“LOVE HIM AND EVERYTHING ELSE WILL FALL INTO PLACE”: AN ANALYSIS OF NARRATIVES OF AFRICAN-AMERICAN FATHERS OF CHILDREN WITH AUTISM SPECTRUM DISORDERS

A Dissertation in
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by

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Abstract

This exploratory qualitative dissertation analyzed the narratives of six African-American fathers of children with autism spectrum disorders (ASDs). Contributors were identified via snowball sampling and data were collected using in-depth interviewing and analyzed using analysis of narratives. Findings are presented via individual case presentations and with cross-case comparisons, utilizing emergent theme analysis to highlight themes across the fathers’ narratives.

Findings suggest all of the fathers engage in a form of assessment of themselves, their resources, and their environments when describing their experiences as African-American fathers of children with ASDs. The fathers’ description of their life histories and learning about fatherhood yielded two themes of intentional engagement and ecological stressors, with some additional subthemes. The fathers’ description of being African-American fathers of children with ASDs yielded two shared themes of experiencing an orientation process and an adjustment process. This description also included several subthemes. The fathers’ descriptions of the meaning they attach to being African-American fathers of children with ASDs yielded a theme of self-assessment. Implications for counseling practice, counseling research, and counselor education are discussed.
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Chapter 1: Introduction

Prologue

The circumstances leading up to my coming back to graduate school for a doctorate in Counselor Education and Supervision is directly tied to my dissertation topic and broader research interests. I am a married, African-American father of a child with an autism spectrum disorder. So, what happened between finding out about Avery’s diagnosis and my enrollment?

I was working as a school counselor in an urban, NJ high school and generally enjoying my job and overall career. LaChan, my wife, was ready for a new career challenge. She was a tenured high school English teacher who contributed significantly to the school community through helping develop student leaders. She was an athletic coach and advised the school’s Student Council. Nile, our 4-year old daughter, was in a stable, generally happy and emotionally healthy home and on all accounts was developing typically. However, Avery, our 21 month old son was having some challenges. After discussing our concerns with the kids’ pediatrician about Avery’s limited verbal communication (e.g., he had about 7-10 words at 21 months), he recommended we do two things: contact our county’s Early Intervention Services (EIS) unit to schedule a home visit and make an appointment to see a developmental pediatrician.

The EIS professionals were gracious, but at the end of their home visit and assessment we knew what they had to share would be difficult to hear. Their discomfort was written all of their well-meaning faces. They were not allowed to offer a diagnosis, but knew of our upcoming appointment at Cooper Hospital in Camden to see the developmental pediatrician. After sharing their narrative reports with us that communicated Avery was developmentally delayed in many areas, they said we should be prepared to hear the word, autism. Our meeting with the developmental pediatrician a few weeks later confirmed the EIS assessment. Avery’s diagnosis was Pervasive Developmental Disorder – Not Otherwise Specified (PDD – NOS).
I grieved as if I lost a loved one. Who is Avery? Who would Avery become? How bad was this? Did we do something wrong? Whose fault is this? Whose family and gene pool was responsible for this? Why was this happening to us? Why was it happening now?

As we looked to our faith to help us make meaning of this new and scary situation, LaChan channeled her anger, frustration, sadness, and hope into developing a non-profit agency. The Greater Expectations Teaching & Advocacy Center (GETAC) for Childhood Disabilities, Inc. was created to support parents and siblings of children with developmental disabilities. LaChan is an entrepreneur at heart. I had since switched jobs and was as the counselor of a university-run, college-access program for low-income, high achieving high school students from the same community where my former school counseling job was situated. I had a great job with great benefits. It seemed to be a place where I could commit to spending the next several years. However, I did not feel intimately connected to LaChan’s vision for this non-profit agency she started.

One Sunday during church service, I believed God gave me clarity about my contribution to this organization. I needed to finish my school counseling supervision certification coursework, earn a doctorate in counseling/counselor education so that I could lend competency in the area of mental health (coping, adjustment, meaning-making) to our efforts with parents and siblings of children with developmental disabilities. After talking it over with LaChan and spending lots of time in prayer, I was finally clear about what type of terminal degree I should pursue. I have wrestled with a dissertation topic since my studies commenced. I originally wanted to study siblings of children with autism. My experiences, convictions, combined with sound advising from my dissertation committee, however, have led me to the intersection of race, fatherhood, and children with disabilities.
Overview

In this chapter I present a brief description of the prevalence of autism spectrum disorders (ASDs) in children living in the United States and how the presence of ASDs in families can influence the lived experiences of those children’s fathers. I share what I believe to be research gaps in the study of how ASDs influence the lived experiences of fathers, which demonstrate the value of the study. The chapter concludes with what I believe to be the benefits of a qualitative approach to the study, the significance of the study’s results, and the study’s research questions.

Autism spectrum disorders (ASDs) are among the broader category of pervasive developmental disorders (PDDs), as articulated in the fourth edition of the Diagnostic Statistical Manual of Mental Disorders -Text Revised (DSM-IV-TR) (APA, 2000). Pervasive developmental disorders are considered Axis I disorders because they are typically diagnosed in early childhood and can carry a lifelong diagnosis. The DSM-IV-TR describes the broad symptomology of PDDs as “…characterized by severe and pervasive impairments in several areas of development that can include: reciprocal social interaction skills, communication skills, or the presence of stereotyped behavior, interests, and activities” (APA, 2000, p. 69). The range of autism diagnoses fall on a continuum based on the presence and severity of symptoms in patients. The DSM-IV-TR describes ASDs as, “…the presence of markedly abnormal or impaired development in social interaction and communication and a markedly restricted repertoire of activity and interests” (APA, 2000, p. 70). The current range of ASDs include: autistic disorder, Rett syndrome, childhood disintegrative disorder, pervasive developmental disorder- not otherwise specified (PDD-NOS), and Asperger’s disorder.

Autistic disorder can present as mild or very severe, but generally require evidence of the most symptoms for a diagnosis. Rett syndrome has a delayed onset, with children experiencing
typical development for the first several months of their lives, followed by the emergence of symptoms between five months and four years old. Child integrative disorder is arguably the most drastic diagnosis, with children experiencing typical development for up to two years, followed by a diminishing of previously acquired skills (e.g., verbal communication, etc.) by 10 years old. An Asperger’s disorder diagnosis is unique in that the broad symptomology (e.g., social impairment, restricted range of activities) is present, but there are no significant delays in language or cognitive development. Pervasive developmental disorder-not otherwise specified (PDD-NOS) diagnoses represent a broad combination of symptoms that may vary in severity, but may not meet criteria within the spectrum of a more specific diagnosis. The PDD-NOS diagnosis is most reflective of Avery’s symptoms and I believe was the accurate diagnosis for him at the time he received it.

It is important to discuss the pending publication of the fifth edition of the Diagnostic Statistical Manual of Mental Disorders (DSM-V), which is scheduled for release in May 2013. Customary with any revision of the DSM, mental health and medical professional organizations and their leaders have been invited to offer their respective critiques and support of the new edition. There are several new and revised diagnoses that will appear in the DSM-V with autism spectrum disorders (ASDs) being among them and among the most significantly contested. The American Psychiatric Association (APA) released a press release in January 2012 communicating the criteria by which autism will be diagnosed in the DSM-V. The document, in part, reads, “The proposal by the DSM-V Neurodevelopmental Work Group recommends a new category called autism spectrum disorder which would incorporate several previously separate diagnoses, including autistic disorder, Asperger’s disorder, child disintegrative disorder, and pervasive developmental disorder not otherwise specified” (APA, 2012, p.1) and be categorized
as either severe, moderate, or mild. Currently, the DSM-IV-TR identifies over 2000 ways to be diagnosed as having some form of autism, while the DSM-V will identify 11 ways.

The Center for Disease Control and Prevention (CDC) reported in March 2012 that approximately 1 in 88 children living in the United States are diagnosed with some form of autism (2012). These diagnoses rates are on the rise considering the last report from the CDC that indicated approximately 1 in 110 children were diagnosed with an ASD in 2006 (2010). The influence of these diagnoses rates has direct implications for the families, schools, and communities in which children with ASDs live and engage. There are also implications for counselors who serve these children and their families.

The lived experiences of parents of children with ASDs have been studied, but rarely have they intentionally sought to capture the singular experience of fathers, especially African-American fathers. Many of the studies have sought to quantitatively measure how parents report the disability’s influence on the parental experience, primarily within the domains of stress level reporting (Pottie & Ingram, 2008; Davis & Carter, 2008; Hastings, Kovshoff, Ward, Espinosa, Brown & Remington, 2005; Dunn, Burbine, Bowers, Tantleff-Dunn, 2001), the influence of stress on the partner relationship and the potential for divorce (Freedman, Kalb, Zablotsky, & Stuart, 2011; Hartley, Barker, Seltzer, Greenberg, Bolt, Floyd, & Orsmond, 2010; Brobst, Clopton, & Hendrick, 2009), experiences of social stigma (Gray, 2002), and gender differences in coping style (Gray, 2003). Many of these studies have either intentionally focused on, or were primarily only able to capture the mothers’ assessment of the influence. The literature on this topic has yielded a largely consistent finding: parenting a child with an ASD is more stressful than parenting a typically-developing child and, arguably, more stressful than parenting a child with another type of developmental disability.
The current literature has yielded important findings even within the limited empirical research devoted to better understanding how fathers report their experience fathering a child with an ASD. However, because of my own lived experience as an African-American father of a child with a specific ASD (PDD-NOS), I became interested investigating how other fathers described their respective lived experiences. In a comparative study on the differences in child effects on father-child relationships reported by fathers raising typically developing children, children with ASDs, and children with Down Syndrome (DS), Rodrigue, Morgan, and Geffken (1992) found that fathers of children with ASDs and DS reported more negative effects than fathers of typically developing children. The analysis also yielded two additional and important findings: fathers of children with ASDs reported more avoidant coping strategies than the other two categories of fathers, and that fathers of girls with ASDs reported lower levels of available social support than other subgroups.

Empirical research has documented that fathering children with ASDs is more stressful and challenging than raising typically developing children (Herring, Gray, Taffe, Tonge, Sweeney, & Einfeld, 2006). Fathers of children with ASDs also report more stress and less satisfaction in their partner/spouse relationship and less available social support than other parents (Brobst, et. al, 2009). It is no surprise that considering the aforementioned findings that fathers of children with ASDs also report poorer sleep quality than parents of typically developing children (Meltzer, 2008).

One strand of research has examined genetic relationships between children with ASDs and their relatives. A significant amount of this inquiry has included the biological fathers of children with ASDs (Mouridsen, Rich, & Isager, 2008; Scheeren & Stauder, 2008; Veltman, Thompson, Craig, Dennis, Roberts, Moore, Brown, & Bolton, 2005). Family members, and
fathers, in particular, have been found to exhibit milder forms of ASD characteristics, but usually not enough to meet diagnostic requirements (Fombonne, Bolton, Prior, Jordan, & Rutter, 1997; Hughes, Plumet, & Leboyer, 1999; Piven & Palmer, 1997). The research informs our knowledge base about fathers of children with ASDs, but I had two overarching concerns about the existing literature: (1) there are little to no qualitative studies investigating this phenomenon which limits the methodological diversity and, (2) many of the samples represent college educated White men. MacDonald and Hasting (2010) reported the vast majority of research on fathers of children with ASDs has used quantitative methodologies. They report finding only two studies using qualitative research traditions since 2000 by the same author. In those two studies, Gray used interviews to analyze gender differences in parent coping styles (2003) and interpretations of social stigma (2002). I argue the need to investigate this topic because there is virtually no literature on how African-American fathers describe fathering children with ASDs.

**Purpose of the Study**

This exploratory study of how African-American fathers of children with ASDs describe their lived experience assists those providing support to families, including, but not limited to counselors, social workers, teachers, principals, and policy makers. An African-American sample of fathers can further assists these service providers because it helps them understand how these men make decisions about seeking formal services and support generally, and how they specifically perceive the utility of counseling for this experience.

Sutton and Muson (2004) reported that approximately one of two marriages in the United States end divorce. Associated with this trend, Cabrera (2010) reported that over one-third (35.7%) of children born in the United States are born to unmarried couples, many of whom are cohabitating at the time of the child’s birth. However, this issue is much more prevalent in the
African-American community. Martin, Ryan, and Brooks-Gunn (2007) shared that approximately 70% of African-American children are born to unmarried parents and that children born in these unions are not likely to reside consistently with their biological fathers. Because the existing research has identified, in some ways, how fathers report their experiences raising children with ASDs related to stress, relationship quality with spouse, and child effects on the family, a study that gives voice to married African-American fathers’ narratives tends itself to making a significant contribution to our counseling knowledge base. An important question that emerges is: How do African-American men describe their fathering experiences as fathers of children with ASDs?

**Systems Theoretical Framework**

One way to better understand the influence of disability on the family is to study the phenomena through a systems orientation lens. Friend and Cook (2002) offered that family systems theories view the family as a complex and interactive social system in which all members’ needs and experiences affect the others. In fact, there have been some researchers who have argued that African-American families should only be studied through a systems framework (McAdoo, 1982; McAdoo, 1988; McAdoo, 1993; McAdoo & McAdoo, 2002). Carter and McGoldrick’s (2005) *family life cycle theory* offers an appropriate theoretical framework that captures the ways in which a childhood disability might enrich and stress the family at designated times throughout the family life cycle. Carter and McGoldrick (2005) offered a conceptualization of families and their normative experiences noting:

…families comprise people who have a shared history and a shared future. They encompass the entire emotional system of at least three…generations held together by
blood, legal, and/or historical ties. Relationships with parents, siblings, and other family members go through transitions as they move along the life cycle. (p. 1)

Studying this specific phenomenon through the family life cycle theory lens can increase understanding about the normative and unique rewards and challenges experienced by families, and specifically, African-American fathers raising children with ASDs.

My goal with this study was to gain a more in-depth understanding of how this specific sample of fathers described their experiences. An in-depth exploration of this phenomenon provided key insights on their mental health and well-being and it helps counselors work more effectively engage and support them. A qualitative approach was most appropriate in order to gain a deeper understanding of an understudied phenomenon and its influence on the fathers’ daily experiences.

Benefits of a Qualitative Approach

Wang (2008) wrote that functions of qualitative research are to, in part, help, “…understand the specifics of particular cases…[and]…capture the individual’s point of view through the use of multiple strategies…(p. 256-257). Kazdin (2008) suggested that using qualitative methodologies can be a key strategy for bridging the gap between practice and empirical validation in delivering counseling services. A qualitative approached help study the richness, uniqueness, complexities, and nuances of fathering children with forms of autism through the participants’ narratives.

I framed this qualitative study from an ontological and epistemological position that embraces social constructivism. Social constructivism desires to take into account the multiple realities of any specific phenomenon. The knowledge generated from this study was co-constructed between the contributors and me. Social constructivism is a belief system that
argues objective truth does not exist because of the varied contextual and subjective voices that label truth in scientific pursuit (Hays & Singh, 2012). Patton (2002) emphasized the importance of a collaborative relationship between researchers and participants in order to accurately collect, define, and interpret data and findings within the specific context in which the phenomenon is studied. Studying fathers of children with ASDs using qualitative approach offered balance, validity, and challenged some of the previous research that has relied on quantitative traditions. In their recent review of literature about fathers of children with ASDs, MacDonald and Hastings (2010) found only two studies since 2000 by the same author that used the same qualitative data collection method: recorded interviews. The studies analyzed how parents of children with an ASD experienced social stigma (Gray, 2002) and documented gender differences in coping between parents of children with children with Asperger’s disorder (Gray, 2003). This study builds on those previous and limited contributions to describe the lived experiences of African-American fathers of children with ASDs through their narratives. Rossman and Rallis (1998), describing how phenomenological data collection methods assist in this endeavor, write that research on lived experiences, “…focus in-depth on the meaning of a particular aspect of experience, assuming that through dialogue and reflection the quintessential meaning of the experience will be reviewed” (p.72). The lived experience, then, influences the meaning an individual or group attaches to the experience itself.

**Significance of the Study**

An analysis of narratives of African-American fathers of children with ASDs offers important information to a number of stakeholders that includes counselors. Counselors benefit from the results that offered a deeper and richer understanding of how these fathers experience this phenomenon in a specific context. The findings inform counselors on what aspects of their
experience raising children with ASDs trigger the most stress and their respective coping strategies. The findings identify what the fathers communicate as the most rewarding aspects of this experience and the most useful forms of support. School personnel, including but not limited to regular education teachers, special education teachers, principals, and school counselors, benefit from how to better empathize and more better engage with these men. A qualitative research design offers an alternative method of inquiry that can address in-depth, unique, and nuanced characteristics of this experience, which is limited within the current literature on this topic.

**The Research Questions**

My review of the existing research on fathers of children with ASDs reveals several key, but basic questions that I addressed in this study. My questions were:

1. How do African-American men describe their experience as fathers?
2. How do African-American fathers describe their fatherhood experience raising a child with an autism spectrum disorder?
3. What meaning do African-American fathers associate and/or derive from this experience?

The construction and refinement of research questions relied on an emergent design method (Lincoln & Guba, 1995), which emphasizes the importance of keeping the research design flexible to most effectively understand the phenomenon being studied. The emergent design allows research questions to change or shift as the researcher enters the field, engages in self-reflection, and collects data.

**Strengths and Limitations**

A strength of this study is its exploration of an understudied phenomenon of interest with an understudied population. Understanding fatherhood more deeply among these African-
American fathers of children with ASDs gives us information on how they make meaning of the experience. The findings show us how that meaning influences other family, school, and community relationships. The existing research on this topic provides an appropriate starting point for this study since the large majority of it quantitatively measures theoretical constructs (e.g., marital quality, stress, psychological well-being) or it qualitatively interprets specific parts of this experience (e.g., qualitatively different coping mechanisms between parents). This study broke new ground by documenting and analyzing how these fathers have made meaning of this experience. It has helped to uncover and document the subjective authenticity of the experience. Additional studies using quantitative and qualitative methodologies with different types of participants (e.g., gay fathers, Latino fathers, Asian-American fathers, etc.) can empirically test the findings for validation or alternative explanations.

An additional strength of this study is my membership in the group being studied. I am confident that my identity as a counselor, aspiring counselor educator, researcher, and African-American father of a child with an ASD contributed to this study’s findings. I look forward to engaging with these men and trust my ability to offer what might be similar or different perspectives to their narratives by accurately re-telling them and offering my own.

The primary limitation of the study is related to not using different methods of qualitative data collection and analysis. For example, collecting data via focus group interviews might lend itself to a stronger representation of a collective shared experience among participants versus collecting data via individual in-depth interviews.

**Conclusion**

This chapter began with a brief description of autism spectrum disorders (ASDs) and the research highlighting how ASDs influence fathers of those children. The benefits of a qualitative
research design, significance of the proposed study, prospective research questions, strengths, and limitations of the study were also discussed. A review of the literature about fathers, the effects of fatherhood on mental health, help seeking behavior in men, and mothers and fathers of children with ASDs follows in next chapter.
Chapter 2: Literature Review

In this chapter I provide a comprehensive review of literature that has addressed the effects of disabilities and, specifically autism spectrum disorders (ASDs) on families. I give particular attention to the effects on fathers. Definitions, descriptions, and an evaluation of the current research regarding fathers of children with disabilities, and particularly ASDs, is included. I also note the strengths and limitations of that literature and share potential directions for future research.

Defining Disability

Consideration of and support for people with disabilities is an important topic in America and globally. Three key pieces of legislation were passed to increase understanding about, and communicate institutional responsibilities, to people with disabilities. They are: Section 504 of the Rehabilitation Act of 1973, the Americans with Disabilities Act of 1990 (ADA), and the Individuals with Disabilities Education Act of 2004 (IDEA).

Section 504 of the Rehabilitation Act of 1973 prohibits discrimination on the basis of disability in programs administered by federal agencies, programs receiving federal financial assistance, in federal employment, and in employment practices of federal contractors. It further requires those agencies receiving federal support to make reasonable accommodations for people with disabilities. The Americans with Disabilities Act (ADA), a wide-ranging civil rights law enacted in 1990, denies discrimination against people with disabilities. Lastly, the Individuals with Disabilities Education Act (IDEA) is the federal law that ensures specialized services to children with disabilities in educational settings. The legislation provides special education and related services for students who qualify for services until they are 21 years old. The IDEA website (http://www.idea.ed.gov) indicates that more than 6.5 million infants, toddlers, children,
and adolescents are eligible for IDEA services. ADA defines the term disability as, “…(A) a physical or mental impairment that substantially limits one or more of the major life activities of an individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment (Equal Employment Opportunity Commission and the U.S. Department of Justice, 1991). The type and severity of disabilities vary; however, three broad categories are generally identified in the discourse about disabilities: physical disabilities, intellectual/cognitive disabilities, and developmental disabilities. These categories are not mutually exclusive since they can present simultaneously in individuals.

The broad focus of this literature review is on how childhood disabilities affect the lives of family members. Special attention will be given to autism spectrum disorders (ASDs) and their effects on families and fathers because of the disorder’s increasing diagnosis rate in children and its understudied influence on fathers.

**Theoretical Framework: Family Life Cycle Theory**

Carter and McGoldrick’s (2005) *Family Life Cycle Theory* is a theoretical framework that captures the ways a childhood disability might enrich and stress the family at designated times throughout the family life cycle. Carter and McGoldrick (2005) articulated six stages within the family life cycle, all requiring some process of emotional transition. The stages and transitions include: (1) single young adults leaving home and accepting emotional and financial responsibility for themselves; (2) the forming of couples, and subsequently, the joining of their families, through committed partnership and commitment to a new family system; (3) the creation of a new family with young children and the accepting of those new members into the previously established family system; (4) the raising of adolescents and increased flexibility of boundaries to permit independence; (5) the launching of adolescents into adulthood and
accepting a number of exits from and entries into the family system; and (6) the family existing in later life and accepting shifting generational roles. It is important to note that there are a number of secondary and tertiary changes that result from these stages that include but are not limited to: identity development in individuals exclusive of family of origin, realignment of family of origin relationships after entering into a committed romantic relationship, negotiation of child rearing practices and roles, redefining relationships with parents as adult-children, and confronting deteriorating health of parents in old age.

It is important to note the kinds of stressors that may be associated with the aforementioned stages and the ways families confront and adjust to those stressors. McGoldrick and Carter (2003) discuss horizontal and vertical stressors within families. Vertical stressors, the authors note, are family memories, traditions, and expectations that are passed down through generations (e.g., family attitudes, expectations, taboos, etc.). Vertical stressors represent the ways individual family members respond to experiences based on their collective family identity and their constructions of what is or is not acceptable. Horizontal stressors are stressors experienced by a family through time as they cope with and adjust to the transitions in the family life cycle. Horizontal stressors can be predictable (e.g., life cycle transitions) or unpredictable (e.g., untimely death). The combination of vertical and horizontal stressors for families can influence functioning based on a number of factors that include, but are not limited to economic resources, community resources, and/or coping strategies.

Horizontal and vertical stressors can also lead to shifts in family roles. Norris and Tindale (2004) and Cicirelli (1995) emphasize how boundaries in families shift, how emotional and psychological distance between members change, and how the roles within and between subsystems are regularly being redefined over time. Turnbull, Summers and Brotherson (1986)
note there are four main components in a family: *subsystems, cohesion, adaptability, and communication*. Within each component, families are confronted with challenges that facilitate or hinder healthy functioning, based on how they manage the vertical and horizontal stressors associated with each component.

Turnbull, et. al’s (1986) four family subsystems – the spousal/partnered subsystem (romantic partners in relationship), the parental subsystem (parent and child), the sibling subsystem (child and child), and the extra-familial subsystem (extended family, friends, etc.) – are influenced by families’ structural characteristics (e.g., vertical stressors: passed on attitudes, beliefs, assumptions, roles) and its current life cycle (e.g., horizontal stressors: new family with young children). The second component, *cohesion*, is illustrated by behaviors of enmeshment or disengagement. Minuchin (1974) describes enmeshment within families as those having weak boundaries between subsystems and disengagement as those having rigid subsystem boundaries.

*Adaptability*, is a family’s ability to change in response to a stressful event (Olson, Sprenkle, & Russell, 1980). Marshak, et. al (1999) notes that a family with rigid boundaries may have difficulty adapting to a new challenge or stressor, while a less structured family may have no consistent response to unfamiliar stressors or challenges. *Communication*, the fourth component in families, represents how family members convey and receive messages. Turnbull and Turnbull (1990) suggest that breakdowns in communication are rooted in interactions between people and interventions to assist in communication barriers should be focused on the communication system, not the members in the system.

Power and conflict negotiations naturally emerge within families during the numerous family cycles. Negotiations of power and the associated conflict resolution strategies vary by family type and configuration (Recchia, Ross, & Vickar, 2010). Cultural factors can have a
significant role in how the cycles, and the negotiations of power and conflict during the cycle, are resolved. Slater and Mencher (2001) offer constructive criticism of Carter and McGoldrick’s *family life cycle* theory, by highlighting how idiosyncratic families and their respective life cycle management styles might present. Slater and Mencher (2001) discuss the importance of family therapists being aware of how single parent families, ethnic minority families, gay/lesbian families, unmarried partners and their children, and or blended families may or may not be reflective of more general life cycle management practices or rituals.

The diversity of family composition has slowly become more evident in American discourse. Americans, however, still generally construct the ideal form of family as being a heterosexual, legally married couple and their biological children (Carter & McGoldrick, 2005) while other diverse family configurations can be considered unprotected (Burke, 1991), vulnerable, or considered to be functioning at a deficit (Rice, 1994). An important consideration for counselors working with families is to be sensitive to family structure, which Marshak, et. al (1999) suggest can vary based on membership characteristics (e.g., number of children, single-parent status, extended family members living in the same household) and cultural factors (e.g., values, attitudes, and traditions). For example, Adkison-Bradley (2011) acknowledges the multiple sources of stress African-American parents can feel when attempting raising their children to make meaningful life choices, while living in environments known to be hostile toward them and their children, and potentially being perceived as incompetent parents.

**Childhood disabilities and the family life cycle**

“When first confronting a disability, the family not only responds to the event itself but also must confront its beliefs about people who have disabilities” (Marshak, et. al, 1999, p. 5).
Marshak, et. al (1999) highlights seven typical family roles across diverse family configurations, which include: (1) economic role (e.g., income generation and management); (2) domestic/health care role (e.g., transportation, medical visits, preparing food); (3) recreation role (e.g., individual and collective hobbies); (4) socialization role (e.g., interpersonal relationships); (5) self-identity role (e.g., sense of belonging); (6) affection role; and, (7) educational/vocational role (e.g., career exploration and choice). The authors additionally suggest the effects of a disability can specifically influence or change at least four of those roles: family’s self-identity, earning capacity, recreational activities, and career decisions.

Children with disabilities influence the family system in unique ways. Those influences have been the subject of extensive empirical investigation. Research exists on how childhood disabilities influence the experiences of parents/caregivers, on typically developing siblings, and a comparatively small amount on fathers of children with disabilities (Dyson, 2010; Seligman & Darling, 2007; Canary, 2008; DeMarle & LeRoux, 2001; Riechman, Corman, & Noonan, 2008; Gerstein, Crnic, Blacher, & Baker, 2009; Trute, Hiebert-Murphy, Levine, 2007; Watzlawik & Clodius, 2011; Barr & McLeod, 2010; Iriarte & Ibarrola-Garcia, 2010; Smith & Elder, 2010; Barr, McLeod, & Daniel, 2008; Atkins, 1991; Ross & Cuskelley, 2006; Nixon & Cummings, 1999; Green, 2003; Meyer, 1995). Childhood disability in the broadest sense, particularly when not identified prior to birth, places a horizontal stressor (McGoldrick & Carter, 2003) on families. Families are challenged to confront their own assumptions and beliefs about people with disabilities based on what they have learned from their families (i.e., vertical stressor), and adjust to the stress associated with the experience. This adjustment is influenced by the type and severity of the disability and contextual influences that might support or stigmatize the disability. Seligman and Darling (2007) discuss how stereotypes of children with disabilities (i.e, vertical
stressor), direct experiences with parents of children with disabilities, or reinforced messages of delivering children without disabilities can all contribute to the ways families respond to finding out about a child’s disability. The authors identify some normative responses to the stressors as mourning, experiencing stigma, and partner/marital adjustment. They articulate these responses are influenced by the range of the impairment(s), the severity of the disability, and extent of care needed to meet needs associated with the disability. Some disabilities (e.g., intellectual) have been found to increase family stress, contribute to parenting discrepancies, yield negative reactions from extended family members, cause interaction difficulties in schools, and have mixed effects on siblings (Dyson, 2010).

It is important to consider family context, traditions, and constructions of what is and is not normal when attempting to understand how disabilities affect a family. While quantitative methodologies generally seek to generalize findings across a particular population, qualitative methodologies aim to deeply understand, authenticate, and contextualize a phenomenon of study. Most qualitative methodologies subscribe to social constructivist ontology and a transactional epistemology (Wang, 2008). That is, individuals experience multiple socially and individually constructed realities that are highly influenced by context. Those experiences, in specific contexts, generate knowledge about the studied phenomenon.

A family’s conceptualizations of normal are largely based on its own set of subjective experiences. A childhood disability diagnosis might fall outside of a family’s construction of normalcy and initiate stress. Consequently, work is required to negotiate contradictions of normal in their lives, especially when abnormal (i.e., disability) emerges within the family system (Canary, 2008). It is important to note that living with and caring for a child with a disability is not always negative. Riechman, et al (2008) argued positive outcomes for families
can include increased awareness, capacity for resolve, and enhanced family cohesion. The emergence of *disability studies (DS)* and its corresponding lens of *disability studies in education (DSE)* can help in this process. Collins (2013) writes that DSE “…seeks identify and disrupt the deficit ideologies and discourses that shape the process of *otherizing* people whose behaviors, bodies, ethnicities, or linguistic repertoires are perceived as ‘different from social expectations’.” (p. 284). Families’ construction of disabilities, influenced by a number of factors, can be a crucial factor in how they respond the rewards and challenges of the experience.

**Childhood disability influence on parents**

Stress has been a consistently studied variable in the literature addressing how various childhood disabilities influence parents. Intellectual disabilities have been found to yield different patterns of stress in parents, by gender. Gerstein, et. al (2009) measured reports of daily parenting stress and found mothers’ stress increased significantly over time, while fathers’ stress remained fairly constant about their children with intellectual disabilities. Decreases in mothers’ stress reports was related to both partners’ psychological wellbeing and perceived marital adjustment. Decreases in fathers’ stress was solely related to mothers’ psychological wellbeing and perceived marital adjustment. This finding seems to be consistent with developmental disabilities, as well. Trute, et. al (2007) found families’ adjustment to their children with developmental disabilities was generally predicted by parents’ negative or positive appraisal of the disability’s influence on the family. Adjustments that took longer within a family were strongly related to negative parental appraisal and were influenced self-reported levels of esteem in both parents. Mothers engaged in more positive appraisal and experienced higher levels of self-esteem than fathers. Majnemer, Shevell, Law, Poulin, and Rosenbaum (2012) found parents of school-aged children with cerebral palsy are likely to experience high stress, increased time
constraints, and financial and psychological burden and suggested the need to monitor family functioning intermittently to optimize child and family well-being to mitigate some of the associated stress.

Riechman, et. al (2008) suggests that the psychological wellbeing of parents is at risk when raising a child with various disabilities. The stress makes them more vulnerable to experiencing guilt and grief, and a places them at a heightened risk for separation. These risks are perpetuated by having to identify resources for specialized child and health care, having to adjust career plans, or not being able to socialize as much because of the child’s needs. Uskun and Gundogar (2010) confirmed the reported stressful experiences of parents of children with disabilities in Turkey, finding that societal attitudes, financial problems, and having limited free time all contributed to parental stress in raising children with various disabilities.

Two interpretations can be made from the literature on parents raising children with disabilities. The first is unanticipated, and sometimes extreme psychological stress is a major part of this lived experience. Focused research on interventions to assist in stress management of raising children with disabilities can yield important findings on how to better meet the needs of the population of parents of children with disabilities. This study informs how and when this stress is experienced. For example, while Trute, et. al (2007) found that families’ adjustment to their children with developmental disabilities was generally predicted by parents’ negative or positive appraisal of the disability’s influence on the family, mothers’ positive appraisal occurred sooner than fathers. However, fathers’ positive appraisal scores matched mothers’ positive appraisal scores during the second data collection point in the longitudinal study. Results from this study offered some indication of why some fathers of children with ASDs may not be
inclined to positively appraise their children’s disability as soon as the children’s mothers, when earlier positive appraisal can support healthier overall family functioning.

The second is individual parents interpret and manage the stress differently. Directed research on how childhood disability is constructed, interpreted, internalized, and externalized for parents is important. One might conclude that interventions suited for mothers may not work as effectively for fathers, and vice versa. The findings from the Gerstein, et. al (2009) study were very useful, but one of its major limitations was its assessment of psychological wellbeing in parents. The authors assessed psychological wellbeing through reports of the number of psychological symptoms, versus assessing wellbeing through reports of a positive range of functioning. This study inquired specifically about the rewards (strength-based construction) and challenges (psychological symptoms and stressors) associated with this lived experience.

**Childhood disability and influence on typically developing siblings**

Moen and Washington (1999) assert that sibling relationships are usually the longest and most enduring of the family relationship. The relationship between siblings is unique from other family relationships because, “Siblings provide a continuing relationship from which there is no annulment (Powell & Gallagher, 1993, p. 14). Bank and Kahn (1997) note that sibling relationships are cyclical and have their own life cycle within the larger family system. Seligman and Darling (2007) describe sibling relationships as intense, long term, cyclical, and complex and that, depending on a host of factors, may be more or less vulnerable and affected by having a brother or sister with a disability.

In Carter and McGoldrick’s (2005) third stage of the family life cycle (families with young children), one of the transitions includes accepting new family members into the current family system. Children who have siblings are required to make adjustments based on the
siblings’ needs. This adjustment may be more demanding for children who have siblings with disabilities. The adjustments made by the typically developing child are influenced by the ways the parents (and others) engage with and construct the interaction patterns with the child with the disability. Stoneman and Berman (1993, p. 4) articulate this complexity:

…the sibling relationship is directly affected by specific characteristics of the individual siblings, by characteristics of the family in which the children live, and by the childrearing strategies used by the children’s parents or primary caregiver. The childrearing strategies used by parents, in turn, are influenced by several factors, including characteristics of the parents and the emotional climate of the family and of the individual siblings.

Siblings influence each other’s interpersonal identity development (Watzlawik & Clodius, 2011). We might infer that children with disabilities have unique influences on their typically developing siblings and vice versa. Studies about siblings of children with disabilities have found typically developing siblings can feel largely overlooked, unheard, and frustrated in the context of their families. Barr and McLeod (2010) report five important findings about siblings of children with developmental disabilities (e.g., speech/language impairments). Siblings reported: (1) they felt like strangers often stared and had negative attitudes toward their brother/sister with a disability; (2) that peers did not demonstrate empathy and used negative words about them and their brother/sister with a disability; (3) that their families loved them, but did not have much time for them; (4) that their plans were often interrupted due to their siblings’ needs; and (5) they were given a significant amount of responsibility.

Similar findings have been associated with the typically developing siblings of children with intellectual disabilities (e.g., mental retardation). Typically developing siblings have been
found to be more involved in conflicts resulting from insults toward their brother/sister with an intellectual disability in various contexts (e.g., school, neighborhood), to experience differential treatment at home, and to experience a significant amount of worry and unease about their brother or sister’s future (Iriarte & Ibarrola-Garcia, 2010). The research on how childhood disabilities influence siblings has been specified by its internal and external effects. The external effects include challenges with peers, challenges with parents/caregivers, challenges with their sibling with a disability, and the documented benefits associated with having a sibling with a disability.

Typically developing siblings of children with disabilities can be at risk for a number of challenges (Barr, et. al, 2008; Atkins, 1991; Ross & Cuskelley, 2006; Nixon & Cummings, 1999; Hannon, 2011). Findings across disabilities seem to be fairly consistent. Barr, et. al’s (2008) comparative study of typically developing children who have siblings with speech and language impairments to children with typically developing siblings found children with siblings with speech and language impairments reported more stress than those with typically developing siblings. Atkins (1991) offer a compelling argument for children with siblings with learning disabilities, finding they were at higher risk for low self-esteem than those with typically developing siblings. Additionally, children with siblings with disabilities seem to be increasingly sensitive to normative family stressors (Nixon & Cummings, 1999).

Some literature suggests that the experience of children with siblings with disabilities has implications for relationships and externalized behavior. In my article, I informed school counselors to be mindful of this vulnerable population as they navigate their relationships with peers and authority figures in schools (Hannon, 2012). Children with siblings who have disabilities have been found to become targets for teasing and other forms of negative
interactions. Green (2003) found that siblings of children receiving physical, occupational, or speech therapy experienced stigmatizing peer interactions in schools and neighborhoods based on the siblings’ disability. Iriarte and Ibaroola-Garcia (2010) found that children with siblings with disabilities were subject to and at risk for conflicts because of discrimination and insults toward their siblings at school and other contexts. As a natural consequence, typically developing siblings have been found to assume or be assigned to a caregiver role for their sibling, functioning as a protector or interpreter to people insensitive to or unaware of the siblings’ uniqueness (Barr, et. al, 2008)

Research has documented some specific relationship challenges between typically developing children (who have siblings with disabilities) and their parents, and in the relationship between them and their siblings with disabilities. Beyond having to protect and interpret for their siblings with disabilities, Barr, et. al (2008) found typically developing children also experience feelings of sympathy and concern for their parents and might assume more responsibilities within the family system in an effort to relieve them of some of the stress associated with this experience. This phenomenon is further complicated because typically developing siblings have also been found to receive and be frustrated about receiving differential treatment in the home (Iriarte & Ibaroola-Garcia, 2010). Ross and Cuskelley (2006) found children report being angry at their sibling with a disability. The authors recommend helping the typically developing siblings find healthy coping techniques because of the mixed emotions, conflicts and loyalties associated with their identity as the brother or sister of a child with a disability. These common findings have prompted interventions, particularly in school and community settings, to assist this population. Naylor and Prescott (2004) developed a support group for school-aged siblings of children with disabilities, between 8 and 18 years old, with
overwhelming success. Outcomes associated with this particular intervention were self-reported increases in: self-esteem, quality of life, social interaction, coping strategies, and understanding of disability issues. Additional support for group work has come from the Sibling Support Project (Meyer & Vadasy, 2008), whose program is broadly designed to provide the brothers and sisters of special needs children with peer support in a highly recreational context. This project has been modeled in over 200 locations, including 8 countries.

There are empirically supported benefits to having a sibling with a disability. In addition to the potential for resolve and resilience within families and higher reported levels of cohesion (Riechman, et. al, 2008), Macks and Reeve (2007) found that children with siblings with developmental disabilities (e.g., autism spectrum disorders) demonstrated higher levels of empathy than children with typically developing siblings when demographic risk factors were controlled. And, children have been found to report feelings of great admiration for their siblings with visible/physical (e.g., Down Syndrome, spina bifida, cerebral palsy) and invisible/developmental (e.g., learning disabilities, cognitive disabilities, speech/language impairments) disability (Nixon & Cummings, 1999).

This research can help counselors better understand the complexity associated with living with and caring for children with disabilities. The range and severity of disability will influence the degree to which these challenges surface and impact families’ lived experiences, but there can be certainty about a more stressful and demanding life than those not caring for a child with a disability. Along with the inherent complexity of this experience are the intrapersonal and interpersonal implications for the population of individuals living with and caring for children with disabilities. One specific type of developmental disability, autism spectrum disorders (ASDs) has received a considerable amount of attention because of its rising diagnosis rates. I
focus on the ways ASDs influence the lives of siblings and parents, with a particular focus on fathers in the next section of this review.

**Autism spectrum disorders**

Autism spectrum disorders (ASDs) are described in the fourth edition of the Diagnostic Statistical Manual of Mental Disorders -Text Revised (DSM-IV-TR, APA, 2000) as, “…the presence of markedly abnormal or impaired development in social interaction and communication and a markedly restricted repertoire of activity and interests” (p. 70). The current range of diagnoses among ASDs include: autistic disorder, Rett syndrome, childhood disintegrative disorder, pervasive developmental disorder- not otherwise specified (PDD-NOS), and Asperger’s disorder. ASDs fall within the broader category of pervasive developmental disorders (PDDs). They are Axis I diagnoses because they are usually diagnosed in early childhood, typically carry a lifelong diagnosis, and the developmental impairments associated with the diagnosis can have impeding effects on activities of daily living.

It is common for people with an ASD (e.g., Asperger’s disorder, PDD-NOS, etc.) to be referred to, or consider themselves, as having autism or being autistic. However, the range and severity of symptoms associated with the disorders dictate specific diagnoses along what is considered the autism spectrum. Autistic disorder diagnoses generally have the widest range or highest number of symptoms, which can present as mild or severe. A Rett syndrome diagnosis, by comparison, can have a delayed onset. Children with Rett syndrome can experience typical development for the first several months of their lives, followed by symptoms emerging between five months old and four years old. Child integrative disorder diagnosis can be the most dramatic. Children experience typical development for up to two years, followed by a diminishing of previously acquired skills coupled with an emergence of associated symptoms.
(e.g., repetitive behavioral patterns) by 10 years old. An Asperger’s disorder diagnosis is unique because the common symptoms (e.g., social impairment, restricted range of activities) are present, but there are no significant delays in language development. Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) diagnoses represent a broad combination of symptoms that vary in severity, but do not meet specific criteria for one of the aforementioned diagnoses.

Trends in ASD diagnosis rates in the last ten years are alarming. The Center for Disease Control and Prevention (CDC) reported in March that approximately 1 in 88 children living in the United States are diagnosed with an autism spectrum disorder (2012). These diagnoses rates are on the rise considering the CDC’s last report that indicated approximately 1 in 110 children were diagnosed with an ASD in 2006 (2010). The influence of these diagnoses rates has direct implications for the families, schools, and communities where there are children with ASDs. There are also implications for counselors who serve these children and their families. One of these implications is the pending publication of the DSM-5 in May 2013. Over the last several months, the American Psychiatric Association (APA) has called on mental health and medical service providers and leaders to offer their collective critiques and support of the new edition. Autism spectrum disorders will be among the disorders whose diagnostic criteria and classification will change in the fifth edition. The American Psychiatric Association (APA) released a press release in January 2012 communicating the criteria by which autism will be diagnosed in the DSM-V. The document, in part, reads, “The proposal by the DSM-V Neurodevelopmental Work Group recommends a new category called autism spectrum disorder which would incorporate several previously separate diagnoses, including autistic disorder, Asperger’s disorder, child disintegrative disorder, and pervasive developmental disorder not
otherwise specified” (APA, 2012, p.1) and be categorized as either severe, moderate, or mild. Currently, the DSM-IV-TR identifies over 2000 ways to be diagnosed as having some form of autism, while the DSM-V will identify 11 ways.

The potential implications for these changes to how forms of autism will be diagnosed and categorized can be significant. The first way is how one of the current diagnoses – child disintegrative disorder – is listed in the same category as Asperger’s disorder or pervasive developmental disorder. Child disintegrative disorder symptoms are qualitatively different than some of the others that will be grouped together in the new category of autism spectrum disorder. Children who have symptoms of child disintegrative disorder develop and then lose some ability to communicate verbally. Children with PDD-NOS or Asperger’s generally possess and are able to enhance their expressive communication with appropriate and effective speech interventions. Another implication is the number of children whose symptoms may not fit within the newly identified 11 criteria for diagnosis. This may mean that several children who are experiencing some symptoms of what used to be considered symptoms of ASDs may not be eligible for empirically validated interventions because their symptoms do not fall among the 11 criteria. Lastly, it is important to remember that whenever sweeping changes in diagnostic criteria are implemented we can expect that the most vulnerable in our communities, particularly the poor, may not have the support to navigate a newly constructed pathway to receive the help they need.

In the following sections, I present findings on how childhood ASDs influence family members. It specifically addresses the disability’s influence on typically developing siblings and parents. I also devote a section on how ASDs affect fathers.

**Influence on typically developing siblings**
The current empirical and experiential knowledge has helped raise our awareness about living with and caring for people with disabilities and offers clues about the ways autism spectrum disorders affect the lives of family members. This understanding is critical considering the rampant increase in diagnoses rates in children. Smith and Elder (2010) suggest siblings of children with ASDs be assessed to determine their risks for future maladaptive behavior, based on the stressors associated with living with a brother or sister with a form of autism. They suggest interventions for this population will be important to help their ongoing adjustment to this complex phenomenon. Scholars have given attention to understanding the ways typically developing children interact with and report on the relationship with their sibling with an ASD. Kaminsky and Dewey (2001) found children with siblings with an ASD demonstrate less empathic behavior than children with siblings with Down Syndrome (DS) or typically developing siblings. Children with siblings with ASDs demonstrate less pro-social behavior, less intimacy, and less nurturing behavior than the two comparison groups. However, their findings also acknowledge the inherent complexity within these relationships. Siblings of children with an ASD and DS also reported greater admiration for their brothers and sisters and engaged in less competition and quarreling than children with typically developing siblings.

These interaction patterns between children with ASDs and their typically developing siblings can be a challenge, especially when we consider the severity of the symptoms (e.g., limited verbal language, behavioral tantrums, hyper-focused behavior, etc.). Ross and Cuskelley (2006) compared behavioral and relationship challenges between children with typically developing siblings and those with siblings with ASDs and their findings were noteworthy. They found aggressive behavior initiated by the sibling with an ASD (e.g., physical aggression, verbal aggression, destruction of property, general disruption) was the most commonly reported
interaction problem by their typically developing brother or sister and anger was the most frequent response from the typically developing siblings. Mediating the typically developing children’s capacity to cope effectively were skills such as wishful thinking, appropriate emotion regulation, and knowledge about the disability.

Children with ASDs have been found to positively influence their typically developing siblings’ psychosocial and emotional adjustment when demographic risks are minimized or controlled. Macks and Reeve (2007) compared the psychosocial and emotional adjustment of children with siblings with an ASD and children with typically developing siblings. They found the presence of a child with an ASD can enhance the psychosocial and emotional development of their typically developing sibling when the family meets a certain demographic profile. That is, these findings can vary by socioeconomic status, number of children, birth order, and gender. Consequently, when demographic risk factors rise (e.g., lower SES, more children, etc.), the presence of a child with an ASD appears to have an unfavorable effect on their typically developing sibling. The ways children with ASDs affect their typically developing brothers and sisters appears to be complex and dependent upon variables such as age of child with the ASD, severity of the ASD, age of sibling, family status/structure, socioeconomic status, and other demographic variables. One central theme that resonates in the literature is ASDs can contribute to an overall demanding, stressful, rewarding, and unpredictable relationship experience for typically developing siblings. An examination of how ASDs affect parents is an appropriate consideration in this review, as well.

**Influence on childhood ASDs on parents**

Similar to findings on the influence of other childhood disabilities on parents, parents of children with ASDs generally report higher levels of stress than parents raising typically

One source of stress associated with parenting a child with an ASD is stigma. Goffman (1963) articulates that experiences of stigma come from: (1) overt or external deformations (e.g., visible physical disability), (2) deviations in personal traits (e.g., mental illness), and (3) tribal stigmas (i.e, imagined/assigned or real traits of an identity deemed to deviate a widely accepted norm or standard of a dominant group). All of the aforementioned triggers of stigma can be associated with structural stigma (Corrigan, Watson, Garcia, Slopen, Rasinski, & Hall, 2005). Structural stigma occurs when large social institutions convey stigmatizing messages about differences or disabilities. Corrgian, et. al (2005) discuss the significant influence on large media outlets, such as newspapers, can have on structural stigma occurs by way of newspaper reporting.

Gray (2002) studied how parents of children with Asperger’s disorder experienced felt and enacted stigma and found the majority of parents in the study experienced felt stigma, or made to feel different because of their children’s diagnoses. Parents’ feelings of embarrassment were the most common manifestations of this felt stigma. Enacted stigma was defined as behaviors toward, or in response to the parents based on the child’s disability. Enacted stigma
was manifested by people staring, being avoidant, or making rude comments. Fathers in the study reported experiencing less felt and enacted stigma than mothers.

There is evidence suggesting specific coping strategies predict more positive moods and overall better psychological wellbeing in parents of children with ASDs. Pottie and Ingram (2008) found coping strategies that were problem-focused, engaged social support, used positive reframing, emotion regulation, and compromise predicted more positive psychological wellbeing and better moods in parents. Coping strategies that included escape, blaming, withdraw, and helplessness behaviors predicted decreases in daily positive mood. One of the salient sources of stress for parents has been focused on the social challenges (e.g., peer interactions) that children with ASDs confront. Specifically, the children’s social challenges – a significant barrier children with ASDs can experience – have been found to influence parents’ overall stress, parent–child relationship quality, and feelings of distress in each parent. Children’s regulatory problems (e.g., emotion regulation, ability to adjust to stress, etc.) was the primary trigger for stress in mothers, while children’s externalizing problems (e.g., interpersonal/behavioral challenges) was the biggest trigger for fathers’ stress (Davis & Carter, 2008). Dunn, et. al (2001) studied the interaction effects between stressors, social support, locus of control, coping styles, and negative outcomes among parents of children with ASDs. Their study’s results indicated that higher levels of social support predicted fewer problems between parents and that certain coping styles predicted problems between parents. Escape/avoidant coping styles, which were higher among the fathers, correlated with increased feelings of depression, isolation, and spousal problems in both parents.

Counselors work with parents to identify their children’s strengths and to assist in their adjustment to the challenges associated with ASDs. A close look at the stress variable indicates
that mothers and fathers interpret the stress differently and they influence each other’s stress levels. Hastings, et. al (2005) offers important insight into how mothers and fathers perceive and are affected by their children with ASDs. The influence of each parent’s perceptions on the other is noteworthy. In their study, mothers reported higher levels of positive perceptions and more depressive symptoms than fathers. Mothers’ positive perceptions had no significant relationship to fathers’ psychological wellbeing. Fathers’ stress ratings, on the other hand, positively correlated with mothers’ levels of anxiety and depressive symptoms. In sum, paternal stress and positive perceptions of their children’s condition were influenced by maternal depressive symptoms while maternal stress was influenced by their children’s behavior problems and by the fathers’ depressive symptoms. These studies suggest that fathers’ assessment and interpretation of their children’s disability can be different than mothers’ assessment. It also highlights what might be the different triggers of psychological distress for each parent.

The amount of psychological stress experienced by parents of children with ASDs can lead to questions about risk for separation or divorce; however, the literature is not consistent with findings about the potential for divorce or separation in parents of children with ASDs (Freedman, et. al, 2011; Hartley, et. al, 2010). Two recent studies are juxtaposed, with each offering competing results. In a cross-sectional, population based study, Freedman, et. al (2011) surveyed parents of children with ASDs and found they were not at an increased risk of living in households without two biological or adoptive parents than children without ASDs. A study challenging these findings compared the timing of divorce or separation in parents of children with ASDs with parents of typically developing children found parents of children with ASDs did have a higher rate of divorce than the comparison group (23.5% v. 13.8%) and that variables such as mothers’ age and children with ASDs born later in the birth order were predictors of
divorce (Hartley, et. al, 2010). What has been documented is that fathers of children with ASDs report more stress, less satisfaction in their partner/spouse relationship, and less available social support than mothers (Brobst, et.al, 2009). An additional source of stress is related to parents’ educational aspirations for their children. My wife and I discuss the challenge of using a strength-based perspective about our son’s ASD diagnosis, while acknowledging the potential of his being stigmatized in his educational pursuits (Hannon & Hannon, 2013)

These interrelated and complex findings make important contributions to how differently mothers and fathers perceive this experience, cope with the stress related to it, and the influence their individual responses have on each other. Although these findings offer insight into the ways parents cope with stress associated with raising children with ASDs, one major limitation I have found is there is generally no report on the severity of the autism or specific autism diagnosis in the children. The rare cases that do report the specific ASD diagnosis is usually Asperger’s disorder, which is a milder form of autism. Information about the severity of the diagnosis can provide contextual insight into the magnitude of the disability in the parents’ lives.

Additionally, the differences in parent perception, appraisal, and coping strategies with the challenges associated with raising children with ASDs warrants attention.

Both qualitative studies by Gray (2002, 2003) offer readers insight into specific ASD diagnosis, as the children referred to in the studies were identified as having high functioning autism (i.e., Asperger’s disorder). Gray’s (2002) study on stigma makes a significant contribution, but offers little in terms of complimentary literature that validates or challenges parents’ experiences of stigma with different ASD diagnoses (e.g., Rett syndrome, Child Disintegrative Disorder, etc.). The author notes that ongoing trends of integrating children with ASDs in mainstream educational settings may be assisting in the acceptance of this population,
but leaves questions about more severe forms of the disability. Gray’s (2003) study on gender differences in coping is valuable because of its illumination on how the differences in coping are practiced. However, the study’s limited inquiry and subsequent discussion on the influence their respective coping strategies have on the marital subsystem or the entire family system is not addressed. This study offers the flexibility to engage African-American fathers’ narratives on how their interpretation of this experience may influence his child with an ASD and other members of the family system. The following section offers an introduction on fathers and how they have been found to interpret raising children with disabilities, and with autism spectrum disorders, specifically.

Fathers

My earlier discussion on the influence of disabilities and specifically, autism spectrum disorders (ASDs), on family members has highlighted the complex nature of this phenomenon. However, there is utility in closely examining how ASDs influence fathers because of their historic, various, and emerging roles within the family system. The transition to fatherhood affects men’s mental health. Experiences as a father are likely to shape men’s identity within fatherhood. Studies have documented that fathers of children with disabilities respond to stress differently, interpret experiences differently, and cope differently than mothers. It is appropriate to broadly consider how fatherhood is conceptualized in the United States and research associated with the experience of fathering a child with a disability, and specifically, a child with some form of autism. This can aid in better understanding processes associated with these differences and their consequential behaviors and attitudes.

Fatherhood is defined in academic literature in very direct terms, although depending on the cultural contexts, father roles can vary. Pleck (2010) defined fatherhood experientially,
offering that fatherhood denotes two specific experiences. The primary denotation of fatherhood is in parental status. Someone who is a father is, generally, one of the two biological parents of a child, or he is a man functioning as a father figure in a child’s life. The father figure role might be filled by a biological relative (e.g., uncle, grandfather, etc.), a stepfather in a blended family, an adoptive father, or the romantic partner of the child’s biological parent who may be cohabiting with the parent and child. A man situated in any of the aforementioned categories can be considered a *father figure*, thereby engaged in a *fathering relationship*. Pleck’s (2010) second denotation of fatherhood, referred to the behavior of fathering, or the male’s role in parenting the child. Empirically, fathering has been measured by paternal involvement. Measures for involvement have included, but are not limited to: types and frequency of interactions, warmth-responsiveness, and control in decision making for and about the child.

An additional perspective on fatherhood exists within the social constructivist philosophical tradition, whereby fatherhood is a socially constructed identity and phenomenon. This perspective asserts that individuals in fathering relationships have learned how to engage in them as a result of their various contextual identities, roles, and influences. DeKanter (1987) argues that the construction of fatherhood reflects a constant positioning between at least 3 levels of meaning: the person of the father (i.e., father’s embodiment), the position of the father (i.e., father’s socio-cultural capital), and the symbol of the father (i.e., the father’s role in the life of his child). Additionally, Mahalik, Good, and Englar-Carlson (2003) introduced the construction of *scripts* men are socialized to follow in their development, inclusive of fatherhood. They include the: *strong and silent script* (e.g., restricted emotionality), *tough guy script* (e.g., projection of fearlessness, aggressiveness, and invulnerability), *give’em hell script* (e.g., use of aggression to take control of an uncomfortable feeling), and *playboy script* (e.g., engaging in
frequent and risky sexual behaviors). These conceptualizations provide an appropriate starting point to discuss how fatherhood roles have evolved over time in the United States while acknowledging the ways different contexts have and will continue to shape how fatherhood is practiced and experienced.

**Historical fatherhood roles in the United States**

Pleck (1987) and Palkovitz (2002) discuss four distinct phases of American fatherhood role development. The earliest role, during the 18th and early 19th centuries was as the authoritarian/moral figure in the household. These fathers authored the first handbooks on childrearing and served as principal instructors of their children. Their responsibilities centered on moral teaching, and also included discipline, provision of material needs, control of family property, and veto power concerning relationships and romantic courtships for their children. Another term that refers to fathers’ roles during this time is the *colonial American father*.

There have been differing perspectives on the how the enslaved African father in America engaged with his family during this time, as well. Fathers of African descent had roles that were quite different during this time since the large majority of them were slaves and subject to balancing their own values, customs, and traditions with those of their slave masters or overseers (Samuel, 2002; McAdoo, 1998). McAdoo (1988) acknowledges research (primarily via narratives and analysis of historical documents) points out enslaved African men were generally permitted to take on one of two roles within his family. Some fathers were prohibited by law to engage with and exercise authority within the context of their families resulting in their abandoning of a parental role. On the other hand, some slave owners recognized slave families and allowed them to exist as units. This allowed fathers to assume direct roles in supporting their children. Genovese (1976) summarized that the average enslaved Black male lived in a
family setting and had strong families and Black fathers were able to enact a variety of fathering roles, even under extremely adverse conditions.

Between the early 19th and middle 20th centuries, White fathers assumed a distant breadwinner role. These fathers, functioning in America’s industrial age, devoted increased time to employment outside of their home and mothers functioned as the primary caregivers to their children beyond infancy. This time period was significant for African-Americans because it was inclusive of the Emancipation Proclamation. McAdoo (1988) reported that emancipation left Black families under extreme political, social, and economic pressures because newly freed slaves transitioned from slave status to a caste system. Frazier (1966) documented that slave family functioning before emancipation could be a predictor of family functioning after emancipation. If a slave family was generally intact prior to emancipation then the transition to freedom did not result in family disorganization. In these cases, Black fathers had deep and committed relationships with their partners and children and there were no significant differences between Black and White family and fathering behavioral patterns. Fathers confronted pressures from two institutional barriers as Black families migrated north seeking employment: employment discrimination and public welfare policies that implicitly encouraged fathers to be absent so that mothers might be eligible for more welfare support.

Fathers’ roles continued to evolve between 1940 and 1965 as they were expected to function also as the gender role model within their families. These fathers continued to function in their earlier role as distant breadwinners, but larger societal influences integrated the gendering role model with the breadwinner role, communicating that fathers’ masculinity was synonymous with being an emotionally distant, financial provider. The civil rights era ushered broader access to employment and educational opportunities for Black men in the United States.
However, Black men were generally employed and enrolled in post-secondary education at significantly slower rates than their White counterparts (Samuel, 2002). Research suggests that two-thirds of African-American fathers were reported to be residing with their families in 1970, in spite of the aforementioned barriers (Neckerman & Wilson, 1986).

America’s current father, the *nurturing and contemporary* father, emerged in the late 1960s and continues today. This father takes more pride in his identity as an emotionally engaged and highly involved family member. He is willing to divide household responsibilities more equally with his partner, a departure from expectations in earlier times. It is important to note that critics of this model say it is largely reflects a middle-class, heterosexual father. It offers no distinction between fathers of different social classes, sexual orientations, ages, or cultural backgrounds. Samuel (2002) suggests that while African-American fathers largely were socialized to assume the role of protector and provider for their families, the assuming of the role has been largely influenced by systematic challenges and obstacles. However, one can interpret that in America, and cross-culturally, mothers or other female family members are the primary caretakers of children (Barry, Josephson, Lauer, & Marshall, 1977; Barry & Paxon, 1971). Seligman and Darling (2007) also highlighted that traditionally men have been socialized to assume an instrumental role in their families, while women were socialized into an expressive role. Darling and Baxter (1996) illustrated this point, indicating the instrumental role is one that is task-oriented and involves problem solving, independence, rational thought, and an unemotional stance. Consequently, these constructions of fatherhood have had an undeniable influence on the ways in which fathers engage with their families.

McAdoo (1993) reinforces many of these roles in his articulation of African-American father roles in families over the course of history. He asserts that African-American fathers
assume many of the same roles as fathers from other ethnic groups that include provider, protector, shared decision-maker, child socializer, and supporter of his spouse. These roles align, in many ways, as those articulated earlier and reinforce a shared sense of responsibility across racial and ethnic lines in America. McAdoo (1993) argues, though, that understanding the evolution of African-American fatherhood must be considered through a systems perspective that recognizes the influence and effects of institutional racism on Black fathers’ ability to fulfill their assumed roles.

Fatherhood and influence on mental health

The experience of becoming a father has been studied in a number of contexts in the United States and has documented its effect on the wellbeing of these men. Becoming a father can be the catalyst for an overall improvement in men’s wellbeing because it has been found to facilitate more positive overall health and healthy behavior in men. These positive behaviors include healthier diet, more physical activity, less alcohol use, and less risky sexual behaviors out of a desire to be present and serve as good role models for their children (Garfield, Isacco, & Bartlo, 2010). New fathers’ attitudes about fatherhood are also influenced by their own fathers’ level of involvement in their lives as children and can be predictive of their new fatherhood experience. Guzzo (2011) found new fathers whose fathers were less involved and/or not co-residential were less likely to agree that their fathers functioned as authority figures or were an important source of financial support or direct care compared to new fathers whose fathers were highly involved and co-residential.

There is also a psychological effect on men in the process of becoming fathers. Becoming a father is a major cornerstone of adult development, in which families are forced to reorganize over time and when paternal identities develop during both the initial transition and
longer term reorganization. This is one example of horizontal stress, as articulated by McGoldrick and Carter (2003). The reorganization and renegotiation of roles is complex, leading to extreme satisfaction and pride, as well as significant distress (Shezifi, 2004). Chin, Daiches, and Hall (2011) found this process for fathers involves confronting distress over “finding a place” in the new family system and larger ecological systems. These changes for and in men reflect a significant shift in attitude, disposition, pride, and stress associated with becoming a father. Considering these factors, it is important to better understand ways in which empirical research has documented how fathers can influence their children’s development.

**Fathers and their influence on child development**

A significant amount of research suggests fathers have a unique and specific effect on their children’s development (Pleck, 2010; Lamb, 2010; Easterbrooks & Goldberg, 1984; Flippin & Crais, 2011; Conner, Knight, & Cross, 1997; Shannon, Tamis-LeMonda, London, & Cabrera, 2002). This discussion focuses on two specific contributions to child development by fathers. Pleck (2010) offers the *essential father* hypothesis, which states fathers make essential, unique, and uniquely male contributions to child development via the *fatherhood-masculinity model*. This model has six component ideas that assert: (1) there are gender differences in parenting; (2) there are relationships between father presence and child outcomes; (3) those relationships are mediated by level or frequency of paternal presence; (4) one can attribute paternal presence effects to fathers’ sense of maleness; (5) there are some effects on child outcomes that can be specifically attributed to presence of fathers; and, (6) one can make associations between fathers’ paternal sense of masculinity orientation to level of paternal involvement and child outcomes.

Contrasting research from earlier decades when fathers’ observed behavioral patterns with their children was centered on play (Lamb, 2010), we now know that fathers engage in
different forms of interactions with their children that help facilitate development. Fathers’ interactions and presence influence their children’s socio-emotional (Easterbrooks & Goldberg, 1984), cognitive (Shannon, et. al, 2002) and linguistic development (Conner, Knight, & Cross, 1997). In their literature review on how to better engage fathers in training programs for helping their children with autism spectrum disorders (ASDs), Flippin & Crais (2011) specifically discuss the role of fathers in children’s positive social and communication skill development. The review highlights fathers’ unique contributions to language development in typically developing children and postulate that similar contributions are possible for children with ASD.

Fathers can be confident that their influence on their children’s development is tangible and measureable. This influence is highly contextual, depending on a number of factors that certainly include the child’s physical, cognitive, and developmental trajectory. Because childhood disabilities have been documented to be a source of stress in parents’ lives, I now turn my attention to the ways men seek help.

**Help seeking behavior in men**

Cross culturally, men are generally not encouraged to engage in help seeking behavior because of its construction as a feminine activity. Empirical research demonstrates that globally, men face challenges in seeking help because of how it is interpreted in larger social contexts. Seeking help has been constructed as needy, subject to being belittled, and/or needing help only from a divine or Godly source. The following citations highlight the ways help seeking behavior in men challenges a widely constructed gender role stereotype of being resilient.

Farrimond (2012) found that men from high socioeconomic backgrounds in the United Kingdom (UK) admitted having to consciously reframe ideas about going to the doctor from a *neanderthal man* concept to an *action man* concept because of what they believed constituted
manly and responsible behaviors for their health. Griffith, Allen, and Gunter (2011) report some social and cultural factors influencing the extent to which older African-American men visit their doctors. Participants reported relying more heavily on partner support and desires to fulfill social roles as influencing their help seeking behavior because of the belittling tone of physicians when being addressed and little support in identifying healthier behavioral and lifestyle changes. Pearson and Makadzange (2008) found Zimbabwean men’s choices to seek help for their sexual health was grounded in their cultural, spiritual, and religious traditions and attitudes. Participants attributed sexual health concerns stemming from either natural causes (e.g., disease, psychological stress) or supernatural causes (e.g., displeased ancestral spirits, witchcraft). Gender norms of self-reliance and resilience, coupled with shyness and embarrassment, all were found to delay health seeking behaviors.

Chang and Subramaniam (2008) inform readers of the reticence Asian and Pacific-Islander American men possess toward seeking mental health services due to cultural values, beliefs, gender roles, and racial stereotypes. Cabassa’s (2007) study on Latino immigrant men found they were more inclined to seek help from family members and/or rely on their faith in God versus seeking clinical services for depressive symptoms. Structural and financial constraints also emerged as a barrier to seeking mental health services for these Latino immigrant men.

These studies offer important insight into men’s, and by extension, fathers’ rationale for help-seeking behavior. We might conclude men are far less likely to seek help for their own needs. Fathers of children with disabilities, particularly ASDs, confront unique experiences and stressors. Next is a review of scholarly literature focusing on parenting, and by extension, fathering children with autism and other disabilities in the next section.
Fathers of children with autism spectrum disorders (ASDs) and other disabilities

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. The majority of recent empirical research on fathers of children with ASD and other disabilities have focused on three related, but distinct areas. Most studies have addressed fathers’: (1) reported stress levels, (2) feelings of stigma, and (3) coping strategies. It is important to note that most of these studies are not exclusive to fathers. In my literature review I found only three empirical studies focusing on fathers’ singular reported experiences. Even with these limitations, the existent literature does offer critical insight into the experience of fathers of children with ASD and provides a starting point for additional empirical studies to uncover fathers’ experiences with this phenomenon. Studies have generally attempted to either measure ASD effects on parent relationships or compare parent experiences. The studies’ designs are overwhelmingly quantitative, with notable diversity in data analysis among them. The majority of the literature focuses on comparisons of ASD effects on parents and caregivers and comparisons between ASD and other disabilities.

In addition to the literature cited earlier, Heaman (1995) sampled 203 American parents (133 mothers/70 fathers) of children with developmental disabilities between the ages of 2 and 5 and found significant differences in perception of stressors and coping strategies between parents. Mothers reported being stressed primarily about identifying capable agencies to meet their children’s needs. Fathers were more concerned about having adequate health insurance, the quality of their spousal relationships, and the children’s overall health. The differences in coping were notable; mothers reported conflicting ways to cope including: wanting to change something about themselves, being inclined to hide the severity of their children’s diagnoses, and...
reminding themselves that their situations could always be worse. Fathers reported coping by imagining a better time and place in comparison to their current situation and internalized blaming.

Very few empirical studies focused solely on the experiences of fathers, and especially African-American fathers, of children, with ASDs or other disabilities. Given this limitation, these studies still are helpful in how they inform readers and provide starting points for more in-depth research. In a comparative study of 60 fathers of children with ASDs, Down Syndrome (DS), and typically developing children (20/group), Rodrigue, et. al (1992) found fathers of children with ASDs and DS reported more negative effects on their families than the comparison group. They also reported more avoidant coping strategies than fathers of typically developing children, and fathers of girls with ASDs reported slightly lower levels of social support than fathers of typically developing children. These types of comparisons are useful because they situate this phenomenon within the context of the fathers raising the children. The findings seem consistent with studies mentioned earlier, but offer more specific implications about how gender might influence how fathers make meaning of their experiences.

Hartley, et. al (2012) conducted a similar comparative study measuring the psychological wellbeing of fathers of adolescents and young adults with ASDs, Fragile X Syndrome (FXS), and Down Syndrome. The study measured depressive symptoms, levels of pessimism, and coping within the 240 fathers (135 ASD; 46 FXS; 59 DS). Findings indicated that fathers of children with ASDs reported higher depressive symptoms than the comparison groups and that factors contributing to the between group differences in wellbeing included fathers’ age, extent of child’s behavior problems, presence of additional children with a disability, and maternal depressive symptoms. Although the overwhelming majority of the sample was college educated,
white men, these findings are crucial to better understanding this population. An additional limitation was that it did not report on the severity of the ASD diagnosis.

MacDonald & Hasting (2010) sought to better understand the degree to which mindful parenting practices influenced interactions between fathers and their children with intellectual disabilities. A sample of 105 fathers of children with intellectual disabilities was surveyed about mindful parenting and parental involvement. Results indicated fathers who were more mindful (i.e., person-centered attention in relationship with child) were generally more involved with their children in direct parenting roles and roles related to their children’s socialization.

**Synthesis**

There are several conclusions I have made from the literature devoted to the relationship with and influence of childhood disabilities and the family system, and particular conclusions pertaining to the relationship with ASDs and its influence on fathers. One recurrent theme within the literature is raising and living with a child with a disability can be extremely stressful on family members. This stress will require the family to adjust to the unexpected changes associated with their family member’s disability during a number of the life cycles. Siblings are affected in a number of ways, across a number of domains, including but not limited to their: psychosocial and emotional development, relationships with the shared parents/caregivers, peer interactions outside of the home, and internalized meaning-making processes. Parents are affected in many of the same ways, experiencing various levels of stress and coping with them in sometimes very different ways, depending on their social and cultural capital. Fathers, in particular, can make specific meaning about this experience, which can lead to unproductive coping strategies and a failed acknowledgement of how the experience is influencing others.
within the family system. Seligman and Darling (2007) nicely capture the ways fathers, in comparison to mothers, respond to knowing their child has a disability.

Fathers tend to respond less emotionally and focus on possible long-term concerns, whereas mothers respond more emotionally and are concerned about their ability to cope with the burdens of child care. Thus fathers tend to perceive the diagnosis of the disability as an instrumental crisis, whereas mothers see it as an expressive crisis. Fathers may be more instrumental…, however some fathers are concerned about the day-to-day demand of the disability. Fathers tend to be more concerned than mothers about the adoption of socially acceptable behavior by their children – especially their sons – and they are more anxious about the social status and occupational success of their offspring. (p. 223)

The entirety of the literature on this topic is important, but not without inherent strengths and limitations. One of the major strengths is its broad scope of comparative studies investigating differences and similarities in how parents cope with the challenges of raising a child with a disability. An additional strength is the number of comparative studies informing differences in coping strategies within parents and siblings by type of disability. The quantitative methodological rigor and diversity within research designs and analyses is another strength. This diversity offers a unique way to understand what effects childhood, adolescence, and disabilities can have on families and fathers. Findings about how fathers confront, adjust to, and cope with the stress associated with this experience are meaningful contributions to increased and empirically informed understanding.

One major limitation is that there is generally no consistent report on the severity of the disabilities in the children. Information about the severity of the diagnosis can provide
contextual insight into the magnitude of the disability’s effect on the families’ lives. Another limitation is the lack of in-depth understanding of fathers’ experience and interpretations of ASDs. My literature review cited only two qualitative studies since 2000 reporting on fathers of children with ASDs, indicating a need to study this issue in ways that are more in-depth and give voice to the nuanced characteristics of this experience for fathers, especially after acknowledging its inherent complexity. An additional limitation within the literature is the few empirical studies focused solely on the experiences of fathers of children with ASDs. Much of the literature reflects the experiences of both parents; however, studies focusing on fathers’ experiences can complement or challenge existing findings. Lastly, among the studies published on this topic, none have intentionally sought to accurately capture the experiences of African-American fathers of children with ASDs.

Engaging more qualitative studies designed to explore fathers’ experiences in-depth will contribute to the current knowledge base. Different categories of fathers (e.g., gay, single, separated, divorced, widowed, etc.) from different demographics (e.g., SES, race/ethnicity, etc.) can significantly expand our understanding about their experiences with ASDs and other disabilities and represents an appropriate continuation point for serious inquiry. The following chapter offers a qualitative methodology to explore this topic.
Chapter 3: Methods

In this chapter I present the design of my qualitative research study to investigate the ways African-American fathers of children with autism spectrum disorders (ASDs) make meaning of their experiences. I offer a rationale for using a qualitative research design to answer my research questions, which includes sharing the philosophical assumptions of qualitative methodologies. I present the study’s sampling and data collection methods and describe my procedures for data analysis.

Philosophical assumptions in qualitative research

Philosophically, qualitative research is aligned with social constructivism, which asserts individuals possess and operate with multiple socially and individually constructed realities. Social constructivism posits, “…that what is known or understood derives from communities of understanding rather than an individual operating as an isolated ‘psychological’ entity” (Cottone, 2007, p. 193). I align directly with this ontological and epistemological position. Social constructivist philosophy has a presence in mental health research, represented in a wide variety of topics and publications (Hartung, 2010; Raskin, 2011; Cottone, 2001; Haas, Levant, & Pollock, 1997) and has become accepted among mental health paradigms (Cottone, 2007).

Several qualities of social constructivism distinguish it from other philosophical paradigms, which provide an appropriate justification for use in this study. Social constructivism asserts that knowledge is generated from interpersonal processes, through language and other ways individuals engage in relationships (Cottone, 2007). Whatever a social group comes to believe together becomes truth to that specific group or community. Maturana (1988) described this phenomenon as objectivity-in-parenthesis. Cottone (2001) distinguishes this position from the traditional objectivity vs. subjectivity binary in research methodological traditions. The
contributors to this study engaged with me through interviews and sharing their narratives about their specific experiences raising children with various forms of autism. The study highlighted their collective and individual objectivity-in-parenthesis because our discourse allowed them to discuss what they believed to be truth, based on their subjective experiences. Social constructivism is unique because it assumes that change is a fundamental process in nature. Because change is a naturally occurring phenomenon, it only becomes structured - and thereby constructed - through interpersonal interactions. (Cottone, 1989; Cottone, 2007). This research study, employing a qualitative research design, is framed in a social constructivist philosophical paradigm. I gained a more in-depth understanding of how identities as fathers of children with ASDs have been constructed through their narratives and the meaning they attach to their lived experiences.

**Combined Research Design**

**Case study design**

Creswell (2006) described a case as a specific, unique, and bounded system. A case study allows researchers to study individuals, events, activities, or processes of a bounded system. Stake (2005) further articulated that for a case to be studied using a case study design, the case must be bounded (i.e., have distinct boundaries), be functioning or have working parts, and possess indicated patterned behaviors, such as sequence or coherence. Plummer (2001) wrote that case studies aim to research specific phenomena in depth and the data are delineated by time period, activity, and place. Donmoyer (2000) offered that the rich, descriptive case study approach provides an important means for addressing the complexity of applications in counseling, social work, and education.
This study is a collective case study (Stake, 2005), because multiple cases (i.e., 6 African-American fathers of children with ASDs) were used to investigate a more general phenomenon or population. A case study approach is appropriate when a researcher has clearly identifiable cases with boundaries and seeks to provide an in-depth understanding of the given case (Creswell, 2006). The cases in this study were bound by space (i.e., 6 African-American fathers of children with ASDs) and time (i.e, the time the fathers learned of their children’s diagnosis until the present). Lincoln and Guba (1985) proposed a case study structure to be inclusive of the problem, the context, the issues, and the lessons learned. Hays and Singh (2012) described case studies as the universal tradition because it can be applied to several other qualitative research traditions. This study combined the collective case study approach with narrative inquiry. I decided to blend the collective case study approach with narrative inquiry because of how I wanted to use and analyze the collected data. The collective cases offered comparisons across the cases, while the narratives assisted in finding similarities across the contributors’ stories.

Narrative inquiry

Narrative inquiry assumes every individual has a story to tell and that story is considered knowledge. Polkinghorne (1995) wrote that narrative is a specific type of discourse that draws together diverse events, happenings, and actions of human lives into a thematically unified, goal-directed process. Verbal narratives are data because they are sequential and causal accounts of events, people, and processes that express how individuals make sense of their worlds (Murray, 2003). Stories, which include temporal references (e.g., beginning, middle, end) and a plot, are included within narratives. Each of the contributors in this study shared their narratives across
three different interviews. The opportunity to gain knowledge through their narratives aligned directly with my research questions and justified using this particular tradition.

Stories are suited as a linguistic form in which human experience as lived can be expressed (Ricoeur, 1991). Bruner (1990, p. 64) offered, “People do not deal with the world event by event or with text sentence by sentence. They frame events and sentences in larger structures”. Stories are modes of knowledge that capture richness and nuances of meaning in human affairs (Carter, 1993). Polkinghorne (1995) wrote that plots within any story are the narrative structures through which people describe and understand the relationship among events and choices in participants’ lives. Plots are the structures that function to compose and configure events into a story by providing: (1) a temporal range to identify beginning and end; (2) criteria for including events into a story; (3) a temporal order of events into movements that culminate into a conclusion; and, (4) the clear and explicit meaning events have for story contributors in a unified way.

Bruner (1985) and Polkinghorne (1995) challenged assumptions about what Western scholarly traditions have promoted as the type of discourse that communicated knowledge. They noted knowledge was formerly communicated through hypotheses, reported evidence, and inferred conclusions. Storied narratives, poetry, and poetic discourse were considered appropriate only for communicating and evoking emotion. Their collective position is that narrative knowledge is more than emotional expression; it is a legitimate form of reasoned knowing. This point is particularly important for the contributors to this study because it provided the men with validation of what they believe to be true. I intentionally sought their narratives because those narratives represent what they know, based on what they have lived.
Bruner (1985) suggested there are two distinct ways individuals know the world: *paradigmatic cognition* (i.e., scientific mode of knowing through quantifying and categorizing) and *narrative cognition* (i.e., storied knowing). Polkinghorne (1995) described two forms of narrative inquiry: *paradigmatic analysis of narratives* and *narrative analysis*. The classification of narrative inquiry into these two types is based on Bruner’s (1985) distinction of two ways individuals know the world (*paradigmatic cognition* and *narrative cognition*). The difference between the two forms of narrative inquiry lies in the treatment of data and the actual product of the data analysis. In paradigmatic analysis of narratives, the presentation of analyzed data consists of storied narratives and a form of thematic analysis. Paradigmatic analytical procedures are used to produce categories out of common elements across the database (Polkinghorne 1995). The products from my study’s data analysis process included both a paradigmatic analysis of the data and a presentation of the data through re-told narratives of each contributor.

Additional assumptions about narratives and narrative inquiry are that recorded data are seen as revealing cultural and personal information about an individual with potential application to a larger context. Individuals communicate their sense of their worlds through their stories, by speaking in narrative form and connecting events over time through stories which are constructed in personally and culturally meaningful ways. Narrative inquiries seek to understand what stories reveal about individuals, and people form and share identities as they recount and disclose the stories to others. Narratives can change depending on the narrator, the audience, and the context and that these three dimensions dictate what is important in the narratives (Hays & Singh, 2012).
Fathers of children with disabilities, and specifically, fathers of children with autism spectrum disorders, are a largely understudied population (Seligman & Darling, 2007). There have been some studies about fathers of children with ASDs and other disabilities using qualitative methodologies (Gray, 2002; Gray, 2003), but much of the existing research has employed quantitative methodologies (Brobst, et al., 2009; Hartley, et al., 2010; Freedman, et al., 2011; Hastings, et al., 2005) to help readers better understand their experiences. This study relied solely on the narratives of fathers of children with ASDs – derived from in-depth interviews – as data. Their narratives offered new insight into how their specific experiences have influenced their identities. This insight has implications for counselor education and supervision, counseling practice, counselor research, and potentially for family policy.

**Sampling method**

I used a purposeful sampling method (Patton, 2002; Denzin & Lincoln, 2000) to identify African-American fathers of children with ASDs. The inclusion criteria for participants were that they: were fathers of children with some form of autism, spoke and understood American English, and identified as African-American. *Snowball sampling* was the best purposive sampling method for the study. *Snowball sampling* is a convenience sampling strategy that required me to identify a case example, and rely on that participant to refer other cases (Hays & Singh, 2012) until an adequate sample size was identified. One of the benefits of snowball sampling is that it can sequentially build variation within the sample, increasing the potential for diverse presentations of the studied phenomenon (Polit & Beck, 2003). In one of the few books on fathering children with disabilities, *Uncommon fathers: Reflections on raising a child with a disability*, Meyer’s (1995) contributors were generally college educated, professional, White American men. The volume is a critical contribution to this topic and our understanding of
fathers’ experiences with this phenomenon, but it did not offer the diversity a snowball sample provided. Another biographical book, Not my boy: A father, a son, and one family’s journey with autism (Peete, 2010), provided a compelling account of the former NFL quarterback’s process of understanding, accepting, and celebrating his son’s differences. However, while Peete is an African-American, he made no attempt to intentionally speak through a racial identity lens. My study’s fathers’ cases were information-rich, or telling because they moved beyond presenting what may be considered typical cases, in order to use the case material differently. Mitchell (1985) distinguishes these two types of case studies, saying:

A good case study, therefore enables the analyst to establish theoretically valid connections between events and phenomena which previously were ineluctable. From this point of view, the search for a “typical” case for analytical exposition is likely to be less fruitful than the search for a “telling” case in which the particular circumstances surrounding a case, serve to make previously obscure theoretical relationships suddenly apparent. (p. 239)

Additionally, because fathers of children with ASDs are an understudied population, a snowball sampling method provided me a useful way to network and gain access to larger samples within the population. The sample included six contributors (Polkinghorne, 1989), although Boyd (2001) regards two to 10 participants as sufficient to reach data saturation.

Participants

The snowball sampling strategy yielded six contributors (n = 6). The fathers’ ages ranged from 38 – 54 (i.e., 38, 39, 41, 42, 49, 54) years old. They were all married to the biological mothers of their children with ASDs and had college degrees. Their occupations
included: educational product salesman, graphic designer, information-technology professional, banking executive, pharmaceutical salesman/manager, and information technology manager.

All of the fathers reported their children with autism were diagnosed with pervasive developmental disorder-not otherwise specified (PDD-NOS), autism, or high-functioning autism. The children ranged in age from 5 – 22 (i.e., 5, 7, 9, 13, 16, 22) years old and all of the children with autism were boys, except for one. All of the children represented in the study were diagnosed with a form of autism between 1 and 5 years old. The children’s family configurations ranged from being only children, first born, oldest, and middle children. One child was dually diagnosed, and her diagnoses were Cri-du-Chat and PDD-NOS. Cri-du-Chat is a rare genetic disorder that impairs intellectual, gross and fine motor development, and expressive language development.

**Data Collection**

**Overall structure**

The data I collected captured, described, and represented the fathers’ experiences in the way they communicated them. I used phenomenological, or in-depth interviewing (Seidman, 2006) to collect the fathers’ narratives. Each interview served a specific purpose. I audio recorded and hired a transcriber to transcribe each interview verbatim (Seidman, 2006; Yin, 2003). I solicited suggestions from each father on the safest and most conducive environments for the interviews. Walcott (1990) advised interviewers to select an interview environment and conditions that promote comfort, security, and the privacy to openly discuss experiences. The range of interview locations the fathers chose included their homes, my home, and one father’s church.
I obtained informed consent prior to interviewing and recording, and pseudonyms were created for each father to conceal identifying information in the potential publication of the study. The interview questions broadly addressed fathers’ experiences raising children with ASDs in a specific social and cultural context. The interview structure adhered to protocol established for phenomenological interviewing. They were semi-structured to allow for flexibility in their administration.

**Phenomenological interviews**

I designed my interview structure based on Seidman’s (2006) phenomenological, or in-depth interview method. Phenomenological interviews are designed to provide an in-depth understanding of people’s experiences and the meaning they derive from those experiences through their language. “A basic assumption in in-depth interviewing research is that the meaning people make of their experience affects the way they carry out that experience…Interviewing allows us to put behavior in context and provides access to understanding their action” (Blumer, 1969, p.2). Holstien and Gubrium’s (1994) description on the importance of language justifies this data collection method. The authors wrote language is viewed as the primary symbol system through which meaning is both constructed and conveyed.

The overall structure for in-depth interviewing requires three separate interviews over the course of three to four weeks, with each interview taking no more than 90 minutes (Seidman, 2006). Schuman (1982) recommends 90 minute interviews, noting 60 minutes may encourage participants to be time conscious, while anything over 90 minutes can be demanding or might compromise the interview purpose. I interviewed each father three times, resulting in 18 total interviews. My interviews with the fathers ranged from approximately 40 minutes to approximately 75 minutes.
Researchers should be mindful of participants’ needs and be flexible in interview coordination process. Seidman (2006) suggests researchers space interviews between 3 and 7 days apart. “This allows time for the participant to mull over the preceding interview but not enough time to lose the connection between the two” (p. 21) and also facilitates a specific, relatively brief, but very meaningful time frame to work with each participant. I was able to maintain this recommended schedule with three fathers, but there were some instances when the time between the interview times was as short as 6 days and longer than 10 days. These were challenges due to scheduling conflicts.

The focus of our first interviews was on their personal life histories. I asked questions about events and experiences that have been meaningful in their personal lives up until the present time and how those experiences have shaped their personal ideas about fatherhood and fathering a child with an ASD. The prompts and questions included: “Share one or two stories from your life that helped you learn about fatherhood”, and “What personal characteristics do good fathers possess?”

The second interview’s focus shifted to include questions about the degree to which raising a child with an ASD influences their lives on a regular basis. One of the goals in this interview is to allow fathers to communicate their lived experience and share how this phenomenon has been contextually constructed in their lives (Seidman, 2006). The questions included: At what age was your child diagnosed with an ASD? How have you helped others understand your child’s diagnosis? How do you describe fathering a child with an ASD to someone else? The third interview’s goal is for the participants to consider the personal meaning they have attached to or derive from this lived experience. Questions were about the meaning participants derive from raising a child with an ASD, the parts of this particular experience that
may be intrinsically rewarding and challenging, and its meaning in the broader social and
cultural contexts of their lives. Interview questions are documented in appendix D.

Transcriptions

I digitally recorded all of the interviews and had them transcribed verbatim by a hired
transcriber, with the exception of my first interview. The transcription process in the study was a
challenge for several reasons. I initially hired a transcriber who underestimated the demand of
the work. That person never completed the first interview transcription, which I transcribed.
The second transcriber was much more efficient, but by the time I completed the hire I
completed three additional interviews. The second transcriber began at a deficit and rarely was I
able to forward transcripts reflective of the most recent interview. Our process evolved into my
forwarding transcripts usually about 10-14 days after interviews for their review.

Ochs (1979, p. 168) writes, “What is on a transcript will influence and constrain what
generalizations emerge.” Ochs (1979) spoke directly to the importance of giving particular
attention to the process and potential implications of the transcription process. The transcriber
and I developed a process whereby I placed the interview data into a mutually accessible,
password-protected file for her to retrieve. She would then transcribe the interview data and
send it to me electronically. I simultaneously listened to the recorded interviews while reviewing
the transcripts for accuracy. In several cases I would make amendments to the transcriptions to
include nonverbal behavior, emphasis, and other additions not evident to the transcriber but
memorable from my interview, which Ochs (1979) discussed. For example, there were some
instances in reviewing the transcripts when I had to edit the language because the transcriber
may have misunderstood an exchange that included slang or cultural nomenclature (e.g., I’m
“straight”, meaning I’m well or okay) or I added emphasis by capitalizing words to communicate
passion or emotion attached to their words (e.g., I wasn’t into car racing AT ALL!). After my review, I sent the transcribed interviews to the fathers for their review and approval. No fathers requested the transcripts be amended or revised.

**Data Analysis**

Bogan and Biklen (1982) offer both theoretical and practical suggestions to appropriately analyze qualitative data. Those suggestions include systematically searching and rearranging interview transcripts, memos and other materials accumulated to increase understanding about them and to assist in the presentation of what has been discovered to others. My analysis included organizing the data, sorting them into manageable parts, synthesizing, searching for patterns, discovering what is important and what is to be learned, and deciding what and how to report findings.

Data were analyzed through analysis of narratives, using the *emergent themes approach* (Glaser & Strauss, 1967). This method required my extensive review of all 18 interview transcripts to identify at least two things: (1) commonalities in experiences and shared perspectives, and (2) interpretation of participants’ experiences. The emergent themes approach assumes that conceptual themes will emerge from the data. Analysis of narratives uses paradigmatic cognition to deduce categories and configure order among narratives from the interview data (Polkinghorne, 1995). I identified common themes and conceptual categories between the narratives by reviewing the interview data and member checking. Identifying the common themes and concepts required recursive movement from identified themes to researcher-proposed categories (Hammersly, 1992).

I coded patterns within and across narratives based on frequency and consistency of shared experiences, perspectives, and interpretations. Van Manen (1990) suggests that searching
for themes is an essential process for interpreting a lived experience. My process of identifying themes began with coding, in which the raw data were labeled (Strauss and Corbin, 1990). I closely examined the fathers’ narratives to determine what statements or phrases seemed essential or revealing about the nature of being the African-American father of a child with an ASD. Codes were categorized based on their common properties, frequency and consistency of shared experiences, perspectives, and interpretations reported by participants (Lavlani, 2011). The identified codes were organized under more abstract categories, with each category containing a cluster of codes that pertain to broader themes. I then created a matrix to identify and display the prominent themes that emerged across the narratives (Miles & Huberman, 1996) and to determine which occurred most frequently.

The remaining portion of the data analysis process consisted of reporting of my own personal narrative, which was autoethnographic in its presentation. Autoethnography offers a first person account of events, interactions, and relationships within a researcher’s culture or experience (Murphy & Dingwall, 2001). Autoethnographers offer their own thoughts, feelings, documentation of fieldnotes, and other personal experiences in response to their ethnographic examination of culture as data (Ellis, 1991). I responded to the questions I asked the fathers and crafted my own narrative the same way the others are presented. The benefit of including this in the analysis is it offered my own personal and cultural experience with the phenomenon of study as a member of the population, which allowed me to further compare and contrast the narratives of study participants. The thick description also helped in deepening the understanding of this phenomenon and further benefited the knowledge base because of its scant presence in counseling literature.

**Claims within and across narratives**
Claims about the findings addressed the unique and shared perspectives, experiences and interpretations of being an African-American father of a child with ASD. The data and its interpretation addressed how we experience and express fatherhood as African-American men raising children with ASDs, within our specific social and cultural context.

The study’s findings are not intended to generalize. Johnson (1997) discussed the utility in the study’s transferability, noting that the more times a research finding is supported for various members of a population, the more confidence we can place in generalizing the findings beyond the original participants. In the pursuit of more knowledge about this topic, the testing of findings from study, through methodological replication with different samples of fathers, are critical in increasing readers’ understanding about the idiosyncratic and shared experiences of these fathers.

Trustworthiness

Trustworthiness in qualitative research broadly refers to the process of following established research protocol to maintain the integrity of the research and its findings. Hays & Singh (2012) articulated that trustworthiness involves various aspects of the research endeavor, including the research process and design, data analysis, and reporting of findings. Furthermore, they wrote there are criteria, or standards, for trustworthiness in a research study and strategies to maintain trustworthiness throughout the study. My five strategies for trustworthiness to meet the criteria for trustworthiness included: (1) reflexive journaling; (2) simultaneous data collection and analysis; (3) member checking; (4) persistent observations; and (5) creating an audit trail. No one of the strategies is more important than another; rather, the execution of the strategies helped insure that the fathers’ narratives were captured, described, communicated, and analyzed in a manner that accurately reflected their experiences.
Glesne (2011) wrote that reflexivity “…involves critical reflection on how researcher, research participants, setting, and research procedures interact and influence each other” (p.151). It additionally requires, “examining one’s personal and theoretical commitments to see how they serve as resources for generating particular data, for behaving in particular ways…and for developing particular interpretations” (Schwandt, 1997, p. 136). I consistently monitored and addressed my positionality throughout the data collection and analysis process by journaling. Positionality is a researcher’s “…social, locational, and ideological placement relative to the research project or to other participants in it” (Hay, 2005, p. 90). Hammersly (2000) suggested researchers cannot be isolated or detached from their own presuppositions and should not pretend they can be. My membership in this group dictated extremely close attention my positionality, particularly because my interviews with the contributors were the sole data source.

Prior to entering the field, I engaged in a form of phenomenological analysis, *epoche’*, as an early reflexive exercise. Patton (2002, p. 484) and Creswell (2006, p. 67) wrote that *epoche’* requires researchers to fully document and describe their personal experiences with the studied phenomenon to become aware of their personal biases, to eliminate personal involvement with the subject material, and to gain clarity about their preconceptions. I maintained a journal during data collection to document how I was personally affected and responded to the overall research process. I journaled after each interview and the journal entries included reactions to participants, inclinations about potential findings, and thoughts and feelings about the data collection and analysis process.

Member checking is the ongoing consultation with participants to test “goodness of fit” of developing findings, and has been cited as a key strategy for establishing trustworthiness (Lincoln & Guba, 1989). Member checking requires involving participants in the research
process to accurately communicate their intended meanings when outlining overall themes. My member checking processes involved clarifying responses during interviews, requesting contributors to review transcripts for accuracy, and asking each contributor to review his respective narrative that I developed, based on our time together. The member checking took place at three separate stages: during interviews (e.g., asking for clarity and confirming understanding), after interviews (e.g., showing and forwarding transcripts for review), and after crafting each contributor’s narrative to insure its accuracy.

The fourth trustworthiness strategy I used was persistent observation. Persistent observation produces data depth because of the intentional effort to seek detail regarding aspects of a particular phenomenon (Hays & Singh, 2012). In-depth interviewing can facilitate persistent observation because of the frequency of interaction with participants. I interviewed almost all of these fathers in their homes and got the chance to interact with them and their family members during interviews. The last trustworthiness strategy I used was creating an audit trail. An audit trail provides physical evidence of systematic data collection and analysis procedures (Hays & Singh, 2012). It is an effort in transparency of the research process by allowing an auditor or any reviewer to examine each aspect of the research endeavor. My audit trail included a timeline of research activities, participant contacts, informed consent documents, reflexive journals, interview protocols and transcripts, and a codebook.

**Researcher-as-instrument statement**

Many qualitative authors discuss the ways in which researchers should document their role in the context of their work (Wang, 2008; Anfara, et. al, 2002; Glesne, 2011; Hays and Singh, 2012). I am a 37-year old, father of an elementary school-aged son (Avery) diagnosed with PDD-NOS, married to the child’s biological mother (LaChan). LaChan and I are also
parents to Nile, who is 19 months older than Avery. Prior to starting my doctoral studies, I worked as a school counselor and co-founded a non-profit advocacy agency with LaChan to support parents of children with developmental disabilities, particularly ASDs.

**Reporting**

I adhered to Creswell’s (2007) recommendation in reporting the study’s results. I assumed that these fathers were experts of their own experiences and their narratives communicated a form of data and knowledge. I communicated the analysis in a way that accurately deepens readers’ understanding the fathers’ narratives.

**Conclusion**

These introductory chapters conclude with an examination of the qualitative methodology I used to better understand the experiences of African-American fathers of children with autism spectrum disorders through their narratives. The study’s rationale and literature justified the way I investigated this topic. The methodological design enriched and deepened readers’ understanding of how African-American fathers describe their experiences raising their children with autism.
Chapter 4:
“I want other people to see me as a good presentation of a father”
Alvin’s Story

Alvin is a 54-year old African-American father of a 16-year old son, Xavier, whose autism diagnosis is Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). Alvin and his wife, Victoria, have been married for over 18 years. Xavier was diagnosed just two weeks before his 3rd birthday and is the youngest of three children; he has two older sisters. Alvin describes Xavier as a high-functioning, verbal, social, affectionate young man who loves interaction with his peers. However, the start of Xavier’s life was traumatic. He spent his first 2 months in a pediatric Intensive Care Unit (ICU). Over time, though, Xavier rebounded from that initial setback. In fact, Xavier’s current presentation is quite a contrast from children who have more severe forms of autism.

Alvin works in educational sales, providing reading comprehension software to school districts. However, Alvin describes himself as a coach. He was a high profile student-athlete during high school and college and his children have all participated in sports. Alvin’s mother was a longtime educator and administrator in the community in which he lives, which is predominantly White. Both of his daughters compete at high levels in their respective sports. He continues to spend a significant portion of his free time coaching basketball, football, and soccer in his community. Xavier has had an active presence in his community, through sports and church, from the time he could appropriately engage. His participation and reception have been consistently warm and supportive.

Alvin was motivated to help design sports programs for special needs children as a result of Xavier’s diagnosis. Years ago, he created and implemented the Champion program, a community-based athletic program designed to facilitate positive interactions between children with developmental disabilities and typically developing children.

Describing the Fathering Experience

Memories that taught me about fatherhood

There are two really strong memories I have that helped shaped my ideas about fatherhood. I was fortunate because I had some really strong men in my life. My father and I had a great relationship, but I also benefitted from my relationship with my uncles, my mom’s brothers. We were just one, really big extended family that interacted a lot. Most of my family lived in either Buelah or Buckley. And the memories I have are of the annual Buelah vs. Buckley high school football game. My dad played for Buelah back in his day, but because our family is so big, he had all these friends that he played with who still lived in Buckley. Every year, all of the men in my family – me, my dad, my uncles and cousins – would all go to the
Buelah vs. Buckley game and just interact with all of the families from the two communities. I would see dads there with their sons and it established a tradition for us. Those games were an opportunity for me to connect with and compete with my friends and family.

I also have strong memories of my Uncle Hampton’s advocacy work in Buelah. We never really understood what he did for a living because he moved a bunch of times when we were kids. But, we found out as teenagers that uncle Hampton worked for the American Friends Service Committee, an advocacy organization that fought for equal housing in segregated communities. In fact, Uncle Hampton and his family were one of the first Black families to live in Buelah and he spent his career working to desegregate communities and provide access to homeownership and better living conditions for African-Americans. Those are two really strong memories I have of learning about fatherhood and what good fathers do in the homes and in their communities and it left a strong impression.

**Personal qualities of good fathers**

Good fathers are those that have a lot of patience, love, empathy, and provide their kids with a strong self-concept. What I mean by that is helping their kids be confident in their identity, even if it contradicts what is popular. With all of my kids – Giselle, Samantha, and Xavier – I want them to know that it is okay to not go along with the crowd and thankfully, I believe my kids, especially the girls, are secure in who they are. They’ve told me about a bunch of times when their friends are doing things they know are wrong, and they are quick to respectfully decline and call me to come get them from a party or something like that. For me, it’s about instilling a sense of morality in the kids so they are strong enough to be true to those morals and standards that they have been taught.

**Life experiences associated with being African-American**
You know, it is interesting to think about the times in my life when I have had experiences that happened because I am Black. There have been both positive and negative experiences. Being raised in Buelah, I was usually a minority but I was able to make friends and generally enjoyed my time as a young person. That experience – having to establish relationships with people of different races – actually helped me as a college student when I left Buelah. I was a pretty good football player in high school, I was class president of my senior class. So, those experiences let me know that I could connect with people who were different from me. I definitely challenged negative stereotypes of African-Americans and offer a different perspective to my White peers, teachers, and teammates.

One positive experience I remember was as a teenager. I had a White female friend, someone I never dated, but with whom I was pretty close. There was a party my friends and I were attending, and she wanted to come. Well, her dad told her that she could only go to the party if I was going to be there with her. This dad did not trust any of our other White friends to look after his daughter. Now, mind you, this is in 1976. A White dad telling his White daughter that the only way she could attend this party is if her Black male friend was accompanying her.

I definitely have had some negative experiences that are related to my being Black, too. Many of them have to do with stereotypes and perceptions of Black people, and specifically Black men. I remember I had a job in sales where I was outperforming everyone in my unit, enough for my peers to take notice. I was not only out selling my peers, but I was also sharing my ideas for marketing, development, and strategy implementation. One my colleagues eventually addressed me saying

Alvin, I don’t know what’s going on. You sell far more than anyone else. You come over and help everyone else in terms of developing strategies, you help the company in terms of developing…not only a sales strategy, the implementation strategy, the customer service strategy, and you work with the developers in the development of the product.
But, for some reason, the president of the company says you will never be a VP in this company

And even though I was raised in a predominantly white community, I was raised to know that growing up in the 1960s and 1970s you had to outperform your peers as a Black student, athlete, or in any other environment. This was just an example of that truth. I knew I deserved to be a vice president, but I was not going to one, according the president. Another negative experience was during my brief stint on Wall Street. My career counselor told me not to take that job, but I took it and was pretty successful. I guess I didn’t have a phone voice that signaled to my clients that I was Black. Well, usually making clients lots of money results in being invited to lunch or dinner. There were plenty of times when I never heard from clients again after meeting me in person.

**How becoming a father influenced my sense of identity**

Becoming and being a dad is probably the most important set of experiences I have had. Being married has been great and I am proud of my educational and career accomplishments, but becoming a father has just been a huge influence on who I have become. It is really important for two reasons. I always want to be a model for my kids. And, I want other people to see me as a good presentation of a father. When Giselle was in high school, the school secretary made a comment that she didn’t realize I overheard. She said, “Bar none, Mr. Alvin [beginning to cry slightly] is the best father.” Now this woman has been in that position for about 25 years and interacted with thousands of parents. I was really touched by that. Now when I think about being the father of a child with autism my ideas don’t really change too much.

**Fathering a child with an autism spectrum disorder (ASD)**

**Ideas and knowledge about disabilities and autism before diagnosis**
You know I was raised to believe and still believe that you should treat people the way you want your family to be treated. So, although I did not have much experience with people with disabilities before Xavier’s diagnosis – there was a student in my high school who had a developmental disability, there’s been a man in my church who also has a developmental disability, and my cousin who is a lot younger than me (37) has a form of autism – I have always tried to treat people respectfully and with empathy. And autism, man, I knew very little about it, even with a cousin with autism. I felt like once we heard the doctor use those words, “He’s autistic”, Victoria and I had so much work to do because we knew nothing about it. The idea of having a kid with autism never occurred to me, which made it difficult to really understand and deal with in the early stages of the diagnosis.

**Most rewarding and challenging aspects of fathering a child with an ASD**

My journey as a father of a child with autism has been overwhelmingly rewarding. Adults and children alike have really rallied around him and help him be as successful as possible, and that’s been the most rewarding aspect of this. I can remember when he played youth football, which was something I DID NOT want him to do. I played football and I did not want him to play. Victoria had to talk me into letting him play when he was in elementary school. But the way his team supported him as he learned the game and how they wanted him to be successful was just amazing. And these are the kids who have maintained a sincere relationship with Xavier since that time. They come to his birthday parties, they invite him places and it has just been really great. The really great thing is that the community has done that with many of the special needs kids, not just Xavier. So, to me, it’s like the community values the inclusion and Xavier has benefitted greatly from it. The fact that he is successful and embraced, even with his unique qualities, is the most rewarding.
Now the most challenging part has really been when people do not appreciate or understand Xavier’s differences. For example, there’s only been one teacher that has been really insensitive to Xavier. This was when he was in elementary school and the teacher took all the students in the class on a field trip except for Xavier and another girl who had special needs. We couldn’t believe it! Xavier came home so upset, telling us, “I didn’t get to go on the bus! I didn’t get to go on the bus!” and we had no idea what he was talking about. It turns out that the principal found Xavier and the female student sitting alone in the cafeteria. I couldn’t believe teacher left the kids in the building! I worked hard to get that guy fired.

One of the things fathers have to do is be prepared to help their kids prepare for the future. This has been really hard at two specific points: at the beginning of our journey and right now. At the beginning, when you first get this news it shocks you. You don’t know what to do. Even if you’ve had other kids, this is a totally new experience with a new set of challenges. In the beginning, I felt like I wasn’t prepared and that lack of preparedness, at times, made me feel like I wasn’t a good enough dad. Now, Xavier has been pretty successful. He’s verbal, he has friends, and he can express himself pretty clearly, most of the time. So, he’s one of those kids who can fit in pretty well with his peers unless you spend more intimate time with him. Because he can fit in, he is noticing his friends and his sisters reach these points in their lives when they begin to talk about college and driving and boyfriends and girlfriends. It’s become really difficult to work through this.

Xavier is eligible to be in school until he is 21 years old. But why would he want that if the kids in his class are graduating in 2015? We recently had to coach him through losing his “first love”. Now, this girl he’s known for a really long time, since they were younger children. Xavier began to tell her some time ago that he was going to marry her. She’s always been really
nice to him, really gracious. She comes to his parties, she dances with him at school dances, and has just been very nice to him. But, June 18th was a hard day. She finally told him they were not going to get married and the boy was crushed. She says, “Well, Xavier, we’re not going to get married. You know that we’re not going to, you know that.” But the bigger question is how do you prepare for these transitions? How do I prepare him to drive? What do I tell him about the prospect of college? What do I tell him about romantic relationships? Getting married? Having children? These are the questions that wake you up in the middle of the night because as a dad you want to help him prepare for his future.

**Coping with the challenges**

The main way I cope with the tough parts of raising a son with autism is to remember that my experience could be so much worse. There are many parents whose children have much more severe disabilities or just more severe forms of autism. I have a friend whose daughter has a much more severe form of autism. She’s not verbal and does a lot of stimming. It’s so bad that the stress split him and his wife. He thinks that at some point, he will likely have to institutionalize his daughter; I just can’t fathom that. So, when I think about my challenges, I really shouldn’t complain.

Another thing that helps me is trusting I’ve done everything in my power to give Xavier, and my daughters, the opportunity to be successful. Xavier is in a great educational program that will support him until he is 21 and they are preparing him to be a contributing citizen. He’s had so many wonderful experiences with us as a family, in school, and in the community. I can honestly say his quality of life has been good and that makes me feel good.

**Increasing understanding of diagnosis within the family**
One of the things about raising a son with autism is being sensitive to the way it may impact everyone else in your household. Victoria and I have made some intentional decisions to help Giselle and Samantha better understand Xavier in terms of his gifts and areas in which he struggles. I have to admit that because Xavier is higher-functioning, our task has not been as difficult as other parents. But, that does not mean we can overlook or minimize how to best support him and his sisters.

I’m a firm believer in creating opportunities for the kids to spend time together because it allows them to learn from each other, learn about each other, and challenge each other. Samantha has spent the most time with Xavier because of how close they are in age. They are only 15 months apart. But I think they would all say they’ve spent significant time together, even with Giselle as a college student now. We, of course, have had direct conversations with Giselle and Samantha about how to best support Xavier and how there will be times that Xavier might do or say something that they may not anticipate or understand. It has been nice to see their relationships evolve because they are not hesitant to challenge him and help him understand their points of view. They know that is what he will experience out in the real world.

**Raising an African-American child with ASD**

When thinking about our being Black and how that relates to Xavier, I immediately think of how Xavier is perceived. We have lived in this community for so long that everybody knows us and knows Xavier. But he doesn’t have that luxury in the real world. Your race and your level of ability matter. And there are stereotypes of Black boys and men that have led to violence against them. Thank God, that hasn’t happened to me. I have been victim to annoying things like being followed in a store, or a White woman clutching her purse in the elevator, or that same woman moving to the other side of the parking lot when she sees me.
But, I remember watching a documentary in which a young man – maybe 14 or 15 years old – with a developmental disability had a really bad encounter with a police officer because the officer did not understand the kid. And when I think about Xavier getting bigger, I mean he used to be this cute, young kid. But now he’s bigger, he’s got broad shoulders and I worry about the scenario wherein he is with people who do not understand him. He could be in a situation in which he does not communicate well enough for people to understand him and some of those challenges. That’s really scary.

**Describing this fathering experience to someone**

Being a father is being a father, whether your child has autism or not. Your job is to love your kids as much as possible. For me, what that means is you have to remember that the rules that apply to your more typically developing kids probably won’t apply to your child with autism. But as a parent, you have to remember that principle whether you have kids with disabilities or not. The most important thing about this experience for me is to make sure I am patient and that’s how I would describe this experience. You learn that you have to develop a level of patience that you might not need with your other kids. For example, although Xavier is 16 there are times when he may act like a pre-teen, or sometimes even a toddler. It’s easy to think he understands what I am communicating because of how mature he looks, but I have to mindful about where he is in his development. Fathers of kids with autism have to do what it takes to help their children understand what is expected, and that takes patience and flexibility. Listen, we’ve all got challenges, every one of us. I just figure these are the challenges God gave me and I have to work hard to meet and exceed those challenges to help Xavier be successful.

**Making Meaning of the Experience**

**What does it mean to be an African-American dad of a child with autism?**
Being the dad of a child with autism, it means feeling pressure. I feel pressure because there are a lot of unknowns for us and Xavier moving forward. Some of the things I’ve mentioned already include graduation, work, more education, and things like that. Even though he is considered high-functioning at 16, the differences between him and his peers are more noticeable than when he was a toddler. So the question, again, is, what do we do from here? How do we prepare? So I’m feeling a little pressure.

But, I’m also hopeful. I’m hopeful because of the successes that Xavier has had in the past. I’m hopeful because at every point in his life we have been able to figure out what it takes to be successful. I’m looking forward to getting the answers to these questions and figuring out how to help Xavier be independent. I’m nervous, but hopeful about getting a better sense of the possibilities for work, for independent living and maybe even for relationships. These next five years are going to be crucial, and likely as tough as the early years. Can he live in a group home with five or six guys? Who knows? But we are definitely going to find out as we move forward. Thankfully, we’ve had success in the past so I can feel good about that. What I don’t want to do is wait to get these answers. It’s my job as Xavier’s dad to be proactive and be as prepared as possible. We want to minimize mistakes moving forward versus waiting for them to occur because I haven’t done my job.

Words of wisdom to the father whose child is newly diagnosed

The most important information I would give to any dad whose child has been diagnosed with autism is to get busy! You have to be ready to make immediate and longer-term decisions that require your input. How old is that child? If the diagnosis is early, then get him into a developmental kindergarten that’s appropriate for him. And, if it’s not appropriate, get him sent out of district to a more appropriate setting.
You have to know what services your child is entitled to receive. That’s going to take a lot of reading and researching about IDEA and talking to other parents who have gone through this process before you. Where is the child along the spectrum? Is he verbal? Does he give you eye contact? How severe are his symptoms? I ask that because if Xavier had more severe symptoms, he would not have benefitted from all of the interventions he received. Be ready to talk! Talk to other parents, talk to the teachers, talk to the Child Study Team and the administrators. You even have to talk to people who may not understand the diagnosis. Victoria and I never hid the fact that Xavier had autism. We did that because it gave people some context when Xavier had a meltdown, like in the grocery store. Now, people comment to us about how much Xavier has come along. But that’s because we told people and we talked to people. It’s tough in the early years because you are learning about your kid’s needs and you are responding to them. That is a hard balance to strike. So, getting in touch with other parents and organizations for your child and for your entire family is critical.

Now this message would change just slightly if I was talking to an African-American dad. The African-American dad has to do all of the things I mentioned before. But, he also has to take inventory. What I mean by that is the African-American dad has to assess everything in his home and within his family. He has to assess what kind of social capital he has in the community. I had social capital because of my work in the community and my mom’s reputation. We also had it because my girls were great student-athletes. That goes a long way when you are in the racial minority. But, even with that capital, you might still get prejudged or stereotyped based on race or ability status.

For example, Xavier is one of very few Black boys in the high school compared to the number of White students. Even with all of our history in this community, we still have received
subtle messages about people’s discomfort with Xavier. There is a girl Xavier and Samantha have known for a long time because the girls danced at the same studio. Well, Xavier would approach her after dance class and tell her that she did a great job. He did that every week. Well, for whatever reason, the parents told us that they did not want Xavier approaching her any more. Now, was that because he has autism? Was it because he is Black? Is it both, or neither? My point is that you just do not know when you are in the minority.

Support

The most helpful supports for me are those that have helped Xavier the most. So, that means getting the support from his peers in and out of school has been huge for him. The fact that so many kids really enjoy Xavier – as a teammate and classmate – means that he is much less likely to be victimized by bullying or something like that. The overwhelming majority of his teachers and therapeutic professionals have been a great support for us. It helps that Xavier LOVES being in school, so he has these really strong relationships with his teachers and therapists who have increased his level of confidence. They have helped him feel like he really belongs.

The other critical support for us has been our spiritual support. Our church and other partner churches who have known Xavier from the time he was born have been absolutely amazing. I can remember Xavier being on all of the churches’ prayer lists when he was in ICU as an infant. And those same church members still pray for Xavier today, sixteen years later. Community organizations have been especially helpful, too. Because we have never hidden Xavier’s diagnosis and been so visible in the community, Xavier gets flyers to attend camps and special events through our relationships with the various community organizations. That helps him, so it definitely helps me.
I wish, though, that Xavier had more opportunities to interact with kids of color, especially African-American kids. That is one thing that his experience has lacked in comparison to others. When I consider all of the great experiences we have had as a family this is one area where I know he can benefit. Those opportunities just do not present themselves as naturally where we live, so I need to really seek them out for Xavier’s benefit. There is only one Black kid he interacts with in the special needs after school program, but Xavier gets tired of hanging out with him. And, like I mentioned earlier, he’s got girls on his mind. He told us recently that he wanted his girlfriend, “to be brown like me”. I need to look for opportunities beyond the local community to support Xavier in this area.

**Relevance or need for counseling services**

I’ve considered counseling in the past, but never pursued it. I don’t have anything against it. In fact, I’m really considering couples’ counseling for Victoria and me as we embark on these new transitions with Xavier. We are really nervous about it and need some feedback and direction. I know it’s going to be an emotional time and we can use the help from a professional. Addressing things like driving, marriage, and children is really hard. We have no idea where to start. We also need help just with the logistical parts of Xavier’s transition like employment and housing and things like that. I’m definitely thinking about that for us in the near future.
Chapter 5:
“My son having my name requires me to maintain an honorable reputation”: Brandon’s Story

Brandon is a 38-year old African-American father of two children: daughter, Ivy, who is 7 years old and Brandon, Jr. (BJ), who is 5 years old. BJ was diagnosed with high-functioning autism this year at 5 years old. Brandon has been happily married to his wife, Sheila, for twelve years.

Brandon is an artist. He loves music and professionally he is a graphic designer. He does a considerable amount of freelance work and frequently contributes to art exhibitions in the major northeastern city closest to his home, in addition to having a more traditional full-time job. I met with Brandon at his local church for each of our three interviews. He and his family are very active there. In fact, Brandon oversees the church’s audiovisual ministry – everything from recording services, operating the soundboard, supervising the photographers – and Sheila is in charge of the church’s children’s ministry. He is very open about the way his faith influences how they have helped them adjust to BJ’s needs.

Brandon and Sheila waited for some time to get BJ evaluated by a developmental pediatrician to receive a formal diagnosis. Instead, they used their own research – talking with friends, using the internet as a resource, talking to their children’s pediatrician – and assumed that BJ may have had some form of autism. BJ was able to receive early intervention services, even without an autism diagnosis, because of his developmental delays. BJ has limited expressive language but definitely has receptive language. I have had the opportunity to watch Brandon and BJ interact and have seen, first hand, the ways they communicate because of BJ’s currently limited expressive language.

Brandon was raised by his stepfather, but had an inconsistent relationship with his biological father, who passed away literally days before our first interview. Brandon is the oldest of his siblings, but he is the only child from his biological parents’ relationships. His other siblings are blended family members from his biological father’s relationships or his mother’s relationship with his stepfather.

Describing the Fathering Experience

Memories that taught me about fatherhood

I learned about fatherhood from two men: my biological father and my stepfather. But, let me be clear – I had challenges with both of them. My stepfather was present and more consistent. My biological father was not so present. I benefitted from them both, but I learned more about fatherhood from my stepfather. In fact, my relationship with my biological father was so rocky that I actually got counseling as a teenager because of relationship when I was that age. I was lucky if I saw my biological father a couple times a year. Many times, we would
have this scenario when he would plan to come pick me up for a weekend and then not show up at the last minute.

My biological parents were never married and they stopped being a couple when I was really young. My mom married my stepfather when I was about seven or eight years old. So, my mom and I spent a lot of time together alone before she married. When she did get marry, I usually inserted myself in the middle of their conflicts because I wanted to defend or protect her point of view. With my biological dad, the memories that stand out the most are the ones when he didn’t pick me up because that would really hurt me. But, when he did pick me up and had something planned it was great. He loved vacationing and spending time around water, so we spent a lot of time relaxing at the shore when the weather allowed for it. When he didn’t plan anything, I felt like a total outsider because he had a new family and I would have to try and enjoy spending time with “my little brother” who I really didn’t know that well. Or, I would have to do whatever my stepmom was doing and that wasn’t really enjoyable.

Now, I didn’t have a really strong relationship with my stepfather. But, I learned about fatherhood from him. He and my mom eventually divorce but he was still a pretty strong influence. He taught me what it meant to have a strong work ethic. He was a car guy, a mechanic by trade. He was handy and knew how to fix things so he was always working on some project – either in our house or in the neighborhood – and was always able to provide for us in that way. Even now, if I have a question about anything I know I can pick up the phone and reach out to him to find the answer. That’s how smart he is with that stuff.

**Personal qualities of good fathers**

All good fathers are available. That’s the number one quality that good fathers possess. Also, being able to show love is important. Listen, it does no good if you are available but can’t
show love to people in a way they can receive it. You’re doing no good then!! So a good father is available and able to show love in a way that the people he loves can receive it. A third quality is being respectable. You know, your reputation is everything. You might be available and loving, but that would be worthless if you were a hypocrite. I’m glad both of my fathers were respectable. They didn’t act one way in one place and act differently in other places. They knew who they were and other people knew who they were.

I guess the last quality I would say, and this is really important, is the ability to communicate. And not just communicate anything, but communicate your feelings. I really think this issue was at the root of some of the problems I had with my fathers. A lot of men just aren’t very vocal when it comes to their feelings and things like that. But, somehow, I was usually pretty comfortable talking and voicing my feelings – which got me in trouble in school a lot – and I think my fathers’ issues with truly communicating their feelings hindered our relationships. And going to counseling as a teenager definitely helped me understand my feelings and expressing them.

I remember the point when I realized that if I wanted an enjoyable relationship with my stepfather, I would have to initiate it. I told you he was in to cars as a mechanic. He also watched a lot of NASCAR races. I realized that if I wanted him to talk to me, I had to connect with that stuff. And I was not into cars and racing AT ALL! I would go into his room and watch NASCAR races with him and ask him stupid questions so that he would talk to me. Otherwise, he really didn’t say much. Now, my mom and I – we could talk all day!! But, that was probably because we had some years together all by ourselves.

Life experiences associated with being African-American
The first thing that comes to mind for me when I think about this is being called a nigger, which has not happened very often. It’s happened maybe twice in my whole life. It was actually not far from here, right at the mall a few minutes away. I was in high school and I happened to be dating a White girl at the time. She and I were in classes together and ended up connecting really well as friends. Well, you know if you spend enough time with someone you’ve got a strong connection with, chances are you might become attracted to that person. We started dating. I know my mom wasn’t really excited about her son dating a White girl, but she never made me feel bad. She was more concerned about what others might do or say.

Well, we were outside of the Macy’s at the mall. These two rednecks saw us together and yelled, “Nigger!” at me as they drove away in their truck. That really bothered me because all we wanted to do was to be able to enjoy each other in a relationship and these guys had to show their ignorance. As I think about it now, we probably broke up eventually because I’m Black. She would never admit to that and her parents seemed to be cool with me and our relationship. But, I know her relationship with her grandparents was strained because we dated. She ended up breaking up with me over some random reason I’m still not clear about, but I wouldn’t be surprised if my being Black had a major part in it.

**How becoming a father influenced my sense of identity**

Becoming a dad made me want to be a better man. That’s the best way I can say it. I remember a sermon my pastor preached about the value of your reputation. He basically preached that giving your child a name is a big deal because in naming your child, you’re giving him a reputation based on YOUR name. It’s like, if someone looks at BJ, he or she needs to know that BJ is my son based on my reputation. And, it’s funny because I didn’t always think that way about names. My stepfather named his son after him. My biological dad named his
other son after him. And based on my experiences with those guys, I was vehemently opposed to naming my son after me. Now, I feel differently. My son having my name requires me to be respectable and maintain an honorable reputation.

**Fathering a child with an autism spectrum disorder (ASD)**

**Ideas and knowledge about disabilities and autism before diagnosis**

I had some prior experiences with disabilities, you might say, with my younger brother. He actually was born with a disfigured hand. The umbilical cord wrapped around a few fingers on one of his hands and they grew together so that it looks like he has two or three fingers on one hand. I remember a lot of doctor’s appointments, therapy visits, and even surgeries to help correct it. And, I had a direct role in some of that stuff. I would have to bathe his wounds while he recovered from a procedure sometimes. The funny thing is that we were able to make him feel good about his hand, especially when he was younger. I don’t know if you remember the Teenage Mutant Ninja Turtles. Well, when he was around 3 or 4, they were really popular. It got to a point where we told him that he was like the Teenage Mutant Ninja Turtles. He even had some kids in school and in the neighborhood that were jealous of his hand. He would actually introduce himself as a Teenage Mutant Ninja Turtle!!

I think that because of those kinds of life experiences I’ve been pretty sensitive about people with disabilities. We all know about stereotypes, and I’m sure I have stereotyped before, But, I don’t think that has been the norm for me. I have memories of even defending my younger brother to my stepfather because of his differences. My stepfather was a pretty good musician. He was a saxophone player in the church. There was a day when my brother told my stepfather he wanted to play the sax and my stepfather told him he couldn’t because of his hand. Before anyone said anything, I snapped at him and asked why he would say anything like that!
It really frustrated me. I told him that there were ways for my brother to play the sax and learn. And, that my stepfather could help him. So, I think my ideas about people with disabilities were pretty positive. I don’t believe they were negative at all.

Before really understanding BJ’s diagnosis, I always thought of Rain Man When I heard the word autism I automatically thought of Rain Man. Now I realize that people who are savants are so rare but that was my perception of what autism was and what it looked like in people. People who had autism functioned really poorly in most areas and really excelled in others. That’s all I thought I knew before my experience with BJ.

**Most rewarding and challenging aspects of fathering a child with an ASD**

This may not seem like much to most people, but it’s most rewarding when I teach BJ a concept and I know he gets it. I mean, you know how this goes. You have to chip away and try all of these different strategies to see if a skill or a concept sticks. You sometimes have to do it for a long time. So, when I realize he gets it, it’s awesome! It’s the moments when he says something out of the blue; he says something I was trying to get him to say like a week ago. It’s great when its random or spontaneous…and in the right context! Man, it’s such a relief to have those moments happen. A lot of BJ’s language comes from TV shows and video game lines. So, when we hear him use something appropriately it’s really rewarding. I get the chance to celebrate with him and with Sheila and Ivy. But, then it’s on to the next challenge, you know?

The most challenging part of this is really the communication barrier. We take for granted that talking is easy and we all have words. Well, that doesn’t always apply when you’ve got a kid with autism. I want to be able to talk to my son and him to be able to talk back to me. I want to be able to have a conversation. Right now, our conversations are very one-sided where I say something and he responds with one or two words. Or, I’m prompting with the words to
answer my questions. That’s hard. The other challenging part is being concerned about his safety. There have been times when he has run out into the street. Or, when he was younger, put his mouth on electrical wires. Those communication barriers make the safety issue even more concerning. Thankfully, he doesn’t run out into the street nearly as much as he did when he was younger. So yeah, I would say the communication barrier and safety issues are the most challenging for me as his dad.

Coping with the challenges

Well, one of my releases is bowling. I go bowling once a week. So, I do have some time when I’m not with the family. I can go hang out with my bowling mates, so that’s a release. And I have a pretty nice collection of vinyl records and CDs in my music room. So, I’ll retreat there sometimes and listen to those. Those are two of the main things I do to cope with some of the frustrations and challenges. I usually don’t get to a point where I feel like I have to just leave. But, when the stress gets a little high, I usually do one of these two things.

Increasing understanding of diagnosis within the family

I think until we got a formal diagnosis, Sheila and I would just explain to Ivy that BJ learned differently than she does and it takes him a little more time to understand things that she understands with ease. That’s the kind of message we had to reiterate when she would be confused and ask about his speech or when she assumed that he should understand something easily. Now that we actually have a diagnosis and “it” has a name, she seems to be even more comfortable with it and clearer about BJ’s challenges and the things he does well.

Overall, Ivy has been really supportive of BJ. She’s patient with him. Well, not as patient as we are, but patient for a 7-year old. She is supportive. You see it from her when he communicates verbally. She’ll cheer him on and she’ll tell us about one of his achievements if
Sheila and I aren’t there to hear or witness it. I will say, though, that sometimes she is lonely. I think she appreciates the interactions she has with other kids, like in her school or at church, that don’t have autism. I think she wishes she could have more interactions that look like those outside of the home with BJ. She wants to play with him the way she plays with other kids.

**Raising an African-American child with ASD**

Sometimes race may come into play with BJ, but I think, overall, that his teachers and other people are there to support him and it’s not a big issue. I think the bigger issue now for BJ is people perceiving he is older than his age. He’s a big kid for 5. He could probably pass for 7 or 8 years old now. So, when people hear him talk and notice some of his communication challenges they are usually surprised. The other really important thing right now for us is for me to just be present. I know a lot of brothers who aren’t with the mothers of their children without disabilities. So, I’d like to think I’m among a greater caliber of brother because I haven’t run away and have exercised my faith as Sheila and I work through this stuff.

Now as he gets older, I get a little concerned about people’s perceptions of BJ. I know people already have negative perceptions of Black men. Well, what happens if things don’t get better for him with his speech or things like that? People already don’t have high expectations of Black people. The thing I think about is people being dismissive of him because he will be a Black man with a disability and it may feed into their stereotypes that really aren’t true of us.

**Describing this fathering experience to someone**

My first reaction is that this is like teaching a second language to a child. Or, it’s like getting an exchange student that does not speak any English. The host parent has to find a common ground from which to communicate with that exchange student. But, imagine the exchange students has a few quirks about him that neither one of you can really explain. You, as
the host parent, are just forced to accept those quirks while still trying to find a common ground in your communication. And then you realize that that exchange student is not just learning English from me, but he’s also learning it from my wife and my daughter. There are some similarities in the way we speak, but we also have our individual styles of communication. We each may have our own slang based on our age or school or work.

That kind of effort takes a lot of work. The host family has to get on the same page in what they want to teach the student and then they have to learn by trial and error what works best for that exchange student in his learning of our language. And we have the responsibility to learn at least a little bit of his language! I mean, that’s where you work to find the common ground. Yeah, that’s how I would describe this overall experience.

Making Meaning of the Experience

What does it mean to be an African-American dad of a child with autism?

To me, being an African-American dad of a child with autism means developing patience. I have to be more patient because I feel like I have to learn things that I may not have had to learn with my daughter, you know? The things I had to learn with my daughter I felt may have come more naturally, but with BJ, I have to research and learn how to parent in a different way than I thought originally. I have to research and learn things like how he’s wired, his preferences, and the things that make him upset. But, in doing that research I have to be selective. You know the saying, “take the meat, leave the bone”? There is so much out there about autism and caring for your kids with autism that I have to learn about the things that work for BJ and the things that don’t work so well. It means I have to put in more time and energy, which requires more patience than I think I might have to put in if BJ did not have autism.

Words of wisdom to the father whose child is newly diagnosed
I would tell that dad that he better be prepared to deal with IEPs (Individualized Educational Plans) and all that comes with having to go back and forth with schools. I would also tell him to get ready to have more than one diagnosis. One specialist tells you something one week, and someone else tells you something in a different week. That can be an emotional roller coaster. And that’s why you have to be up on the IEPs and what services are guaranteed to your child.

I would also tell him to get prepared for the costs involved with services and dealing with insurance. Services cost money, especially once your child ages out of the Early Intervention program. Sheila and I are researching this program now, called Brain Balance, where they claim that their patients with autism have been cured of it. I don’t know if it’s true, but if we decided to get those services we would probably have to take out a second mortgage. Not all services cost that much money, but sometimes you have to be ready to fight with your health insurance about certain therapies.

I would tell him to be ready for the conversation you have with yourself about if you may have caused it. You start asking yourself questions like: Was it something I ate? Was it something I drank? Was it something about my lifestyle or my wife’s lifestyle? Is it something genetic that I passed on to him? Shoot, I ended up asking myself if I had autism myself when I looked at all of the symptoms! Be prepared to be more patient and be embarrassed from time to time, too. What I mean by that is there are going to be times when you are out in public and your kid just does not act like the other kids and he is going to stand out. And if he does something that is over the top, people are going to notice. You might get some curious stares and looks from other parents and children. And, you know what? That actually applies in your own house. You and your wife have to come up with the way you’re going to tell your other children and
other family members about autism. And, you are going to get feedback from other family members who really don’t understand the diagnosis saying things like: “Oh, he’ll grow out of it!” Or they’ll want to give their own diagnosis, like: “Aw man, he just needs some help in focusing!” The last thing I would say to that dad is to be prepared to be flexible because stuff is not always going to go as planned. You may be someplace and everything is going fine. All of a sudden, something has set your kid OFF! You have to be ready for that. You have to be flexible.

My message would change in a couple of ways if I were talking to a Black dad. You know, there’s a stereotype about us that we are deadbeat dads. People think we run from responsibility. People think that when things get tough we are likely to disappear, maybe because our own dads decided to bail on us when things got tough for them, and let the women in families handle the business. It’s a shame because I would say that it seems like when Black men face challenges and think they can’t provide for their families, especially financially, they don’t want to stick around. I realize that even though things are better for African-Americans from generations passed, but it’s still hard out there for us. So if you add autism, or any type of disability, on top of some of the other challenges out there for brothers it can be pretty daunting. I think about if I was going through this with my wife and we were still early in our marriage. I wonder how I might respond to this kind of thing. Think about the brother who is married, has a child with autism, and just lost his job or lost his house, or had some other kind of financial hardship. What if the marriage was already rocky? Those are all reasons to leave for some brothers. So, I would be ready to tell the Black father that he has to be ready to stick it out because I’ve seen brothers leave over much less. He has to know that this experience, at times, will be really stressful and he has to be able to handle the emotions attached to that stress.
Seeing BJ progress in his school has been a great support. He’s made a lot of progress in the time he has been there. And this interview process has been helpful, too. Being able to connect with other parents who have gone through similar experiences is really good for me and for us. I think really having the opportunity to talk – at workshops, in one on one conversations, with therapists – they all have been the best kinds of supports for me. The Early Intervention program was helpful, even though our time with them was short-lived. We only had about six months with them because BJ was aging out at three years old. Yeah, those things have been most helpful.

I wish, though, that there was a way to catch it sooner. Catching it sooner would give people a better head start to help their kids. That’s why I really liked Early Intervention because they provide services for the kids when they are young. And, it’s FREE! They send someone to your house to work with your child and I wish more services like that were available. If Early Intervention went beyond three years old that would have been really helpful.

I also wish there were more support groups out there for parents. With the diagnosis rate so high, you would think that more support groups would be available. The only other thing I would say that I wish was more available would be more businesses sensitive to kids with autism and other special needs. The same thing with support groups applies here: with so many kids with autism, why aren’t businesses responding to the needs of those kids and their families? Some places do have special days and programs. Sesame Place has a few days in the summer just for kids with autism and their families. If Sesame Place can do it, why can’t Chuck-E-Cheese and other places do that? As a parent you just want to go into a place of business trusting
that you won’t get the weird looks from other people because your kid is having a meltdown. Yeah, that would be really good.

**Relevance or need for counseling services**

I’ve not thought about counseling for this particular situation because I’ve always had someone like a mentor to talk to when things get tough. I’m fortunate because I have enough people in my life that are available for me to talk to about a range of things – things with BJ, career aspirations, relationships – so I don’t feel like I’ve needed counseling for this particular issue. If I didn’t have those supports in my life, counseling would definitely be an option for me. If you remember, I went to counseling while I was in high school. And I would recommend counseling for anyone who is going through any kind of challenging situation, especially if that person doesn’t have people in his life that can give honest feedback that’s usually not your family. Family is always biased! Having a resource like a professional counselor who knows how to ask certain questions and give you constructive criticism is really helpful. Unfortunately, I don’t think many of us African-Americans are open to counseling. Most people that I’ve suggested it to or even just mentioned it usually show some resistance or hesitation. It just doesn’t seem to be something we do as a people. And it’s a shame because it can be really helpful. I had a really good experience with my counselor and I know I benefitted from it.
Chapter 6:
“We’re not afraid of the uncertainty anymore”:
Cameron’s Story

Cameron is a 41 year old African-American father who has been married to his wife, Liz, for 15 years. They celebrated their 15th anniversary in February. They have three children: Tyler, Jermaine, and Nicole. Tyler, who is 13, is the oldest child. He was diagnosed with Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) when he was two years old.

Cameron described himself as an Information Technology (IT) professional and works at a major university in the southeastern region of the United States. My interviews with Cameron were conducted by Skype over the course of three (3) consecutive weeks. Unlike some of the other contributors, I did not get the opportunity to meet any of Cameron’s other family members.

Cameron is a man of deep Christian faith. He volunteers in his church’s ministry. As a child, he remembers his family always being active and visible in the community, both within and outside of the church. But he describes his relationship with his father as inconsistent when he was younger.

There are two qualities of Cameron’s case that make it very telling. The first is that when I was referred to Cameron he was (and currently still is) in the midst of a major fight with the administration of Tyler’s school. At the start our interviews (January), Cameron shared that Tyler had been suspended out of school three times that year for issues he argues are symptoms of his son’s diagnosis. It has been very contentious between Cameron’s family and the school, which was very stressful for Cameron. Cameron is currently seeking legal recourse against his son’s school district. The second quality that makes his case telling is that Tyler’s birth represents a second chance at fatherhood for Cameron. He disclosed during our interviews that his first child was stillborn. That experience has influenced his story.

Describing the Fathering Experience

Memories that taught me about fatherhood

I learned about fatherhood by experiencing things that weren’t so positive. My relationship with my dad was off-and-on. As a teenager I moved around a lot. I lived with friends, my uncle, my aunt, my grandmother, and my mom sometimes. I only had a few years living in a two-parent household. My dad was visible in the community, though. He was what you would call a community activist. He helped low-income families afford their first homes in the 1980s and 1990s. I remember a random old man catching me on the street when I was younger. He thanked me for how my father helped him get his first house. I was proud in that moment, but I was also frustrated. I was frustrated because I felt like I never got all of what my
dad could offer me until I was an adult. Personally, I did not want to duplicate that kind of inconsistency when I had children, though. I wanted my kids to have both parents in the home, all the time.

**Personal qualities of good fathers**

A good father is one who can listen and guide his child. He has a bunch of roles that he has to play that are all important. He is a counselor. He needs to be able to listen and respond to his kids in the right way. He really needs to be a good listener. He needs to be able to protect his kids and family. When I say protect, I mean that in a couple of ways. He needs to protect them physically and mentally by giving them a safe roof over their head so the kids don’t have to worry about bills and money and things like that. He also has to protect them emotionally by keeping drama out of their lives. The environment he creates for his kids needs to be safe. And probably most importantly, he needs to be a prayer partner. You know how important prayer is in life. I pray with my kids. My wife and I both pray with our kids. They know that prayer is important and serious. It’s one of those things that are just a part of their lives in the same way getting up and eating cereal for breakfast. Those are the qualities of a good father.

**Life experiences associated with being African-American**

I have some good and not-so-good experiences that happened to me because I’m African-American. My parents made sure that I understood my African-American heritage. I came up in a time when it was okay to show your pride in your cultural heritage. I understood the sacrifices that people in earlier generations made so that I could have an education and have opportunities that they did not have. It was important to my parents because the city in which I lived was not always the safest place and other Black people weren’t always doing positive things. So, my parents made sure I knew not just one part of Black people’s experiences in this
country. They told me stories that included sacrifice and success and achievement. They told me about people who made it from really hard times of segregation and poverty and made great contributions to America.

Now, some of my negative experiences that I think are related to me being Black were with the police in my city. The relationship between the police and the people in my neighborhood was always tense. When you combine that tension with being a teenager and sometimes doing things that are not so wise, it can be pretty dangerous. My friends and I were targets of profiling and things like that. There were certain neighborhoods in town we knew not to visit.

That kind of profiling wasn’t limited to just the police, either. I went to a pretty diverse high school and had relationships with some of the white kids in my building. We all knew, though, that our relationships really could not extend beyond school. I would never consider visiting my white friends’ homes in their neighborhoods, and I KNOW their parents would not let them visit my neighborhood. Their parents generally did not think we were good enough to associate with them. That happened with both White and Latino parents. My boys and I knew we couldn’t really try to get with any Latina girls from school. Their parents were not having that! Those are things I remember happening to me that I think were based on my being Black.

**How becoming a father influenced my sense of identity**

When I was 18 years old, I got a young lady pregnant and the baby died. The baby was stillborn. The grief I experienced from that made me want to commit suicide. The only way I came out of that, man, was because of God’s intervention in my life. He stopped me from committing suicide. I believe that with all of my heart. When God prevented me from committing suicide He showed me I had another chance at life and at fatherhood
Most of my friends either had negative male figures in their lives or no male figures in their lives. I realized that I was not going to be that negative kind of figure once I got this second chance. I was going to be the exception and be there for my kids and my wife. My kids would have me in the home. Consistently. They would benefit from me being there and being involved and loving them in ways I was not loved all the time. I had a second chance.

**Fathering a child with an autism spectrum disorder (ASD)**

**Ideas and knowledge about disabilities and autism before diagnosis**

Honestly, I only knew a little about kids and people with disabilities before Tyler was born. The only real personal experience I had with people with disabilities was with a cousin of mine who had Down Syndrome. Our interaction was limited to occasional family visits. I mean, my interactions were usually positive but I had to overcome the kinds of attitudes and stereotypes people associate with disabilities. Disabilities don’t really hit home until it becomes really personal like it has with us raising someone with a disability. And I didn’t know ANYTHING about autism before Tyler’s diagnosis. I knew absolutely nothing.

**Most rewarding and challenging aspects of fathering a child with an ASD**

When I think of raising Tyler I say to myself that it takes special parents to raise children with special needs. It took me a while to really see it that way but God had to reveal that perspective to me because of how hard this can be sometimes. People who are raising special needs children can see this thing one of two ways: as a blessing or as a curse. And I refuse to believe that God cursed me with my son. It would not matter what kinds of challenges he faced. Tyler is a blessing to me, his brother and sister, his mom, and to everyone around him. He is even a blessing to those teachers in school who treat him the way they treat him. I only see Tyler the way the Bible talks about all of us – that we are all fearfully and wonderfully made.
All parents hope and pray for healthy children. We want children with no issues, who go on to college, have a career and change the world. Liz and I had that same idea about Tyler when he was born. We have realized that God has already taken care of Tyler and he just has a set of challenges we did not expect. Even though we didn’t expect them does not mean that we can’t overcome them. We have a great opportunity to make other people aware of autism and how it can impact families. And it’s not only a negative impact. It can be stressful, but so can anything else in life!

It was really hard at the beginning, man. You are waiting to hear those first words from your kid, like mommy and daddy. We got none of that for a long time. When we did realize he was talking, the words just weren’t audible; we just didn’t understand. That was hard. Another really hard part of this was our coming to grips with not getting the things for which we prayed. Tyler is 13 and we prayed for YEARS about his condition and his healing. His name was on everybody’s prayer list. We prayed for one thing and got something else. We got something else for which we were not prepared. For me, it was like denial. I denied this thing for like 8 years. We had no peace at all because we would not accept that he might be this way for the rest of his life.

You see your friends and their kids don’t have any major issues and it makes you upset. It can make you jealous. And when you get over your jealousy your friends still have NO IDEA about your experience. They can’t connect with you about this stuff! Their kids are rolling through school. They get good grades. Their kids have relationships with friends. The disconnection between you and your friends causes your relationships with them to change. They take a different form. We invited people over less and secluded ourselves. We didn’t want to have friends and their children over because we knew there was a strong chance the kids
playing together would be awkward. My kid would get rejected. And if he gets rejected, I feel rejected. We feel rejected. Who wants that?

We had to have a come to Jesus moment, man! We did a lot of crying, a whole lot of crying. Thankfully, we got to the place where we just trusted God’s providence for Tyler. God’s providence will allow God to use Tyler and the same way God uses us. We’re flawed, aren’t we? We’ve got some limits, don’t we? So why can’t God use Tyler the same way He uses anybody else? I don’t want to stand in God’s way because I’ve got some issues.

Coping with the challenges

Being more and more prayerful has helped me cope with this stuff. Coping became less of a challenge once Liz and I started REALLY trusting God to provide for Tyler’s needs. We realize these experiences are tests of our faith and I have had to think about it in that way – that God wants me to have more faith in Him than in anything or anyone else. I also exercise frequently through playing and coaching basketball a few times a week. The other thing I do is connect with one other brother, in particular, who is going through a similar situation. He’s got a child with autism and I definitely benefit from talking to him every now and then.

Increasing understanding of diagnosis within the family

I’ll start with this story. I was listening to NPR one day and they were interviewing an author who wrote a memoir about his brother and mom. The author was obviously a grown man but still very bitter about his childhood because his mom devoted so much time and attention to his brother who had some special needs. The author felt neglected and he was angry. It broke my heart because I could relate to feeling neglected and I realized that I did not want Tyler’s younger sister or brother to have the same kind of experience because of something that I did or
did not do for them. I do not want my other two children growing up feeling bitter and neglected.

In our home Tyler’s brother and sister have to adjust in some of the same ways Liz and I have to adjust. That kind of adjusting requires space and freedom. I have to allow Tyler’s younger brother and sister to be able to voice frustration and be honest so they know it’s safe to do that. I also make sure they take care of each other. I require that when they play in the neighborhood they include Tyler and protect him if someone is trying to get over on him. They know they better not shy away from those responsibilities they have to each other as siblings. I know that responsibility can be hard for them because Tyler needs more attention and more consideration. That’s what I require, though.

**Raising an African-American child with ASD**

Honestly, man, thinking about raising a Black child with autism is just hard to talk about. Period. You can’t really begin to talk about raising your son or daughter with autism until you have some peace about what this experience means to you. It’s hard to talk about raising a child who has a disability that, in some cases, is really severe. You speculate about the child’s future. You speculate about whether your child’s symptoms will lessen as he gets older. I don’t find a lot of brothers talking about how they are going to raise a child with autism because brothers just don’t do a lot of talking! I don’t try to push myself on others but I try to make sure other brothers know it is alright to talk about the fears and concerns you have for your child with autism.

We can talk about politics, sports, and all of these other things but when it comes to real personal issues it becomes a problem. For me I just realized that this is a story still being written and I don’t know the end. What I do know is that I better not place any limits on my child –
because of his race or because he has autism – because that is the moment when God starts to
shake those ideas up and show me that He will take care of Tyler better than I could ever take
care of him. People already believe things about Black men that I will never change. All of the
negative things going on right now in Tyler’s school and his services may have to do with him
being Black but God continues to show us that Tyler’s needs are covered. We are not afraid of
the uncertainty anymore. There is no one that can protect and provide for Tyler like God.

**Describing this fathering experience to someone**

I would tell someone else that fathering a child with autism is like a journey of discovery.
The discovery is about you and about your child. Your child is discovering what he does well
and the things with which he struggles. He begins to challenge those things with which he
struggles if he gets the right kind of support and learns new things about himself. The parent is
going through EXACTLY SAME THING! The dad is learning about himself during this whole
experience. And, with the right kind of support he can learn to stop placing limits on himself and
his child with autism.

I would describe it as learning to celebrate everything! Every new word Tyler says, we
congratulate Tyler and thank God for it. Every time Tyler responds to a question with three
words we are thankful and give him a high-five. There was a time when we didn’t notice those
things. Now we celebrate every little bit of growth and development because he deserves it. I
would describe it as an experience that balances me. I can come home from work frustrated and
wanting to take my frustration out on him or someone else. Even if I do that, he knows how to
communicate with me without a bunch of words. That boy will sit next to me, give me a hug,
lay hands on me and start praying in the way that he prays. He knows that is the right thing to do
because we pray for and with each other in my house. Man, once he does that, I’m straight!
Making Meaning of the Experience

What does it mean to be an African-American dad of a child with autism?

To be an African-American father of a child with autism is to be in a position to help build a life and see your child with autism reach his or her potential. It is going to require some things from you that you may not have been ready to give. It requires more patience, more character, and more love than you probably anticipated before your child got a diagnosis. Your child’s success will depend on those things. The extent to which you are selfless will relate to how successful your child with autism will become. It means that you will sometimes blur the lines of fairness between your children because some standards apply to all of your kids and some only apply to the kids who do not have autism. I wrestle with that, but sometimes Tyler just is not ready or able to meet some expectation or standard.

Words of wisdom to the father whose child is newly diagnosed

My words of wisdom to that father are to come to grips with his feelings, his emotions, and his expectations of his child with autism. I would share my own personal story about how it took me eight years to come to grips with those things and how much time I missed because of that type of denial. I would tell him that it is going to be tough and require a lot from him. The dad also may not be like me. He may be more in tune with his emotions and feelings. The child may not have as severe a diagnosis as Tyler but I imagine some parts will still be difficult. The other important thing I would tell him is make sure he is surrounded with other men who can relate to his struggle. He needs to find some men who can show a genuine compassion for him because they know his fears, his prayers, his hopes and things like that.

This would be a different conversation with an African-American dad versus a dad who was not African-American. I would assume that because if he were Black he would have some
understanding and some experience with how we don’t always have access to the best services, teachers, education, and things like that. This is really important if he had his child in a public school. I don’t know many of us who can generally afford the private schools where the service and education may be of a higher quality. And, it’s a shame that I feel like I have to have a different conversation with a Black dad because of how we may not have access to resources. If I was the mayor I know I would have access to all kinds of services and therapies. My child would not be going through the things he has gone through. Unfortunately, I don’t think African-Americans usually get to receive those kinds of services and that’s a shame. I would tell him to make sure he knew what his kid needs and the services entitled to his child because that might not be made really clear dealing with the schools and the bigger systems.

Support

The most helpful supports for me have been those that allow me to open up to other men about what I am going through. This interviewing has been helpful. When I get a chance to open up to other African-American men it really does me well because I can get pretty frustrated and angry especially with what is going on now with the people in Tyler’s school. It’s just good to be able to be honest – no reputation, no attitude, no roles to play – and share what is going on in this struggle. The ability to do that with men, and especially Black men, who will take what you say seriously, give you good feedback, let you know where you can get other kinds of support, is really helpful. This is so important in that early discovery phase. You need someone with whom you can discuss ideas and process information. I had a brother say to me that he would give up everything in his life for his son to be *normal*. Hearing that shook me up because I know he was probably in that early discovery phase when he didn’t know how to make sense of
all of the information he was receiving. We did not talk a lot but we talked enough to be a support to each other.

What is offensive to me is the cost of getting your kids the help they need. Getting kids services should not be a financial burden! It should not be financially prohibitive to get therapies and services! That’s an injustice to any child – Black, White, Latino, Native American, Asian – any child! All special needs children should have access to not just a free and appropriate education. It should be free and exceptional education! I wish we had more effective, caring, and compassionate teachers. That’s really important to me.

**Relevance or need for counseling services**

I never thought about getting counseling throughout this experience with Tyler. Well, let me just say I have no issue with seeing a counselor. I think if someone would have suggested I see one during that early discovery phase, I probably would have jumped on it. Now we’ve got thirteen years in to this and I don’t think the need is as great. That doesn’t mean that everything is easy but I have had some people in my life that probably functioned kind of like counselors to help me get to a healthier place. There is no way my wife or I could be at the place we are now without good people who have “counseled” us in hard times.

Really, the only time I think of counseling is for marriage counseling with the pastor. Many of us think about counseling for couples when something is wrong or for pre-marital counseling but I can see the need to just go see a counselor for the benefit of just talking to someone. Put it this way: I bet I’ll have a conversation with my wife about it now! I would not just want to see any counselor, though. I would want to see someone who knew my experience and could relate. I can’t just talk to some random person who knows nothing about why I am coming to see him or her. That would be a requirement.
Chapter 7:
“We don’t go to counseling…you get you some Jesus!”: Darryl’s Story

Darryl is 49-year old, African-American father and husband. He has been married to his wife, Janine for over 25 years. He and Janine have one son, Malik, who is 22 years old. Darryl shared that Malik was diagnosed with autism when he was 3.

Darryl is a banking executive who works in the greater metropolitan region of a northeastern city. Darryl and I met for three consecutive weeks in his home. I had the privilege of meeting both Janine and Malik and got some opportunity to see how Darryl and Malik interact. I would describe Malik as a person whose major challenge with autism is his receptive and expressive language. I saw Malik demonstrate his receptive language capacity and saw how he struggles with expressive language.

Darryl, too, would describe himself as a man of deep faith. He and Janine serve at their local church. Darryl leads a very physically active life and also sings as a hobby. The telling qualities about Darryl’s case are that he has the oldest child with a form of autism among the contributors to this study. Malik has recently transitioned out of secondary school, which means Darryl and Janine have and continue to think intentionally about an occupational fit for him. Darryl was also raised by his maternal grandparents, to whom he refers to as his mom and dad. Darryl’s biological mother gave birth to him as a teenager and his grandparents assumed legal guardianship for him within months after his birth. He has met his biological father but does not maintain a relationship with him. He does have a relationship with his biological mother, but considers his grandmother his mother. He was raised with his biological aunts, to whom he refers to as his sisters. He was 14 years old when he found out that the woman he referred to as one of his aunts was, in fact, his biological mother.

Describing the Fathering Experience

Memories that taught me about fatherhood

I learned about fatherhood from my grandfather. My grandfather was such a great role model that he actually made me excited to be a father. He worked two jobs during the week, but spent a lot of time with my sisters and me during weekends. Even though he was my grandfather there was never a time when I felt like I was anything other than his son whom he loved. I never knew I was his grandchild until he told me I was his grandchild.

He was a provider for us. He provided financially, but also mentally, physically, and emotionally. He had a way of telling me and showing me that I should set high expectations of myself and meet my obligations. He taught me how to plan and be intentional throughout my entire life. It seems like once I was about 16 or 17 years old he would have these conversations
with me every 6 months about setting my expectations. He and I would talk in specific terms about what I wanted to get out of life. Then he would make sure he told me what his expectations were of me. He wanted me to graduate high school and go on to higher education. He wanted me to be respectful of women and once I found a wife there were certain roles I had to fulfill in the marriage relationship. He was serious, man!

He came from an old-school generation and raised me with those old-school values. The man is the financial provider and spiritual leader in the home and the woman is the homemaker. He made sure I knew that before I married anyone that I needed a solid plan to be married and have children. If I did not have a plan then I better not get married because no plan meant a much more difficult relationship. He would make me and my sisters earn everything we got! If it costs $2 to go to the dance, he would ask: “How you gonna earn the money to go to the dance?” I would go cut grass and do other jobs in our neighborhood to earn that money. He made sure I knew that everything costs and everything requires preparation. And even as hard as he worked - and worked us - he made fathering look easy. He made it look so easy that it made me look forward to being a father one day.

**Personal qualities of good fathers**

That’s a real opinionated question, but I would say good fathers have to know how to love hard and love unconditionally. A good father has to know how to communicate and give time to his kids. And I cannot say this enough: a good father knows how to provide financially, emotionally, and physically to the entire family, including his children. You know, a lot of people use this phrase in tough times, “We’ll make a way.” A good father does not just use those words. He actually finds a way because he has the loving dedication, commitment, and wherewithal financially to make a way for his family.
Life experiences associated with being African-American

I remember the day when Martin Luther King was assassinated. I was about 5 years old. And I remember my mother screaming, not knowing what was wrong. The way she was screaming, though, let me know that something was really bad. I remember seeing images on the TV and realizing that something happened to Dr. King. My father wasn’t home yet and a bunch of our neighbors made their way to our house and gathered in our living room. They were consoling each other and I remember hearing some of the conversation. They were asking questions about what was going to happen to the children. From their perspective, MLK was paving the way so that their children could have opportunities they did not have. My parents and my community made sure we knew our African-American history. We knew the opportunities we had as children and teenagers growing up right after the Civil Rights Movement were the result of the previous generation’s sacrifices.

I also remember when we started school integration by being bussed to schools outside of our neighborhoods. I was still pretty young. My parents actually followed my bus to school because they were concerned. Eggs got thrown at the bus and I remember not really understanding why people had such negative reactions. And, of course I’ve had the times as an adult when White peoples’ stereotypes show up. I am the ONLY African-American executive in my company and one of the only African-American employees in the company. Every time a question about race comes up I am their “go-to-guy” and that gets on my nerves. I have mixed feelings because there are times when I want to address their questions but I also want them to use other resources to help answer their questions.
About a month ago, a comment was made about fried chicken at a board meeting. Our Senior Vice President says: “Let’s let Darryl address that.” I couldn’t believe it. So, I’m at the board table and I say:

So tell me what you would like me for me to address about that? Do you want me to say it comes from the poultry family? Do you want me to talk about how fried chicken arrives as fried chicken? Tell me exactly how you want me to address that.

**How becoming a father influenced my sense of identity**

Okay, before Malik I was just Darryl. It was just Darryl and Janine. After Malik was born, I became Darryl, Malik’s dad. To be identified as a dad and father was and still is everything to me. I have a bunch of titles and roles. I’m Darryl the banker, Darryl the senior vice president, Darryl the money guy. People knew me as the banking guy. When I become a father, though, none of those titles mattered any more. This is THE MOST important thing to me. Don’t get me wrong; I love my wife and I love being a husband. There is something different, though, about understanding this responsibility with which God has blessed me.

My identity became Darryl the dad. My friends and co-workers make fun of me. Whenever anyone invites me to hang out they make jokes and ask if I’m going to leave Malik. They know me as the dad. Becoming a dad changed my whole life. It changed my whole world. A lot of men consider themselves successful in their jobs and in their finances. I’ve done some pretty good things in my career. None of that matters when I think of my role as a dad. It is one of my greatest rewards and most fulfilling roles. Yes, identify me as the dad.

**Fathering a child with an autism spectrum disorder (ASD)**

**Ideas and knowledge about disabilities and autism before diagnosis**
I really don’t know how I saw people with disabilities before Malik’s diagnosis. People really didn’t talk about disabilities when I was younger. You just heard the stories of your “special” relative or someone’s “special” uncle who never came out of the back room. I consider myself a pretty compassionate person. I remember while in high school there was a young lady who had a pretty severe disability. In those days everyone was in class together, so there were no self-contained classrooms or pull-out replacement rooms. I remember people being really uncomfortable with her in our class but I interacted with her. People gave me weird looks when I would talk with her, but I didn’t really care about that. I even went so far as to pick her up for events sometimes. I just tried to treat people who were different from me the same way I would want to be treated.

What did I know about autism? I knew absolutely nothing; I had no knowledge. You figure Malik was born in 1990 and there was little out about autism compared to what’s out there now. He was actually diagnosed at that time with Pervasive Developmental Disorder. You know how I really got information about autism? Oprah. Oprah had a special on sometime in the early 1990s and her show was what helped me get more familiar with it. We had such a terrible situation with the diagnosis. When we were trying to figure out why Malik was having challenges we went to see a developmental specialist. We went to see her twice. The first time she didn’t really tell us anything conclusive. But early in the second visit, she just began to talk about what Malik would not do. He would not go to college, he would not talk, he would not do all of these things. We were completely devastated! We did not go there here to hear what he couldn’t or wouldn’t do! We had no knowledge of autism until that point.

**Most rewarding and challenging aspects of fathering a child with an ASD**
The biggest reward to me is just having a son. Having a son with autism has made me a very, VERY patient man. I think I have the patience of Job because of this life. Honestly, though, it has just made me love harder. My special child is the reward itself. I don’t think there is a father of a child with autism that can tell you there are no rewards with this. Do you know how much worse this situation could have been? You or I could have had a child that was stillborn? We could have kids who could never recognize us as their parents. So, again, the reward is just having Malik as my son. I am rewarded every single day God gives me the breath of life to wake up and have another day with Malik and Janine. The reward is telling people that special needs child is my son.

The most challenging thing is not being able to protect him. We live in a world that is not very compassionate. Everyday Malik walks out of the door and goes to his program. My mind is wondering with questions the whole time we are apart. Is he going to come back to me? Is he going to be okay when he comes back to me? When he leaves I ask God to be with him. It can be stressful because Malik can’t come back from his program and articulate with words if someone hurt him. I’m glad we know how to communicate with him even without him using words. We notice his mood and other changes that give us hints. There are just some things that seem to be even more out my control in certain environments as the dad of a kid with autism. Not being able to protect him is the most difficult thing.

Coping with the challenges

It is really tough some days but my faith gets me through it. I honestly do not know what I would do if I did not have my faith in God. I’ve known the Lord for a long time, but to be real with you sometimes my faith feels like it doesn’t match the overwhelming stress. Of course
most days, everything is working like clockwork. Then you have the ONE day when everything gets thrown on its head!

How do I cope? I walk. I go to the backyard. I meditate and talk to the Lord. If Malik is still having an episode when I come back in, I try to watch him and let him know I’m here. I tell him, “I’m here, bro.” I say to him, “Tell me what you’re feeling, man.” I ask him, “What can daddy change? What can daddy do?” I just try to talk him through it. So, I cope by praying and relying on my faith because I know God will not put more on me than I can bear. I also cope by walking and taking a break. Thirdly, if he’s having an episode I try to just be there with him. I try to understand what he’s experiencing to show him that I care.

**Increasing understanding of diagnosis within the family**

You know one of the things I sincerely regret is us not having more children. I think we were selfish in that regard because he is the only child. Malik enjoys company, but he counts down the minutes to when everyone is gone so he can have his castle back. We try to get people over so he can interact with others. We’ve even considered adoption but it just has not played out for us. So with other family members we make sure to tell them not to treat Malik like he’s got a special need. That’s number one. We tell them to treat him like they would treat anyone else, but you know some family members don’t do that! They tiptoe around him and are all shy, but he knows what they are doing and he just eats it up.

**Raising an African-American child with ASD**

This is an interesting question because of Malik’s age. I will say this. When we were in the discovery stages, just learning about his condition I did feel like we ran into some racial stereotypes and things like that. When the specialist told us all the things Malik would not be
able to do, she did tell us that Malik would be good at sports. What? Would you say that to White parents? Are you thinking of stereotypes of Black people?

The crazy thing is, Malik is grown. He is aged out of school and goes to a day-long program for adults. I talked earlier about how the most difficult thing for me was not being able to protect him. I know, from my own experience, how others look at Black people. I know based on the things that have happened to me in my job and when I was younger. Just as much as I may be concerned about his being an adult African-American man with autism is the fact that Janine and I won’t be here forever. We know we won’t be here forever and that’s a hard reality when I think about Malik’s needs.

Describing this fathering experience to someone

I would describe it as an experience that will require you to have balance. The stress that can be attached to this can cause you to get out of balance. Listen, we are men and we need balance. I also describe it as having the potential to have a pity party, but you can’t do that. Not long ago, my neighbor says to me, “I just feel so sorry for you.” I’m like, “There is no need for you to feel sorry for me. You have a son and I have a son.” I told him, “There’s no difference between my son and your son. You love your son, I love my son. You would do anything in the world for your son and I would do the same thing.” I also said, “The only difference between our sons is that mine is 22 and your son is 30. That’s it”. Yeah, don’t feel sorry for me. And don’t feel sorry for yourself.

Making Meaning of the Experience

What does it mean to be an African-American dad of a child with autism?

Being the father of a child with autism today has helped me be a blessing to others, especially other fathers of kids with autism or special needs. I’ve been doing this for quite some
time and I’m pretty confident I can spot the pain on the faces of parents of children with special needs. I have a comfort level with talking about disabilities and my son’s challenges. Many parents do not have that voice yet and don’t quite know how to communicate their feelings. This means I can be a resource for them and help them understand those feelings they are having. It means having a sense of confidence that even though this is hard at times, I know I can handle it.

But being an African-American father means that I can take all of my experiences and talk to that Black mother or Black father and encourage them to not be ashamed and not be embarrassed. I have credibility with them and I can tell them there is no need for them to feel ashamed because their children are no different than other children. In fact, they are more special than other children. They can be proud because that special child is their child.

**Words of wisdom to the father whose child is newly diagnosed**

I’ve been approached on several occasions about this. Actually, I was just approached last Saturday at the gym. Saturday is Malik and my gym day. We go every weekend. I work out and he has his own workout routine. And there are times when you can tell my son has a special need. Saturday, a man approached me and asked if he could stop me and ask a question. Of course I said yes. He couldn’t even get the words out. After stumbling a bit, he said, “Your son.” He didn’t say anything else. I just jumped in and responded, “Yeah, my son has autism.”

I could see the tears welling up in his eyes, so I took a risk and just hugged him. I said, “That’s Malik. He’s 22 and has autism.” He told me his son was four. I tried to encourage him by saying that I hope Malik was an inspiration to let him know that his kid will be able to have success. I told him that it does get better and to make sure he gets every resource for his son to help him grow and develop. I reminded him that he had a loving child who is God’s blessing and that God gives special kids to special parents. I gave him my phone number and let him
know he could call me whenever he needed to talk. Then, he told me he didn’t have many people to which he could talk so he was happy to get my phone number. I told him to just love his son. Love him and everything else will fall into place.

The words of wisdom change with a Black dad. You know how it changes? It changes because I have a responsibility to the Black dad. That’s different even from the guy on Saturday. I was just in the right place at the right time. If the brother comes up to me and tells me about his child with autism, I have an obligation to make sure he has every piece of information I can give him to guide him with his child. All the guidance I can give him, I would give him. That’s the kind of thing my dad taught me coming from his generation. You have to look out for each other and support each other. That’s the difference.

Support

The most important support has been family. Hands down. My in-laws, our extended family and friends have been critical. There has never been a time when Janine and I called on some of those folks and they told us no, if they were around. We bring Malik to them, they come pick Malik up, or they do whatever they can to help us when we need it. There are a couple of family friends who have special needs children that bowl with Malik. They offer to help, too. They see us all as family. To them, Malik is their cousin, their nephew. He is just a part of their family. I don’t ever remember having to get formal program care, like the respite programs offered by Human Services, because our extended family and friends have always been there for us.

Relevance or need for counseling services

In 22 years, I have never sought counseling services for this stuff. Why? BECAUSE WE’RE AFRICAN-AMERICAN!! We don’t go to counseling. We go to church and pray about
this stuff. If you have a problem, you get you some Jesus and he’s going to take care of it all! That has been the mindset. My sister-in-law is a licensed clinical social worker and she has never suggested counseling.

Now, do I still have that mindset? No. But it’s hard to shake something that you have been taught for your entire life. We don’t need to see counselors. And then I think – God has blessed these people with training and degrees and talent enough so you can sit down with them and talk about your life problems. But, in African-American households things have to be really bad if you get counseling. Do I think counseling could help with some things? Yeah, I do. There are day-to-day things that we confront and a counselor could help with those things. The stuff related to Malik, though, God has blessed me to have a great relationship with my wife for us to be good parents. He has guided our footsteps through 22 years. Counseling just hasn’t been the route we have chosen to take while on this journey. I can’t say we won’t ever try it. We just haven’t tried it up until now. And I have to be honest, because I have had the chance to finally talk about this stuff with someone about MY experience – now it’s been 22 years and I have never had anyone ask me about my experience – it has been very, very helpful. I feel like I have been able to exhale a little more.
Chapter 8: 
“No one will ever be harder on my kids than me”: Ethan’s Story

Ethan is a 39-year old, African-American father and husband of three children. Ethan has been married to his wife, Karlene, for 12 years. Their children are Jason (10 years old), Kayla (7 years old), and Aubrey (5 years old). Ethan is a pharmaceutical salesman and manager. Prior to entering pharmaceutical sales and management, he played in the National Football League briefly. Ethan and Karlene’s middle child, Kayla, has a dual diagnosis of Cri-du-Chat and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). The PDD-NOS diagnosis was offered when Kayla was 3 years old. Ethan and I met on three consecutive weeks in his home and I had the pleasure of interacting with all of his entire family, including his biological mother. They live in an upper-middle class suburb of a major northeastern metropolitan city. On our final interview, Ethan and his family invited my family to have Sunday dinner with them, which gave our children the opportunity to fellowship with his children.

Cri-du-Chat is Kayla’s primary diagnosis. It is a rare genetic disorder whose symptomology includes significant intellectual delays and significant gross and fine motor impairment. Kayla’s activities of daily living (e.g., walking, bathing, brushing teeth) are severely limited at this time. She has minimal expressive language but does have receptive language. Ethan and Karlene combine sign language and verbal language to communicate with her. The most telling quality about Ethan’s case is that he is the only contributor to this study who has a daughter with a form of autism. Boys in the United States are diagnosed six times more frequently with autism than girls. Kayla is also the only child represented in the study who has a dual-diagnosis.

Ethan’s biological parents divorced when he was young, which was a bit of an obstacle to his relationship with his father immediately following the divorce. Over time their relationship deepened and he reported having a good relationship with both his biological and stepfather as a young man while being raised in the inner city of a major city. As a high school student, Ethan’s athletic and academic talent provided a scholarship opportunity for him to attend a private military school and eventually play Division 1 football. Ethan’s biological mother lives with their family to support them in providing care to Kayla and to receive support as a cancer survivor. Ethan’s highly competitive, goal-driven values were evident in my spending time with him and his family.

Describing the Fathering Experience

Memories that taught me about fatherhood

The good memories I have of my [biological] father include playing sports. Playing with and against my dad was his way of showing his love and teaching me life lessons. We played a lot of basketball and he NEVER let me win because he believed I had to earn the right to win. I had to earn everything with him; nothing was ever just given to me. That helped me learn that
when you earned something, you valued it. I remember the first time I blocked one of his shots. It was one of those “a-ha” moments for both of us because we realized the “game changed” at that moment. Those games and his making me work for everything was his way to teach me the value of hard work.

I have good memories with my stepfather, too. He pretty much raised me from about junior high school, through college, and into my adulthood. He has always been there for me. He came up pretty poor and never had much, but he never let our poverty be an excuse for what we could not do. Even though there was a lot of crime, drugs, and violence he always told us that our environment should not define us. He taught us that there was more to life than some of the bad things we saw in the inner city. He told us that there was more to experience. He really motivated me and has always been a positive influence.

**Personal qualities of good fathers**

The first quality of a good father is one who is present. That’s the first thing. And being a father isn’t about being your child’s best friend. You have to be able to set boundaries with your kids and know that sometimes they are not going to like you. In fact, if they like you all the time you are probably being too nice! They shouldn’t always like you!! A good father gives his kids what they need spiritually, physically, and mentally to prepare them for the future. He wants them to be prepared to be productive in society when they leave their fathers’ care. A good father is stern, strong, and steadfast; he is spiritually grounded so that he can guide his family. He thinks not just about his kids’ immediate circumstances but he has insight and seeks clarity about the future, too. He’s thinking, what is going to happen for my children in the future? What do I need to do to prepare them for the future?
A good father is also realistic. No one will ever be harder on my kids than me. I’m going to be the one to push them to levels I know they can reach so if they get that kind of challenge from other people they are already familiar with it. I am okay with my kids being mad at me and not understanding why I do what I do in the moment. I know when they get older they will understand my motivation; that’s how it was for me. There are so many things that influence our kids, like the stuff on TV and the internet. That is why it’s important for us to be present. A good father is present at the school, at concerts. He is involved. His kids should see him in the stands at sporting events. And, it’s so important that he shows love. A good father tells his kids he loves them and doesn’t wait until it’s too late. His kids know because he has told them and he has showed them his love.

**Life experiences associated with being African-American**

I have always known the negative stereotypes that people have of African-American children, especially boys and men. My parents really helped me understand those things and that I did not have to fall into the trap of trying to change peoples’ ideas about me. I played football with a lot of Black and White teammates and it helped build relationships. I also had some really strong influences in my life that included both Black and White teachers who reminded me of the stuff my stepfather told me years earlier. They reiterated the messages about not being bound by my circumstances of being poor or peoples’ attitudes about inner city kids. I knew who I could become and the potential I possessed.

There was a time, though, shortly after I graduated from college and began working with my first pharmaceutical company. I worked in an area that was what you might call lower income, but the population was lower income White residents. I walked into the Medicaid clinic CLEAN! You know, I had the suit, tie, and everything. I was professional and had that
professional Black man image. I was setting up for a luncheon and checking out the space to make sure everything was in order and take time to converse with the nursing staff and the health commissions in the area who were attending the luncheon. This White nurse walked back and asked me, “What are you doing back there? Are you stealing anything?” It just reminded me that there are some people who will always have a mindset of stereotypes and racism. I’m glad I know who I am and what skills I bring to the table.

**How becoming a father influenced my sense of identity**

You never know what selfless love is until you have children. Before kids you know how to love a little bit. You love your relatives and your parents. You love your significant other. But it changes when your children are born. When I held my kids I knew I would give anything for them. My needs became an afterthought once I became a dad. Even when your kids don’t really understand what selfless love is, you still know that you would do anything for them. I would take a bullet for my kids. I would protect my kids from any harm or danger. I would assume the consequence of harm or danger to keep them safe. The crazy thing is that it evolves and deepens over time. Right when you think you can’t love your kids any more you find a reason to love them even more.

And being a father comes natural to me because I enjoy kids. I enjoy coaching kids and bringing out the best in them. That is what good fathers do for their kids. I like seeing my kids rise to the occasion in the midst of a challenge or adversity. I love coaching kids in football and seeing how a child can go from hating physical contact in the beginning of the season to becoming a competitive, aggressive tackler when the season is over. I love seeing my kids make progress and move forward.

**Fathering a child with an autism spectrum disorder (ASD)**
Ideas and knowledge about disabilities and autism before diagnosis

My attitudes were pretty bad growing up and even before I became a parent. As kids, we all made “short bus” jokes for kids who we thought may have had problems in school and learning. I did laugh at those kinds of jokes. Then, as an adult, I would be the impatient person on a plane or in restaurant who would want you to control your kids. If I couldn’t read or watch a movie, or have a quiet flight because of a kid, I would get irritated. I wouldn’t think that maybe the child had a special need. I would just be thinking about how their need, whatever it was, affected me. I don’t remember anybody in my family with any kind of disability that may have helped me have different ideas about special needs kids or adults. The only thing I knew about autism was because I worked in pharmaceutical sales. Even that didn’t give me a really strong understanding of the disorder. I had no idea about the variety of symptoms or how severe the disorder could be for people.

Most rewarding and challenging aspects of fathering a child with an ASD

One of the most rewarding things about being Kayla’s father is experiencing her love. I know that regardless of what is happening all my kids love me, and I get to see Kayla show me love in her own unique ways. When I come home from work she looks at me. When she hears the door open she crawls to the door, looks for me to sign to her that she can now watch one of her favorite shows, “Signing Time”. She waits all day so we can watch it together. As soon as I get home I put it on and turn it up. She will literally grab my hands and make me make the sign for the show. She laughs and gets giddy, and then she walks, or crawls over to the TV and waits for me to turn it on.

That’s just one part of it. The other part is the hug. When she hugs me and kisses me she is telling me that she is here and she wants to spend time with me. She is telling me that she
loves me. It’s really the small things for me that make the difference. The last thing is being able to watch her grow. Kayla is 7 years old and 4’3” and she is now learning to walk. When she wants to eat she can get to the table, lift herself up and put herself in the chair. She lets us know she’s ready to eat with sign language or an attempt to verbally communicate. There was a time when we would have to sign and tell her that it was time to eat and do other things. Now, she tells us she wants to eat or she wants more to eat by signing. She signs to say, “thank you” and when she’s done using the bathroom she’ll sign for “done”. These are things she didn’t do last year. I revel in those moments because they are priceless.

The hardest thing about this is how much it is a 24 hour job. We got to work and do our day jobs but we also have to make sure Kayla is getting the services she deserves and needs. She is at the age where she can crawl out of bed in the middle of the night and wander so we have to make changes to the room to keep her safe. She doesn’t speak clearly all the time, so when she gets frustrated and lashes out we have to respond differently to her than we would with her brother and sister who can talk to us. There is also the frustration that comes with Kayla not getting services we think she deserves and needs. As a dad, you always want the best for your child – disability or no disability. When you have a child with a disability those feelings get a little more intense. I want Kayla to walk and to talk. I want to have a conversation with her but she will do that on her own time. The challenges are with the expectations.

I’ve learned to not put expectations on Kayla for what she will do or when she might do something. I have stopped placing dates on things, but that’s been really hard. I used to just set all these goals, like: I want to achieve this goal on this date. This is our quarterly goal and this is the mid-year goal. I can’t do that with Kayla. I have to set daily goals with her. We set goals every day.
Coping with the challenges

I’m pretty self-aware so I know what things might trigger me. I learned to cope with difficult situations a long time ago between athletics and being a business professional. You have to deal with so many people who might push your buttons and get you frustrated. I work out. Working out has always been a great release for me. I go to the movies – by myself. When I can get a little alone time I’m usually good. That’s really all I need to get resituated. Sometimes I need to walk away briefly to get some perspective and avoid saying or doing something that will make the situation worse. Those kinds of things work for me; it’s nothing too over the top.

Increasing understanding of diagnosis within the family

This was pretty hard because my oldest son, Jason who is three years older than Kayla, did not understand everything initially. He just avoided her. He would do what he wanted to do and when Kayla would try to interact with him he would avoid her. He might walk away, go downstairs and begin to play alone. Since then I have tried to help him understand her and help develop his interest in and appreciation for her. I explained to him that she was his sister and he needed to love her and protect her because she can’t fight for herself. I told him he had that responsibility with both of his sisters, but it was really important for Kayla.

I sometimes force them all to play and interact with each other. I feel like if I don’t force it when they are young it will never become a habit. If I let them just do what they want to do, they will always do what is easiest and most comfortable versus what is right and sometimes takes a little more effort. I’ve had to instruct Jason and Aubrey about how you play with your sister. This is how you understand her and learn about her, and learn from her. This is how you
love her. You do these things when people aren’t here so it becomes a habit when people are here. You love her all the time the same way she loves you all the time.

Raising an African-American child with ASD

Kayla is such a minority. It’s like she’s a double or triple minority. At the national meetings for families and kids with Cri-du-Chat there may be four or five Black children that I have seen. This genetic disorder is so rare, but even with the rare cases we know we are being judged. In some places where we have lived, service providers assume we want handouts. They don’t assume we know what questions to ask or that we have access to some resources because we are not poor. When they see me in a 3-piece suit you can see the attitudes change entirely. It’s like they are saying to themselves, “Oh, he’s not THAT kind of Black guy.” You know, the stereotypical uneducated, poor Black guy. I always think that I’m going to be here to help Kayla get what she needs because her needs are so prevalent right now. I will always want to be her buffer and protector from those kinds of folks who want to judge her.

Describing this fathering experience to someone

This experience is work, man. It’s constant work, but it is work that is worth it. It is a 24 hour job that requires you to be selfless most times. I don’t mind though. I don’t mind picking her up and taking her to the bathroom. I don’t mind driving on all of our vacations – driving from here to Florida - because we want to keep Kayla comfortable as we travel. That’s what good dads do. They are present, they are visible, and they know how to sacrifice their own preferences for their kids’ needs. Good dads remind themselves that these challenges are not about them. These challenges are about making their kids’ lives better so they can be prepared and feel supported. The work is worth it.

Making Meaning of the Experience
What does it mean to be an African-American dad of a child with autism?

Fathers have the task of stewarding their children. They should help them grow, learn right from wrong, and be productive members of society. Fathers should instill values like giving back to the community and to those who may be less fortunate. Those are things I try to instill in my kids and I am humbled by who I see my kids becoming. Fathering Kayla, who has two diagnoses, demands a little more from me. I have the same responsibility of helping her meet her full potential even with her physical and developmental disabilities, so I have to do more to make sure she is getting her services to help in that process. I have to make sure she gets everything that will help her walk, talk, communicate, and have a voice. That’s what it means to be a dad of a child with special needs. I’m her voice and advocate.

Kayla’s diagnosis is so rare that it means I am an educator, too. Being a Black dad who has to educate people around him about his daughter’s condition is sometimes received well and sometimes it may not be received so well because I am Black. People have become more familiar with autism, but Cri-du-Chat? It’s so rare that I find myself having to educate people about it and I know that because I’m Black some people may not take everything I have to say as seriously because of their ideas about Black people and Black men, in particular. That’s what it can mean to be an African-American dad of a child with autism and Cri-du-Chat today.

Words of wisdom to the father whose child is newly diagnosed

Two things I talk to fathers who have children who are newly diagnosed is to communicate they are not at fault for their child’s conditions and they are not alone. It’s important to remind them of that because those are the first two things most people think about when they hear their child has a lifelong condition. You can take that news and the overall experience in one of two ways. You can take it personally and question everything. Those
people usually question God or think that “bad” people are more deserving of this kind of thing. They think people who are irresponsible or unmotivated deserve this kind of news. Or, there are people who realize that even though this will be hard, they can work through it and help their kids reach their potential. They take steps to find out what to do and how to help. They ask questions. What is interesting is both types of people can be reluctant to reach out because they aren’t quite sure what to do. They ask themselves, how do we tell people about autism? How do we tell people about Cri-du-Chat?

I tell them DO NOT keep quiet about it! When fathers keep quiet it ends up hurting the child. I tell them to not be embarrassed. Assume the role of educator anywhere it has to be done. You have to do it in the restaurants when you get the weird looks. I educate. I tell people, “She has Cri-du-Chat. She’s a little different than how you usually see children. She’s going to communicate with you a little differently than what you are used to seeing and hearing.” The third thing I tell dads is that I’ll be here to help whenever they need it. This kind of transition takes time to fully understand and accept. Dads take a little more time to come around and I don’t ever try to force my help. When they are ready, though, I try to communicate I’m there to support and help.

The script changes a little bit for Black dads, though. I think sometimes it may be harder for Black men to accept it because of our ego or pride. And I don’t say that in a bad way. When Black people understand their history of struggle in this country and see what we have overcome, it can be hard to accept something that may seem so concrete and final. Black dads question, just like any other dad, why they are having this experience. I feel like with Black dads they have to focus on the child. What I mean by that is, even though you have to worry about the glass ceiling and discrimination and stereotypes, you can’t let those things stop you from fighting for
your kid. Those things are about you and your experiences, but this is about your kid. You can’t let your negative racial experiences stop you from fighting for your kid because that is selfish. That’s what I would tell another Black dad who has a child with a new diagnosis.

Support

The best support for me came from my fraternity brothers when we lived in the Midwest. Karlene and I also had great support from other parents of kids with a variety of disorders. There were parents in our group whose children had developmental disabilities, genetic disorders, chromosomal disorders, and some children had conditions that were not diagnosed yet. This group was really helpful because it seemed like we were on the same journey. We supported each other by sharing resources, referring specialists, talking about IEPs for our kids, and all of that kind of important stuff.

We also were connected with a specific group of parents of children with Cri-du-Chat. They really helped us understand Kayla’s condition. The geneticist we went to was so damn negative. He told us all the stuff she would not do over her lifetime. She won’t walk. She won’t talk. She should be hospitalized. He gave the bleakest prognosis. Our group helped us find another specialist and he was the exact opposite. He was focusing on her strengths and what she could be able to do with the right kind of support. That is what we needed. It is what I needed. I’m not naïve or blind to the uphill battles and the challenges because I’m a realistic person. I also see her potential. I see the moments now and I also see what could be in the future. Kayla is happy, she smiles, and she is growing.

I realize that even though this is difficult, Kayla’s condition could be a lot worse. We’ve seen kids who cannot communicate or have tubes or will probably be confined to a wheelchair
for their whole lives. In those moments I am thankful that we can have hope for her beyond what is going on right now.

What do I wish I had to help me even more? It would be great if there was a universal book! A book that lets you know all of the services you can get for your child with a disability would be perfect. It would stop you from having to navigate this huge system or having to put resources together because the service people never give you the full spectrum of services. They tell you parts and pieces and you have to put the pieces together. One of the hardest parts is that parents don’t know what they don’t know. You don’t know what other opportunities or interventions are out there for your kids. For example, we had the typical set of services for Kayla. She got occupational therapy. She got physical therapy. You know, the standard stuff. Thankfully, we stumbled upon hippotherapy, where they use horses for gross motor development. Kayla has been riding horses for four years now. It helps her control her trunk and supports her gross motor skill development. We find ourselves having to tell parents about that because they don’t know it, just like we didn’t know it. Yeah, we need a universal book!!

*Genetic and Developmental Disorders for Parenting Dummies* should be the name!

**Relevance or need for counseling services**

Karlene and I talked about getting counseling early in the process. In our relationship, we’re like ying and yang. She does much of the nurturing and I’m like the drill sergeant in the house. I think in our situation, Karlene took this a little harder because Kayla was our first baby and our first girl. I think her attachment is different because she carried the kids for nine months. She felt more guilty and thought she did something wrong. She also had to reset her expectations about some of the things she looked forward to doing with Kayla. She looked
forward to proms and dates and some of the things she wanted to experience with Kayla that made her have to rethink that stuff.

Over time Karlene became the resource person with other parents. She would reach out to other people and make recommendations for service providers and things like that. She became an advocate for other parents and kids, which was good for her. So, to answer your question, no we never got counseling but we thought about it. We know how trying this kind of situation can be for parents and how vulnerable they are to separation or divorce. Thankfully, we have been pretty solid in spite of the challenges and we know it is always an option.
Chapter 9:  
“I try to take what he does and apply it to my own life”: Frederick’s Story

Frederick is a 42-year old married African-American father of William. William is an 9-year old boy diagnosed with Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS). William was diagnosed when he was 1 according to Frederick.

Frederick is married to Serenity and they have 3 other children in addition to William. Their oldest daughter, Shanelle is 26 years old and does not live with the family. William has an older brother Frederick, Jr. and a twin sister, Wandria. Frederick has an Associate’s degree and is a manager at a local distribution center.

I had the pleasure of meeting with Frederick for three consecutive weeks at his home, where I met his wife and the three children that reside there. I had a chance to see the children interact a bit and the ways the family sometimes interacts with William. William is considered a child who is high functioning. He has receptive and expressive language and generally enjoys social interactions. He was polite and charming in my interactions with him.

Frederick was raised by his biological grandparents. He did not discuss his relationship with his biological mother or father. He considers his grandparents his parents and expressed great pride in the relationship he had with his grandfather. Among the telling qualities of Frederick’s case are the strong faith that he and his wife profess and William’s high functioning diagnosis.

Describing the Fathering Experience

Memories that taught me about fatherhood

My grandfather was the person who taught me about fatherhood. He was the one who was there for me and taught me the things dads are supposed to teach their kids. He taught me how to ride a bike, throw and catch a football, and things like that. I was an only child; he and my grandmother didn’t raise anybody else when I was with them. And they only had two children: my dad and my uncle.

He was an old-school man, from the South. He was born in 1918 so he had a different perspective on life and work and people. He was drafted into the army and after he was discharged he and my grandmother made a home in New Jersey. We went to church EVERY Sunday. He and my grandmother ran a tight household where he made me understand what it meant to be responsible and accountable for my actions. Because I was the only child in the house I had him all to myself. By the time he was raising me he didn’t work as much so we
could do activities together and things like that. He worked as a shade tree mechanic and was good with his hands. He taught me how to work on cars on other kinds of mechanical projects. What I learned the most from him was how to raise my own child. His example helped me know what to do when I became a father myself.

**Personal qualities of good fathers**

Good fathers are honest. They are honest with themselves and with other people. They want to have open and honest relationships and avoid keeping secrets. You can expect the truth from good fathers. If a child goes to his dad and needs some advice, they can expect to get a truthful response from a good father. He also has to be able to communicate. He has to be able to say what is on his mind in a way that other people can hear and understand him. Those two things help kids find out who they are and help them find their identity. If a dad can be honest and communicate well, he is going to be able to help his kids with their own identity. That’s one of the roles good fathers have to serve with their kids. The kids can see their dad being honest and know him in a real way which helps them be honest and know themselves in a real way.

Good fathers lead by example and they want to be honorable. They don’t lie, cheat, or steal. They actually challenge that motto that says: “Do what I say not as I do”. Good fathers actually say, “Do what I do” because he is a good model for his children.

**Life experiences associated with being African-American**

I actually think I have been discriminated against for a job opportunity. Years ago I was working in a job for which I was already overqualified. I took the job to get my foot in the door at this place and eventually there was an opening for a manager position. I never got an interview or anything when I applied for the promotion. I was never was informed about why I wasn’t considered more seriously. The manager they selected was not a strong manager. Over
time, he eventually got relocated and the position opened again. Of course, I applied for it. This time around I get an interview and do so well that one of the people in the interview let me know before-hand that I was going to get offered the job.

Once we made the new position official, that same person in the interview told me that the person who was transferred was a racist and did not want you to take the position he applied for years earlier. I thought to myself – if this person could figure out that some of these folks were racist, why couldn’t other people admit that too? I realized at that moment there was one person, with a bunch of influence, who prevented me from getting that job earlier. I think that was only because I’m Black.

How becoming a father influenced my sense of identity

I can’t find words to express the experience of becoming a father. Wow. It’s really special because you wait for 9 months thinking about whom this child is going to be and how you are going to care for him or her. When the child arrives you finally get the chance to see and interact with this person you have been speculating and guessing about for months. It grounds me. It’s like when you are a kid and you wake up on Christmas morning. You are looking for the one gift you really want under the tree and it ends up being your child. This new baby is looking at you for all his or her needs. You know you have to mold this person into one who will contribute to society and that’s a big responsibility.

Fathering a child with an autism spectrum disorder (ASD)

Ideas and knowledge about disabilities and autism before diagnosis

I don’t remember having a lot of interactions with people with disabilities when I was younger, but as a professional I have worked with several people with disabilities. Those
experiences have really helped me have better insight, be more sensitive, and understand how they can help make a workplace better.

Now, I didn’t know anything about autism before William. The only information I had was basically from the movie *Rain Man*. When they told us that he had autism I thought to myself: Is he going to be like the dude in *Rain Man*? That’s all I knew. I didn’t know all of the different forms of autism. I just knew *Rain Man*. I had to get educated on autism in its entirety.

**Most rewarding and challenging aspects of fathering a child with an ASD**

William’s accomplishments make me most proud. I’ll give you an example from school. In math, this boy is perfect. He sets an example for his other siblings. Neither one of my girls was strong math students, so to see him be an example to his twin is really nice. I’m proud to see how focused he can be. I know they say that can be a problem sometimes, but when you see him set a goal and work toward that goal with such focus is a motivator for me. I try to take what he does and apply it to my own life. If he can work that hard and accomplish those things, why can’t I have the same kinds of accomplishments and success? William motivates me.

One of the challenging things can be that same focus. William sometimes can’t see anything beyond what he normally does and that can hard for him and for us as a family. For example, we always go in the same door at school in the morning, except for when it rains. On rainy days we use a different door. The door for rainy days is actually closer to the drop-off spot so parents and kids don’t have to walk as far. Well, guess what? William doesn’t want to go in the closer door because we are supposed to go in the main door. THAT will get on your nerves! He will tell me using the closer door is not the right way and we have to go the main door. He’ll argue with me for 5 whole minutes because we have to stick to the routine. Those are the times
when I really have to prepare. I may have to wake him up a few minutes early because we all know how focused and rigid he can be sometimes.

**Coping with the challenges**

I try to adapt to the challenges. I try to be flexible because I know he can be rigid. If he is having a problem, I have to ask myself: how can I rethink this? How can I find something useful in this situation to help him move forward? That’s why his rigidity is like a catch-22. I can show him something once or twice and he thinks that is how it’s supposed to be done ALL THE TIME. I show him a certain way to make up his bed. That’s how he’s going to do it. When I come back to try to show him a better way, he’s going to fight me. I have to carefully introduce a new way to make up the bed, knowing he’ll fight at first. I have to be consistent in introducing the new way. You know? I have to do it for a few days straight and then he might accept it. Even though that part is frustrating, it keeps me on my toes. It keeps Serenity and me sharp and quick-thinking. I don’t think I get too frustrated but when I do, I know it’s time for me to change up and try something new.

**Increasing understanding of diagnosis within the family**

Serenity and I talk to his brother and sisters. We helped them understand how William is really good at some things – like math – and how he can have a hard time with other things. In the beginning it was hard because Freddie, Jr. and Wandria didn’t really understand what was going on. We explained to them that autism sometimes makes hard for people to use the right words when they want to talk. We explained that sometimes autism makes people want to spend more time with themselves than with other people, even their brothers and sisters. The good thing is that William is higher-functioning. Even though it took him a little bit longer for his words to come, he has them now and his ability to talk is not really impaired like it was when he
was younger. They know what sets him off and what helps him calm down. It also helps that his symptoms are not really severe.

**Raising an African-American child with ASD**

Raising two Black boys in this world can be pretty tough. Thankfully, we haven’t seen too many ugly situations because we live in pretty diverse neighborhood and town. You saw that when you came up the street all the different races of people who live just on this street. I’m not foolish enough to think that nothing can happen to William. I know how it goes. Things like “Driving While Black” still go on today. William is going to be a productive member of society. He is a good student, he can make friends, he can follow directions and he can think for himself. Even more than that, though, is that I know God will take care of him. It’s hard to think about him being a man and being on his own. That’s when I have to trust God and know that William will be okay, even as a young Black man in America. I just have to trust God.

**Describing this fathering experience to someone**

This experience has its challenges, but it’s just like anything else in life. You have difficulties and you have challenges AND you can get through them. It has helped me be more patient and less judgmental. That’s what this experience will do for you. It will make you think twice about passing judgment on a parent who is having trouble with their kid. You don’t assume the parent is just a bad parent. You think about the possibility of the child having a disability. You don’t make any more assumptions when you live this and see other parents having challenges with their kids.

**Making Meaning of the Experience**

What does it mean to be an African-American dad of a child with autism?
It means the world to me. I know I do him a little different than my other kids because he’s special to me. He’s sweet. He’s loving and affectionate. That kind of gets me right in my heart. He’s the kind of kid who still walks up to me and gives me a hug and tells me how much he loves me. That’s all a father really wants to hear from his children. He wants to hear they appreciate him and love him. It means the world to me to be his dad.

**Words of wisdom to the father whose child is newly diagnosed**

I would say to him that he should expect to deny it at first. He is going to be convinced somebody missed something or there has been some kind of mistake. He is going to be resentful at the medical people for saying that there is something wrong with his child. Once he gets through that denial and anger phase he should make sure he is able to talk and express his feelings. He needs to be able to talk it through. I would definitely make sure he knew that I could support him because I have been through it.

The next thing I would tell him is that he is going to feel overwhelmed with all the information that people are giving him. So, I would want to be there for him so that he can get some support because he is going to ask: What do I do now? Where do I go from here? I would want to be there to point him in the right direction of resources and help. He needs to talk to his child’s pediatrician and he needs to start reading up on autism and getting familiar with it. I would advise him to understand how his child functions. Is the child’s diagnosis more severe? Can the child communicate? He has to remember to put his child first, even when things get hard for him. I’ve seen some parents get so wrapped up in their own stuff they can’t be a good support to the child. The most important thing I would tell him is to be patient. It may feel difficult and overwhelming in the beginning, but it will get better over time. When he sees his kid have success or meet goals, it helps.
If I was talking to a Black dad you have to take age into consideration. You have to consider his maturity. A Black dad is only going to want to hear from you if you can talk to him in his language. That lets him know that I know what he’s experiencing and I know what I’m talking about. He is not going to want to hear a bunch of technical words and things like that. You have to communicate to him the need to be brave and man up. You have to make sure he knows how much his child is going to need him; he needs a strong Black father in his life to be successful. You have to give it to him straight. That’s how he would want to know and that’s how I wanted to know. No fluff, just the real information.

Support

The best support I have had through this whole thing is my wife. She took the initiative in the beginning and did all of the research. Guys, you know, we move a little more slowly with that. She helped me understand. She took all of that information and made it easy for me to make sense of it. She motivated me to do my own research. I realized that William was my son, too, and I had a responsibility to understand as much as I could about this condition. We also have good doctors and a great school system. Everyone has worked with us and William to help him get the help he has needed over the years. Yeah, my wife, the school system, and William’s doctors have been the best supports.

I wish the doctors and the specialists could have been clearer about William at the beginning. In the early years it was frustrating because we knew something wasn’t quite right, but everyone had all these opinions. What I mean is that no one could tell me what caused it or the cause of the autism. Did we do something? Was it something in the environment? No one could tell us that kind of stuff. I know people still don’t have answers to those questions, but we’re human. We want explanations and we want clarity. We want to know the source. How
can we stop it from happening again? How can we fix it? It’s hard for me to accept that with all these kids with autism doctors still aren’t really clear about where it comes from or why it’s happening so much in kids. Was it a vaccination shot? Was it genetic? Is my kid going to be like *Rain Man*? I wish we had more answers about the source.

**Relevance or need for counseling services**

Actually, we never considered counseling because our faith helps us through this. We realize that this is just one of those things life presents to you. You just have to find a way to work with it, deal with it, and cope with it. Many people get counseling when they feel overwhelmed and don’t feel like they have the ability to deal with life situations. They can’t cope with something. They can’t get their stress under control. We have never felt that way. We have always felt like our faith in God and our relationship with each other has been enough to get us through the hardest times.

I’m not saying counseling is bad. If you don’t have the kind of support you need to get over something, then seeing a counselor will be good for you. For Serenity and me, we believe the Bible gives us all the answers we need to get through this. It’s like a life manual that answers our questions and gives us the tools we need to make it. So we never felt like we needed to get that kind of support. It may be the kind of support another dad or another couple might need. We’ve just never needed it. We communicate well and talk all the time. She knows how to help me open up and she’s comfortable doing that with me. If I could not do that with her I would probably see a counselor. I’m glad I have the kind of person who can listen and talk to me openly and honestly.
Chapter 10:
“He reminds us to not apologize for being individuals”: Mike’s Story

Mike is a 37 year-old African-American married father of two children. He has been married to LaChan for 12 years and their two children are Nile, who is their 10 year-old daughter and Avery, their 8 year-old son. Avery was diagnosed with Pervasive Developmental Disorder – Not Otherwise Specified (PDD – NOS) at 21 months. Mike is a counselor who is completing his doctoral degree in Counselor Education and Supervision. He worked as a counselor and student affairs professional for 10 years before returning to graduate school and is the author of this study.

Mike has spent a significant amount of time considering the questions he has asked the six fathers who have contributed to this project, knowing he would have to answer them for himself. His relationships with his wife and children are strong and healthy. His family has been extremely supportive as he has pursued his personal and professional goals. His desire to better understand the effects of rearing a child with autism was the catalyst for this project. He became aware of his own ideas about how having a son with autism family might influence everyone in his family.

Avery is a high-functioning child. He has expressive and receptive language. He is extremely affectionate and seeks interaction with his peers and family. His behavioral attributes were very different in the earlier parts of his life. He had very limited language as he approached two years and was assessed to be far behind many developmental milestones when he was younger. He has benefitted from strong extended family support and excellent therapists and service providers.

Mike has had a strong relationship with his biological father over the course of his life. He has also benefitted from positive relationships with his grandfathers, uncles, and other male role models. In an attempt to bridge their life experiences and their professional passion, LaChan and Mike developed a non-profit agency in 2007 whose mission is to support parents living with and caring for children with developmental disabilities. They are both very visible within their local community as educators.

Describing the Fathering Experience

Memories that taught me about fatherhood

I have all kinds of memories that have taught me about fatherhood. The strongest of them are spending time with my dad doing work around the house. Those days doing yard work – cutting the grass, shoveling, landscaping – they all provided a chance for my dad and I to connect about what was going on in each of our respective lives. My dad eventually told me that while those times may have seemed random to me, he was actually really intentional about that. His childhood was very different from mine in that he was raised as an only child. My dad had
an older sister who passed away before he was born and his parents never had any more children. So, while he loved his parents he was very aware of feeling a bit disconnected with no siblings and not spending much time with his own father. My dad always attempted to be available and present for me. In the large majority of cases, he did that. Of course, we had misunderstandings and frustrated each other at times. Overall, though, he availed himself.

I have memories of doing yard work on Saturday mornings. He would make me get up fairly early in the summer so we didn’t have to work into the afternoon when it was really hot. I would have to cut our grass and he would begin the landscaping. I would have to make sure the grass clippings were up and help him if he wasn’t finished. Those were good memories. They were hard days, but good experiences. The other memory I have about learning about fatherhood was during my engagement period with LaChan. There was a day when we were talking and he made it a point to remind me of role of a husband and father from a Biblical perspective. He told me that the word husband is derived from the term, *house-band*. He went on to tell me that it was my job to *form a band around my house* to protect my family – my wife and eventual children – from things that may hurt them spiritually, emotionally, or physically. That message has stuck with me for years as a husband and father.

**Personal qualities of good fathers**

Good fathers are available, teachable, motivated, and willing to sacrifice. When I say available I’m thinking that good fathers are accessible to their children. The children are clear about the ways they can connect with their dads and hopefully, the kids can connect with their dads in a number of ways. They can connect emotionally, they can connect by way of shared interests, or they can connect just because they care about each other and are interested in seeing each other happy and fulfilled. Good fathers are teachable, too. I have seen a lot of dads –
particularly fathers from a generation before mine and those in the Black Christian faith community – assume a role that they are “keepers of all knowledge” and can never be wrong about something. That’s crap. Good fathers are vulnerable enough to admit mistakes, apologize, and assume responsibility. I know that’s hard for many of us, but I believe it really sets good dads apart from dads that aren’t as good.

Good fathers are motivated. The good dads I know really don’t ever need much to pursue a goal. There is an internal drive they possess that exists regardless of what is going on in their lives. Good dads don’t need pep-talks to want to provide and support their families. It is a trait that is either inherent or is developed over the course of their lives and is enhanced when they become fathers. Associated with this motivation is the willingness to sacrifice. Good fathers will go without so their families do not have to go without. This is not a sacrifice for vanity, though. Good fathers don’t remind their families how much they sacrifice in their personal lives. They quietly go without when necessary so their families’ needs can be met. They may discuss that with other dads, but they are willing to put their needs aside to meet a need within their household.

**Life experiences associated with being African-American**

Most of my life experiences I attribute to being African-American, particularly as a kid, are negative. This is hard, too, because they were mainly associated with my spiritual life and development. I am a Christian and my early experiences learning about my faith was in the context of a largely White faith community. I had this unique experience because my home community and school was Black but my church – where we spent A LOT of time – was largely White. It’s crazy what kinds of experiences you remember as a kid!
There was a night when the teen group had a fundraiser by preparing dinners for the congregation. After serving folks we were all sitting at a table recuperating. One of my friends was drinking a glass of water and I noticed something black in his cup. You know, it was one of those floaters that you find in Styrofoam cups sometimes. Well, I began to make a joke about how something nasty and black was in his cup and he was about to drink it. He responded by reminding me that I was black and nasty, too. Folks laughed, although many new that the joke was over-the-top. This was my boy. I spent time with him, stayed over his house, was cool with his parents and siblings and everything. I didn’t know what to say and STILL have not told him how much that hurt.

It wasn’t until I became a college student that I remember thinking intentionally and positively about my racial identity. Those were the days that I remember acknowledging, celebrating, and making other folks aware of my own family’s rich cultural heritage and that has carried on with my own children.

**How becoming a father influenced my sense of identity**

When I became a father I really began to understand those qualities I described above. I was excited to be available and had been coached enough by the men in my life to have a sense of what I needed to do. What I didn’t realize was the toll it could take if I didn’t communicate with LaChan and try to find balance while being supportive. Nile was born first and I was excited to have a little girl. I don’t feel like becoming a father prompted me to forsake my other roles, but it was important. What I learned as a young adult in church was that my primary relationship role was as a husband and partner to my wife. So, while becoming a dad was rewarding and exciting I was very aware of wanting to make sure I tried to nurture and develop my connection to LaChan while connecting with our newest family member, Nile. I was hype,
though. I was hype to assume the new role and to “live out” being a father. I just did not want to get swallowed up by my role of father and forsake my role as partner.

**Fathering a child with an autism spectrum disorder (ASD)**

**Ideas and knowledge about disabilities and autism before diagnosis**

I really didn’t know too much about disabilities and didn’t know anything about autism before Avery’s diagnosis. My mom’s brother, my uncle, has an intellectual disability and I have interacted with him regularly all my life. He is probably close to 60, but intellectually he probably functions as a 10 or 11 year old. I have always understood that about my uncle. I think I’ve generally been warm and understanding with him. We have a good relationship. It’s not a deep relationship, but we enjoy each other’s company when we are together. Unfortunately I don’t remember that kind of empathy extending beyond my immediate family, unless people had severe or visible disabilities. I don’t think I was ever a jerk or insensitive, but I probably felt more sorry for people with disabilities than considering them as folks who can make contributions to my life as much as I might make a contribution to their lives.

I knew nothing about autism. Nothing. I still haven’t even seen *Rain Man*, like many of the other contributors. When Avery was diagnosed I was so panicked and scared because I had no frame of reference. I didn’t know what it meant, what it looked like, how you responded to the needs of someone with autism. I was totally working at a deficit with it.

**Most rewarding and challenging aspects of fathering a child with an ASD**

One of the most rewarding aspects of being Avery’s dad is to watch him enjoy his life. Avery is intentional about everything he does. Rarely does he reply with “I don’t know” if you ask why he has done something. He’s a happy kid. He’s an intentional kid. And he has no reservation about being himself. He makes no apologies for loving to dance, telling people they
hurt his feelings, defending himself when he has to do that, or wanting to kiss you in what
sometimes seems like most inopportune times. I’m thankful to be his dad. I’m thankful to be
able to watch him grow and develop and become the boy he has become. He is such an example
for our family because he reminds us to put our best feet forward and to not apologize for being
individuals. I really admire that quality in him.

The challenges are more about me than they are about Avery. I can get pretty hung up
about people’s perception of me. That issue with other’s perception extends to my family, too.
In Avery’s earlier years I would be very conscious of how I thought he was perceived in social
settings. Some of my concerns were legitimate. I can remember people looking on as Avery had
a meltdown or his behavior was a little peculiar. As recently as last year, he had an episode in
his karate class where he totally shut down and stopped using words. I had to restrain him.
EVERYONE in the class watched as we both talked ourselves down and regained our focus. I
realize I have to be less concerned about what other people think, what they have to say, or how
they interpret my interactions with my kid. That’s my own hang up and has much more to do
with me than with Avery.

Coping with the challenges

How do I cope with the challenges? I’ve got a great support in LaChan. She reminds me
of who I need to be for Avery. She reminds me that the man I have been for our son is who he
needs me to continue to be. She reminds me that his growth and success has, in part, been
because of who I have been in Avery’s life. I guess one coping strategy is being reminded of
how I can help Avery continue to be successful.

I also have to acknowledge my extended family in being able to honestly deal with my
issues. I am fortunate because I live in close proximity to my parents and my younger sister.
My maternal grandmother and her husband live very close to us. Most of my mom’s sisters, are all within a 15-20 minute drive of me. The same can be said of LaChan’s family. A bunch of us are all situated here. LaChan’s parents, grandparents, her aunts, uncles, and cousins are here. They are a huge resource and help keep me grounded when I get stressed out or start overreacting to some of the stress that can come from parenting.

Relying on my faith and spiritual beliefs is the most important coping strategy for me. It also helps that most of the people who I’ve mentioned share the same spiritual beliefs. I’m a Christian who believes that God has given all of us a purpose. I have a purpose, LaChan has a purpose, and so do Avery and Nile. The Bible I read tells me that I will never be confronted with more challenges that I can handle. Choosing to believe that gives me comfort and confidence. It helps me weather storms that can sometimes be pretty loud and intimidating.

**Increasing understanding of diagnosis within the family**

I’ve been pretty intentional about how to help other members of our family understand Avery’s strengths and the areas in which he struggles. We have been pretty candid with Nile. She understands Avery’s form of autism. Sometimes it is hard because Avery can present like he has no diagnosis. We all forget sometimes. We forget the progress he has made over his life and just assume he hasn’t worked hard to achieve success. He’s so social and affectionate that we get our feelings hurt when he actually acts like a kid with autism and doesn’t want to interact with anyone for hours at a time. This strategy of talking openly about Avery has worked with some of our other family members, especially those who are our age and younger.

How have we tried to help the older members? That’s a different animal. My grandmothers have been interesting cases. My grandmother and LaChan’s grandmother still think that helping Avery overcome his challenges is just a matter of following a formula. They
are very old school. And, remember, one of them has raised her own special needs child, so you can’t tell her anything! I can’t tell you how many times one or both of them would give us the “All you gotta do is…” speech. That’s the speech where if you wanted to help him use more words, “all you gotta do is…” If he was having behavioral problems in school, “all you gotta do is…” That doesn’t happen as frequently now, but it was pretty regular occurrence when Avery was younger.

**Raising an African-American child with ASD**

I get really concerned about this topic. If I don’t monitor myself, this can scare me. I have Black son with autism. I believe racism and prejudice are real and tangible. There are times when my son’s behavior is peculiar and misunderstood by those who don’t know him. I consider these things when I imagine him as an adolescent and an adult. Every parent considers how their kids will connect with their peers. We all want our kids to have solid, healthy relationships with friends. I generally trust that will happen. I think about race, though. For example, many of Avery’s teachers now are White women. Avery is a handsome and charming kid. He likes to show affection and one way his sensory needs are met is by touching hands or giving people hugs. He does this especially when he knows he has done something wrong or made a bad decision. He will often want to hug you or hold your hand as a show of reconciliation. His current teacher loves this about him.

I don’t trust that all people will like that about him as he gets older. He can’t take the liberty of hugging people without their permission as a pre-adolescent or a teenager. Those situations are the ones where behavior is misinterpreted or misconstrued. I don’t need that and Avery certainly doesn’t need it. I think about his interactions with authority figures. I’ve had very few encounters with police but I have seen some officers abuse their authority. I shudder at
the idea of Avery having an interaction with a cop who doesn’t understand him. I just want to raise a responsible and savvy kid who knows how to respect boundaries and communicate his needs because he will likely already be stereotyped because of his race before he says word.

**Describing this fathering experience to someone**

This experience is mixed with lots of joy and a fair amount of frustration. I would describe it as an experience that requires a shift in some of the expectations you may have for your child. It’s a roller coaster! It’s an experience that will probably stretch and challenge you in ways you’ve never been challenged. It can be fun and exhilarating. It can be sad sometimes. You can be frustrated with a bunch of people. You can get frustrated with your child, your spouse, your child’s doctors and therapists. I think the biggest reflection of this experience is how interdependent you really become when you raise a child with autism. People talk about the advantages of kids being raised in two-parent household, but a two-parent household may not be enough support for you at times. You become really vulnerable and have to rely on support in ways you likely have not in the past. It can be really rewarding when you find the support. When you don’t have it, I can really see how any dad can get frustrated and overwhelmed.

**Making Meaning of the Experience**

**What does it mean to be an African-American dad of a child with autism?**

To be an African-American dad of a child with autism means you better be ready to confront stereotypes, prejudice and other societal challenges for you and for your child. This ain’t for the faint of heart! It means you have to be an advocate and scholar in autism, at least as it pertains to your child. It means that you have to have a strong support system to help you through the tough days and celebrate the awesome days! Being the father of an African-American child with autism means you need to keep your eyes wide open. You have to be
willing to question decisions that people make for your kid and about your kid, especially in school. When you do that, you have to know that people’s responses to your questions will be interpreted in some way based on your gender, race, and your child’s ability level. It means you have to balance trusting your instinct with being knowledgeable about your child’s condition. Being an African-American dad of a kid with autism means there is just one more variable to consider as you seek and secure services for your child.

**Words of wisdom to the father whose child is newly diagnosed**

The father who has just learned of his child’s diagnosis is going to grieve. I really believe that. He is going to grieve a loss of expectation. My encouragement to him would be to expect this process. His emotions are going to be up and down. There may be days when he wants to walk away because the challenges seem so extreme. There will be other days when he feels like he has a handle on those emotions. My words of wisdom would be to expect the grieving and find someone with whom he could talk to about them. That person might be a counselor or a close friend. But, he has to find someone. It’s really easy to withdraw and turn inward, which can become pretty lonely and isolating.

If he is in a committed relationship, I would tell him to LISTEN TO HIS PARTNER. In my experience, my wife continues to balance me. She provides a sense of equilibrium in our marriage. It is important for the partner to be able to talk and share those feelings, as well. I would also encourage him to work hard to engage with the child. This is going to take work, but he will have to find the ways his child responds to him. He may have to learn a new way to play or communicate with his child. He has to be open to these new ways to engage or he may end up being totally frustrated with himself, his family, and with his child with autism.
The only different message I would send to a Black dad is to STAY. I know relationships don’t always work out. I appreciate and understand the external stressors Black men experience for a number of reasons that may encourage him to leave. Our children – Black children – need their fathers. I can’t say it more plainly than that. They need their fathers to be around consistently. They benefit from a father who lives with them and is accessible. My conversation would be very candid and I would want to help him assess the state of the relationship with his partner to determine how it can be sustained. I would tell him to work hard to stay.

Support

The best supports for me have been my family. My immediate family – my wife, our sisters and their partners – has been an invaluable support. Thankfully, our support does not start or stop there. My extended family has always been willing to step in and provide respite care, mediate arguments, and help out when relationship and parenting challenges emerge. My parents, LaChan’s parents, both of our grandparents, our aunts, uncles, cousins have all influenced the extent to which I have been able to be a good father.

The schools have been a pretty good support, but that wasn’t always the case. We fought pretty extensively with one of the districts about Avery one year. I’m glad that was the exception and not the norm. Our extended church families have been great, too. Lastly, I’m really thankful Avery has had really good therapists. There are people who still keep in touch with us who provided services to Avery from before he was 2 years old. They were genuinely interested in Avery’s success then and now. That makes me feel good.

The only support I wish was more available was the opportunity to send him to a developmental daycare. There were no childcares equipped to meet his needs when he first got
diagnosed. We had to rely on family to care for him while LaChan and I worked which was hard. The absence of appropriate childcare was our motivation for developing our non-profit organization. Our long-term vision is to build care center that meets the needs of young children with developmental disabilities. I wish that was an option for us. The only organization I know that provides those kinds of services is Easter Seals.

**Relevance or need for counseling services**

I have considered getting counseling services to help me manage my feelings as the parent of a child with autism. I haven’t done it, though. I have received counseling before, as a younger adult, but not for this. I know I can benefit from it, but I’ve just not been resolved about looking for and finding an appropriate service provider. It will be important that I do engage in it so that I have a frame of reference and so that I can be reminded of the experience of seeking counseling services. I almost feel like a hypocrite to not have sought counseling for this need as I advocate for the need for counseling with the population of dads raising kids with autism. There are so many things to share and things for which to seek feedback. I just haven’t done it yet. LaChan has been a great support and my close friends and family have offered the kind of support that has been tremendously helpful. I know, though, that it’s not the same kind of help a counselor can provide. I’m resolved to do it for my own needs and to lend credibility to its utility.
Chapter 11: Findings and Discussion

Several themes emerged from the data that directly addressed my three research questions: (1) how do African-American men describe their experiences as fathers?; (2) how do African-American fathers describe their fathering experiences raising a child with autism spectrum disorders (ASDs)?; and, (3) what meaning do African-American fathers derive from fathering children with autism spectrum disorders (ASDs)? The connection between all of the themes, across all three interviews, is the fathers’ willingness to assess themselves introspectively – about their personal qualities, resources, and environments – to describe the experience of being African-American fathers of children with autism spectrum disorders. I used in-depth interviewing (Seidman, 2006) to collect these data and present it below. Quotations from the fathers elucidate the identified themes.

African-American Men Describing Their Experiences as Fathers

The first interview, which allowed the contributors to discuss their life histories, elicited two major themes that directly addressed the ways they described their experiences as fathers. The themes were: intentional engagement and ecological stressors. The intentional engagement theme included of three subthemes: engagement with father figures, engagement with their own personal development, and engagement with their children.

Intentional Engagement

I interpreted the fathers’ discussion about their life histories – including memories that shaped their ideas about fatherhood, qualities of good fathers, and words their children would use to describe them as fathers – directly related to how they engage with their children and others. This theme of intentional engagement was presented in three separate and nuanced ways:
engagement with father figures, engagement with their personal development, and engagement with their children.

**Engagement with father figures.** All of the fathers communicated the ways they learned about fatherhood due to the presence or absence of a biological father, and stepfather, or another father figure. Alvin, raised in a two-parent household, discussed the importance of his father’s presence in his life and the benefit of having a large extended family with many uncles who were present for him. He fondly remembered being introduced to the concept of tradition with his dad and uncles at a football game they attended annually.

Well, there are, well, I had a lot of very, very strong males…growing up in addition to my father. Um, you know, one [experience] was going to the [annual] Buelah – Buckley football game. Right? You know, my dad played for Buelah, but he had all these friends in Buckley and we went to those games from the time I was four years old. And, you know, I just remember seeing other fathers there with their kids – from Buelah and Buckley.

Brandon had a very different narrative. His relationship with his biological and stepfather were not very strong, although he learned about fathering from both of them.

[With] My real [biological] father, I was lucky if I saw him a couple times of year and a lot of times he would decline at the last minute to pick me up. And my stepfather….him and my mother would argue a lot over various things and I always felt the need to come to my mother’s aid because…it had been just me and my mom for a while and I guess I was like eight…when she get remarried…but my stepfather was a good man. He was a good father. I mean, most of what I learned about fatherhood is from my stepfather because my time with my real father was limited…
Darryl and Frederick were both raised by their grandfathers who they call their fathers. Darryl’s story was telling, in part, because of the way he found out that his grandparents were not his biological parents. Darryl reported never feeling like anything but a son even in that challenging moment. He actually shared that the example he saw in his grandfather excited him about the prospect of fatherhood.

So, to specifically answer your question as far how did I learn about fatherhood? I have to say I learned from my grandfather…he worked two jobs and the time was pretty much free on the weekends. So, on the weekends he concentrated on making sure that he was there and participating in the home with my sisters [biological aunts]...and with me and, like I said, he never made me feel that I was...anything other than his son…I had the most learning experience from him on how to be a father was [by] him just providing, not [just]...financially, but mentally, physically and emotionally. With me being the only boy, he just made sure that I had...that I saw a real man, a responsible man…I did eventually meet my biological father but, um, you know, my father that I know is my grandfather and that’s who taught me how to be a man. He taught me how to love as a man. He showed me a clear example of how to be, as he would say, head of a household…He made me excited about becoming a father one day.

This finding is consistent with previous literature on the influence of an African-American adult male presence – biological fathers or extended male family members – in African-American males’ lives. Richardson (2009) noted the important role of African-American uncles in the lives of urban African-American adolescents. Reckley (2001) argued both the important and affirmative role African-American fathers assume in the socialization and development of their sons. Sampling from an understudied population at the time, Greif,
Hrabowski and Maton (1998) found that the parenting practices of African-American fathers of highly successful African-American boys included fostering a strong identity as a Black male and support from the broader community in which the boys lived. Zimmerman, et. al (1999) reiterated the point that for Black male teens, a strong relationship with a father is important, whether the father is residential or non-residential.

**Active engagement with their children.** All of the contributors used action words to describe the qualities that good fathers possess, which I interpreted as expressions of love for their children and spouses. For Frederick, good fathers are role models for their children who provide them with a standard to pursue and maybe even surpass. Frederick challenged a paradigm shared by many in the African-American community that asserts, “Do as I say, not as I do”. He shared:

> Basically, to me, I think that’s one of the top qualities, just being honest and, you know, knowing that you could go to that person and talk to them about just about anything and not being judged for it, you know, or pre-judged for it…Also, I would say communication, you know. You gotta communicate, You gotta talk about basically what’s on your mind or how you feel…I think the most important role that a father could play in a child’s life is try to help them find themselves in their identity, who they are. Because then they’ll know who I am but they have to find who they are…you’re your son’s first role model basically. So, they kind of look up to you [and] so you kind of lead by example. So you want to have a good setting already in place for them to model themselves behind…because, you know, we always grew up with the mentality of: do as I say, not as I do. But I kind of beg to differ. I think if they see you practice that way, then they kind of develop that kind of concept of…that’s what I’m supposed to do as a
man, you know, because I see my father carrying himself that way. Then I want to be more like my father, then I want to carry myself the same way…

Cameron’s perspective was similar because he talked about demonstrating his love through engagement with his children, but he specifically discussed the role of his Christian faith in his fathering. He shared that a good father is, “[one] who can listen, can guide their child. A father is a counselor, protector, provider, [and] prayer partner”. Ethan described good father qualities as those that included engaging his children directly by helping children prepare for their future and providing a safe spiritual context where the children can grow and develop. He said a good father:

…[is] present, [you need to] tell your kids you love them, [be] stern, strong, steadfast, [have] clarity of thought about not just the now, [but be] realistic, giving your children everything they need from a spiritual level…spiritually, physically, and mentally to get them prepared so when they leave their house, when they’re of age, [and] they leave, that you did everything you could do to make them productive people in society.

Several researchers offer important insight by confirming this active, task-focused orientation among men, and by extension, fathers (Seligman & Darling, 2007; McKelley & Rochlen, 2010; McKelley & Rochlen, 2007; Sheinfeld, et. al, 2011; Flippin & Crais, 2011). This is especially illustrated in men’s helping-seeking behavior; that is men and fathers need to do something. Seligman and Darling (2007) encourage professionals delivering services to men to consider the ways in which men might perceive crisis. The authors’ recommendations highlight that men perceive the crisis of disability as instrumental versus expressive. That is, men are more inclined to reflect on and then respond to the day-to-day, logistical issues associated with a crisis via their behavior. McKelly and Rochlen (2010; 2007) discuss the ways men are receptive
to one-on-one help, finding in their research that men are more receptive to those they perceive as coaches versus counselors. In this relationship, a coach is one who motivates and moves his players to *action* as opposed to internal reflection or a verbal expression. Sheinfeld, et. al (2011) and Flippin and Crais (2011) also found the utility of and preference for physically active interventions for men seeking help, both of which align with this study’s finding.

**Engagement in their own personal development.** The last theme I found among the fathers in their descriptions of fathering was that they all communicated that being a good father requires a deliberate choice to personally develop and mature. The specific question from which this theme emerged asked: in what ways did becoming a father influence your sense of identity? The men reported that becoming a father was critical in their personal development and it remains a central part of their identity. In fact, all of the men communicated that being a father is their most salient role or identity. I interpreted all of their narratives rooted in the responsibility to model and set an example for others which requires consideration of their own development.

Among the most telling narratives shared was Cameron’s, who talked about fatherhood representing a second chance in life. As I listened to him, it was clear to me that he believed that one’s earlier life experiences must function as a catalyst for change and maturation in fathers. He shared:

So, when I was 18 I got a young lady pregnant and the baby died. It was stillborn. And that caused a lot of grief in my life to the point where I wanted to commit suicide. I was very suicidal and because of God’s intervention in my life, it stopped me from, you know, committing that tragedy. Looking, you know, having that second chance on life, and then even another chance at fatherhood, was key. And I know that a lot of the
African American men in my life, as far as my family is concerned, there weren’t too many that were stable. I wanted to be more than that. You know? I wanted to have an opportunity to be that example. And if I was the only one, I was gonna be the only one...So being an African American man, seeing a lot of my friends, you know, in my neighborhood, you know, where there wasn’t, you know, that strong African American male presence in the home. I just didn’t wanna duplicate that, man.

Brandon talked very specifically about being and becoming more mature because of how his reputation as a father would influence his son’s experiences and opportunities. Fathering, for Brandon, was intentional and deliberate, even down to naming his son.

[deep sigh] I think it’s made me want to be a better man. In fact, I named my son after me for that reason because I felt, like, I remember a sermon that my pastor preached where he was saying that giving your child a good name is one of the best things that you could give to the child, not his actual name, but a reputation. The namesake, having a reputation, says a lot. If you say “so and so” was my father and they say he was a great man and they treat you a certain way as a result of what they know of your father. So, that kind of thing made me make a decision to name my son after me because I wanted to keep that before me. I want people…when they hear his name, they’re gonna say you must be Junior.

Frederick likened becoming a father to finding your most desired gift under the Christmas tree and the associated responsibility of being a good steward with that gift.

…I would say it was, it had to be like a feeling like, um....like you...like when you’re a kid and you wake up Christmas morning and you’re looking for that one gift to be under that Christmas tree....it kind of make me think in a way because it’s like, you know, you
got a new life and this person’s like looking at you and you…gotta like mold this person into who you would want them to be as far as a person in life that…that’s going to contribute to society in a way and it’s like, that’s a big responsibility!

Alvin’s ideas about fathering as role modeling included both his family and the broader community. As a visible man in his community, he wanted to make sure he could be identified with positive and admirable qualities as a dad. Being identified as a good dad by others was especially important.

Fatherhood, for me, is probably the most important set of experiences that I’ve had. I’ve had wonderful experiences being married, you know educational and professional, but for me, fatherhood has just help form who I’ve become…It’s just really there at the center because I want to be not only a model for my kids but I want other people to say, you know, that’s what a father should be. And the, uh, secretary at Brookville High School, one time she didn’t know I was there and she said, I’m emotional [holding back tears]. But she said: “Bar none, Mr. Alvin [beginning to cry slightly] is the best father”…And that, you know, that really touched me…I mean she’s been there for 25 years…and she says I can tell that he loves his kids, all of his kids…And for me, that says a lot.

The transitions of becoming a father have been documented to elicit a number of changes in men’s lives, with the majority of them being positive changes, as indicated in the findings of this study. Among the challenges associated with becoming a dad is related to new dads becoming clear about their new roles. Carter and McGoldrick (2005) discuss this as one of the six family life cycles - the creation of a new family with young children and accepting new members into the previously established system – a normative stressor associated with family life. Chin, et. al (2011) reiterate this challenge, as the men seek to cement their roles within all
of the systems in which they function now as fathers. Shezifi (2004) documented that becoming a father is a major cornerstone in adult development and Garfield, et. al (2010) found that fatherhood influences more healthy behavior in men, as evidenced in better diet, more exercise, and less risky behavior.

**Ecological Stressors**

I found that all of the fathers in this study could point to experiences in their lives they believed to have occurred solely because of their being African-American. Some of them discussed positive experiences, but data saturation occurred in all of their reporting some negative experiences because of their race. Their stories about the negative experiences all pointed to some form of stereotyping or prejudicial attitudes toward African-American men in a variety of settings, including their professional work spaces, as consumers, and as teenagers.

Darryl, who is the second oldest among the fathers in the study and has the oldest child with a form of autism (49 years old, with a 22 year old son), easily recalled his frustration about being the only African-American executive in his workplace.

…I know you’ve heard the terminology, the token. I don’t feel that I’m the token in my company because I’m educated and I know my skill set…But I feel like I’m patronized sometimes at the company because, you know, every African American inquiry, question or whatever, comes my way…I want you as a Caucasian, you get that information on your own. We have the web, you can look this up. About a month ago, a comment was made about fried chicken and our Senior Vice President says, “Let’s let Darryl address that.” Yeah, that was one of those statements. So, I’m at the board table and I say, “So tell me what you would like for me to address about that?” And I said, “Do you want to say it comes from the poultry family?” I said, “Do you want me to talk about how fried
chicken arrives as fried chicken?” I said, “So I don’t know...tell me how you want me to address that.” So then he said, “You know, I was just joking.”

Ethan, a 39 year old pharmaceutical sales representative and manager, recalled being mistaken for a server and accused of stealing while at a company presentation he was making, dressed in a three-piece suit.

I remember walking to a Medicaid clinic as a professional - in a suit, clean, you know, professional, just ready, just that image, that professional Black man that you want to see. And I was setting up for a lunch...And this Caucasian nurse walked back and asked, “What are you doing back there? Are you stealing anything?

Alvin, 54, recalled times casually walking and shopping while working in New York City as a finance professional on Wall Street.

I’m walking and I see a white woman coming and she goes to the other side of the parking lot. Or, she’s in a car and sees me heading toward the car and locks the door. Or, you walk into an elevator and the mother pulls the child just a little bit closer. Or, no matter what I’m wearing, I just remember one day being on Fifth Avenue and I can’t remember where it was, but being followed.

Cameron, 38 years old, shared his frustration as a high school student in the 1990s triggered by having relationships with a diverse group of friends in school, but not feeling comfortable maintaining those relationships outside of school.

Even in high school, you know, you would have friends, which is a diverse group, you know, talk, you know, help counsel each other, man, help each other with homework, projects and all that kind of stuff, man, you know? And.....it was just…one way at school…but you couldn’t get personal, you couldn’t get close to them as far as their
family experience because of the ideas that certain parents had towards us because of the nature of our skin...And even in the Latino community, man, you know, it’s uh....they didn’t want us to be around their daughters or be involved with their daughters because we were Black.

Carter and McGoldrick’s (2005) family life cycle is important to consider, as this kind of stress experienced by these fathers could be horizontal or vertical. Cameron, whose father was a community activist, could have learned from his father to expect and be ready to respond to racial stereotyping (e.g., vertical stressor). Brandon, on the other hand, did not report having a negative racial experience until his teenage years as a result of dating a White woman (e.g., horizontal stressor). McAdoo’s (1993) scholarship on understanding African-American fathers through an ecological systems lens is also fitting when considering these fathers’ negative experiences due to their race. These experiences recalled by the fathers could be identified as microaggressions. “Racial microaggressions are brief and commonplace daily verbal, behavioral, or environmental indignities, whether intentional or unintentional, that communicate hostile, derogatory, or negative racial slights and insults toward people of color.” (Sue, Capodilupo, Torino, Bucceri, Holder, Nadal, & Esquilin, 2007). The experiences represented among the fathers in this study represent both direct and indirect microaggressions, which have been documented to take place across a variety of personal, educational, occupational, and clinical settings (Constantine, 2007; Ford & Whiting, 2010; Teti, Martin, Ranade, Massie, Malebranche, Tschann, & Bowleg, 2012). Their stories further illustrate the prevalence of the stereotypical assumptions associated with African-American men regardless of their presentation. This finding is of particular importance because of the way it can shape what these fathers believe can
or will happen to their children having two minority statuses: as individuals with disabilities and as members of a racial minority group.

African-American Men Describing Their Experiences as Fathers of Children with ASDs

The fathers in the study answered questions about how they describe their experiences raising children with autism spectrum disorders (ASDs). True to Seidman’s (2006) in-depth interview protocol, these questions in our second interviews explored the influence of the disability on their fathering experiences. The second interviews were the most extensive and resulted in two (2) shared themes, with several subthemes, across their descriptions. The first major theme was their orientation process. Their description about their orientation to ASDs included two subthemes: (1) knowing very little about ASDs, and (2) orienting others about ASDs. The second major theme was the fathers’ adjustment process. Within their adjustment processes emerged four (4) subthemes: (1) adjusting attitudes about autism, (2) adjusting notions of success for their children, (3) adjustments to implement effective coping strategies, and (4) adjusting to perceptions of race and ability for their children.

Orientation Process

I asked all of the men to describe their ideas about and experiences with people with disabilities and their knowledge of ASDs prior to their children being diagnosed with autism. Their answers to those questions reflected a common theme about having to go through an orientation process in learning about autism because they knew very little. This orientation process comprised of two related experiences within the orientation process: orienting themselves to ASDs and orienting others, particularly within their families, about ASDs.

Orientation to ASDs. All of the fathers reporting knowing little to nothing about ASDs before their children were diagnosed. I was particularly struck by this finding with some of the
dads. Alvin had a younger cousin with autism and Ethan works in the health care industry.

However, I could relate to this finding because I knew nothing about ASDs before my son was diagnosed. I heard the term before but never had a real grasp of the disorder’s symptomology or its potential spillover effects in families. There has been research, though, that supports this finding. Canary (2008) suggested that parents may not be inclined to consider anything outside of what has been their subjective experience, which they consider normal. If childhood disability is considered abnormal based on the parents’ life experiences it is easy to consider the likelihood that these fathers did not know much about ASDs. Seligman and Darling (2007) also share how reinforced messages of delivering children without disabilities can contribute to parents knowing little to nothing about ASDs or any other disabilities prior to their children being diagnosed. These fathers’ limited knowledge of ASDs was evident in this study.

As a pharmaceutical salesman, Ethan shared knowing some things about autism, but certainly not grasping the breadth and depth of the diagnosis. He shared: “Autism, it was essentially because in my realm of business you hear about autism spectrum to some degree, but the depth and breadth of understanding and to be able to articulate…not at all.” Alvin, who has a significantly younger cousin, who is now an adult with autism shared:

…I didn’t really know anything about autism and I really didn’t know anything about the spectrum until that woman [physician] mentioned the words, “Oh, he’s autistic.” I really didn’t know that much..., I knew there were differences, but I can’t say that I really knew much about autism itself prior to that doctor…and in a quick amount of time, we got up to speed on it.
Brandon, Frederick, and Darryl, all shared the role popular media had in shaping their ideas about autism spectrum disorders. I was not surprised when Brandon and Frederick both shared that the movie *Rain Main* was their only reference to ASDs. Brandon recalled:

Like when I thought of autism, I think Rain Man......that’s the thing that jumps into my head and I guess my perception was that there’s several who are, you know, dealing with autism or very intelligent people that are, you know, that are kind of locked in, you know, and aren’t functioning the way that they like to function. But they excel in some area. So, that was my, that’s what I knew of autism beforehand. But it wasn’t a lot.

Similarly, Frederick shared:

I didn’t know anything about autism. The only information I had basically was given to me from the movie *Rain Man* and, you know, that’s the only kinda definition I had of....cause they said it was a form of autism…So that automatically clicked when they said it was a form of autism, you know, automatically reverts back to *Rain Man*. And I’m like, well, is he gonna be in that capacity as far as like, you know, the *Rain Man* story…?

Darryl’s reported knowing nothing about ASDs until Oprah Winfrey did a special on it. Darryl’s son was born in 1990 and diagnosed in 1993, when the ASD diagnosis rate was significantly lower than its current rate. He described learning about autism in this way: “You know how I really got a lot of knowledge of autism? Oprah. Oprah had this special at one time that I believe that she brought it to a lot of people’s attention.”

**Orienting others to ASDs.** Each of the fathers discussed the ways they oriented others, particularly within their families, to ASDs. Their strategy was intentionally creating opportunities for interaction among family members, even in the family members’ discomfort.
All of the fathers in the study had multiple children except for Darryl. Malik was Darryl and his wife’s only child. Even in Darryl’s case, he talked openly about the how he made sure other family members engaged with Malik to increase their understanding about his differences and develop a sense of comfort and confidence with him. He talked about making sure his family treated Malik with an expectation that he is capable and not needy in ways family members might assume. He said,

Um, even with the other family members, um, they come around…[my expectation is] it’s not treating him like he has a special need for one. Treating him regular and sometimes some of the family members don’t do that. [My response is] “No, don’t do that, he’s fine, he’s fine. Just go on!”

Ethan has three children and Kayla is diagnosed with Cri Du Chat and Pervasive Developmental Disorder – Not Otherwise Specified (PDD – NOS). Kayla is the middle child and is 7 years old. Her older brother, Jason is 10 years old and her younger sister, Aubrey, is 5. Ethan described the challenges in helping Jason understand Kayla and develop a desire to know her more deeply, and protect her, if necessary, due to Kayla’s developmental delays.

And that’s…initially was a challenge because my oldest son who is three years older than Kayla, he initially didn’t understand. He, you know, he just [does]… what he want to do and Kayla wants to try to come around him [and] he [automatically] wants to go downstairs and play with his own stuff. And [I] just kind of try to…show him that, [saying to Jason] you know what, this is your sister. You love and protect your sister…because she can’t fight for herself…it’s important for them to understand and be with Kayla and sometimes I force it because…if you don’t force it, you don’t create a habit. If you let them do what they do, the habit will be,…[siblings thinking], “I’m going
to do what I do now and it should be alright.” No. Love your sister, be there for her, learn to understand her and work with her and do the little things right now. Don’t do it when people are around, do it when people aren’t around because that’s the love that she shows you all the time.

Cameron’s son, Tyler, is 13 and the oldest of three children. Cameron spoke clearly about how he communicated his expectation that the younger children needed to include Tyler in activities at home and in the neighborhood with peers. And, if they did not, there would be consequences to their excluding Tyler.

…when those kids played together and they played with kids in the neighborhood, man, for a season and a half, I was like, “Look, do not run off and leave your brother behind, right? If y’all gonna play, make sure you include your brother...And if anybody’s, you know, speaking about him, you have to protect him. And I better not see you shying away from that responsibility”...we have to encourage my children not to exclude him or to forget about him easily…And then I had to take that extra step with my friends’ kids and explain it to them, you know, the same way I explained to my child. It’s like, there’s a language barrier there, there’s some shyness there, some social stuff there, but he wants to reach out. He wants to be included.

These strategies are critical to helping develop healthy relationships between family members, especially between siblings, considering the complex nature sibling relationships can assume. Siblings influence each other’s’ interpersonal development (Watzlawik & Clodius, 2011) and there has been considerable research pointing the positive and challenging effects of having a brother or sister with a form of autism (Kaminsky & Dewey; 2001; Smith & Elder, 2010; Ross & Cuskelley, 2006; Macks & Reeve, 2007).
Adjustment to ASDs

The fathers in the study also consistently talked about the ways they personally adjusted to their children’s diagnoses. This personal adjustment theme was evident within four subthemes: adjustments in their personal attitudes about autism, adjusting notions of success for their children, adjustments to implement effective coping strategies, and adjusting perceptions of race and ability for their children.

**Adjusting attitudes about autism.** The fathers all confronted the challenge of how they would interpret their children’s strengths and limitations. All of the men received very negative prognoses about their children’s future which contributed to their fears and concerns. They also had to simultaneously increase their understanding of the different forms of autism. This adjustment took place in two distinct ways for the men: developing more patience and developing a sense of pride in their children’s strengths. They talked about the patience they need in helping set appropriate developmental goals for their children versus setting goals based on what they may want their children to meet based on more typically-developing children. They also discussed the pride they have learned to take in what others might consider “small victories”, but for their children are significant developmental milestones.

Brandon talked about developing patience in the same way a person would need it in teaching someone a different language. His description resonated with me because when children are delayed in their expressive or receptive language, learning a new way to communicate (i.e., a new language) is often required. He said:

…I think it would be like teaching a second language to a child. Like just getting an exchange student that doesn’t speak any English at all. And having to, you know, find common ground and be able to explain to them and communicate with them. That’s part
of it. But, not just the language thing. It would have to be like teaching an exchange student that has a few quirks and tics about them...So, but I think if I had to explain it, like, it feels like teaching another language to a child because, even though I’m teaching my son English and he’s learning not just from me. I mean, he’s learning it from all kinds of places. It’s still more than words. It’s one thing to learn words, but it’s another thing to teach what the words mean and how to make them applicable. And that’s what I was saying. Part of the joy is when he makes words work for him and he realizes it...So, I think that’s how I would describe it, it’s like teaching another language even though it’s his native language. It’s so much more and because it’s...it can be draining at times. Because what you could say one time to one child and they get it, you may have to say three times, four times, remix it a little bit and then mom might try.

Asking Cameron how he would describe this experience, he framed his response as a story still being written by an almighty God. His response was thoughtful and eloquent as he shared the following sentiment:

There’s a story that is still being written, number one, because we don’t know the end. I think that’s the best way to say it. It’s a story still being written...So, every new word that we hear Tyler say, we notice it and thank God for it. When he responds to a question with three words, we’re thankful. We thank God for it. We give our son a high five. We acknowledge it. Every little change that’s in his life, we can see it now. Before we couldn’t see it. So, we’re just appreciative of every nanobit of growth that’s in his life that’s expressed in some way. We’re thankful for it, man...So, like I said, we just appreciate everything in this life and, yes, man, there’s some serious challenges, dude. But we’re not afraid of the uncertainty anymore...
Alvin talked specifically about having to develop more patience than he might need for his children who do not have disabilities.

For me, being a father is being a father, whether it’s a child with autism or not. You love your kids and I guess what I explain [to another person] is that when you have a child and when they’re younger, there’s things you have to do to nurture and help them in terms of their development…[But] that when as a father of a child with autism, that sometimes…that toddler stage or pre-adolescent stage is longer. Whereas a typical father [of a typically developing child] might transition for the same kid, you’ve got to be able [to]…father [your older child with autism] the same way that you did when they were a toddler, pre-adolescent to teenager all at the same time and that’s a challenge…

Hannon (n.d.) found that among the fathers of sons with Asperger’s interviewed, they all found pride in their sons’ unique abilities. One of the recommendations from the study was the ways in which counselors can use this finding to frame strength based interventions for fathers or families of children with autism seeking counseling services. For example, the term, autism, has been reconstructed within the community into a strength-based acronym: Always Unique Totally Interesting Sometimes Mysterious. Efforts like this are used to reduce the stigma associated with an ASD diagnosis and highlight the strength found within it.

Adjusting notions of success for their children. I have only found one study (Hannon, n.d.) that has intentionally asked fathers about what they consider rewarding about fathering children with autism. This study allowed them to think intentionally and respond to such a question. I was not surprised that some of them found it challenging to identify the most rewarding aspects in this experience. All of the fathers communicated that the most rewarding part of fathering a child with autism was their children experiencing success. I interpreted their
difficulty in articulating those rewards because of how easy it is to discuss our children’s limitations as a result of their diagnoses. Nonetheless, they talked about the intrinsic value of their children’s success as most rewarding.

The fathers discussed their children’s success in a number of ways including success in relationship building (i.e., with peers and parents), success in skill development and academic success (e.g., in and out of school) and success in demonstrating family values and norms. Cameron, who is a Christian, passionately conveyed how he and his son, Tyler, have learned to pray together, although Tyler has limited expressive language. Tyler has learned to communicate, without words, that he knows when Cameron is upset or frustrated. Instead of words, Tyler participates in prayer by laying hands, or touching, Cameron. He shared:

Because I can yell at him, because I’m frustrated, carrying that stuff from work to home, see him, he’s an easy target, you know, yell at him…That brother [Tyler] will come right back and sit next to me, give me a hug, lays his hands on me and start praying because he imitates that, because that’s what we [laughing] do at the house. We lay hands on each other, we pray. And he’ll just come up to me and just be like, “You need prayer?”…But his hand on my head and hearing Holy Spirit, that’s enough to put me in check. That’s enough to give me that boost I need.

Alvin’s son, Xavier, has had considerable success in school and in extracurricular activities. Alvin shared one of the most rewarding times he remembered with Xavier. He was moved as he talked about how Xavier’s football teammates and classmates have embraced him, in spite of some of the developmental differences.

Just seeing how they rallied around him and really wanted him to be successful and feel good about himself...So, that’s something that really, really stuck with me, you know,
that his team embraced him. He was developing this pride in participating in something like this…When he graduated from elementary school and was going to on to the upper elementary school [we] had a party for him and all these kids, just all these kids came to his party, showed up…So, that really helped him in terms of feeling a part of this community.

Frederick shared how his son, William’s academic success is so rewarding that it motivates him to be a better man and father.

I would say his accomplishments, you know?…I’ll give an example, um, you know, just in school. Um, math-wise: [he’s] perfect……so, so, I would say his achievements is like really rewarding because, you know, he have other siblings, but I would say my oldest daughter she didn’t too good in math. Um, and my youngest daughter, she’s coming up to that level. But to see him at that level already…And he’s dedicated to it and that to me is rewarding because he’s dedicated….he’s got the dedication, man, you know….And I take that positive aspect and try to apply it to my own life because I said, you know, there’s some areas I could do better...But he, you know, it...just by seeing him do that, it motivates me to pursue that and to focus on that as well.

Relatively little is known about how fathers of children with autism describe their most rewarding experiences in that role. Many studies have identified the ways in which families and parents benefit from having a child with a disability. Some of them include, but may not be limited to: families’ increased capacity for resolve, increased awareness, and higher cohesion (Reichman, et. al, 2008); higher reported levels of empathy in siblings of children with disabilities (Macks & Reeve, 2007); siblings of children with disabilities reporting great admiration for their brother or sister with a disability (Nixon & Cummings, 1999). However,
Hannon (n.d.) found that a group of White American fathers of boys with Asperger’s syndrome identified their sons’ uniqueness as one of the most rewarding aspects of fathering a child with an autism spectrum disorder.

**Adjustments to implement effective coping strategies.** “Coping mechanisms are emotions and behaviors that allow an individual to adjust to problems. The survival of all people depends on their being able to regulate personal feelings, beliefs and actions so that their anxiety remains at a manageable level” (Henderson & Bryan, 2011, p. 157). It was important to for me to ask these fathers how they cope with the challenges associated with their experiences considering the copious amount of scholarship on the problems and challenges associated with raising children with ASDs,. The children had various forms of autism. Some children were verbal and some were nonverbal. Some children had significant gross motor delays and some were very high functioning. All of the fathers expressed that coping with the challenges meant achieving a sense of balance for themselves, regardless of the children’s presentation of symptoms.

While there is limited scholarship on the coping strategies of fathers of children with autism, one consistent finding has emerged: coping strategies are relative. Hannon (n.d.) found that each of the fathers in a qualitative study all reported different coping strategies. Gray (2003) found that parents, including fathers, reported two main practical coping strategies that are in direct opposition to each other: (1) to anticipate the difficulties likely to emerge and plan an appropriate response; and, (2) taking things one day at a time and dealing with problems as they emerge, recognizing the sometimes unpredictable effect of the disability. Also, Gray’s (2003) study reported no consistent general coping strategy among the fathers, a finding consistent with this study. Other studies on fathers’ of children with ASDs or other disabilities and their coping
strategies seems to reflect practices that include imagining a less stressful time in their lives (Heaman, 1995), or engaging in distant or withdrawn behavior (Pottie & Ingram, 2008).

The coping strategies for these fathers varied, too. They included leisure activities, reframing, being thankful that their children’s challenges aren’t more significant, and engaging in prayer and reflection. Ethan, a former professional football, talked about being self-aware and knowing what simple things to do when he feels stressed.

I just kind of learned, I’m self-aware and I understand, you know, those different things that can trigger…I work out. Work[ing] out has always been a great release for me. You know, going to movies. I go to movies by myself. I’m good…I’ll take a deep breath if I need to walk away for a minute and revisit it…

Brandon offered a similar perspective in doing those things that help him achieve balance in his life. His reprieve is through his leisure activities, which are bowling and dee-jaying. He shared:

Well, one of my releases is bowling. I go bowling once a week. So, I do have some time when I’m not with the family and I can go and hang out with my bowling mates and just get to go out and talk with them and hang out, so that’s a release…or sometimes I’ll go and spin some… records… I got my own music room full of vinyl and CDs.

Alvin said that whenever he gets overwhelmed he is reminded that there are many other children and parents in more intense or challenging circumstances.

Honestly, from me, I look at, I look at other families, I look at other kids that don’t have what Gregory has… that don’t have the support system or [have] the parents…who are in denial and until the kid was 7 or 8 years old and lost 4 or 5 years, those important years of development…I try to be thankful for what we do have, because Gregory is somewhat social so he is going to be able to work…I realize there are a lot of people that have it a
lot tougher. I have a guy that I work with whose daughter is non-verbal…and she will probably have to live in an institution at some point…so that’s how I cope is by knowing and understanding that while we, our challenges may seem to be great, there are others that are far greater.

Darryl and Cameron talked about their faith anchoring them to find balance. Darryl shared a compelling narrative about how his faith grounds him.

It’s tough sometimes but, um, man, my faith gets me through it all…it all. [rubbing hands together to maintain emotional composure]…if I did not have that faith…I know I would’ve handled some situations much differently. But I’ve known the Lord for a while... How do I cope? I walk…I will meditate. I will talk to the Lord.

Cameron offered a similar sentiment saying, “We are in a different place…me and my wife are in a different place, dude, and that’s God’s help and that’s people…praying for us and encouraging us because you know the effect it has on marriages.”

Adjusting to perceptions of race and ability for their children. All of the fathers discussed ways they believe their own racial identity and their children’s racial identity and level of ability will influence their collective experiences. The men spoke directly about their concerns regarding stereotypes or attitudes about people who are African-American or with disabilities. With respect to the range and quality of services, the fathers discussed a general distrust of service professionals not providing or referring the best therapeutic resources. All of the fathers except for one (Ethan) have boys with autism. Darryl felt his son was racially stereotyped as soon as he got diagnosed with Pervasive Developmental Disorder. He noted:

…it was pretty much kind of racial how that one doctor diagnosed. For one, [the doctor told us] he’ll be good at sports…And I always wondered that, okay, if I….if I was a
Caucasian, I walked in with my child and how would she see that, that young man.

Would he be good at sports? Would he adapt to his environment?

Alvin expressed concern about Xavier’s presentation – a tall, stocky African-American teenager with some communication challenges – and the perceptions people, particularly authority figures, might have of Xavier as he gets older.

....part of the challenges that, that I have are just society’s perceptions of Black men period…I remember [a documentary] …and they were just taking about this incident where there is a young man, he might have been 14, 15 years old, [with a] developmental disability, that ended up in this really bad encounter with a police officer simply because the police officer didn’t understand this child. This young man had a developmental disability and part of that is as Xavier gets bigger, you know, he’s this cute, young kid [when he was younger]. Now he’s this, he’s big, he’s got broad shoulders…and…part of my fear is that if…he’s in a situation where people don’t understand and it escalates because for whatever reason…he doesn’t communicate well enough for people to understand his role in this situation.

Brandon communicated a similar sentiment:

Now, as he gets older…I think about sometimes, what will people’s perception of him be? It’s hard enough to have some people’s perception of you as a black man be that you’re not as intelligent or things like that. So I wonder sometimes when he gets older, if things don’t get increasingly better, what will they think of him?…will they just say, oh well?...[as if] they didn’t have high expectations to begin with...
Ethan’s daughter, Kayla, has a dual diagnosis of PDD-NOS and Cri-Du-Chat, a rare genetic disorder. Ethan talked about her status as a minority being accentuated because of her diagnoses and the way Ethan and his family are perceived as they secure services for Kayla.

…there may be four or five kids, Black kids with her syndrome that I’ve seen. So she’s a minority. In some of the areas…where we were, you know, you see Black folks, [and the attitude people have toward them is]…”What do you want?...What handouts do you want?” They didn’t understand, our background…I’m coming with this three piece suit...what I do every day and [the perception changes for people to think] “Okay...he’s not that black guy.”

There is plenty of research that illustrates and justifies these fathers’ concerns for their children regarding their race and level of ability, all of which seem to be grounded in prejudice. Henderson and Bryan (2011) wrote that prejudice, “is a conclusion drawn without adequate knowledge or evidence” (p. 36). The fathers in this study all discussed the ways prejudicial attitudes toward African-Americans have negatively influenced their lives. The concerns they share for their children is likely connected to their own experiences as Black men living in America, which are noteworthy and worth further investigation. Equally important and worth further investigation are the consistent themes of strength, resilience, effective coping, and personal development in other fathers living this experience.

**The Meaning These African-American Fathers Attach To Raising Children with ASDs**

The third interview in Seidman’s (2006) in-depth interview protocol seeks to discover the meaning study participants attach to a particular phenomenon. I used this interview to inquire what meaning these fathers attach to raising children with ASDs. The six questions to address this concept asked:
1. What does it mean to be the father of a child with autism today?

2. How would you describe this experience to a father who has just found out his child has autism?

3. In what ways, if any, might that description change to an African-American father who has found out his child has autism?

4. Describe the most helpful supports for you as a father of a child with autism?

5. Describe those supports you wish were more readily available?

6. To what extent have you ever considered counseling as a support mechanism?

The answers to these questions yielded one major theme, which was about self-assessment.

Their self-assessment was specifically related to: assessing their personal qualities and assessing their resources.

**Self-Assessment**

The fathers in this study should be commended for their self-awareness and willingness to share their personal strengths and limitations. They talked openly about what personal qualities they possessed that made them good fathers and those qualities they needed to improve. This level of transparency and awareness was indicative of a consistent and intentional willingness to self-assess. I’m don’t know if they were as willing to self-assess before their children’s diagnoses, but I do believe that the diagnoses has aided in this practice for these fathers. The self-assessment was related to their personal qualities and their resources.

**Assessment of personal qualities.** Each father talked about personal qualities necessary to be a dad is suited to engage with the challenges and the rewards of this experience. I interpreted the two most important of the qualities to be communicating honestly and acting with intention. These factors both emerged when I asked the fathers how they would describe this
experience to a father who just received news of their own child being diagnosed. They all talked about the importance of communicating honestly with the people in their lives (e.g., wives, extended family members, educators, therapists, etc.) and making decisions very intentionally. I was not surprised by their answers based on our previous time together, especially in their responses to the qualities good fathers possess. All of them described this experience to another father by the need to take action for themselves and for their families.

Darryl said he was approached by a random father the Saturday prior to our interview. He shared the importance of talking honestly with someone in stressful times.

…actually I was just approached on Saturday. Saturday is me and Malik’s date... and Malik does quite well in the gym. But there are occasions you could see that my child has a special need. So, we’ve been going to this gym a long time and the gentleman comes to me and said, “Sir, can I disturb you?” I said, “Sure…what can I do for you?” And he said, “Your son.” And he just looked and he could not get it out. I said, “Yeah, my son has autism.” And he’s looking and I saw the tears in his eyes…and I hugged him. I said, “So…you’re feeling and…thinking that your son can’t do certain things, I hope my son was an influence for you today… all I can say to you is make sure that you get him every resource…that you can to help him grow…God gives special kids to special parents…so, what I say to you, I will help you out in any way that I can.” I gave him my phone number. I said [to him] “…there are gonna be some days that you do need to reach out to talk to somebody else.”

Self-awareness was at the core of Cameron’s response, advising that fathers are going to experience a range of emotions and the importance of talking about those feelings with someone who has had a similar experience.
...initially to that father I would absolutely say you have to come to grips with your feelings, your emotions, your expectations about that child, number one, number one, and you have to deal with that and I would share my own personal stories…I would encourage him not to make those same mistakes that I made with the disclaimer that’s going to be tough to just embrace all of that…And then the second thing is like, look man, just make sure you’re around some cats that can relate to you. You know. Seriously. Because those people will have a greater compassion for you and your child because they know what your struggle is, they know what you’re dealing with, they know your fears, they know your prayers, man, and what you’re hoping for. They’ll know the challenges that await you and your child as you navigate this life. So, I think those are two biggest things that I would say to that individual.

Frederick mentioned the potential for denial and self-blame, and then the importance of sharing feelings to someone trustworthy who intimately understands the experience.

I would say first of all deniability. Because it’s gonna be, somebody missed something [in the diagnosis]. This can’t happen to me or this is not happening to me. That [the] people are wrong. Resentment, you know. But then, you know, once…you get past that phase or that part of it, you know, and a lot of times what is going to help that particular father or the dad that…asked me that question, is just by talking and expressing their feelings…and just talking it through with someone, you know. And hopefully, if I’m that person, I…would definitely help that father with that…

Brandon’s story highlighted the benefit of communicating with others (e.g., family and strangers) about the BJ’s differences.
Just, you know, just being honest. There’s time where, you know, it’s like, your child doesn’t act like other children do and…you gotta be prepared for the people’s faces that are…curious and…perplexed…Um, and…if that person had other children, I would say …try to figure how you’re going to explain to your other children how…your child with autism is different than them…Not only your other children, but your other family members…A lot people are just starting to hear about it…But a lot of people don’t understand about it and, you know, you gotta be prepared to educate not only yourself but educate other family members…

African-American fathers describing their experiences to fathers who just find out their children have been diagnosed with a form of autism is useful because it provides insight into the fathers’ appraisal of the disability. I have not found any research specifically inquiring about how African-American fathers of children with ASDs appraise their children’s condition. There is research communicating how broader populations of fathers appraise their children’s condition. Trute, et. al (2007) found that families’ adjustment to their children’s needs was predicted by parents’ negative or positive appraisal of the disability’s influence on the family. In their study, mothers were found to engage in more positive appraisal of the influence, and consequently experienced higher levels of self-esteem than fathers. It seems that the fathers in this study may have initially appraised their children’s autism diagnosis as negative, but were quickly able to associate a positive meaning to their experience. This was evident because of the content and message in what they would communicate to fathers just learning about their children’s ASD diagnosis.

**Assessment of resources.** One of the most significant findings in this study derives from this subtheme. In response to the question about if and how their description would be different
to other African-American fathers of children with ASDs, all of the fathers communicated a
difference. I interpreted the difference in an assessment of their resources. This resource
assessment can be categorized in two forms: (1) social support beyond the immediate family,
and (2) social and financial capital.

*Social support beyond immediate family.* All of the dads mentioned the importance of
support beyond their wives when I asked them to identify the most helpful form of support in
being fathers of children with ASDs. The specific types of support they talked about came in
three forms: peer/male friend support, extended family support, or community based support
(i.e., therapeutic, school personnel, etc.). This finding came as no surprise as literature on the
psychosocial aspects of disability has consistently documented the importance and benefit of
extended support for those caring for children with disabilities (Hannon, n.d.; Canary, 2008;
Dunn, et. al, 2001; Rodrigue, 1992; Reichman, et. al, 2008; Trute, et. al, 2007). These fathers
confirmed this finding in sharing their stories. Darryl talked about his extended family’s
continual support.

Family. Number one. Hands down…My sister-in-laws, my brother-in-laws, my mom…

They always come and offer to pick Malik up. Take him wit’em…Our family, even with
Malik’s diagnosis, they have just always been there, no question…So, um, with that
support of the family, it helped us, it made…it made our lives that much fuller raising
him.

Ethan discussed a network of parents of children with genetic and developmental disabilities
being important in his feeling supported.

We had a very tight support group…[with parents of children with] all types of
developmental disorders and genetic disorders from Down’s, autism, we had some …that
weren’t diagnosed. They had chromosomal disorders that had no names. So they had different things. They had a piece of autism, they had, you know, the spectrum, they had a piece of maybe some different things… But it was very tight, the families because some of our journeys were the same. Some of the challenges, making sure our kids had the right services, our IEPs, making sure we know we can get funding which we all, which we could get more of for our kids and make sure all of the resources are there.

Cameron emphasized the need for and benefit of friends he could talk to about his challenges.

So, it’s good to be around brothers that you can really just say, look, I have....I don’t care, I don’t have no reputation to uphold, I don’t have none of that, man. This is where I am [clapping hands for emphasis] and that’s just....that’s one side of it…So, we need more brothers being able to talk about where they are and get the counsel that they need.

Alvin, Brandon, and Frederick discussed the value of community support being most helpful for them. Alvin mentioned his family’s church and neighboring churches as a huge source of support, considering Xavier’s challenges when he was a newborn. “…there’s the spiritual support...from the church and churches…everyone’s praying for Xavier [when he was]…in the ICU. [And]… that they continue to pray [for] him and keep him in their prayers as he’s developed.” Brandon said, “You know, the school that we have my son in has been really helpful.” Frederick talked his son’s therapeutic service providers, saying, “The physician and then the school…I think those two support elements…”

Social and financial capital. Financial capital refers to the financial or economic resources needed to accomplish a goal. These fathers are all college-educated and fall within the middle class. They have become acutely aware of the financial costs of interventions and the sophistication to successfully navigate the health care system and health insurance. I also
realized that they intentionally became well-versed in the law and the types of services their children were entitled to receive in school. They have made decisions about how to afford the interventions their children need based on their own research and cost-benefit analyses.

Their discussion on social capital was insightful to me. Portes (1998, p. 7) offers a clear and contemporary definition and function of social capital, writing, “the consensus is growing in the literature that social capital stands for the ability of actors to secure benefits by virtue of membership in social networks or other social structures.” In the dads’ discussion of their assessment of social and financial capital, they provided evidence of these kinds of considerations. Alvin talked openly about the capital he has as a member of the community where his mother was an educational administrator and his two older daughters were student athletes:

It’s going to depend on that environment. We already had relationships because we had two other girls in the town so we already had relationships with families of various nationalities and races. So there was already a foundation of people that we knew…the principal already knew, okay, that’s Samantha’s brother, alright, that’s coming in. And it also helped that my mom was a teacher in the district. So, that there…in the elementary school, the principal was…someone that my mom had mentored… So, the principal knew Xavier.

Cameron talked about the challenges of finding financial resources to provide for his son’s needs and how more social and financial capital would be helpful in his case.

I think there would be a difference because they understand, if they’re middle class, lower income, they already know the struggles with just the general education population, let alone adding that special needs dynamics…Because I don’t know those families that
go to those high end private schools, Christian schools, or just private schools. You know what I’m saying? I don’t know a lot of those folks. [Laughing] …So, that’s my experience, you know. If I was running in a different circle, then maybe my conversation would be different, based on the affluence. And that to me is a daggone shame, man. You know what I’m saying? So, yeah, I’m getting worked up, man. That’s the truth. Oh, man, so, oh man, think about that, boy. [deep sigh]. You know, where affluence just gives you access to more things, man, and that’s the truth…I could be, you know, Bilal Jones, whose the mayor, you know. Have that kind of status, right, and if I had a child with special needs, you know, there would be a wealth of people or information right there…

Ethan talked about his role as a Black father and the amount of social capital he hopes to possess because of his educational attainment:

It’s...as a dad, as a man, as a person, as a black man. I’m dealing with all these different challenges. I gotta worry about the glass ceiling, I gotta worry about if people gonna...if I’m going to this job, [do] they see me as a black man or educated? Do they see me as educated? Or, do they see me as another black man is trying to take something that they own? Or, am I a criminal, or what have you versus I [just] need you to see my child. Look beyond who I am or what your perception until I say anything but look at my child and make sure she’s given everything she can to be successful.

It is important to note that I did not achieve saturation with the question about which supports did the fathers wish were more readily available. Their responses varied widely and included wanting to know more about the disorder’s etiology, effectively coordinating services, support groups for fathers, opportunities for the children to interact with more children of color
with disabilities, and free or low-cost services. However, the study’s findings offer important implications for counselor education, future counseling research, and clinical practice. My discussion follows with those considerations.
Chapter 12: Implications, Strengths, and Limitations

Implications

Findings from this exploratory study align with previous research about African-American males and the importance of male presence in their development (Zimmerman, et al., 1999; Reckley, 2001; Greif, et al., 1998; Richardson, 2009) and African-Americans’ experiences with microgressions (Sue, et al., 2007; Constantine, 2007; Ford & Whiting, 2010; Teti, et al., 2012). The findings also reiterate previous research findings about men’s tendency to translate emotional concepts into behavior and action (Seligman & Darling, 2007; McKelley & Rochlen, 2010; McKelley & Rochlen, 2007; Sheinfeld, et al., 2011; Flippin & Crais, 2011) and how being and/or becoming a father can be a catalyst for personal development (Garfield, et al., 2010; Shefizi, 2004, Chin, et al., 2011, Guzzo, 2011). The findings most relevant for the counseling audience are related to the ways these fathers reported engaging in their own personal assessment and development and how it has influenced their hopeful narratives.

Implications for Practice

If I were in a counseling relationship with these men, it would be important for me to acknowledge the hopeful and positive outlook they possess in spite of some challenging experiences. My interventions would be grounded in a strengths-based orientation in order to help facilitate their continual assessment of themselves and their resources. I would specifically want to: (1) help them sustain healthy coping strategies in times of distress; (2) help them assess their social and financial capital to support their children’s success; (3) remind them of the rewards of raising children with autism; and (4) increase their understanding of counseling by engaging with their faith communities.
Healthy coping strategies. Data from this study highlighted when and how raising children with ASDs can be particularly stressful. These men reported their orientation to ASDs was stressful and the reality of environmental stressors also contributed to their stress levels. Both of these are forms of vertical and horizontal stressors (McGoldrick & Carter 2003). Vertical stressors are family memories, traditions, and expectations passed down through generations (e.g., family attitudes, expectations, taboos, etc.). They can contribute to stress based on how the family system assesses the triggering event. The fathers in this study had no experience with autism prior to their children being diagnosed. Their orientation to autism was influenced by how their family system made meaning of the disability. Horizontal stressors are stressors experienced by a family through time as they adjust to the transitions in the life cycle. They can be predictable (e.g., child getting married) or unpredictable (e.g., untimely death). Horizontal stressors for these fathers included negative racial experiences in different contexts that translated into concerns for their children.

I have previously cited the limited literature on how fathers cope with the challenges of raising children with ASDs. Much of the literature points out how fathers have been found to use some unhealthy coping strategies (e.g., escape/withdraw, blaming) (Pottie & Ingram, 2008; Davis & Carter, 2008; Dunn, et.al, 2001) and that there does not seem to be one or two emergent coping strategies across different samples of fathers. What some limited research has documented is that fathers’ coping strategies are relative to the individual (Gray, 2003; Hannon, n.d.), a theme that emerged with the fathers in this study. Each father reported his own individual, effective strategy that was different from anyone else. The important finding among all of these fathers’ strategies was they all contributed to their sense of personal balance. Counselors can use this information to help fathers raising children with ASDs identify or
remind them of healthy coping behaviors that foster their sense of personal balance. Counselors’ acknowledgement of each father’s healthy coping strategies aligns also itself with a self-directed, empowering orientation for clients in the counseling relationship. The fathers in this study can be celebrated for the various ways they engage in self-care with healthy coping strategies that included, but were not limited to prayer time, listening to music, exercising, and walking. The outcomes associated with these strategies directly contrast what can be the negative effects of such stressors (Henderson & Bryan, 2011; Sue, et. al, 2007; Constantine, 2007; Ford & Whiting, 2010; Teti, et. al, 2012).

Social and financial capital. The fathers discussed the importance of their personal and external resources, which I interpreted as social and financial capital, in order to secure services for their children. According to Portes’ (1998) definition of social capital, these fathers have consistently assessed their ability to access services by virtue of membership within a social network or other social structure. All of the fathers are members of a larger social network of college educated, married, middle-class fathers, but they still consistently questioned if those memberships were sufficient to secure adequate care for their children. Their need to do this form of assessment can be considered a horizontal stressor (McGoldrick & Carter 2003). Research has shown that fathers of children with disabilities are likely to be stressed more about the financial burdens of securing appropriate care for their children with disabilities (Rodrigue, et. al, 1992).

The findings in this study yielded an overwhelmingly positive outcome for their assessment of social and financial capital, evidenced by the fathers’ ability to secure adequate services by utilizing their capital. Counselors working with these fathers should pay particular attention to how they assess their resources and how the lack or abundance of resources can be a
source of horizontal stress. Counselors can spend significant time helping the fathers identify the types of resources they possess and take steps to access resources necessary to support their children.

**Rewards of fathering a child with autism.** The only study that I have found to ask fathers to identify any rewards to fathering children with ASDs was my own prior study (Hannon, n.d.). The fathers identifying their children’s success as the most rewarding part of their experience offers counselors a strength-based framework to engage these men if they sought counseling services. Counselors can intentionally inquire with these fathers about stories of when and how their children are most successful and how that success makes them feel. These success stories can be a tool to assist them in their adjustment to the empirically documented demands of raising children with ASDs.

**Increase understanding of counseling.** I asked the fathers if they ever considered counseling because of the challenges associated with raising children with ASDs during our third interviews. This question did not achieve saturation, but their varied responses offer insight into how these men perceive the utility and experience of counseling. Two fathers said they considered it in the past, one said he is considering it now. One said he never considered it because it was not suggested to him during his orientation to ASDs. Two said they have not needed it for this issue because of their unified, supportive families. Two of the six talked about their perceptions of counseling through a racial and spiritual lens that might help counselors in their outreach.

Darryl and Cameron shared their belief that African-Americans usually do not seek counseling. In the rare times they do, it is typically via one-on-one pastoral counseling or couples’ counseling within the context of the church. Cameron said, “And, honestly, the only
time I think of counseling is with marriage counseling [in church], man. Honestly. That’s the only time I think of counseling…” Darryl responded:

You don’t...you don’t go to counseling. You go to church. You pray about this. You get you some Jesus and He’s going to take care of it all! Okay?...That was the mindset.

Now, do I still have that mindset? No, I don’t have that mindset. But have I been to counseling? No.

This sentiment of African-Americans feeling safer within religious contexts versus mental health contexts has been confirmed in previous research. Figuero, Davis, Baker and Bunch (2006) recommended that spirituality be a foremost consideration in delivering health care services, inclusive of mental health care, to African-American clients. In Mpofu’s edited volume, Counseling People of African Ancestry (2011), he suggests integrating mental health services with what he terms as “traditional healers”, or spiritual authorities in the African diaspora community. He wrote, “about eighty percent of Africans seek health care services – and by extension mental health care services – from traditional healers” (2011, p. 314). Some of the apprehension of African-Americans to seek formal mental health services has been documented by previous scholarship, and includes, fearing institutionalization (Takeuchi, Bui, & Kim, 1993), believing more in the efficacy of clergy versus mental health professionals (Leaf, Bruce, Tischler, & Holzer, 1987), and distrust of provider competence with racial/ethnic minorities (Whaley, 2001).

Counselors should consider the value of spiritual leader endorsement of counseling for an improved perception and reception of counseling among African-Americans. Adkison-Bradley, Johnson, Lipford-Sanders, Duncan and Holcomb-McCoy (2005) made a strong argument for how counselors and clients can benefit by counselors forging strong connections with the
African-American church. Their recommendations for potential collaboration included: assessing congregation demographics in light of counselors’ specialization and church’s current outreach programs, cultivating relationships with African-American clergy, and honoring cultural values that exist within African-American faith communities.

**Implications for Research**

More qualitative and quantitative research on fathers of children with autism and other disabilities is needed. 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. The dearth of studies on fathers of children with autism and other disabilities illustrate the exploratory nature of this study. Additional research on fathers of children with autism and other disabilities can go in a number of important and complimentary directions.

**Future qualitative studies.** The limited research on fathers of children with ASDs provides a rationale to study this phenomenon more deeply with qualitative methods. Future qualitative studies could include narrative inquiries with more diverse samples of fathers of children with ASDs (e.g., gay fathers, racially diverse fathers, single fathers, fathers with a wider range of educational attainment). Narrative inquiries about fathers of children with different disabilities (e.g., Down syndrome, cerebral palsy, spina bifida) has begun and should continue to inform the counseling knowledge base.

Narrative inquires about the experience of fathering children with ASDs or other disabilities could provide the rationale for an eventual grounded theory study. Grounded theory is a qualitative methodology used to develop a theory that is grounded in data collected based on lived experiences in a social context. A study that seeks to articulate a theory applicable to fathers’ experience raising children with autism and/or other disabilities could be an important
contribution to the counseling community. Research studies that explore and document the experiences of other family members in African-American, and additional understudied populations (e.g., narrative inquiry of African-American siblings of children with ASDs, narrative inquiry of African-American mothers of children with ASDs, etc.), can aid in the deeper and broader understanding of the psychosocial aspects of ASDs for family members.

**Future quantitative studies.** Quantitative studies can continue to broaden how counselors understand the experiences of fathers raising children with ASDs and other disabilities. Quasi-experimental studies on interventions for fathers of children with ASDs receiving counseling services can be especially helpful to help counselors increase their understanding on modalities and interventions that may or may not be effective with larger samples of fathers (e.g., fathers in group vs. individual counseling, solution-focused brief therapy, narrative counseling interventions, etc.). Correlational studies measuring the relationship between the severity of children’s autism symptoms (e.g., severe, mild, moderate) and fathers’ rating of their relationships with other family members can assist counselors in assessing the influence of the diagnosis on the family systems. Regression studies that seek to predict how a diagnosis may influence fathers’ and other family members’ career choice, career change, and career stability are also important contributions to the counseling knowledge base.

**Implications for Counselor Education**

The narratives in this study illuminate the resounding strength of these fathers of children with ASDs. Preparing counselors to work with diverse populations requires counselor educators to engage counselors in training (CITs) to intentionally consider their clients’ strengths. The counseling profession’s orientation lends well to this strength-based approach because of our focus on clients’ wellness and consideration of their life-span development. This strength-based
orientation also attempts to prevent or mitigate issues that put clients at-risk, and attempts to empower them through the counseling experience. This study illustrates how these fathers would benefit from and align with such an orientation. They shared experiences that highlighted how counseling could work for them by acknowledging their strengths, reiterating the value of prevention and early intervention, reminding them of the developmental nature of fatherhood transitions via the family life cycle, and empowering them to have hope. It also positions them for further success in their personal lives.

There are also implications for practice, research, and training when considering how to help fathers navigate the interrelated systems that support children with ASDs. Clinical implications about this process are related to how to effectively cope with the frustrating experience of seeking and finding appropriate help, especially during fathers’ orientation to ASDs. Research that communicates successful stories of this navigation can inform our counseling knowledge base. CITs benefit from learning the ways these systems compliment and sometimes contrast each other to best support fathers’ orientation to ASDs.

**Strengths**

The men in this study have provided an in-depth understanding of their experiences raising children with autism spectrum disorders that has been missing from counseling literature. Specific strengths of the study include: sample composition and size, in-depth data collection method and analysis, and the strength-based findings. The sample of six African-American fathers makes an important contribution to the counseling knowledge base. This study offers our community – comprised of counselors, counselor educators, counseling researchers, and policy makers – the unique voices of two distinct, but related populations: African-American men/fathers and fathers of children with ASDs. Both populations have been virtually absent in
counseling literature about fathering or autism. The number of contributors is also among the study’s strengths. A qualitative study with six participants is considered a large sample size. The strength of such a size offers both a broader and deeper glimpse into this phenomenon than might not be offered with a smaller sample size.

The research design was a strength of this study. The in-depth interviews and an analysis of narratives required I spend an extensive amount of time in the field with the fathers and analyzing the data. These methods provided a more detailed and nuanced examination of how these fathers live and make meaning of fathering children with autism. The data collection and analysis methods captured their voices, their stories, and their interpretations. The study’s design complements existing literature on broader research on fathering children with disabilities. The fathers were also given the platform to speak about the rewards of raising children with ASDs. Discussing the rewarding aspects of fathering children with ASDs provides counselors the data to frame strength-based interventions for these men. Prior to this study, no research has asked them to communicate how raising children with autism is rewarding.

**Limitations**

The study had several limitations that warrant discussion. Most of them were related to the interview process. One limitation was distance. I was not able to interview one father in-person. I had to interview Cameron, who lives in a different region of the country, via Skype. This limitation did not allow the opportunity for the persistent observation I had with the other fathers. Another limitation was with interview scheduling. Seidman (2006) suggests interviews take place between 7 and 10 days apart. I was able to maintain this schedule with three participants (Ethan, Darryl, and Frederick). However, some interviews were scheduled shorter
than 7 days apart (i.e., Cameron, Brandon) and longer than 10 days apart (i.e., Alvin, Frederick) because of scheduling conflicts.

The turnaround time for transcriptions was also a challenge. I had to release my first hired transcriber, which made it difficult to complete transcriptions between interviews. Hiring a second transcriber helped this process, but in most cases contributors were given the transcripts up to two weeks after interviews for their review and feedback. The last limitation was the sole reliance on individual interviews as data. The data set may have been enhanced by conducting focus group interviews which may have yielded stronger representation of a collective shared experience among participants.
References


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Lavlani, P. (2011). Constructing the (m)other: Dominant and contested narratives on mothering a child with Down syndrome. *Narrative Inquiry, 21*(2), 276-293. DOI: 10.1075/nl.21.2.06lal


Murray, M. (2003). Narrative psychology and narrative analysis. In P. M. Camic, J. E. Rhodes, & L. Yardley (Eds.), *Qualitative research in psychology: Expanding perspectives in*


### Appendix A

#### Demographic Data

<table>
<thead>
<tr>
<th>Contributors</th>
<th>Age</th>
<th>Marital status</th>
<th>Highest level of education completed</th>
<th>Current occupation</th>
<th>Gender of child with an ASD</th>
<th>Diagnosis of child with an ASD (self-reported)</th>
<th>Age of diagnosis (self-reported)</th>
<th>Current age of child with an ASD</th>
<th>Siblings?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alvin</td>
<td>54</td>
<td>Married to BM of child with autism</td>
<td>Bachelor’s degree</td>
<td>Educational software salesperson</td>
<td>Boy</td>
<td>PDD-NOS</td>
<td>2</td>
<td>16</td>
<td>Yes – older sister and younger sister</td>
</tr>
<tr>
<td>Brandon</td>
<td>38</td>
<td>Married to BM of child with autism</td>
<td>Bachelor’s degree</td>
<td>Graphic designer</td>
<td>Boy</td>
<td>High-functioning autism</td>
<td>5</td>
<td>5</td>
<td>Yes– older sister</td>
</tr>
<tr>
<td>Cameron</td>
<td>41</td>
<td>Married to BM of child with autism</td>
<td>Bachelor’s degree</td>
<td>Information technology professional</td>
<td>Boy</td>
<td>PDD-NOS</td>
<td>2</td>
<td>13</td>
<td>Yes – younger brother and sister</td>
</tr>
<tr>
<td>Darryl</td>
<td>49</td>
<td>Married to BM of child with autism</td>
<td>Bachelor’s degree</td>
<td>Finance executive</td>
<td>Boy</td>
<td>Autism</td>
<td>3</td>
<td>22</td>
<td>No</td>
</tr>
<tr>
<td>Ethan</td>
<td>39</td>
<td>Married to BM of child with autism</td>
<td>Bachelor’s degree</td>
<td>Pharmaceutical salesperson and manager</td>
<td>Girl</td>
<td>PDD-NOS (secondary to Cri-Du-Chat)</td>
<td>3</td>
<td>7</td>
<td>Yes – older brother and younger sister</td>
</tr>
<tr>
<td>Frederick</td>
<td>42</td>
<td>Married to BM of child with autism</td>
<td>Associate’s degree</td>
<td>Management</td>
<td>Boy</td>
<td>PDD-NOS</td>
<td>1</td>
<td>9</td>
<td>Yes – older brother, older sister, twin sister</td>
</tr>
</tbody>
</table>
Appendix B

Recruitment Email

Dear:
I hope this message finds you all well and in a position to be thankful as we have embarked on the 2012 holiday season. My name is Mike Hannon and I’ve been referred to you because of your unique status and experience of being an African-American father of a child with autism.

I’m writing to gauge your interest in participating in a research study for my dissertation. As you may know, I am finishing my doctoral studies in counselor education at Penn State and my primary interest is researching and better understanding the experiences of individuals living with and caring for children with autism. My dissertation will specifically sample African-American fathers of children with autism because our population is really understudied. In fact, I believe this study is the first of its kind: one that documents and communicates the experiences of African-American fathers of children with autism specifically for counselors and counselor educators.

In order to participate, you must be the father of (biological father, step-father, or in a fathering relationship with) a child with autism and identify as a Black or African-American, over 18 years old, and speak and understand English. If you are interested in participating, I would love to send you official documents (via snail mail) for you to review and sign. My study will require me to interview you 3 times for between 60-90 minutes and we can coordinate that as we confirm your participation.

When possible, please send me an email indicating your level of interest in participating in the study and we can proceed from there. Or, if you know of any other men who may be willing to participate in this project who fit the criteria, I would appreciate if you sent them this message.

Best wishes for a great holiday season! I look forward to hearing from you.

Best,
Michael D. Hannon, Ed.S., NCC
Doctoral Candidate – Counselor Education & Supervision
The Pennsylvania State University
mdhannon@psu.edu
609.694.8799
Appendix C

Title of Project: An analysis of narratives of African-American fathers of children with autism spectrum disorders

Principal Investigator: Michael D. Hannon, Ed.S., NCC
Department of Educational Psychology, Counseling, & Special Education
Penn State University
mdhannon@psu.edu
609 694 8799

Advisor: Richard Hazler, Ph.D.
Department of Educational Psychology, Counseling, & Special Education
327 CEDAR Building
Penn State University
hazler@psu.edu
814 863 2415

Purpose of the Study:
The purpose of this study is to gain a more in-depth understanding of how African-American fathers describe their experiences as a father of a child with autism. The study hopes to interview 5 African-American fathers of children with autism diagnoses to better understand their lives and experiences.

Procedures to be followed:
You will be asked to participate in 3 audio-recorded interviews each with the researcher. The interviews will ask questions about your past as it relates to learning about fatherhood, being a father, and being a father of a child with autism.

The Pennsylvania State University’s Office for Research Protections, the Institutional Review Board and the Office for Human Research Protections in the Department of Health and Human Services may review records related to this research study. In the event of a publication or presentation resulting from the research, no personally identifiable information will be shared. Fake names, or pseudonyms, will be assigned to anyone participating in the study if any presentations or publications result from this research. The only individuals with access to the originally recorded information will be the researcher and his faculty adviser. All data collected and recorded for the purposes of this study will be destroyed after within 5 years, or no later than 2017, following its completion.
**Duration:**
Each of the three interviews will be between approximately 60 and 90 minutes

**Statement of Confidentiality:**
Your participation in this research is confidential. The data will be stored and secured on a password protected computer. In the event of a publication or presentation resulting from the research, no personally identifiable information will be shared. Fake names, or pseudonyms, will be assigned to anyone participating in the study if any presentations or publications result from this research. The Pennsylvania State University’s Office for Research Protections, the Institutional Review Board and the Office for Human Research Protections in the Department of Health and Human Services may review records related to this research study. The only individuals with access to the originally recorded information will be the researcher and his faculty adviser. All data collected and recorded for the purposes of this study will be destroyed after within 5 years, or by 2017, following its completion.

**Right to Ask Questions:**
Please contact Michael Hannon at (609) 694-8799 with questions or concerns about this study.

**Voluntary Participation:** Your decision to be in this research is voluntary. You can stop at any time. You do not have to answer any questions you do not want to answer.

You must be 18 years of age or older to take part in this research study. If you agree to take part in this research study and the information outlined above, please sign your name and indicate the date below.

You will be given a copy of this form for your records.

______________________________________________  ____________________
Participant Signature                          Date

______________________________________________  ____________________
Person Obtaining Consent                    Date
Appendix D

Interview Guide

Title of Project: An analysis of narratives of African-American fathers of children with autism spectrum disorders

Principal Investigator: Michael D. Hannon, Ed.S., NCC
Department of Educational Psychology, Counseling, & Special Education
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Eligibility/Screening Questions to Participate in Research Project

- Are you over 18 years old?
- Are you able to speak and understand English?
- Are you the father of a child with an autism spectrum disorder (ASD)?
- Do you identify as an African-American?

Interview 1 (Focus: Demographics and Life History)

Demographic Questions

- How old are you?
- In what region of the country do you live?
- How old is your child with autism?
- When was s/he diagnosed with autism?
- What is his/her specific diagnosis?
- Does your child with autism have any siblings? If so, how many?
- What is your highest level of completed education?
- What is your occupation?
- What is the status of your relationship with the child’s mother?

Proposed In-Depth Interview Questions:

- Describe 2 experiences from your past that influenced your ideas about fatherhood.
- What personal qualities does a good father possess?
- To what extent has your identity as an African-American influenced your life experiences?
• What are your memories as a child and a father or father figure in your life?
• What words would you use to describe your experience as a father?

**Interview 2 (Focus: Influence of Phenomenon on Personal Life)**

*Proposed In-Depth Interview Questions:*

• How would you describe your ideas and beliefs about people with disabilities before you had a child with autism?
• What did you know about autism before your child was diagnosed?
• In what ways have you helped others in your family understand autism?
• Discuss the most rewarding aspects of being a father of a child with autism.
• Discuss the challenges associated with being the father of a child with autism.
• How do you cope with those challenges?
• How do you describe the experience of being a father of a child with autism to other people?

**Interview 3 (Focus: Meaning Making)**

*Proposed In-Depth Interview Questions:*

• What does it mean to you to be a father of a child with autism today?
• What words of wisdom would you give a father who seeks you out after his child has been diagnosed with autism?
• In what ways, if any, do those words of wisdom change if the father is African-American?
• What types of support have been most useful for you as an African-American father of a child with autism?
• What types of supports do you wish were more available for you?
• To what extent have you considered getting counseling to help you through this experience? If you have not considered counseling, what prevented you from doing so?
Appendix E

Codebook Sample

Section from Interview 1
<table>
<thead>
<tr>
<th>Unit of analysis</th>
<th>Meaning unit for each contributor</th>
<th>Condensed unit</th>
<th>Code</th>
<th>Category</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Where did you learn about fatherhood?</td>
<td>Alvin Well, there are, well, I had a lot of very, very strong males in my, you know, growing up in addition to my father...And, you know, I just remember seeing other fathers there with their kids...Um, the other was my uncle, my uncle Howard. He, um, this was interesting. He worked with the American Friends Service Committee. You know, I come from very humble beginnings.</td>
<td>Consistent adult male presence - dad, uncles, older cousins - influenced ideas and practices of fatherhood</td>
<td>Presence, or lack thereof, of a male presence influences perspectives and practice of fatherhood</td>
<td>Male presence</td>
<td>Male presence is important</td>
</tr>
<tr>
<td></td>
<td>Brandon My challenges with my father and my stepfather had been difficult. One was present, one not so present and then the one that was present I had my challenges with him so, I did have to go to counseling when I was in high school to deal with the challenges, you know, what I was lacking in fatherhood with both fathers. My real father I was lucky if I saw him a couple times of year and a lot of times he would decline at the last minute to pick me up. And my stepfather, the relationship that...him and my mother would argue a lot over various things and I always felt the need to come to my mother’s aid because he...it had been just me and my mom for a while and I guess I was like 8 something like 7 or 8 when she get remarried...but my stepfather was a good man. He was a good father. I mean, most of what I learned about fatherhood is from my stepfather because my time with my real father was limited</td>
<td>Inconsistent adult male presence - biological father and stepfather - influences ideas of and practices of fatherhood</td>
<td>Presence, or lack thereof, of a male presence influences perspectives and practice of fatherhood</td>
<td>Male presence</td>
<td>Male presence is important</td>
</tr>
<tr>
<td></td>
<td>Cameron Moving around, living with friends, living with my uncle, living with my aunt, living with my grandmother, living with my mom sometimes. Just a few years living with, you know, in a two parent home. That had the biggest impact on me because, you know, I didn’t want to duplicate the example that my father had set at that time. And that’s the first experience. The second experience really is the example of two parent homes, with a father who’s at the home.</td>
<td>Inconsistent adult male presence- when biological father was in and out of personal life - influences ideas of and practices of fatherhood</td>
<td>Presence, or lack thereof, of a male presence influences perspectives and practice of fatherhood</td>
<td>Male presence</td>
<td>Male presence is important</td>
</tr>
<tr>
<td>Darryl</td>
<td>So, to specifically answer your question as far how did I learn about fatherhood, I have to say I learned from my grandfather...So, he worked two jobs and the time was pretty much free on the weekends so on the weekends he concentrated on making sure that he was there and participating in the home with my sisters...and with me and, like I said, he never made me feel that I was other...anything other than his son. I guess the thing that I could say that I had the most learning experience from him on how to be a father was him just providing, not a financial...financially, but mentally, physically and emotionally. With me being the only boy, he just made sure that I had...that I saw a real man, a responsible man. And even as I grew older and became a teenager and a young adult, he always was there to speak specifically about expectation Consistent adult male presence - even when raised by older man (grandfather) - influenced ideas and practices of fatherhood Presence, or lack thereof, of a male presence influences perspectives and practice of fatherhood Male presence Male presence is important</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ethan</td>
<td>...one image that always sticks to my mind with my father, a lot of mixed things. But the good things, I always remember playing sports. Sports for my dad and basketball were his ways of showing his caring and sometimes his lessons...Just playing ball and playing around. He would never let me win. You know, I had to earn that right to win. So it wasn’t like we would go and he would just let me, you know play but it was an earned thing. But he always showed he cared and loved me. So that to me just told me about hard work. The second thing about fatherhood was my stepfather. He was always there. The guy who kind of raised me from, I wanna say, junior high through college, through my adult life. Inconsistent adult male presence - biological father and stepfather - influences ideas of and practices of fatherhood Presence, or lack thereof, of a male presence influences perspectives and practice of fatherhood Male presence Male presence is important</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
And I would say as far as like a role model first influence I would say my grandfather...he kind of like had more time I would say to spend with me as far as like, um, you know, teaching me how to ride a bike, um, just playing catch, football. You know, the interaction was there. I mean, he was working but it's....I guess his shift, you know, allowed him to spend that time with me and to teach me different things. He was also...he called himself a shade tree mechanic. So he kind of taught me how to work on cars and different projects and that sort of thing. So, he taught me a lot, you know, responsibility, you know, for one's actions and then we also grew up, I also grew up in like a, you know, church going household so we went to church every Sunday. That was a norm, every Sunday we had to go to church.
Appendix F

Journal Sample

1.4.13 – Interview #2 w/BRANDON
BRANDON possesses a really calm and steady demeanor. When he describes himself as patient, I can see that demonstrated even in our interviews. This second interview went well and he shared some awesome and meaningful information. I told him I thought about him having to attend services for his biological father who passed away and he seemed to be appreciative.

What did I find myself responding to in this second interview with BRANDON? Two major things really got to me. The first was his response to my question asking him to describe his experience fathering a child with autism. He framed it as taking in an exchange student who had no idea how to adjust American cultural norms and had NO EXPERIENCE with the language. I thought that was awesome and painted a really accurate picture, not just for me, but for other fathers engaged in this role. The other was his overall reaction to the role of race in his life. This guy really, in my opinion, does not see the world through the lens of race or ethnicity. I think it’s evident by way of his comments, his past experience having dated White women, and not having any number of experiences that have caused him to remember his difference. BRANDON is one of those Black men who don’t see color and I just flatly have a different perspective.

I don’t know what I was communicating non-verbally, because he, in turn, asked me about it at the end of the interview. I told him I would end the recording and I began to discuss my personal beliefs that all people operate with a set of prejudices about race all the time and that they can become magnified as a result of disability. I told him about my personal fears of my kid being misunderstood – because of his diagnosis and potentially because of his race – and that was a legitimate concern for me.

After my sharing, BRANDON then began to talk about things in response. He asked if I wanted to re-record and I politely declined but offered him the opportunity to jot down some of his later reactions and share them with me after taking a look at the interview transcript or sending them to me before receiving the transcript. I hope this does not skew the data.
Vita

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Education

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Publications


**Young, L. W., & Hannon, M. D.** (2002). The staying power of Black cultural centers. *Black issues in higher education, 18* (26), 104.
