and gives it right

back to him as long as he can tell him what he did wrong. Participant 12 stated, “I like to discipline my daughter because I does not like her to be mad at me.”

**Child’s awareness of discipline and punishment.** Fathers in this study reported being confused if their child was aware of discipline and punishment. Participant 2 said:

I take things from her and it generally works, but that doesn’t mean 3 days later she won’t do it again. It could be something as simple as clean up your mess, but she’s not as messy as she use to be. Discipling her such as taking something from her works, but it takes repeatedly effort.

Because the father is aware of his daughter’s autism symptoms, it is easier to assess when and how to discipline her. Fathers wanted to be sure they were not punishing the child if he or she were not aware if they were doing something wrong. Fathers reported this being a challenge when deciding if and when to punish the child. Participant 1 said, “I have to make sure the punishment is within whatever he did to be reprimanded.”

Participant 2 said, “I wanted to be sure she was aware of her actions before I disciplined her. The challenge is knowing what is her disorder and her just being an eleven-year-old.” The father described in detail some of the things he daughter does consists of her being a typical teenage girl. For example, she argues with her siblings and has the typical teenage adolescent attitude as other girls her age. It appears when the father is more aware of the child’s and the symptoms of autism, they are able to make better decisions regarding punishment.

Participant 7 shared, “I use to think this little tantrum were because of him being

autistic, but nah.” There were fathers that were adamant their child was aware of their behaviors. Participant 2 said, “If there is someone in an authoritative role, if they let her she will attempt to walk over them.” One father described his son has the ability to understand just like his siblings so there is no need for him to get in trouble. Despite the participants children being diagnosed with autism, participants described their child having the ability differentiate right from wrong.

#### **Research Question 4**

The fourth research question of the study was: What are the challenges African American fathers experience while raising a child diagnosed with autism? One theme reflected a response to this research question, awareness and support for autism. The following subthemes were related to the main theme and they represent the many ways in which fathers describe awareness and support for autism: the first overarching subtheme was identified as the father’s lack of knowledge regarding symptoms, the second subtheme consisted of society’s lack of awareness regarding autism, the third subtheme consisted of resources, and the fourth identified late diagnosis.

**Theme 4: Awareness and support for autism.** The fourth organizing theme to emerge in these data was present consistently throughout interviews with participants. This theme referred to how fathers described their awareness and support for autism. Across all participants accounts, father’s description of awareness and support for autism and codes related to this theme appeared consistently throughout the data. The father’s description resulted in three subthemes. The first overarching subtheme was identified as the father’s lack of awareness of autism, the second subtheme was society’s lack of

knowledge of autism, the third listed as resources for the child diagnosed with autism and the fourth was late diagnosis.

**Fathers lack of awareness of autism.** Fathers described their lack of knowledge regarding autism. Fathers should rely on trained clinicians to provide an accurate diagnosis. The evidence of a child being misdiagnosed could increase the father's experience lack of awareness regarding the autism diagnosis. One father reported his son was given multiple diagnosis and told he would eventually grow out it. Participant 1 said:

They were diagnosing him and they were coming up with all these different things like selected mutism, um different things um, EEB; even telling us not to worry because he would grow out it. They basically said this is what your child is diagnosed with and they gave me a long print-out, but basically that was based on a lot of information that I gave them of the behaviors and the different actions he was going through.

Fathers were unaware of specific signs to look for in the child that was later diagnosed with autism. One father disclosed his son did not show eye contact; but, he thought he was just a shy kid as he too was a shy child growing up. Participant 4 shared, "I also knew there was something different, but I really didn't know um much about autism. I mean I have some experience working with kids, but autism was new to me."

Participant 6 said:

You know at first, I didn't know what the hell they were talking about and I was reading on how to get rid of it. I know that sounds crazy huh, but I'm for real. Me and my wife started asking each other how we missed the stuff these folks were

talking about. I thought he was a pretty normal baby, but I guess if you don't know what you're looking for you would miss it huh? Another father described his lack of awareness regarding autism as well. I didn't know what she meant when she said spectrum.

Fathers described not knowing what autism was and immediately feeling as though the child would be placed on medications or would never be able to have sex. Participant 1 stated, "I didn't know what to do as a parent I was unsure of what it was, but I knew it was something and my, as time went on it got worse, before it got better, but it did get better."

**Society's lack of knowledge of autism.** The first overarching theme was identified as society's lack of knowledge of autism. Fathers described several instances where people around them were not aware of autism and its symptoms.

Participant 1 said:

I often worry about my son being around people that are not aware of the autism diagnosis. I wonder about other people's response when they ask his son a question and he does not respond. I especially get anxious around holidays and family functions when my family members don't understand why he doesn't look them in the eye when he is being spoken to.

Father's reported experiences where those in the community would become obviously frustrated with his child as they were not aware of the symptoms of autism. Fathers explained challenges with family members as well. Another father described his daughter spending time with his mother is a challenge at times as she is not aware of



autism and its' symptoms. The father stated his mother becomes frustrated at times with his daughter and wants her to act like the other grandchildren. However, his daughter has autism and she is different.

Fathers expressed their opinions regarding the lack of autism awareness stating this is a community issue and society should be better informed of the autism disorder. Several fathers reported they were informed by the child's clinician to inform people of their child's diagnosis beforehand to eliminate the possibility of any discomfort. Even though there were fathers that informed others of the child's autism disorder, there were fathers that questioned to inform others of his child's diagnosis they wanted others to see the child for who for who he or she is, not her autism diagnosis.

**Resources.** Fathers described current and needed resources raising a child diagnosed with autism. Fathers reported their children received support in school, but there is a need for continued therapy. For example, the father stated he continues to work with his son to increase his vocabulary, despite him being in speech therapy. The father described his son as enjoying the services such as speech and physical therapy and could really notice progress. One father reported his daughter receives services at home and therapy has helped her with her speech and awareness. Participant 2 said, "There was a time my daughter had no sense of fear and would jump into a pool without a second thought. We would also go to public places and she would sit in other men laps because she lacked the awareness of boundaries."

However, with therapy his daughter has overcome such challenges. Although she has come a long way, the father states supports are still needed. One father reported his

son has a therapist and they get along great. He described the importance of much needed supports for children diagnosed with autism.

Another father described the need for services for the child diagnosed with autism and how his son has progressed since being in therapy. The father described the way his son use to stay in his room and only came out to eat. Fathers described issues with supports as well that are in place currently for the child. Participant 11 said:

My son gets services in school, but I have to go to school and show my face and remind them he has a daddy that knows and cares about what's going on with him now. Yeah, they have trouble remembering his school work is supposed to be accommodated. Just like the damn IEP, I had to get on them about that. But, I think they know I'm serious and I ain't going nowhere so they doing better with it now.

The father found that the more he is visible in the child's school, the more compliant the staff are.

**Late diagnosis.** The fathers in the program reported it was a challenge when their children were diagnosed at a later age. Fathers reported the late diagnosis caused a delay in interventions. Participant 7 said, "I would tell other fathers to take time for yourself and get their child tested early." Fathers reported the significance of early detection and education is the key. The father stated his son was diagnosed at age 9.

Participant 2 shared, "You know your child and if there is something different; there's nothing wrong with seeking advice from a professional. I love my mother, but if I had listened to her it would have been years before my daughter was diagnosed." The

father described how his mother thought his daughter was being stubborn, but he knew there was something more. This father's daughter was diagnosed at age 2 and immediately began receiving therapy. One father reported his son was diagnosed at age 5 and began receiving help that has really been beneficial. A second father reported he too would advise fathers to seek early testing for their child.

Participant 8 shared, "I would also tell them to get that baby tested early because my son been getting help since 2." Participant 11 reported his son was diagnosed at age 7, but wish he had been diagnosed at an earlier age. Participant 7 stated, "I would tell other dads to get their child tested early and there is even help for us out here too to help us." Fathers reported experiencing guilt and blamed themselves for not seeing the signs of autism earlier. He reported he would advise other fathers to start their child in therapy early and try to help other fathers. Participant 9 disclosed, "I mean I wish I knew this stuff when my baby was diagnosed with autism, but I guess it's better late than never huh." Fathers consistently expressed concern regarding the need for early testing of autism.

### **Negative Case Analysis**

Thematic analysis of all the cases considered in this study consistently yielded the key findings of this investigation. However, there were some minor discrepancies between the details of the participant's accounts. Out of the 12 fathers reported during the interview that he noticed something was not right with his daughter and took her to get tested for autism. The remaining 11 fathers were encouraged or told to seek testing by a family friend, family member, teacher, or their child's pediatrician.

“She was diagnosed at 4, but I started seeing signs as early as 3. I realized early on there was something different about her. But you know how we are in Black families; aint nothing wrong with that child, she’s just stubborn. I’ve heard it all,” Another discrepancy during the interviews was the father that never questioned his son’s ability to differentiate between right and wrong. Although, his son was diagnosed with autism at age 5, he was sure his son was aware when he was misbehaving. “He’s the same as other little kids, but he’s just a little different.”

This particular father reported his son with autism always received the same consequence as his daughter without the autism diagnosis. One father felt it necessary to attend friend trips with his son to show the child as well as his peers the importance of interacting with his son. One father reported being in therapy to cope with parenting a child diagnosed with autism. Only one father reported seeking counseling to cope with his child being diagnosed with autism. This father also appeared to be the most vocal regarding interventions for his son diagnosed with autism.

### **Summary**

The purpose of this qualitative, interpretative phenomenological study was to explore the lived experiences of African American fathers who are raising a child diagnosed with autism. This study targeted the 12 fathers providing their lived experiences raising a child diagnosed with autism. I sought to address an identified gap in the literature regarding the lack of information on African American fathers raising their autistic child.

Data from each father were analyzed to identify the essence of their lived experiences through the process of the identification of the major themes that were derived from the interview questions of the research study. The major themes were father's interaction with child, father's emotional reactions, discipline of the child, and awareness and support of autism.

In Chapter 5, I present information regarding the interpretation of the findings as they relate to the social support theoretical framework. In Chapter 5, I address social change implications, recommendations for action, recommendation for further study, limitations of the study, and conclusions. The results from this study identified ways to appropriately prepare and support African American fathers in raising their children with autism. This study has the ability to contribute to social change through understanding and raising awareness regarding the psychological and emotional needs of African American fathers in their task of raising their child diagnosed with autism. This understanding and awareness has the potential to help those African American fathers who struggle with accepting their children's diagnoses and those reluctant to seek help.

## Chapter 5: Discussion, Conclusions, and Recommendations

### **Introduction**

The purpose of this study was to fill the research gap regarding African American fathers and their lived experiences of raising a child with autism. This study was needed because there have been few studies that included fathers when examining being a caregiver to a child diagnosed with autism. Little research exists regarding fathers with an autistic child, with the majority of the research targeting mothers' experiences (Hornby, 1992; Sawyer et al, 2010). Braunstein et al. (2013) discussed potential reasons for fathers' limited inclusion in research as tied to researcher assumptions of traditional gendered caregiving roles, perceptions that fathers are less available to take part in studies, and researcher tendency to overlook the father-child relationship. Scholars have shown fathers can have a positive influence on children by acting as their caregiver, educator, and advocate (Honig, 2008). This pervasive underrepresentation is detrimental for fathers, and by extensions their partners, children, and communities, because research recommendations and corresponding developments in support services cannot account for, and address, fathers' experiences and needs. According to Corcoran et al. (2015) and DePape and Lindsay (2015), of 42 reviews of parents raising an autistic child, only one review involved the father. Due to the prevalence of autism on the rise, the father's perspective of the disorder is vital for future studies.

According to Carr and Lord (2013), there is little research on the experiences of African American families with autistic children. Seligman and Darling (2007) stated that there are still not enough studies of fathers whose children have disabilities, and

conclusions about fathers' adjustment must be made cautiously. Although there is little research regarding fathers and their autistic child, there are few dissertations addressing the complexities of African American fathers and their autistic child. Men are underrepresented in the research as most of the recent studies focus on the mother (Flippin & Crais, 2011).

The purpose of this IPA was to examine the lived experiences of African American fathers raising an autistic child. I chose a qualitative approach versus a quantitative approach because I desired to explore the participants' lived experiences rather than interpret statistical data. According to Creswell (2013), a qualitative study will allow the researcher to gain a new understanding about a phenomenon, gather and develop new ideas, hypothesize viewpoints about facts, and discover issues that are present within the participants lived experience.

The following research questions were used to provide an understanding of the lives experiences of African American fathers raising an autistic child:

1. What are the experiences of African American fathers raising an autistic child?
2. What are the emotional reactions of African American fathers after they have learned of their child's diagnosis?
3. How do African American fathers describe their parenting experiences with their autistic children?
4. What are the challenges that African American fathers experience when raising an autistic child?

There were four themes and 15 subthemes that emerged from this study. The first theme was fathers' interaction with the child with subthemes of playing video games, interacting in outside activities, and taking the child to their therapy appointments. The second theme was emotional reactions of the father with subthemes of sadness, guilt, anger, blessed, relieved, and optimistic. The third theme was discipline of the child with subthemes of child manipulates father, child's understanding of discipline and punishment, and father often unsure of ways to discipline. The fourth theme was awareness and support of autism with subthemes of fathers' lack of awareness of autism, society's lack of knowledge of autism, and resources.

### **Interpretation of the Findings from Interviews**

Participants in this study described their experiences of raising a child with autism. The findings from this study both confirmed and extended the empirical knowledge about African American fathers raising an autistic child. The themes that emerged in this project are supported by findings in the existing literature.

#### **Fathers Interaction With the Child**

The first theme that appeared to be one of the most prevalent was the fathers' interaction with the child diagnosed with autism. The findings showed how fathers perceived their interaction with the child as a benefit as it resulted in several positive outcomes. Researchers reported that the father-child relationship plays a role in determining the outcomes of autism (Falk et al., 2014; Vacca (2013). Jordan (2003) argued that children with autism should engage in physical play with their parents. Fathers in my study reported themselves as the primary parent who engages in interacting



with the child. Although mothers interacted with the child, fathers interacted more. Just as in El-Ghoroury and Romanczyk's (1999) study, children with autism made more verbal play initiations to their fathers than to their mothers, indicating that fathers may still act as these children's primary play partners.

In comparison to my study, fathers also reported a desire to increase interactions with their child to establish a bond and rapport between the father and child. Fathers disclosed that their child's doctor encouraged them to try to find things their child enjoys doing and also increasing more hands-on activities to build rapport with their child. Fathers reported activities such as outside activities, playing video games, and taking the child to their appointments. According to Bagner (2013), children with developmental delays who had actively engaged fathers had significant improvements in their emotional regulation, cognitive development, and language development.

The reported activities stated by fathers in this study may appear simple to some. However, fathers reported that, as a result of these activities, communication was increased between the father and child. Fathers reported communication was once perceived as a deficit for their child before the increased interaction between the father and child. The foundation literature on the intersection of fathers interacting with their child and its benefits has been identified through other studies as well. Fathers in Santos's (2014) study reported their involvement with their child diagnosed with autism was beneficial as well. In other research, play was associated with numerous benefits for children, with and without disabilities (Brown, 2009; Childress, 2011; Coyl-Shepherd &

Hanlon, 2012; Frost et al., 2012). Lamb (2004) also conceptualized father involvement as positive engagement activities, warmth, and control.

Positive engagement activities included direct physical interaction with the child, such as going to the playground, playing video games, playing basketball, and going to the movies and church. Fathers felt a responsibility to interact with their child diagnosed with autism. Fathers did not identify the interaction as a burden, but as an enjoyable experience that would be beneficial then and in the future. Wolfberg (1999) stated that adults (i.e., parents) have the responsibility to facilitate play development with children diagnosed with autism. I stopped reviewing here. Please go through the rest of your chapter and look for the patterns I pointed out to you. I will now look at your references.

Mactavish and Schleien (2004) surveyed parents of children with developmental disabilities, including Autism. The researchers found parental benefits for recreation activities with their children, including improved communication with their children, quality of life, satisfaction with life, and ability to deal with stress. As in this study by Mactavish and Schleien (2004), I also found a similar correlation where fathers reported an increase of communication following interacting with the child diagnosed with autism. However, I did not target life satisfaction and quality of life and these topics did not emerge from the semi-structured interviews.

### **Emotional Reactions**

The second theme focused on the father's reactions once they found their child was diagnosed with autism. Fathers reported experiencing several emotions such as sadness, guilt, anger, blessed, relieved and optimism. Although fathers experienced

challenges, no father reported being angry at the child or feeling resentment due to the autism diagnosis. However, researchers indicated fathers of children diagnosed with autism experience stress and see the diagnosis as overwhelming (Hartley et al., 2010; Hoogsteen & Woodthgate, 2013; Myers et al., 2009). My study did not support the findings of the father being overwhelmed. However, fathers in my study did report feeling negative emotions following the autism diagnosis. Fathers in my study reported a sense of optimism and reported never giving up on their child or their future success despite challenges.

The positive emotions that participants in this study described were also reported in other studies in which fathers described the joys of raising their children with autism and an appreciation for “small moments” of progress and connection. This would likely go unnoticed or uncelebrated by parents of typically developing children (Corcoran et al., 2015; DePape & Sally, 2015). According to Bekhet et al. (2012), parents also reported positive descriptions such as resilience; while others reported feelings of anxiety, depression, and poor mental health. Studies consistently indicated that families who worked together had better coping skills and improved resiliency against the challenges they faced (Altiere & van Kluge, 2009; Bagner, 2013; Bultas, 2012; Cassidy et al., 2008; Hock et al., 2012; Lee et al., 2008).

MacDonald and Hastings (2010) reported children with developmental and intellectual disabilities who were actively engaged in their children’s treatment reported a more positive outlook about the children’s future, provided emotional support and comfort to the mothers, had better family cohesion, and had improved well-being for the

family. However, in another study 41.1% of fathers reported mild levels of depression (Benson & Karlof, 2009; Lee, 2009). I supported these findings as fathers in my study reported feeling a sense of guilt, denial and sadness. In another study, fathers reported facing extreme challenges trying to balance the extra workload, family responsibilities, and providing emotional support to the primary caregiver, which can become overwhelming for fathers (MacDonald & Hastings, 2010). In my study, fathers worked to provide for their families. However, several fathers reported acting in the role of a stay at home father to lessen the responsibilities of the mother and carry the responsibility of taking the child to their appointments and any other needs.

Researchers in previous studies reported that the lifelong burden of autism for the parents can lead to feelings of anger, blame, and frustration; taking on multiple roles; and to a higher divorce rate (Hartley et al., 2010; Hoogsteen & Woodthgate, 2013; Myers et al., 2009). I concluded fathers also experienced anger and questioned why their child was diagnosed with autism. Fathers also reported blame, but not towards the child. Fathers blamed themselves due to the lack of knowledge regarding the etiology of the autism diagnosis. Fathers questioned if past behaviors increased the likelihood of their child being diagnosed with autism such as drinking and criminal behaviors. Fathers attributed their child's diagnoses to their old age or to "being a loner." My results did not support the theory stating fathers experienced frustration for taking on multiple roles and to a higher divorce rate. Rodrigue et al (1992) reported out of 60 fathers raising a child with a developmental disability, 20 fathers raising a child diagnosed with autism reported negative effects on their families. Hartley et al. (2012) conducted a similar study where

out of 240 fathers raising a child with a developmental disability; 135 fathers raising a child with autism reported higher levels of depressive symptoms. In my study, fathers reported a few negative effects such as not having the ability to go to various social environments and being forced to separate the family at times. One father reported sitting in certain areas of restaurants due to the child with autism being uncomfortable and refusing to eat. However, none of the fathers in my study reported depressive symptoms as a result of the child being diagnosed with autism.

### **Discipline of the Child**

Another prevalent theme was the discipline of the child diagnosed with autism. Children diagnosed with autism commonly display negative behaviors in and out of the home. Children with ASD are more likely to present with problem behaviors than those without the diagnosis (Hattier, Matson, Belva, & Horovitz, 2011). Fathers in my study reported that knowing how and when to discipline their child was the most challenging component while raising their child with autism. Fathers reported they struggled to discern whether their children were aware of their behaviors. As a discipline strategy, most fathers reported taking items away from the child to alter their behaviors.

Fathers also admitted there were times they allowed their child to get away with negative behaviors due to the autism diagnosis. Fathers in my study reported several reasons why their passive strategy such as ignoring maladaptive behaviors was effective. Shawlyer and Sullivan (2017) reported a sample of 130 parents of autistic children ages 3 to 11 found parents used harsh punitive parental discipline strategies to alter disruptive behaviors. They found parental discipline strategies should be a major target in the

prevention and treatment interventions for to children with autism to reduce maladaptive behaviors. I did not support the need for harsh punitive strategies as fathers did not report such extreme behaviors from their child. However, results of the present study do support the recommendation for the need of some type of discipline strategy as children with autism may display the same negative behaviors as a child without a disability.

Maljaars et al. (2014) reported a survey that targeted passive mothers of children with and without autism and their parenting style. In the study, mothers completed a questionnaire that showed mothers of children with autism reported significantly lower scores on rules and discipline and higher scores on positive parenting. My study supports these results as several fathers reported they did not discipline their child and found consequences to be very challenging. All fathers in the study reported positives to parenting their child with autism and stated themes of verbal redirecting of negative behaviors.

### **Awareness and Support of Autism**

Fathers in the study reported the need for more support; with special focus on African American fathers. Fathers reported such support should be increased with medical professionals and in the school environment. Fathers also reported a need for family members and communities to increase their knowledge and awareness regarding autism and its symptoms. Although, there is a lack of awareness of information targeting African Americans and autism, it appears that awareness and knowledge regarding autism is increasing in some areas. There are more individuals that seem to know about autism than in recent years. An anonymous survey by Tipton and Blacher (2014) was

given to undergraduates, graduate students, staff and faculty asking their knowledge about autism. Of the 1,057 surveys completed, 76% of respondents had more correct responses than incorrect responses about autism. The survey showed those individuals that had a family member with autism had a significantly amount of correct answers. Dillenberger et al. (2017) surveyed 3,353 16 and 11 years old children and the majority of them were aware of autism. The study also found teenagers were more aware of the disorder than younger children. In addition, 50% of the children knew someone with autism and displayed supportive attitudes. Children in the study reported they would help an autistic kid if they witnessed bullying.

Although there is an increased awareness, there is not much support targeting African American fathers. Medical professionals should study parenting styles and experiences of African American fathers and mothers rather than concentrating only in those of Caucasian mothers and fathers. According to Raina et al. (2005) it was reported that understanding parents' experiences is an important factor for the implementation of policies, effective interventions, and other support services. Professionals should consider fathers how parenting style may differ from mothers regarding the way they parent their child. Research studies suggest that gender may play a role in differences in coping responses utilized as a result to exposure in different parenting stressors and roles within families (Glidden, Billings, & Jobe, 2006; Porter et al., 2000; Pottie & Ingram, 2008). Support such as parent education and behavioral support programs could also be implemented for African American fathers as well. Hall and Gaff (2010a) supported the recommendation of increasing support and awareness where 75 parents and primary

caregivers of children diagnosed with autism were surveyed. The researchers used the McCubbin and Patterson model of family behavior, adaptive behaviors of children with autism, family support networks, parenting stress, and parent coping were measured. Their findings concluded an association between low adaptive functioning in children with autism and increased parenting stress actually created a need for additional family support as parents often searched for different coping strategies to assist the family with continued new challenges. The study also reported medical professionals should possess current knowledge of the supports accessible to families and refer them to the correct resources to avoid overwhelming families with unnecessary and inappropriate referrals.

Hall and Gaff (2010b) interviewed parents of children diagnosed with autism to allow them to express their feelings about challenges to raising their child. The study revealed parents reported the need for supports and resources in need of expansion and development to help them with their child's needs. Parents voiced the need for a partnership with healthcare providers. This study is similar to my study as fathers reported the need for additional help from medical professionals. Several fathers in my study reported their child's doctor simply gave them a print out about autism with no additional direction. Another father in my study reported his child's doctor informed him his son would grow out of the disorder and not to worry. The disconnect between the medical professionals and fathers appears to be a recurring theme in other studies as they too, indicated issues beginning with obtaining a diagnosis for their child diagnosed with autism (Corcoran et al., 2015; DePape & Sally, 2015).

According to Kohl and Seay (2015), African American fathers reported the



resource of parent training was needed to understand cultural adaptation. Findings from the study concluded the need for African American fathers was indeed different from the majority population. The need for parent training to the language and culture of this population was deemed necessary for success. The study correlates to my study as fathers reported the need for continued resources in the African American community.

### **Studies on African American Fathers Raising Children With Autism**

In Chapter 2, I reported that there are no peer-reviewed publications on the lived experiences of African American fathers raising autistic children. Only few dissertations and thesis studies targeted the topic and population. In this section, I specifically compare the findings of my study with these studies that targeted the population and topic. My study and Hannon's (2013) study reached similar results as they both reported fathers felt there was a lack of autism knowledge and awareness in the African American communities. Both studies reported fathers felt various emotions after learning their child was diagnosed with autism, but the most significant was a sense of hope and optimism for their child's future. The studies also compared as fathers in both studies felt there was a disconnect in the school environment and lack of supports as well. My study and Schrader (2013) both reported fathers received limited assistance from medical professionals and desired the need for more supports. There were also similarities in a study by Simon (2013) as she also reported positive and negative reactions from African American families raising an autistic child. Parents reported their child also being misdiagnosed and a late diagnosis of autism. Parks (2017) and Bethel (2016) also

reported similar results as she reported there was a lack of autism knowledge and awareness in the African American communities.

### **Theoretical Framework**

The findings from this study was supported by existing empirical data related to the experiences of African American fathers raising an autistic child and also to the theoretical constructs including the family systems theory. The theoretical framework used in this study was Bowen's (1978) family systems theory. The BFST stated "the human family is a multigenerational, natural, living system and that the emotional functioning of each member of the system affects the functioning of the other members in predictable ways" (Comella, Bader, Ball, Wiseman, & Sagar, 1995, p. 5).

According to Baker, Mailick-Seltzer, and Greenberg (2011) researchers suggested children diagnosed with autism, like any other child, will respond to their family environment rather than acting upon it. My study revealed congruency with this theory as children displayed a positive reaction to their father's interacting with them. Following fathers interacting with their child diagnosed with autism, the father and child bond increased as well as rapport. Fathers reported an increase of communication between the father and child and among other family members as well. Children that once feared the public began to comply with everyday activities such as eating in public, attending church, going to the movies and an act that some may take for granted, showing laughing.

The Bowen's family systems theory was used to shed light into the findings of this research. The theory states the family is a living system and emotional functions of each member is affected. In my study the fathers were greatly affected Though, the effect

was not so much in a negative realm, but mostly positive. Fathers found themselves wanting to engage more with their child with activities they never had not done since children. Fathers experienced sorts of emotions from questioning their parenting styles to the first feeling experienced when finding out the child was diagnosed with autism. Although, fathers did not desire their child to become diagnosed with autism, optimism was very evident. Fathers greatly desired the need for more awareness and resourced for not only their child, but the autism community. The study addressed the affects experienced by mothers, siblings and extended family members due to the child being diagnosed with autism.

### **Limitations of the Study**

There were limitations to this study. All participants were required to be the biological father of an autistic child, at least 18 years of age and fluent in English. The individual thoughts shared by the African American fathers represents their lived experiences and perspectives into the phenomenon and may not be a representative of the population of all fathers raising a child diagnosed with autism. As a result, the study was limited by the characteristics of the sample. In conducting a qualitative study, it was not the intent to generalize to the larger population as this is not the intent of qualitative inquiry (Creswell, 2009). A sample that constituted a larger demographic range may have yielded additional themes not founded by this sample. The findings are therefore a representative of the experiences of this particular group of fathers only and caution should be used in drawing any conclusions when interpreting such findings.

Telephone interviews were also a limitation of the study. Telephone interviews as opposed to face-to-face interviews had several limitations as I was unable to observe the participant's body language and or facial expressions during the interviews. I had no choice but rely on the father's tone of voice to determine any emotions experienced during the interview. One must be cognizant that participants may have been mistrustful of the researcher, may not have been entirely truthful and may have attempted to present themselves in a more positive light to the researcher. Consequently, the findings of the study are limited to the extent at which the participants were being truthful.

Another limitation of the study regards the subjective nature of conducting qualitative research. Qualitative research mainly relates to the use of semi-structured interviews and as such is dependent upon interpersonal exchanges between the researcher and the participant. Researchers are mostly interested in gathering more comprehensive and in-depth data as opposed to specific data in quantitative research and has an active role in data collection (Wimmer & Dominick 1997, 2011). There is always the chance for researchers to influence participants' responses. This is an acceptable limitation of qualitative research. Creswell (2007) reported that researchers, in conducting qualitative inquiry, acknowledge and set aside their personal experiences before beginning their research in order to present a fresh perspective of the psychological experience or the phenomenon being investigated. However, it is difficult to either prevent or detect researcher bias entirely in the study.

### **Recommendations for Future Research**

Through this interpretative phenomenological analysis study, I sought to address the identified gap in the literature regarding the lived experiences of African American fathers raising their child diagnosed with autism. While this study required participants ages 18 and older, further research from any age group is recommended. The participants of this study also resided in the state of Georgia. Future studies may target fathers in other geographical areas as current studies examining African American fathers raising an autistic child are needed in all areas.

This study also targeted African American fathers, future studies may seek to target other minorities as well “since culture has a major effect on concepts such as child rearing, parenting and disability” (Koydemir & Tosun, 2010, p. 57). Most studies examining parents raising an autistic child targets the Caucasian ethnicity and mostly mothers. Future studies may also target the LBGT community as well. Future studies may target LBGT fathers that raise an autistic child alone and with their male partner. All of the fathers except one, was married or cohabitating with the mother of the child diagnosed with autism in this study. Future studies may target single African American fathers raising an autistic child in the home alone.

Future studies may also target extended family members raising or assisting with the care of a child diagnosed with autism. African American families are known for allowing extended family members to help care for children with and without a disability. Extended family members are also affected and may have a certain perception regarding the care of a child diagnosed with autism. This could offer further insight into African

American families' perceptions of caring for their children with autism. This study also did not focus on the gender of the child. The genders of the children were not the focus, though there were 10 boys and only two girls. However, through searching previous studies, there were no studies that targeted African American girls diagnosed with autism.

Fathers reported experiencing a range of emotions when finding out their child was diagnosed with autism including sadness, angry, or guilt among others. They also reported that little information or follow up occurred from the medical staff after identifying the diagnosis. A suggested recommendation may be to incorporate a course for the family that consists of an introduction to autism and its symptoms as a requirement immediately following a child's diagnosis. Fathers also reported a lack of supports for African American fathers and also a lack of awareness in communities. Another suggestion may consist of increasing social supports for African American fathers that begins with medical professionals that could also create a partnership upon the initial diagnosis. Medical professionals should study parenting styles and experiences of African American fathers to grasp a greater understanding of their cultural need. Santarelli et al. (2001) noted that parent training programs have been developed primarily for families and children of European-American backgrounds and such programs may prove less effective for culturally diverse families and children because of the differences in values. Another needed area for African American fathers is the support to extended family members. African American families tend to turn to family, friends and the church community as their first line of support (Rogers-Dulan & Blancher, 1995). In this study, several fathers utilized the supports from family members to cope with raising their child

with autism. However, family members weren't fully aware of the child's diagnosis and effective ways to care for the child. In addition, supports for the African American father and family members should be explored.

### **Implications for Social Change**

The purpose of this interpretative phenomenological analysis study was to explore the lived experiences of African American fathers who are raising a child diagnosed with autism. Fathers reported several challenges while raising a child diagnosed with autism. Fathers reported a lack of information provided to them following the diagnosis. Some fathers reported they never heard of autism until their child was diagnosed. One father reported their pediatrician informed them their son would "grow out of it" and "not to worry."

The research participants provided valuable insight, from an emic perspective, into the father's lived experiences and day-to-day challenges as an African American father raising a child with autism. Understanding their lived experiences, contributed towards understanding the most effective way to raise their child with autism. The findings from this study should help in identifying ways to appropriately prepare and support African American fathers in raising their child diagnosed with autism.

This study should contribute to social change through understanding and raising awareness regarding the psychological and emotional needs of African American fathers in their task of raising their child diagnosed with autism. Professionals have the ability to understand the African American father and their lived experiences to increase community supports in the African American community. Community support and

resources may consist of neighborhood support groups, therapist and or doctor partnerships, in-home therapies and respite options. This need could increase knowledge about autism in the Black community and inform African Americans about its symptoms to increase earlier diagnosis and interventions. The African American fathers should also have community advocates, those designated to help African American fathers say what they want and need, secure their rights, represent their interests, and obtain services they need. There is also the need for increased education and awareness in the African American community. This understanding and awareness should help those African American fathers who struggle with accepting their child's diagnoses and fathers who may be reluctant to seek help from medical professionals and others in their communities. In this study, African American fathers were given the opportunity to voice their experiences of being the primary caregiver of their child with autism. This study will allow professionals the ability to provide African American fathers with resources, advocates, education, and awareness in the African American community.

### **Conclusion**

The goal of this interpretative phenomenological analysis study was to offer a meaningful understanding of the lived experiences of African American fathers raising a child diagnosed with autism. Most of the research findings were a reflection of data stated in the literature review targeting African American fathers raising an autistic child. Participants consisted of 12 fathers selected through a purposeful snowball sampling approach. Data were collected using semistructured- in- depth interviews that were



digitally recorded and transcribed. The microanalysis of the data was aided by the use of the Olympus recorder used for qualitative coding.

The findings revealed African American fathers were very hands-on with their child diagnosed with autism. Fathers experienced several emotions following the diagnosis of their child which consisted of: anger, guilt, sadness, blessed, and optimism. The study also revealed fathers struggled with knowing when and how to discipline their child with autism. Fathers reported being confused of normal behaviors and those symptoms as a result of the autism diagnosis. Finally, the study revealed fathers desired an increase of awareness and supports for autism. Fathers reported the lack of enough awareness and resources. Fathers also reported experiencing a lack of supports from schools and communities. However, there were a few fathers that reported school supports were very beneficial to their family and the child.

The interpretative phenomenological analysis study accomplished its purpose as it allowed fathers to explore the lived experiences of an African American father raising a child diagnosed with autism. Each father appeared to have a close bond with their child and looked forward to this study aiding other African American fathers raising their child diagnosed with autism. I could not end this study on a better quote from one of the fathers, “look at the world through their eyes and get into their world”.

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## Appendix A: Research Guidelines

### Research Guidelines

Researcher will inform the Interviewees of the following:

- Participation in the research study is voluntary. All aspects of the research study will be informed to the Interviewee before they consent.
- Interviewees will understand the research process
- Interviewee can withdraw from the research at any point
- All data will be treated with confidentiality and storage of the data will be conducted as per legal and ethical standards

## Appendix B: Invitation to Participate

Dear Mr. \_\_\_\_\_;

My name is Shannon Burns-Darden and I am a PhD Candidate at Walden University. I am writing to you today to invite you to participate in my research project entitled: African American Fathers Raising an Autistic Child. African American Fathers are severely under-represented in the current literature with regards to being caregivers and this researcher would like to give you as an African American father of a child diagnosed with autism, the chance to share your everyday experiences, to give you a voice and to take this opportunity and recognize your importance within the family dynamic with regards to care-giving.

For this study, I am looking for African American fathers who meet the following criteria: Male, age 18 and older, has a biological child diagnosed with autism that resides in the home with them, (ages six months to 18 years of age), and who are fluent in English. If you meet the criteria and are interested in participating, please respond to this e-mail stating you are interested in participating in this study. If you agree to be in this study, you will be asked to partake in an audio-taped interview lasting anywhere from 30-60 minutes. The interview is a data collection tool used to conduct my study. After you complete the interview, we will meet two more times: one, to go over the data collected (30-60 minutes) and two, to review or disseminate the findings of this study (30-60 minutes). Once the study is complete, a 1-2-page summary of the results will be e-mailed to you.

All information will be kept confidential. I will not use your personal information for any purposes outside of this research project. Your participation in this study will be voluntary. Each participant will be provided a \$25 Starbuck gift card.

If you have any questions, concerns, etc. about this research project you can contact me at: 678-770-1523 or e-mail me at Shannon.burns@Waldenu.edu.

Thank you for your time and attention to this matter. I look forward to hearing from you soon. I will be in contact with you to set up the initial meeting.

Thank you.

Respectfully yours,

Shannon Burns-Darden, MS  
Doctoral Candidate-Clinical Psychology  
Walden University

## Appendix C: Interview Questions

RQ1: What are the experiences of African American fathers raising an autistic child?

Interview Questions RQ1:

1. Please tell me about your child with autism
2. Please describe how your family is composed (e.g. how many members they are, how many members interact with you and your child on a daily basis).
3. How would you describe him/her?
4. What things do you like to do with him/her?
5. What activities do you do with your child?
6. How do you see yourself as father of him/her?
7. How would you describe your relationship with him/her?

RQ2: What are the emotional reactions of African American fathers after they have learned of their child's diagnosis?

Interview Questions RQ2

1. Please tell me about how you learned that your child was diagnosed with an autism spectrum disorder.
2. Please describe to me how you reacted immediately after you learned your child was diagnosed with autism, what were your feelings?
3. In what ways do you cope with the emotions relating to knowing your child has autism?

RQ3: How do African American fathers describe their parenting experiences with their

autistic child?

#### Interview Questions RQ3

1. What are the experiences of African American fathers raising an autistic child?
  - a. How do you relate to him/her?
  - b. How do you discipline him/her?
  - c. How do you play with him/her?
2. How does having a child diagnosed with autism affect your day-to-day experiences?
3. How has the diagnosis affected your role as a father?

RQ 4: What are the challenges that African American fathers experience when raising an autistic child?

#### Interview Questions RQ4

1. What are the challenges you face in raising your child?
2. What is it like providing care for a child diagnosed with autism?
3. What are your thoughts regarding the need for social support?
4. In what ways have you and your family received social support?
5. What impact has it had on your life (e.g. financially, emotionally, and socially)?
6. What advice would you give to other fathers raising their children with autism?

## Appendix D: Participant Flyer

AFRICAN AMERICAN FATHERS RAISING AN AUTISTIC  
CHILD NEEDED FOR A RESEARCH STUDY TO RAISE  
AWARENESS AND INCREASE RESOURCES & SUPPORTS  
IN THE AFRICAN AMERICAN COMMUNITY....



If you meet these criteria, I am looking for you:

- African American Male
- Speaks fluent English
- Must be 18 years of age and older
- Must Have a Child Diagnosed with Autism between ages 6 months to 18 years of age (residing in the home with the father).

Participation is completely voluntary and confidential. Interviews will be conducted by phone or in-person.

A \$25 Starbuck's gift card will be given to all participants.

I, Shannon Burns-Darden, am conducting this research for a dissertation at Walden University.



Interested individuals please contact Shannon Darden, at [Shannon.burns@Waldenu.edu](mailto:Shannon.burns@Waldenu.edu) for more information.

## Appendix E: Demographic Questionnaire

1. Name :

2. Date of birth:

3. Age:

4. What is your race/ethnicity?

\_\_\_\_\_ African/African American \_\_\_\_\_ Hispanic/Hispanic American \_\_\_\_\_

Asian/Asian American \_\_\_\_\_ Native American \_\_\_\_\_ Caucasian/European American

\_\_\_\_\_ Other (please indicate)

5. What is your gender?

---

6. What is the age of your child?

---

7. Please indicate the type of disability your child has been diagnosed with.

---

8. What is your language preference?

---

## Appendix F: Large Codebook

CODE	# TIMES IT APPEARS	# OF INTERVIEWS IT APPEARS
<p>SYMPTOMS OF AUTISM: The overarching theme refers to fathers identifying such descriptions as: anti-social behaviors, repetitive movements, lack of eye contact, lack of emotions towards others, lack of speech etc.</p>	47	FATHERS; INTERVIEW: 1-12
<p>FATHER INTERACTION W CHILD: This overarching theme refers to fathers describing the significance of spending time and interacting with the autistic child to build rapport.</p>	48	FATHERS; INTERVIEW: 1-12
<p>FATHER &amp; CHILD RELATIONSHIP: This overarching theme refers to the bond all fathers (except 1), reported having with the child diagnosed with autism.</p>	15	FATHERS; INTERVIEW: 1,3,4,5,6,7,8,9,10,11, & 12 (NOT FATHER 2)
<p>PROTECTION OF CHILD: This overarching theme refers to the responsibility of the father describing the need to protect the child with autism.</p>	3	FATHERS; INTERVIEW :1 (ONLY FATHER 1)
<p>DISCIPLINE OF CHILD: This overarching theme refers to fathers reporting struggling with knowing when and how to discipline the child with autism.</p>	28	FATHERS; INTERVIEW: 1-12

MARITAL CONFLICT DUE TO RAISING A CHILD W/AUTISM: This overarching theme refers to the marital conflict between the father and mother regarding raising a child with autism.	12	FATHERS; INTERVIEW: 6-12 (NOT FATHERS: 1,2,3,4,5)
REACTION TO AUTISM DIAGNOSIS: This overarching theme refers to emotional reactions experienced by ALL fathers; anger, sadness, guilt, frustrated, happy, blessed etc.	67	FATHERS; INTERVIEW: 1-12
MARITAL SATISFACTION DESPITE HAVING A CHILD W/AUTISM: This overarching theme refers to parents expressing marital satisfaction despite raising a child with autism.	7	FATHERS; INTERVIEW (ONLY FATHERS: 1,2,6,7) NOT FATHERS: 3,8,9,10,11,&12
FATHER'S SACRIFICE: This overarching theme refers to fathers expressing the many sacrifices it takes to raise a child with autism.	1	FATHERS; INTERVIEW (ONLY FATHER 1)
AWARENESS OF AUTISM: This overarching theme refers to fathers expressing the importance of being aware of what the autism disorder is.	46	FATHERS; INTERVIEW FATHERS: 1-12
SUPPORTS FOR AUTISM: This overarching theme refers to fathers expressing the importance of supports (respite) needed for fathers raising an autistic child.	49	FATHERS; INTERVIEW FATHERS: 1-12
COPING SKILLS WHILE RAISING A CHILD W/	20	FATHERS; INTERVIEW FATHERS: 1-12

AUTISM: This overarching theme refers to fathers expressing the need for identifying coping skills.		
EARLY INTERVENTION TO PREVENT SYMPTOMS OF AUTISM: This overarching theme refers to fathers expressing the need to know early and begin interventions regarding autism.	30	FATHERS; INTERVIEW ALL FATHER'S 1,2,3,5,6,7,8,9,10,11, 7 12; (NOT FATHER'S: 4,

**DEFINITIONS:**

**DESCRIPTION OF CHILD'S FEATURES/CHALLENGES:** This code refers to how the participant described his child. Participant described what the challenges were, for example, "non-sociable," or slow moving.

**FAMILY COMPOSITION:** Refers to the make-up of the household.

**FATHER INVOLVEMENT IN CHILD ACTIVITY:** It refers on how the father described his involvement (and connection) in his child's life. For example, with hygiene, homework, help him remember things.

**CHILD'S DIFFICULTY/FRUSTRATION:** Refers to the communication deficits experienced by the child; lack of self-expression

**FATHERS FRUSTRATION:** Refers to the father's difficulty regarding his son's communication deficits and other's around him not understanding his autism disorder and its' symptoms.

**FATHER SUPPORT:** The father assists the son with self-esteem by way of having him state self-affirmations to show he loves him and to build confidence.

**FATHER TRAINED TO HELP CHILD/STRATEGY TO HELP CHILD:** This refers to the interventions the father uses to help the child despite his disorder. The father was taught the self-affirmations through therapy.

**ACTIVITIES FATHER SHARES WITH CHILD:** This refers to the activities the father engages in with the son such as playing video games and play basketball.

**STRONG INVOLVEMENT:** This refers to the father's consistent self-education of

the child's diagnosis and it's symptoms.

**CONFIDENCE:** The father displayed a sense of confidence as he became aware of the disorder, but knew despite the challenges his son would overcome them.

**INVOLVEMENT/TEACHER OF HIS CHILD:** This refers to the father being involved in his son's diagnosis and his will to learn about the disorder.

**RAPPORT WITH CHILD:** The father refers to himself as being his son's number one person on his list and doing whatever it takes to make him happy.

**ENTITY WHO FIRST IDENTIFIED AUTISM: SCHOOL:** The father reported the school first identified his son's symptoms of autism at the age of nine.

**NOT KNOWING ABOUT WHAT AUTISM WAS:** The father reported when his son was diagnosed with autism, he was not aware of the diagnosis or what it entailed.

**FATHER'S EMOTIONAL REACTION:** The father reports feeling sadness, crying and being distraught when he found out details of the diagnosis.

**NOT KNOWING ABOUT WHAT AUTISM WAS:** The father reported again how he was not familiar with the diagnosis as he was given a simple print-out of the disorder.

**SOCAL/SCHOOL SUPPORTS:** The father identified supports provided to him by the school such as; father school programs, work being accommodated, physical and speech therapy.

**COPING SKILLS:** The father identified the school also offered a pamphlet of ways to cope with the stressors of raising a child with autism.

**FATHER'S LACK OF AWARENESS:** The father reported due to him not knowing about the diagnosis caused frustration.

**HEALTHY BOND WITH CHILD:** The father identified his son as being his bestfriend.

**PARENTS SHARED EXPERIENCES:** The father stated he attends peer sessions with other parents that also have a child diagnosed with autism. The father reported sharing experiences with others like him helps to lighten the load.

**SOCIAL SUPPORTS:** The father identified supports to aid with having a child diagnosed with autism such as; autism organizations and counseling for parents.

**COPING SKILLS:** The father reported he and his wife often take trips without the kids and reads his Bible to cope with raising his son.

**OPTIMISM FOR CHILD'S FUTURE:** The father expressed he son will be successful in the future despite being diagnosed with autism.

**CHILD'S SAFETY:** The father states he is always concerned about his son's safety when he is not with him.

**FATHERS SACRIFICE:** The father identified taking steps to be sure his son feels safe such as taking him to school; rather than making him ride the school bus. The father reported he son does not like riding the bus in fear of being around many kids.

**CHILD'S SAFETY:** The father gives an example of actions he takes to make sure his son is safe and comfortable such as sitting at a corner or back table as he does not like being around many people at restaurants.

**FATHER INVOLVEMENT IN CHILD'S ACTIVITY:** The father reports he plays video games with his son to increase his communication with the family.

**DISCIPLINE:** The father reports discipline is the most challenging aspect of raising his son with autism.

**FATHER'S VULNERABILITY:** The father reports he has to really assess his son's behavior when he misbehaves to be sure the behavior is not a result of his disability. The father reports his son tries to take advantage of being autistic when he knows he has misbehaved.

**ATTENTION:** The father explains how his son will act out at times for attention.

**DISCIPLINE:** The father explains ways he disciplines his son such as taking items away from him nor not allowing him to play his favorite video game.

**AUTISM AWARENESS/RESOURCES:** The father reports he became more aware of the autism diagnosis as his son's pediatrician provided more information. The father feels more aware of the disorder by his research and details by the medical professional.

**ACTIVITY SHARED WITH SON:** The father reported he payed attention to his son interest in this certain game and asked him if he wanted to play it. The father stated he purchased the game and began playing the game with him. The father stated this is an activity they engage in together often.

**FATHER'S FRUSTRATION:** The father reported he gets frustrated with his son

as he forgets things he just knew the day before. The father reported this is a symptom of the disorder.

**INTERVENTIONS:** The father reported he and his wife write notes around the house to remind his son of things he often forgets. The father reports he also allows his son to communicate by computer to increase his communication as well. The father reports these are very helpful interventions.

**STRENGTH OF THE FATHER/ ROLE OF THE FATHER:** The father reports he has become stronger as a father by knowing more about the autism disorder and his son's needs.

**FAMILY BONDING:** The father reported he and his wife have become closer as they are forced to lean on each other as they parent their son with autism.

**PROTECTION:** The father stated he has a fear of not being with son as he knows his son as a lack of communication. The father reports others may not understand this deficit and may judge him.

**CHILD'S INABILITIES/ FAMILY AWARENESS:** The father further explained his son's lack of communicating with others that are not aware of his autism disorder. The father reported his family members not understanding his son's autism disorder and how it affects him communicating.

**PROTECTION:** The father explains how he informs others of his son's autism disorder so they won't expect him to respond in a way he is not capable of doing.

**CHILD'S INABILITIES:** The father explains a symptom of his son's autism disorder such as him speaking very soft and slow where others are not able to hear or understand him.

**INTERVENTIONS:** The father explains how he tries to increase his son's vocabulary to help with his lack of communication.

**RESOURCES:** The father identifies resources he son has to help with his autism such as; self-contained classes where he receives extra help to the physical education teacher being trained to teach kids with autism. The father explained how the PE teacher has activities where his son is not forced to interact with so many kids.

**PHYSICAL DEFICITS:** The father reports his son has some physical difficulty with his limbs as they become stiff. However, his son received physical therapy for such handicap.

**CHILD'S PROGRESS:** The father explained his son is now speaking louder and



more because of speech therapy and his counseling sessions.

**EMOTIONAL REACTIONS:** The father reports feeling guilty as he wishes and his wife would have identified the signs of autism earlier. The father also reported the guilt of having a child diagnosed with autism and one not.

**EARLY INTERVENTIONS:** The father reported he wish his son would have began services earlier and at an earlier age.

**FAMILY AFFECTED:** The father reported his eldest son is affected by the autism disorder as his friends often ask what is wrong with his brother as they are not aware of the signs and symptoms of autism.

**ADVICE FOR OTHERS** The father reported his advice to other fathers would be to take time for your yourself, getting your child tested early, building trust and a bond with the child.

**AWARENESS OF DISORDER:** This code refers to the father stating his daughter is aware of her symptoms of her disorder. The father explains how he is aware of his daughter's autism symptoms, but others around her may not be aware of them.

**FAMILY INTERACTION :** Refers to the way in which the father and other family members interacts with her. The father described how the daughter and brother play together like a typical 11 & 15-year-old. The father stated they have the typical sibling relationship.

**FAMILY INVOLVEMENT:CHILD'S INTEREST::** Ok, well during school hours we definitely help her with school work, she's kind of a techy she loves gadgets. She loves pets, we had a little cat, but we had to get rid of him because of her allergies.

**CHARACTERISTICS OF AUTISM:** Refers to the father stating she would much rather be inside, if it's up to her. She has no issues being to herself.

**FATHER AND CHILD INTERACTION:** This refers to the father explaining how they like to play games and she is a little bit of a sore loser.

**FAMILY INTERACTION WITH CHILD/FAMILY INVOLVEMENT**

The father explains she loves family board games and the movies.

**SYMPTOMS OF AUTISM:** This refers to the child not being fond of very loud sounds due to her sensory deficit. The father explains how the child will cover her ears whenever the movies get too loud.

**AWARENESS OF DISORDER:** This refers to the father being aware when the sounds are too much for her due to him knowing his daughter and the signs and symptoms of autism.

**FATHER'S INVOLVEMENT**

: This refers to the father stating he is patient with his daughter and her diagnosis.

**FATHER'S INVOLVEMENT:** The father also states he shows his daughter right from wrong and what and what not to say.

**PROTECTION:** This refers to the father being aware of those around his daughter.

**FATHER'S INVOLVEMENT:** This refers to the father wanting his daughter to become more independent, although he recently stopped engaging in hygiene tasks for her such as putting lotion on her when she gets out of the tub.

**DISCIPLINE:** The father states his daughter will try to take advantage of authoritative figures if they don't hold her accountable.

**LACK OF AWARENESS:** The father explained how it is at times difficult to differentiate between her disorder and her simply being defiant.

**CHARACTERISTICS OF AUTISM:** The father reported his daughter has issues knowing when she hurting someone's feeling by her bluntness.

**FATHER INVOLVEMENT:** The father reported his daughter has a communication deficit, but he tries to teach her how to communicate effectively with others.

**EARLY SIGNS OF AUTISM :** The father reported he and his wife saw signs at the age of four or five.

**POSITIVE-THINKING:** The father reported although he knew something was wrong with his daughter he never viewed the disorder as a negative. The father stated he always knew she would be fine.

**FATHER'S EMOTIONS:**The father admitting experiencing feelings of anger when his daughter's autism diagnosis was confirmed.

**FATHER'S EMOTIONS:**The father stated he was unsure about his daughter's future because of her challenges she faced due to the disorder.

**LACK OF AWARENESS:** This refers to the father stating his family and in most Black families, the response to such children is "ain't nothing wrong with that child, she just stubborn". However, the father states despite such comments he

knew something was not right with his child.

**FATHER'S EMOTIONS:** The father stated he felt relieved when he finally found out his daughter was diagnosed with autism.

**SUPPORTS:** The father stated his daughter began being involved in therapy and he could really notice a difference.

**LACK OF AWARENESS:** The father stated he and his wife had challenges within their marriage as he allowed his daughter to get away with certain things because of her diagnosis.

**SUPPORTS:** The father reported when his daughter was diagnosed, the medical professionals simply gave him a long print-out of information which was basically information he had given them of his daughter.

**LACK OF AWARENESS:** The father stated when he finally begin finding out more information about the disorder, he noticed a lot of the signs were there, but they didn't know what they were.

**SUPPORTS:** The father states following the diagnosis, he was pointed in the right direction for supports and other resources.

**FATHER'S EMOTIONS:** This refers to the father being optimistic for his daughter's future and thankful of the progress his daughter has made

**DISCIPLINE:** This refers to the father being unsure of his daughter's manipulative behaviors and when to discipline her.

**AWARENESS OF AUTISM::** The father stated he is aware of his daughters symptoms as he can tell her something and it is possible she will forget within a couple of days.

**DISCIPLINE TECHNIQUES:** This refers to the father stating he takes items away from his daughter when she misbehaves

**FATHER'S INVOLVEMENT:** This refers to the father stating he is more hands-on with his daughter because she is diagnosed with autism and he knows he would not be as hands-on with her if she didn't have the diagnosis.

**FATHER'S INVOLVEMENT:** This refers to the father admitting he has to do more for his daughter as she is not as other children and she is not as self-sufficient. The father also explains how he helps his daughter with her homework.

**FATHER'S EMOTIONS:** This refers to the father identifying his daughter's autism diagnosis has having a positive effect on him.

**LACK OF AWARENESS:** This refers to the father admitting his family members are not aware of what autism is and also its' symptoms.

**SYMPTOM OF AUTISM:** This refers to the father stating being around his daughter, one may not know she has autism. However, someone may wonder why she does not show eye-contact when she is being spoken to. Or why she repeats the same thing repeatedly.

**AWARENESS OF AUTISM:** This refers to the father admitting at times he wants to tell other people his daughter has autism, but then he wants others to also see her as a normal child.

**LACK OF AWARENESS:** The father explains his mother is not aware of his daughter's symptoms and it is a challenge when she keeps her due to the daughter's communication.

**SYMPTOM OF AUTISM:** The father explains how he has purchased his daughter a cell phone, but she rarely calls them and only speaks a few words she returns their calls.

**SUPPORTS:** This refers to the father explaining how much his daughter has improved since she started therapy.

**SYMPTOM OF AUTISM:** The father reports his daughter use to sit in random men laps before therapy and she didn't know any better.

**FAMILY INVOLVEMENT:** The father explained how the family interacts with his daughter and they all get along well.

**POSTIVES OF AUTISM:** The father stated there have been no financial or social issues because of his daughters autism diagnosis.

**COPING SKILL:** The father stated he advises other men raising an autistic child to seek help from medical professionals and to reach out to others raising an autistic child.

**INCREASED AWARENESS:** The father reported he began teaching and researching himself about autism.

**EARLY DIAGNOSIS:** The father advises fathers to get their child tested as early

as possible and to start interventions early.

**COPING SKILL/PARENTS SHARED EXPERIENCES:** The father states he helps other parents raising autistic children

**SYMPTOM OF AUTISM:** The father advised other fathers to know their child, what autism looks like and don't be in denial of the symptoms.

**SYMPTOM OF AUTISM:** The father explains how they knew at the age of 2 something was wrong with their child

**SYMPTOM OF AUTISM DISORDER:** This refers to the child's symptom of repetitive speech.

**SYMPTOM OF AUTISM DISORDER:** This refers to the child's lack of eye contact.

**FATHER NORMALIZING BEHAVIORS:** The father states his child is just as other kids.

**FATHER AND CHILD BONDING:** This refers to the father stating he and his son like to watch and play football.

**FATHER INTERACTION W/CHILD:** The father states he is a very hands-on father with his son.

**FAMILY INVOLVMENT W/ CHILD:** The father states he and his son are very close.

**FATHER'S INTERACTION W/CHILD:** The father states his son is not bad at all and he listens to him.

**FATHER'S REACTION:** This refers to the father admitting he was afraid his son was going to be on medication.

**FATHER FEARED MEDS:** This refers to the father stating he really didn't want his son on meds bc he didn't know what autism was.

**SOCIETY'S LACK OF AWARENESS:** This refers to the father stating he was concerned about other people's not knowing what autism was.

**PROTECTION OF CHILD:** The father stated he always wants to be able to protect his son.

**FATHER'S EMOTIONAL REACTION:** This refers to the father stating he was relieved when he found out about the diagnosis.

**AWARENESS OF DISORDER:** This refers to the father stating he likes to tell others about the progress his son makes.

**CHILD'S ABILITIES:** This father stated he son makes him frustrated at times, but it's fine.

**NORMALIZING BEHAVIORS:** This refers to the father stating his son is like other kids.

**EARLY IDENTIFICATION OF DIAGNOSIS:** The father stated his son was diagnosed early in school.

**FATHERS REACTION:** The father stated he accepted the diagnosis on his son.

**DISCIPLINE :** The father stated his biggest challenge is disciplining his son.

**DISCIPLINE :** The father stated he uses corporal punishment with his son.

**PARENTING:** The father stated he uses the same method of discipline as his daughter.

**DISCIPLINE:** The father states he also takes toys away from his son as a punishment.

**STRATEGY OF PUNISHMENT:** This refers to the father stating he gives his son a warning before a punishment.

**FATHER'S REACTION TO AUTISM:** This refers to the father stating his son having autism does not affect him daily.

**FAMILY'S AFFECTION W/ CHILD:** This refers to the father stating he makes sure to show love towards his son.

**POSITIVES OF AUTISM ON FATHER:** The father stated his son having autism is a positive.

**ROUTINE FOR CHILD:** This refers to the father stating his son has a routine he does daily and it works well for him.

**POSITIVES OF AUTISM:** This refers to the father stating he has not had many

challenges with his son being autistic.

**DISCIPLINE:** The father stated he struggles with knowing when to discipline his son.

**LACK OF AWARENESS:** The father stated bc he didn't know much about autism, discipline is a problem at times.

**SUPPORTS:** This refers to the father stating when his son was diagnosed they received services immediately.

**SCHOOL SUPPORTS:** This refers to the father stating his son has a therapist at school.

**POSITIVES OF AUTISM:** This refers to the father stating their family has not been affected by autism.

**COPING SKILLS:** This refers to the father stating all fathers should take time for themselves.

**SUPPORTS:** This refers to the father stating all fathers should have a support system.

**PARENTING:** This refers to the father describing his way of parenting his son is easy to him. The father does not identify with any negatives.

**FATHER'S INTERACTION W/CHILD:** The father describes how he interacts with his son such as going to the movies.

**FATHER'S INTERACTION W/CHILD:** The father describes how he interacts with his son such as going to the playground and eating at restaurants.

**SYMPTOM OF DIAGNOSIS:** This refers to the father describing how his son does not like going out much, but then he doesn't either.

**FATHER AND CHILD BONDING:** This refers to the father describing the way in which his son hugs him daily.

**EARLY IDENTIFICATION:** This refers to the father stating his wife identified developmental issues in his son at a young age. The father didn't know it was autism, but they knew something was not normal.

**SYMPTOM OF AUTISM:** This refers to the father stating his son was not interacting with other kids and this was not normal for a child.

**FIRST DETECTION OF AUTISM:** The father reported his son did not talk much at home with family.

**LACK OF AWARENESS:** This refers to the father stating although he had some experience working with special need kids, he did not know his son had autism.

**EARLY IDENTIFICATION:** This refers to the father stating the child received the autism diagnosis.

**FATHER'S REACTION:** This refers to the father reporting he experienced sadness when diagnosed with autism.

**FATHER UNAWARE OF AUTISM:** The father stated although the diagnosis was confirmed, he had no clue of what autism was.

**FATHER'S ACCEPTANCE:** This refers to the father accepting the autism diagnosis.

**FATHER AND SON INTERACTION:** This refers to the father stating he looks forward to his son giving him hugs when he gets off of work.

**POSITIVE PERSPECTIVE OF SON:** This refers to the father knowing his son would be fine despite the autism diagnosis.

**EARLY IDENTIFICATION OF DIAGNOSIS:** This refers to the father stating his son was 5 when he was diagnosed with autism.

**COPING SKILLS:** This refers to the father stating he goes to the movies to cope with having a child diagnosed with autism.

**PARENTING:** The father stated he son is good and rarely gets in trouble.

**PARENTING:** The father stated his son is a normal child to him, but he does try to ignore him at times.

**DISCIPLINE:** The father refers to taking items away from his son rather than spanking.

**INCREASED AWARENESS:** This refers to the father having a new desire to research and learn more about autism.

**CONFIDENCE:** This refers to the father feeling as though he is a better father since the autism diagnosis.



**FAMILY DYNAMICS CHANGING:** This refers to the father having plans to have another child, but being hesitant due to his son being diagnosed with autism.

**SCHOOL SUPPORTS:** This refers to the father stating his son receives supports from his school and the teachers love him.

**SCHOOL SUPPORTS:** This refers to the school having a love for his school.

**FATHER'S EMOTIONS:** This refers to the father stating he feels blessed to be his son's father.

**COPING SKILLS:** This refers to the father advising others to read the Bible, stay faithful and find a church to stay in the word.

**EMOTIONS:** This refers to the father describing his son as being "amazing". The father appears to be proud of his son despite him being diagnosed with autism.

**SYMPTOM OF DIAGNOSIS:** The father describes how he interacts with his son does not like being out much; this is a characteristic of autism.

**FATHER AND CHILD BONDING:** The father describes how he interacts with his son such as playing video games with him as he completes his homework.

**FIRST DETECTION OF AUTISM:** This refers to the father describing how his son was noticed having signs of autism by his Dr.

**SUPPORT:** This refers to the father describing the Dr. suggesting he makes a visit with a psychologist.

**FATHER'S EMOTIONS:** This refers to the father stating he was in denial regarding his son being diagnosed with autism.

**FIRST DETECTION OF AUTISM:** This refers to the father stating the psychologist he was referred to diagnosed his son with autism.

**FATHER'S EMOTIONS:** The father appears to felt relief abt the diagnosis. However, the father stated he wish they would have found out abt the diagnosis earlier.

**FATHER'S EMOTIONS:** This refers to the father stating he felt guilt when he found out abt the diagnosis.

**SUPPORT SUGGESTED BY DR:** This refers to the father stating the psychologist

suggested he is more hands-on with his son for more positive results.

**FATHER'S EMOTIONS:** This refers to the father stating he feels blessed to have his son.

**FATHER/SON INTERACTION:** The father stated he sacrifices time with his friends to spend time and bond with his son.

**EARLY IDENTIFICATION OF DIAGNOSIS:** This refers to the father stating his son was diagnosed at the age of 5.

**COPING SKILLS:** This refers to the father stating his coping skills are playing pool.

**FATHER/SON INTERACTION:** This refers to the father admitting he brings his son with he and his friends at times.

**DISCIPLINE:** This refers to the father stating he disciplines both of his children in the same manner despite the disorder.

**AWARENESS:** This refers to the father stating the daughter understands she is somewhat different from her brother bc of the autism diagnosis.

**INTERACTION W/ CHILD:** The father stated he interacts with both his kids in the same manner and is sure not to show more child attention than the other.

**FATHER'S EMOTIONS:** The father stated he loves both his kids the same and wants to always feel this from him as a father.

**FATHER'S EMOTIONS:** The father stated he is a better father bc of his son.

**FATHER/SON SHARED HOBBIES:** This refers to the father stating he and his son play games and just hang out together.

**EMOTIONS:** This refers to the father stating since his son has been diagnosed, he doesn't take too many things that seriously.

**PARENTING:** This refers to the father stating he has noticed he is not as patient with his daughter.

**DISCIPLINE:** This refers to the father stating his son tries to manipulate him at times.

**MARITAL CONFLICT:** This refers to the father stating he and his wife would

have arguments abt when to give his son consequences.

**MARITAL CONFLICT:** This refers to the father stating when it comes to discipline, he would say one thing and his wife would say another.

**MARITAL CONFLICT:** This refers to the father stating his wife would feel like he was allowing his son to get away with thing he should have received a consequence for.

**MARITAL SATISFACTION:** This refers to the father stating he and his wife found ways to compromise and come to an agreed decision regarding their son.

**COPING SKILLS:** This refers to the father stating his wife has to make him get out of the house at times for self-care.

**SPOUSE SUPPORT:** This refers to the father stating his wife is there for him and understands she has to encourage him to cope.

**SIBILNG AWARENESS:** This refers to the daughter being aware of her brother's autism diagnosis.

**AWARENESS OF DISORDER:** This refers to the father not allowing his house to be rules by autism. The father states there are days his house runs like a sewing machine and other days is like war.

**FATHER EMOTIONS FOR FAMILY:** This refers to the father stating how much he loves his family and is sure to show them. The father stated he wouldn't trade them for the world.

**SON'S FUTURE/INDEPENDENCE:** This refers to the father stating his son has expressed a desire to move-out as he gets older.

**FATHER'S/SON BOND:** The father stated if and when his son does move-out, he will be right there for him as he is now.

**SCHOOL SUPPORT:** This refers to the son's school therapist

**AUXILLARY SUPPORT:** This refers to the son's outpatient therapist.

**POSITIVE OF DISORDER:** The father stated his son having autism has made him a better person/father.

**COPING SKILL:** The father advised other fathers to remember to take care of yourself and get out of the house.

**EARLY IDENTIFICATION:** The father advised other fathers to try and get their child tested and diagnosed at an early age.

**FATHER/SON INTREACTION:** This refers to the father stating he and his son rule the house and also that it's usually the girls against the boys.

**EMOTIONS TO FATHERHOOD:** This refers to the father stating he was happy to find out he was going to be a daddy' and to a boy.

**EMOTIONS ABT DIAGNOSIS:** The father stated when he found out about the diagnosis, he felt sad and angry.

**EMOTIONS ABT DIAGNOSIS:** The father stated the diagnosis made him feel some type of "way".

**EMOTIONS ABT DIAGNOSIS:** The father reminisces about the type of sports he wish his son could play one day, but may never do.

**FATHER'S FEELINGS ABT AUTISM:** The father stated he came to reality and remembered his son has autism and may never do these things.

**EMOTIONS ABT RELIGION:** This refers to the father admitting he questioned God and why he give him a son that was autistic.

**UNWANTED DIAGNOSIS:** The father stated he did not want his son to be autistic.

**AWARENESS:** The father stated he started reading information about autism.

**FATHER'S FEELINGS ABT AUTISM:** The father stated again he started realizing all the things he loved, his son may not be able to do as him.

**AWARENESS OF AUTISM:** By reading, the father is aware he can't play God and there is nothing he can do make his child not have autism.

**FATHER/SON INTERACTION:** This refers to the father despite autism, his son actually does like a few of things he does.

**SYMPTOM OF AUTISM:** This refers to the father stating his son does not like loud noises.

**SYMPTOM OF AUTISM:** This refers to the father stating his son can be a bit anti-social at times.

**FATHER'S ENJOYMENT:** This refers to the father stating he enjoys spending time with his son.

**FATHER/SON BOND:** The father stated he sacrifices time with his friends to be with his son.

**MARITAL SATISFACTION:** This refers to the father stating he does not spend as much time with his wife, but she understands.

**FATHER/SON BOND:** The father stated when he gets off of work and his son thinks something is wrong with him, he tell him everything will be ok.

**FATHERS LOVE:** This refers to the father quoting " that's my man right there".

**FATHER'S REACTION:** The father stated he'll never forget when he found out

his son was diagnosed with autism.

**FIRST DETECTION OF AUTISM:** The father states his son teacher started asking them questions about his son in the home.

**TEACHER'S OBSERVATION:** The teacher asked if he showed eye contact with us in the home.

**AUTISM CHARACTERISTICS:** This refers to the teacher referring to eye contact and talking to us in the home.

**PARENTS LACK OF AWARENESS:** The father stated they never paid attention to see if he was looking at them in the eye.

**LACK OF INFORMATION:** The father stated they just figured he was a shy child.

**LACK OF AWARENESS:** The father stated they didn't think these signs were a big deal.

**EARLY DIAGNOSING:** This refers to the father stating, before he knew it he was signing permission slips to have his son tested by the school.

**LACK OF AWARENESS:** The father admitted he didn't know what they were talking about.

**LACK OF AWARENESS:** The father stated he thought it was something his son could get rid of.

**PARENT'S REACTION:** This refers to the father stating he asked his wife how could they have missed this; and they should have caught it.

**EARLY DETECTION:** This refers to the father stating he wish he would have caught it earlier so his son could have been diagnosed earlier.

**EARLY DETECTION:** The father stated he begin to think of things his son would do that would appear autistic.

**LACK OF INFORMATION:** The father stated how could he have missed it if he didn't know what he was looking for.

**SUPPORT:**

**LACK OF AWARENESS:** The father stated he wish they would have caught it first rather than the teachers telling them.

**OPTIMISM:** The father stated his son want to become an Olympic runner.

**SYMPTOM OF AUTISM:** The father states his son can tell you everything about an Olympic runner.

**COPING SKILL:** The father stated his son gets running from because he likes to run too.

**DIAGNOSING:** This refers to the age this son was diagnosed with autism.

**COPING SKILL:** The father stated he runs and gets out of the house to cope.

**SELF-CARE:** This refers to the father stating he likes to run and it makes him feel better.

**FAMILY TIME:** The father stated he likes to spend time with his family.

**MARITAL CONFLICT:** The father stated he and his wife don't spend time together as they use to.

**SUPPORT:** The father stated they don't like leaving his son with just anyone.

**RESPIRE:** The father stated his mother watches his son to help them out.

**NORMALCY:** The father stated his son was having a temper-tantrum.

**PATIENCE W/ SON:** The father stated the tantrums use to get on his nerves, but not anymore because he now has patience with him.

**FATHER'S BLESSING:** The father stated his son is a blessing to him.

**DISCIPLINE:** The father explains his son is spoiled and it's his wife's fault.

**MOTHER LACKS INTERVENTIONS:** The father explains how his wife does not know how to control him when he acts out.

**FATHER'S RAPPORT :** The father stated his son listens to him and his wife often calls him.

**DISCIPLINE :** The father stated he makes his son get in the corner when he misbehaves.

**DISCIPLINE :** The father stated his son's sisters, his wife and other family spoils him.

**DISCIPLINE :** The father stated he talk to his son to try and calm him down.

**DISCIPLINE :** The father stated he also takes his toys away.

**DISCIPLINE:** The father stated he does not spank his son.

**NORMALIZATION:** The father stated his son is just like other kids.

**NORMALCY:** The father stated his family is like all others; his son just has autism.

**NORMALCY:** The father stated his son is a good kid.

**PATIENCE W/SON:** The father stated he knows he has to be patient with his son.

**BALANCING TIME:** The father stated he makes sure he balances time with all of his kids.

**SIBLING'S EMOTIONS:** This refers to the father stating his daughter told him she felt forgotten.

**FATHER'S EMOTIONS:** The father stated he felt sad when thinking about the way his daughter felt.

**FATHER'S SHARED TIME:** The father stated he knew then he needed to be sure all kids had time with him

**SIBLING REACTION TO AUTISM:** The father stated his daughter started acting out.

**SUPPORTS:** The father stated his son has a therapist at school.

**SUPPORT FOR FATHERS:** The father stated he advises father to seek help.

**MARITAL SATISFACTION:** This refers to the father stating he advises father t be sure to spend time with your staff.

**CLOSENESS:** This refers to the father admitting his son is spoiled by him.

**EMOTIONS TO FATHERHOOD:** This refers to the father stating he enjoys be a father.

**FATHER & SON BOND:** This refers to the father interrupting the interview to inform the interviewer his son was spoiled.

**FATHER & SON BOND:** This refers to the father stating his wife and others always remind him how spoiled his son is by him.

**FATHER'S LOVE FOR ONLY SON:** This refers to the father stating his wife wants more kids, but the father is hesitant as he fears he may not love another child as his son.

**FATHER'S LOVE:** The father states again how much he loves his son and fears he it won't be the same for another child.

**FATHER & SON INTERESTS:** The father explains how his son loves water and so does he.

**CHILD'S HOBBIES:** This refers to the father stating his son likes to go to the playground

**FATHER AND SON HOBBIES:** This refers to the father stating he has been going to the playground with his son for a long time.

**COPING SKILL:** The father states he now likes the water as he feared it in the past.

**FATHER'S CONFIDENCE:** This refers to the father stating he is a better person because of his son.

**PATIENCE:** This refers to the father stating he has patience with his son now, but in the past he did not.

**SYMPTOM OF DISORDER:** This refers to the father explaining his son will ask the same question repetitiously.

**SUPPORT:** This refers to the father stating his wife supports him by giving him a break with his son.

**FATHER & SON CLOSENESS:** This refers to the father stating his son would always rather be with him.

**FATHER'S LOVE:** This refers to the father stating he loves his son so much despite how much he talks.

**CHARACTERISTIC ON AUTISM:** There was a time his son would not talk to him.

**LACK OF AWARENESS:** This refers to the father stating he and his wife didn't know what to look for with autism.

**SYMPTOM OF AUTISM:** This refers to the father stating their church friend identified the autism signs.

**EARLY DETECTION:** This refers to the father stating they took the child to get tested.

**EARLY SIGNS :** This refers to the father stating in the beginning there were signs such as a lack of eye contact with other kids.

**EARLY DETECTION:** This refers to the father stating he and his wife took his son to get tested following advice from the church friend.

**DEFICIT OF AUTISM:** This refers to the father stating when his son was diagnosed, he immediately thought of all the things he thought he would not be able to do.

**FATHER'S INVOLVEMENT:** This refers to the father stating as soon as his son was diagnosed, he knew he would be involved with him.

**FATHER'S HANDS-ON:** This refers to the father stating he takes his son to all of his appts.

**EARLY DIAGNOSIS:** This refers to the father stating the child was 4 at the age of diagnosing.

**COPING SKILL:** This refers to the father stating he jogs, plays basketball and drink a few beers to cope.

**FAMILY INTERACTION:** This refers to the father stating he makes sure he spends time with his family

**MARITAL SATISFACTION:** This refers to the father stating he is sure to spend time with his wife.

**LOVE OF FATHERHOOD:** The father states he loves being a father to his son.

**POSITIVES OF AUTISM:** This refers to the father stating he enjoys his role as a father.

**FATHER'S REACTION:** This refers to the father stating he does get frustrated at times with his son when he is being manipulative.

**SUPPORT:** This refers to the father stating his wife supports and helps him with his son.

**FATHER'S INTERVENTIONS:** The father stated he knows how to handle his son.

**NEGATIVE COPING SKILL:** This refers to the father stating he drinks beer at times, but his wife will only allow him to have 2-3.

**NORMALCY:** This refers to the father stating many times, his son tries to be manipulative and is aware of what he is doing.

**DISCIPLINE:** This refers to the father stating he takes his toys away from him as a discipline.

**AUTISM AWARENESS:** The father stated he began reading more about autism.



**SACRIFICE:** This refers to the father stating he takes off of work so his wife doesn't have to.

**SACRIFICE:** This refers to the father stating he and his wife have different work schedules.

**SUPPORT:** This refers to the father stating they wish they had more support.

**FINANCIAL STRESS:** This refers to the father stating they are not in a position for only one person to work.

**SUPPORTS:** This refers to the father stating he appreciates the support they receive and it is very much needed.:

**SCHOOL SUPPORTS:** This refers to the father stating his son has a school therapist.

**RESISTANCE TO SUPPORTS:** This refers to the father stating in the beginning, he did not want an in-home therapist.

**APPRECIATES SUPPORTS:** This refers to the father stating he now sees the need for his son to have an in-home therapist.

**SON'S SOCIAL:** This refers to the father stating his son is sociable with others.

**SUPPORTS:** This refers to the father stating his son is involved in a support group.

**SON GIVES BACK:** This refers to the father stating his son is involved in community service.

**RESPIRE:** This refers to the father stating he knows his son needs time away from them.

**FATHER/SON CLOSENESS:** This refers to the father advising other fathers to spend time with their son to increase bond.

**EARLY DETECTION:** This refers to the father advising others to get their child tested as early as possible.

**FATHER'S JOY TO FATHERHOOD:** This refers to the father's over joy of being a father to a baby girl for the first time. The father stated he feels blessed to be his daughter's father.

**SIBLINGS INTERACTION:** This refers to the father stating his daughter has the normal sibling conflict with her brothers.

**FATHER & DAUGHTER BOND:** The father stated his daughter makes him smile

and she knows it.

**FAMILY INTERACTION:** The father stated they all attend church as a family.

**BLESSED:** The father quoted again how he blessed he is to have his daughter.

**CHARACTERISTIC OF AUTISM:** This refers to the child having a dislike for church; due to the noise level.

**SYMPTOM OF AUTISM:** The father stated his daughter covers her ears at church.

**PROTECTION:** The father stated he is now more concerned of how and what others say abt his daughter.

**CHILD'S HOBBIES:** The father stated his daughter loves to eat chicken nuggets and at times that's all she'll eat.

**SUPPORTS/PROGRESS:** The father stated his daughter has come a long way in church as she use to have bad meltdowns.

**CONFIDENCE:** The father stated he will do whatever it takes to make his daughter comfortable.

**OPTIMISM:** The father reported he knows his daughter will have a great future.

**FATHER/DAUGHTER ACTIVITIES:** This refers to the father stating he and his daughter color and eat together.

**DISCIPLINE:** The father stated he gives in to his daughter often.

**SACRIFICE:** This refers to the father stating he has taken on a part-time job.

**HANDS-ON:** The father stated he likes to be there so he can be with his daughter at her appts

**FATHERS EMOTIONS:** The father stated at first he felt he was tool old to be a dad again.

**FATHERS GUILT:** The father felt his daughter had autism bc of his age.

**AUTISM AWARENESS:** The father found out his age could not be a factor for his child having autism.

**FATHER'S EMOTIONS ABT AUTISM:** The father stated in the beginning, he felt mad at God for giving his daughter autism.

**EARLY SYMPTOMS:** The father stated his sister-in law noticed signs first.

**FAMILY SUPPORT:** The father stated his sister-in law and himself didn't have the best relationship, but he had to listen to her abt his daughter.

**EARLY DIAGNOSIS:** The father stated he and his wife had his daughter assessed at 5.

**EARLY SIGNS:** The mother noticed signs as well, but was in denial.

**LACK OF AWARENESS:** The father stated his wife mentioned it to him, but he didn't know what she was talking abt.

**MARITAL CONFLICT:** The father admitted he was angry at this wife.

**SUPPORTS:** The father stated his wife was there to support him during his daughter's diagnosis

**COPING SKILLS:** The father stated he likes to write to cope with stress in the home.

**DISCIPLINE:** Again, the father stated he gives in to his daughter a lot.

**PROTECTIVE:** The father stated he describe his parenting style as their protector

**PROTECTIVE:** The father stated he often looks around to be sure the family is safe.

**FATHER'S EMOTIONS:** The father stated he is blessed to be a dad.

**FATHER/DAUGHTER BOND:** The father state he will always be there for his daughter and he is her protector.

**JOY:** The father states he feels nothing but joy when he thinks of his daughter.

**VULNERABILITY:** The father states he is vulnerable when it comes to his daughter.

**ACCEPTANCE:** The father stated he has accepted the fact his daughter is autistic and it's ok.

**FATHER'S EMOTIONS:** The father stated in the beginning he use to cry all the time, now he does not.

**DISCIPLINE:** This refers to the father stating his wife has told him he spoils his daughter; he knows it.

**FATHER AND DAUGHTER BOND:** The father stated his daughter makes him feel like a whimp, but no one else can.

**FATHER/SON CLOSENESS:** This refers to the father stating he has a close relationship with his son.

**FATHER AND SON INTERACTION:** The father stated he spends a lot of time with his son.

**FATHER& SON BOND:** This refers to the father stating he is closer to his son with autism than the other kids.

**SIBLING AWARENESS:** This refers to the father stating the kids in the home are aware of autism.

**HANDS-ON:** The father stated his son gets irritated fast, but he helps him.

**SIDE-EFFECT OF AUTISM:** This refers to light sensitivity

**SYMPTOM OF AUTISM:** This refers to sounds sensitivity

**CHARACTERISTIC OF AUTISM:** This refers to body sensitivity

**FAMILY INTERACTION:** The father stated his daughter aggravates his son on purpose and that's normal aggravation.

**DENIAL:** The father stated he could not accept something was wrong with his son.

**SYMPTOM OF AUTISM:** The father stated he had thought of his son not being as other boys bc of autism.

**ANGER:** The father stated he was mad with God for his son being autistic.

**FEAR:** The father stated he was afraid bc of the autism diagnosis.

**LACK OF AWARENESS:** The father stated he thought him drinking beer was the cause of the autism.

**COPING SKILL:** The father admitted he drinks to calm himself.

**FRUSTRATION:** The father admits he gets frustrated at times.

**SCHOOL SUPPORT:** The father stated the teacher was the first person to encourage testing.

**ALCOHOLISM:** The father admitted he started drinking heavily bc of stress.

**RELIEF:** The father admitted he was relieved to find out his son was autistic.

**INCREASED AWARENESS:** The father stated he wanted to know more about the disorder.

**PROGRESS:** The father stated his son has really progressed verbally with time.

**CHARACTERISTIC OF AUTISM:** The father stated in the past his son was non-verbal.

**EARLY SIGNS:** The father stated his wife thought she noticed signs in the past.

**DENIAL:** The father admitted he was in denial when his wife tried to tell him.

**SYMPTOM OF AUTISM:** The father stated his son was non-verbal

**SIDE EFFECT OF AUTISM:** Sound sensitivity

**DIAGNOSIS:** The child was diagnosed at age 6.

**COPING SKILL:** The father stated they take trips to cope with life.

**COPING SKILL:** The father stated he reads a lot now.

**DISCIPLINE:** The father stated he does not spank his son.

**INTERVENTION:** The father stated he takes his toys or items he likes away from him.

**COMPREHENSION:** The father stated he knows his son understands when he tells him a demand.

**TEACHERS SUPPORT:** The father stated his son's teacher spoils him.

**MARITAL CONFLICTS :** The father stated he and his wife argue abt discipline.

**DISCIPLINE :** The father stated his son tries to manipulate his wife.

**INCREASED DISCIPLINE:** The father stated he has told his wife she has to increase discipline with their son.

**MARRIAGE THERAPY:** The father stated he and his wife have stated they want therapy.

**OPTIMISTIC:** The father stated his son wants to move out one day.

**SCHOOL RESOURCES:** the father stated his son has a school therapist.

**COMMUNITY RESOURCES:** The father stated they have family therapy.

**INDIVIDUAL THERAPY:** the father stated his son also has his therapist that comes to the home.

**ADVICE:** The father advises other fathers to drink, but not excessively.

**FAMILY RESPITE:** The father advises others to allow family members to help.

**FATHER/SON BOND:** the father stated he and his son are very close

**FATHER AND SON INTERACTION:** The father stated he and his son spend a lot of time together.

**FATHER/PRIMARY PARENT:** The father stated he spends most of his time with his son.

**CHILD'S INTEREST:** The father stated his son likes to play video games

**INTERVENTION:** The father stated he talk to his child so he can talk more to others.

**HANDS-ON:** The father stated his won would rather be with him than anyone else.

**CHARACTERISTIC OF AUTISM:** The father stated his son does not like loud music.

**SYMPTOM OF AUTISM:** The father stated his son would often Ignore father at times

**SYMPTOM OF AUTISM:** The father stated his son does not like being around others a times.

**OPTIMISM:** the father stated he is hopeful abt his son's future

**BLESSED:** The father stated he is blessed to have his son.

**EARLY SIGN:** The father stated the neighbor first noticed signs of autism.

**INCREASED AWARENESS:** The father stated he wanted to learn more about autism.

**DIAGNOSIS:** The father stated he was hesitant abt the diagnosis.

**DENIAL:** This refers to the father being in denial abt his son's autism diagnosis.

**GUILT:** The father stated he thought it was his fault and karma for him being in

and out of jail.

**RELIEF:** The father stated they were relieved to finally get the diagnosis.

**DIAGNOSIS:** The child was diagnosed at 6.

**COPING SKILL:** The father stated he likes playing video games.

**FAMILY INTERACTION:** The father stated they all play a lot and ppl say their house is always fun.

**EXCITEMENT:** The father stated he was excited to learn he was having a boy when his wife was pregnant.

**FAMILY DYNAMICS :** the father stated in the past he hesitated abt having more kids, but he felt his child w/ autism was enough.

**HANDS-ON:** The father stated he wanted to be sure he is hands-on w/ all of his kids if there are more.

**DISCIPLINE:** The father stated his son gets in trouble mostly for his mouth.

**DISCIPLINE:** The father admits he gives in to his son at times.

**SCHOOL RESOURCES:** the father stated his son has a therapist at school.

**SCHOOL NON-COMPLIANCE:** The father stated the school use to be non-compliant w/ his son's IEP.

**ADVOCATE FATHER:** the father stated he is at the school often

**HANDS-ON:** The father stated he takes his son to all of his appts.

**FINANCES:** the father stated they have issues with money with taking their son to all of his appts.

**FATHER'S JOY OF DAUGHTER:** The father stated he is very close to his daughter.

**FATHER AND DAUGHTER BOND:** The father state he and his daughter are like best friends.

**FAMILY INTERACTION:** The father admits he spoils his daughter.

**HANDS-ON:** The father stated he is hands-on w his daughter.

**BLESSED:** The father stated he is very thankful for his daughter.

**DIAGNOSIS:** The father stated his daughter was 3 when she was diagnosed w autism.

**SCHOOL SUPPORTS:** The father stated his daughter's teacher noticed the signs first.

**SYMPTOM OF AUTISM:** the father stated the teacher noticed she didn't show eye-contact

**CHARACTERISTIC OF AUTISM:** The teacher also noticed she began to rock back and forth

**SYMPTOM OF AUTISM:** The father stated his daughter is awesome with numbers

**OPTIMISM:**The father stated he is optimistic abt her future

**INCREASED AWARENESS:** The father stated he begin researching autism

**RELIEVED:** The father stated he was relieved to finally get the diagnosis

**DIAGNOSIS:** The father stated she was diagnosed at the age of 3.

**COPING SKILL:** The father stated he plays the piano to cope with stress

**FATHER INTERACTION W/ DAUGHTER:** The father stated he now paint nails to engage w his daughter

**CHILD'S INTEREST:** The father stated his daughter likes boys now!

**AFFECTION :** The father stated his daughter likes giving him hugs

**DISCIPLINE :** The father stated his daughter will have a meltdown at times

**DISCIPLINE :** The father stated he takes his daughters phone away.

**DISCIPLINE :** The father admits he has issues giving consequences to his girls.

**DISCIPLINE:** The father stated his daughter gets in the most trouble due to her smart mouth

**PROTECTION:** The father stated he knows his daughter will be leaving the home soon and he is nervous

**TEACHER OF CHILD:** The father stated he tries to teach all of her girls the tools to survive



**OUTPATIENT THERAPY:** The father stated his daughter likes horses during therapy

**SOCIAL SKILLS THERAPY:** The father stated his daughter is a part of Girl's Inc.

**INCREASED SOCIALIZATON:** The father stated they now talk more as a family

**COPING SKILLS:** The father advises fathers to spend time with all of their children.

## Appendix G: Themes &amp; Subthemes

Themes & Subthemes		
Research Question	Themes	Subthemes
RQ1: What are the experiences of African American fathers raising an autistic child?	Father interaction with the child	Playing video games Outside Activities Taking the child to their appt's (Therapy)
RQ2: What are the emotional reactions of African American fathers after they have learned of their child's diagnosis?	Reaction to Autism	Sadness, Guilt, Anger, Blessed, Depressed, Optimistic
RQ3: How do African American fathers describe their parenting experiences with their autistic child?	Discipline of the Child	Child manipulates father Does child understand discipline and punishment Father often unsure of ways to discipline
RQ 4: What are the challenges that African American fathers experience when raising an autistic child?	Awareness & Supports of Autism	Father didn't understand autism Lack of knowledge regarding symptoms Late Diagnosis Resources