I AM MY SISTER'S KEEPER: A CRITICAL CASE ANALYSIS OF SISTERHOOD, BLACK WOMANHOOD, AND ASPERGER'S SYNDROME IN A BLACK FAMILY

by

SHAQUINTA LAJUANA LYNEA RICHARDSON

(Under the Direction of Zolinda Stoneman)

ABSTRACT

The purpose of this study is to explore the relationship between two Black American siblings when one sibling has Asperger's Syndrome. The study focuses critically on the intersection of race, gender, and disability within the family of the participants to understand their personal experiences related to these constructs. I used dyadic interviews, Photovoice, and participant observation through an intersectional disability critical race theory framework for this study. The study focused on two sisters within one family and their experiences as Black women, one with Asperger's Syndrome, within their family, community, and society. I found that their sibling relationship was marked by mutual support and shared experiences. Their identities as Black women and experiences as a Black family were influenced by societal stereotypes and historical limitations placed on Black families. Extended family also played a major role in the family experience and identity development. Disability studies researchers should consider the role and impact of identity on family experiences, barriers to support and representation, and the mental health impact of intersecting marginalized identities.

INDEX WORDS: Sibling relationships; Black women; Asperger's Syndrome; autism spectrum disorder; intersectionality; disability studies

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DEDICATION

I would like to dedicate this dissertation to the various sisterhoods that have shaped who and where I am today. The concept of sisterhood has been a hallmark of my doctoral journey and my entire life. At every stage, I can identify sisterhoods that supported me, challenged me, and helped sustain me. To my best friend Ashley, who has become my sister, you know me better than anyone else in this world. We became friends in high school and have seen each other through some of the most difficult of times. Ours is a sisterhood that reaches to our deepest depths and I am so thankful for you. I love you.

To the sisters I adopted, Brittney and Brandy, and my bonus sister Samantha, ours is an unconventional relationship, but we make it work so well. Who can say they get to have bonus sisters? Thank you for accepting me and embracing me all these years. I love you all so much.

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challenges, to experience this type of bond. So, this entire degree, I dedicate to her and our sisterhood. I love you beyond words. Thank you.

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CHAPTER I

INTRODUCTION

People with Asperger's Syndrome have been an underserved and understudied population within family studies and disability studies. People with Asperger's Syndrome may experience unique challenges, such as difficulty in family and peer relationships, depression and anxiety, and stigmatization to name a few (Hare, Wood, Wastell, & Skirrow, 2015; Shtayermman, 2009; Tse, 2016). People of color with Asperger's, specifically Black people, have received even less focus in research and practice, likely due to lack of representation and understanding of the impact of intersecting identities. The majority of research dealing with families of people on the autism spectrum have focused on children with significant support needs and the impact on parents. Because people Asperger's are often more independent, there are less support needs, and thus, less perceived challenges for the family members. However, due to people with Asperger's social difficulties, there are still significant challenges that manifest in the familial and other social relationships. The challenges may also manifest differently based on racial, ethnic, or cultural differences.

The current study focuses on the Asperger's Syndrome, which as a part the autism spectrum and is categorized by ongoing social problems that include difficulty communicating and interacting with others (American Psychiatric Association, 2013). This study will focus on a young woman on the autism spectrum with what is formerly known as Asperger's Syndrome in the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2000). Asperger's Syndrome, along with some developmental disorders

was combined to become what is currently known as autism spectrum disorder (American Psychiatric Association, 2013). Asperger's Syndrome is sometimes considered to be a "high functioning" form of autism characterized by the inability to effectively socialize and communicate. Unlike other children on the autism spectrum, people with Asperger's rarely experience difficulty with delayed speech, motor deficits, and other developmental markers (Neihart, 2000). Children with Asperger's Syndrome are often categorized as "gifted" due to commonalities in characteristics (Neihart, 2000). While some may view this part of the spectrum as high functioning, the disorder presents challenges that can severely affect a person's mental, emotional, and social well-being (Hare, Wood, Wastell, & Skirrow, 2015; Shtayermman, 2009; Tse, 2016). For the sake of distinction, the term Asperger's Syndrome will be used in this study to note this particular form of the autism spectrum and to pay homage to people within this category preferring this term.

In general, families of people with developmental disabilities experience unique challenges relative to families of people without diagnosed disabilities (Orsmond & Seltzer, 2007a; Stoneman, 2007; Smith & Elder, 2010; Tomeny, Barry, & Bader, 2012; Whiteman, Becerra, & Killoren, 2009). Developmental disabilities can range from medical conditions that impact physical functioning to disabilities that impact social interactions. Often, the needs of these families extend beyond what is seen in typical families, which may include social supports, therapies, rehabilitation, or educational supports. These needs may require the assistance of extended family and community. Further, societal stigmas, assumptions, and judgments may also impact families' experiences with their family member who has a disability (Jacobs, Lawlor, & Mattingly, 2011; Maul & Singer, 2009).

Family research in this area was born out of the perceived need to understand how the family member with the disability would affect the family members in the home. The research involving families of people with disabilities tended to follow a trend of examining mothers' stress associated with having a child with a disability, siblings' negative internalizing and externalizing behaviors, or caregiver burden (Orsmond & Seltzer, 2007a; Rossiter & Sharpe, 2001; Tomeny, Barry, & Bader, 2012). With the emergence of the Disabilities Rights Movement, researchers began to examine the benefits of having a child with a disability such as increased understanding of differences (Oliver, 1992; Oliver 2013; Taunt & Hastings, 2002).

Siblings were a major focus of disability research because siblings grow and develop closely together and impact one another greatly throughout the lifespan (Orsmond & Seltzer, 2007a; Orsmond, Kuo, & Seltzer, 2009). Many of children's ideas about the world are shaped by these relationships. Whiteman, Becerra, and Killoren (2009) posit that children and youth develop important skills and capabilities through their interactions with their siblings. The interactions they outline include conflict resolution, perspective taking, negotiation, compromising, cooperation, and other forms of social competence. People with disabilities often require some level of support throughout the lifespan, which often means a sibling will intervene to provide care in some capacity once parents are no longer able (Atkin & Tozer, 2014; Kramer, Hall, & Heller, 2013; Orsmond & Seltzer, 2007a).

The research in this area continues to grow but primarily focuses on middle-class White families. The research also focuses on people with more daily caregiving support needs and behavioral challenges. There is little known about the relationships between families of other racial/ethnic groups and even less for people with Asperger's Syndrome. While there is also a growing amount of research involving adult sibling relationships, very few studies examine the

experiences of Black/African American siblings. Black families often experience racial discrimination and marginalization, which has not been thoroughly explored in disability-related research. Because there is very little known about families of Black people with Asperger's, this study will focus on the experiences of this group and highlight the experiences of siblings within the family.

Background of the Problem

One of the biggest challenges with this area of research was the limited inclusion of ethnically diverse samples. Research for families of people with disabilities has traditionally focused on middle-class White families, which emphasizes the negative impact of the disability on mothers and siblings. However, the recent research involving comparisons between ethnic groups as well as within groups demonstrated that families from different ethnic groups did not experience stress or caregiving responsibilities in the same way as White families (Bishop, Richler, Cain, & Lord, 2007; Carr & Lloyd, 2012; Valentine, McDermott, & Anderson, 1998). African American families specifically were less stressed and less burdened by caregiving responsibilities, and drew more positive meaning from having a child with a disability (Bishop, Richler, Cain, & Lord, 2007; Carr & Lloyd, 2012; Jacobs et al., 2011; Valentine, McDermott, & Anderson, 1998). Due to the limited literature available involving African American families and the deviation from the majority literature, there is a need for more exploratory research that deviates from the dichotomy of stress/burden and benefits.

In order to understand family research related to disabilities as well as disability research with people of color, there must be an understanding of the historical entanglement of the two constructs (Stubblefield, 2009). As stated by Annamma, Connor, & Ferri, (2013) and held as a premise of dis/ability critical race theory, "Racism and ableism often work in ways that are

unspoken, yet racism validates and reinforces ableism, and ableism validates and reinforces racism" (p. 6). While some of the family research examines the differences among various ethnic groups and notes cultural differences and discrimination as issues in the treatment of families of color, few studies address the relationship between the two. Further, students of color continue to be placed in special education at disproportionate rates in relation to White peers based on these divisions of the construction of intelligence (Annamma et al., 2013; Stubblefield, 2009). For example, African American students are three times as likely to be labeled with an intellectual disability and Latino, Native American, and Native Alaskan students are disproportionately represented in states with large numbers of students from these groups (Annamma et al., 2013).

Considering that disability studies was developed as a critique of the historical and cultural treatment of people with disabilities, it is important to understand how disability and race relate. Many disability scholars have explored the origins of our current understanding of disability, which includes people with disabilities as objects of pity, social control, and extinction (Annamma et al., 2013; Liasidou, 2014; Taylor, 2015). People with Asperger's also experience social exclusion (Tse, 2016), and may be further marginalized by also being Black. Black people with Asperger's may not only experience exclusion because they are Black, but also because they have a social disability which makes it difficult to fit in even with other Black people.

Because of the historical division of people based on the superiority of one race over others-specifically Black people- the division does not solely rely on intelligence testing, but also a socially constructed association based on physicality and visual representation of color (Liasidou, 2014; Stubblefield, 2009; Taylor 2015). According to Taylor (2015) "The physical embodiment of whiteness -that is, one's assessment as racially 'white'-becomes synonymous with normalcy and stability, a model of beauty, intelligence, morality, and able-mindedness" (p.

185). Social acceptance and functioning are also based on cultural values of normalcy and are societal interpretations of and responses to differences (Annamma et al., 2013; Liasidou, 2014), which are a challenge for people with Asperger's. This division between what is normal and acceptable, typically influenced by race, continues to manifest itself in education, policies for support, economics, and family and societal relationships (Annamma et al., 2013; Stubblefield, 2009).

Considering the historical entanglement and the current challenges of discrimination experienced by families of children and adults with disabilities, there is a need for exploration of the intersection of these experiences within the family. Much of the literature demonstrates parents' experiences with discrimination external to the family unit based on race, such as experiences with service providers and the educational system (Gourdine, Baffour, & Teasley, 2011; Ha, Greenberg, & Seltzer, 2011; Jacobs et al., 2011), but there has not yet been an exploration of how racial identity impacts the family itself or how parents prepare children for these experiences which are likely to carry into adulthood.

Statement of the Problem

Family research is becoming more prevalent in the area of disability critical race studies, but there continues to be an observable need for more studies that adopt a more critical exploration of the family experience. Many disability critical race scholars agree that racial and disabled identities cannot be disentangled because the experience of ableism and racism cannot be addressed separately (Annamma et al., 2013; Liasidou, 2014; Stubblefield, 2009; Taylor, 2015). It is important to note that disability studies scholars are not suggesting that having a disability or a family member with a disability does not present challenges (Stubblefield, 2009) as demonstrated in the majority literature. Scholars are attempting to understand and challenge

the ways in which social constructs related to disability limit people's opportunities to experience life without externally imposed barriers. These barriers are often based on perceptions of difference and normalcy and typically benefit some groups over others. In relation to disability and race, these two marginalized identities often overlap and have an association from the beginning of their classifications. As previously stated, it is difficult to completely disentangle this history (Annamma et al., 2013; Stubblefield, 2009; Taylor, 2015). For people of color with disabilities, challenging experiences are simply a matter of history, but rather a consistent intersection of identity and societal experience of oppression, marginalization, and dehumanization in the present.

There is a need for more research that focuses specifically on family relationships, independent of the assumption that families of color are deficient. The current literature identifies some apparent gaps in the research and practice for families of people with disabilities. However, there remains a gap in our understanding of family relationships across various racial/ethnic groups. While it is important to understand families' experiences with the educational system and services meant to provide support, there continues to be a limited view of the familial relationship in disability literature, specifically where cultural differences are involved. The representation in the literature is overwhelmingly white and middle-class. Further research is needed to understand the complex experiences of families of different cultural groups and the implications of racism and discrimination that families encounter (Gourdine, Baffour, & Teasley, 2011; Ha, Greenberg, & Seltzer, 2011; Jacobs et al., 2011). It is known that disability is defined differently by culture (Harry, 2008). Because the use of comparison groups in disability research suffers an unfortunate history of White researchers labeling other groups as deficient (Stoneman, 2007), ethnic group comparisons only reinforce the marginalization of oppressed

groups. There needs to be more studies focusing on Black American families' experiences beyond comparisons to White families. There also needs to be more focus on ethnic and cultural differences that span beyond race.

Purpose of the Study

The purpose of this study is to explore the relationship of two sisters when one sister has Asperger's Syndrome in a Black American family. The study focuses critically on the intersection of race, gender, and disability within the family of the participants in order to understand their personal experiences related to these constructs. As I discuss the intersection of race, gender, and disability in family research, I will do so from a critical perspective that addresses this difficult history. Without a critical perspective, it is difficult to adequately examine the intersection between race and disability in family research, as much of the research notes difficulties experienced by families of children and adults with disabilities on the basis of race (Blacher & McIntyre, 2006; Carr & Lloyd, 2012; Mandell, Wiggins, Carpenter, Daniels, DiGulseppi, Durkin, Giarelli, Morrier, Nicholas, Pinto-Martin, Shattuck, Thomas, Yeargin-Allsopp, & Kirby, 2009).

Research Questions

1. How do two Black American siblings interact and support one another when one sibling has Asperger's Syndrome?
2. How have two Black American siblings been socialized within their families and neighborhoods on the basis of race, disability, and gender?
3. How have two Black American siblings experienced race, disability, and gender as social constructs in the US?

Overview of the Study

There are limited studies exploring the experiences of African American families and none that focus on sibling relationships, which have a demonstrated importance in the lives of people with developmental disabilities (Arnold, Heller, & Kramer, 2012; Orsmond & Seltzer, 2007a; Smith & Elder, 2010; Stoneman, 2001; Stoneman, 2005). The literature demonstrates that African American families have unique experiences related to racial discrimination (Gourdine et al., 2011; Ha et al., 2011; Jacobs et al., 2011). This study will utilize a critical case study approach through an intersectionality informed disability critical race studies lens to understand how the intersection of race, gender, and disability impact the experiences of African American sibling dyads when one sibling within the dyad is on the autism spectrum.

Significance of the Study

African American families evidently have unique experiences in terms of having a family member with a disability. The studies referenced demonstrate a need for research that considers the ethnic, racial, and cultural influences of their experiences in addition to understanding some of the challenges the family may face as a result of having a family member with a disability. African American families derive different meanings from their experiences and are impacted differently than what has been demonstrated in the extant literature (Frison, Wallender, & Brown, 1998; Gourdine et al., 2011; Ha et al., 2011; Jacobs et al., 2001; McCue, 2011; Zionts, Zionts, Harrison, & Bellinger, 2003). The importance of social support, ethnic identity, and appropriate resources has been consistent throughout the research.

To date, there has been a limited amount of literature focusing on Black families of people with developmental disabilities (Frison, Wallender, & Brown, 1998; Jacobs et al., 2011; Zionts, Zionts, Harrison, & Bellinger, 2003) and none to date that have focused specifically on

sibling relationships. There is not much known beyond the idea that Black families are less stressed and perceive less burden than White families (Carr & Lloyd, 2012; Jacobs et al., 2011; Valentine, McDermott, & Anderson, 1998). Black families not only deal with the challenges involved with having a family member with a disability, but also challenges involving racial and gender marginalization (Jacobs et al., 2011; Stubblefield, 2009; Taylor, 2015; Zionts et al., 2003). This study will add to the literature by exploring, in depth, a Black American sibling relationship and the role of race and gender within their social context. Through this study, we will begin to better understand Black American families' unique experiences and how to most effectively provide support and work towards policy reform.

CHAPTER II

LITERATURE REVIEW

Introduction

Asperger's Syndrome falls within the broader category of intellectual and developmental disabilities within the disability studies field. Research focusing on families of people with intellectual and developmental disabilities is a relatively new area of study, stemming from the transition of people with disabilities from institutions into family and community settings (Oliver, 1992; Stoneman, 2007; Taylor, 2015). With this transition, family researchers aimed to understand how the family member with a disability would impact the parents and the typically developing siblings. Because people with disabilities were viewed primarily as burdens to families, much of the research focused on pathology and mental health of parents and siblings. Studies examining the impact of having a child with a disability on maternal stress and sibling externalizing behaviors were commonplace (Estes, Munson, Dawson, Koehler, Zhou, & Abbott, 2009; Orsmond & Seltzer, 2007a; Seymour, Giallo, & Jellet, 2013; Zablotsky, Bradshaw, & Stewart, 2013). During the rise of the Disability Rights Movement and the emergence of the social model of disabilities (Oliver, 1992), researchers began to question and challenge the notion of family members with disabilities creating burden within the family and looked to uncover benefits of having a family member with a disability.

There are very few studies that focus on Asperger's Syndrome or "high functioning" autism, therefore the literature review focuses heavily on the broader literature. The majority of studies in this area focused primarily on middle-class White families. There have been minimal

studies focusing on different racial or ethnic groups. This narrow focus on middle-class White families disregards the variability of experience regarding race/ethnicity/culture, class, gender, and religion/spirituality. In the few studies that exist, findings have demonstrated that there are differences in perception of disabilities and experiences within the family for different racial, ethnic, and cultural groups (Burkett, Morris, Manning-Courtney, Anthony, & Shambley-Ebron, 2015; Harry, 2008; Jacobs, Lawlor, & Mattingly, 2011; Zionts, Zionts, Harrison, & Bellinger, 2003). The review of literature will discuss the most significant findings regarding people with Asperger's Syndrome, then explore research involving siblings of people with intellectual and developmental disabilities and families of people with intellectual and developmental disabilities in African American families. Unfortunately, there are currently no published studies that involve primarily African American siblings, so this review will focus on African American families and siblings separately.

Asperger's Syndrome

As previously stated, there is limited research focusing on Asperger's Syndrome in families. However, there are studies that highlight various challenges faced by people with Asperger's Syndrome. One of the arguments within this area focuses on the change from Asperger's as a separate category to becoming a part of autism spectrum disorder (American Psychiatric Association, 2013; Montgomery, Allison, Lai, Cassidy, Langdon, & Baron-Cohen 2016; Parsloe & Babrow, 2016). Many professionals and people with Asperger's believe that Asperger's should remain a separate category due to differences within the diagnostic criteria, such as the absence of language delays and increased intellectual pursuits (Parloe & Babrow, 2016). Some people with Asperger's also believe that autism carries a more stigmatizing label (Parloe & Babrow, 2016).

Along the lines of stigma, Shtayermman (2009) conducted a study with adolescents and young adults with Asperger's and found that twenty to thirty percent of participants met the criteria for anxiety and/or depression relating to victimization and stigmatization. Anxiety is also common among people with Asperger's Syndrome (Hare, Wood, Wastell, & Skirrow, 2015; Hofvander, Delorme, Chaste, Nydén, Wentz, Ståhlberg, et al., 2009). Adults with Asperger's Syndrome are vulnerable to anxiety disorders due to challenges relating to communication and social impairments and may struggle to articulate thoughts relating to anxiety and stress (Hare et al., 2015; Hofvander et al., 2009). Due to challenges in articulating feelings, there is a misconception that people with Asperger's may not experience empathy. However, Montgomery, Allison, Lai, Cassidy, Langdon, & Baron-Cohen (2016) found that people with Asperger's were better at interpreting complex emotions than people with high functioning autism, suggesting that the assumption of no empathy is false. Rather, people with Asperger's make sense of the interactions differently (Montgomery et al., 2016).

Other studies have focused on various experiences ranging from college (Cullen, 2015), to parenting (Gardner, Suplee, Bloch, & Lecks, 2016), dating and relationships (Strunz, Schermuck, Ballerstein, Ahlers, Dziobek, & Roepke, 2017) and differences based on gender Gould, 2016; Jarman & Rayner (2015). Despite interpersonal and communication difficulties, people with Asperger's are often partnered, but still experience challenges in intimate relationships (Gardner et al., 2016; Strunz et al., 2017). However, when a person with Asperger's chooses to partner, they are more likely to experience relationship satisfaction with another person who is also on the autism spectrum (Strunz et al., 2017). When women with Asperger's Syndrome choose to become mothers, there may be challenges at different periods that will require guidance throughout the process for the mother and education for nurses and doctors

(Gardner et al., 2016). According to Cullen (2015) students with Asperger's in college may require supports in multiple areas, such as social supports, academic supports in group environments, and daily living supports such as living with parents.

There are some differences relating specifically to gender that create an ongoing debate for professionals. While the prevalence of autism spectrum disorder, including Asperger's Syndrome, is believed to be significantly higher in boys and men, many believe that the diagnostic criteria area biased, leading to misdiagnosing and underdiagnosing in girls and women (Gould, 2017; Jarman & Rayner, 2015). Girls are believed to be more likely to mask their social challenges than are boys and less likely to be assessed due to the tendency towards more internalizing behaviors (Gould, 2017; Jarman & Rayner, 2015). Also relating to school experiences, Jarman and Rayner (2015) concluded that teachers need to be more aware of gender differences in order to better respond and refer girls for the supports they need to prevent some of the aforementioned difficulties such as anxiety and depression. While limited, the research available discusses several issues that can impact the family system. The following sections will broadly address sibling relationships and African American families of people with intellectual and developmental disabilities, keeping in mind that the research in either area does not tend to overlap.

Sibling Relationships

Parents and siblings of children with developmental disabilities may have to adjust in multiple areas of daily life such as extended caretaking needs, teaching social skills, societal pressures, and financial difficulties; which can have an unexpected impact on the sibling relationship. Fostering a strong sibling relationship is important in this context but presents with its own set of challenges (Orsmond & Seltzer, 2007a; Tomeny, Barry, & Bader, 2012; Whiteman

et al., 2009). Parents are typically responsible for most of the care and support in childhood and adolescence. However, as people with disabilities transition into adulthood, sibling relationships become increasingly important (Burke, Taylor, Urbano, & Hodapp, 2012; Kramer, Hall, & Heller, 2013; Orsmond & Seltzer, 2007a). As parents age and require assistance themselves and/or pass away, adults with disabilities continue to need support (Burke et al., 2012; Kramer et al., 2013; Orsmond & Seltzer, 2007a; Tozer, Atkin, & Wenham, 2013). Therefore, strong sibling relationships become more imperative. Due to challenges with developing close relationships, people with Asperger's Syndrome struggle to develop relationships within and outside of the family (American Psychiatric Association, 2013; Gould, 2017; Gardner et al., 2016; Jarman & Rayner, 2015; Strunz et al., 2017).

As previously stated, sibling research gained momentum following the transition from institutions for people with intellectual and developmental disabilities (Oliver, 1992; Stoneman, 2007; Taylor, 2015). Researchers were concerned about the emotional and psychological well-being of the typically developing sibling (Orsmond & Seltzer, 2007a; Smith & Elder, 2010; Stoneman, 2005; Stoneman, 2007). Through these concerns arose a body of research exploring the effects of having a sibling with a disability in childhood and adolescence with more studies emerging exploring relationships in adulthood. However, there are currently no existing studies focusing primarily on African American sibling relationships. Still, there have been studies focusing on support, advocacy, quality of life, and sibling relationships for adult siblings of people with disabilities in the majority literature. Because the current study explores the relationship from childhood through adulthood, the review of literature will include childhood/adolescence and adulthood research involving people with intellectual disabilities.

Childhood and Adolescence

Research exploring sibling relationships of children and adolescents with disabilities has been inconclusive in terms of effects (Orsmond & Seltzer, 2007a; Smith & Elder, 2010; Stoneman, 2001; Stoneman, 2005). Through a meta-analysis of literature involving siblings of individuals with disabilities, Rossiter and Sharpe (2001) found that there was a small negative effect for having a sibling with a disability. Rossiter and Sharpe also concluded that the concern about negative effect has been overstated in the field due to the minimal statistical significance (2001). Studies show that sibling relationships are more likely to be characterized as positive, nurturing, less conflicting, and satisfying for both children in the sibling dyad (Orsmond & Seltzer, 2007a; Stoneman, 2005; Taunt & Hastings, 2002). Relationships may differ depending on the children's age, gender, birth order, etc. (Orsmond & Seltzer, 2007a; Rivers & Stoneman, 2003; Stoneman, 2001). Based on a study by Taunt and Hastings (2002), typically developing siblings were shown to have a positive effect on their sibling with a disability and siblings. Families also experienced improved extended family dynamics, suggesting that having a family member with a disability positively affects other members outside of the immediate family in many of the same ways, such as having empathy and understanding for others (Taunt & Hastings, 2002). Typically developing siblings often have increased sensitivity to people with disabilities and have more opportunities to learn about disabilities and other difficulties in life (Stoneman, 2001; Taunt & Hastings, 2002).

Kaminsky & Dewey (2001) found that siblings of children with autism reported greater admiration of and less competition and conflict with their brother or sister. Pilowsky, Yirmiya, Doppelt, Gross-Tur, and Shalev (2004) concluded that siblings of children with autism were well adjusted. Siblings also spent time in shared activities (Orsmond et al., 2009). The most frequent

activities between siblings included playing together, watching television, and spending time outside (Orsmond & Seltzer, 2007a). In regards to age, adolescents engaged in significantly more shared activities than adult participants (Orsmond et al., 2009). However, Rivers and Stoneman (2003) found that older siblings had better relationships than younger siblings. The research demonstrates that sibling relationships of children with disabilities are complex, but generally no less warm, nurturing, or positive than sibling relationships of typically developing children and adolescents (Orsmond & Seltzer, 2007a; Orsmond & Seltzer, 2007b; Orsmond et al., 2009; Rivers & Stoneman, 2003; Stoneman, 2001; Stoneman, 2005, Smith & Elder, 2010).

Adulthood

As siblings transition into adulthood, the relationship characteristics and quality tend to transform. Relationships in adulthood may depend on several factors including distance, age difference, past sibling relationship, and in some cases, diagnosis (Orsmond & Seltzer, 2007b). For example, Tomeny, Ellis, Rankin, and Barry (2017) found that siblings of individuals with autism reported fewer positive attitudes about their relationship compared to siblings of individuals with autism and intellectual disability while Rosseti and Hall (2015) found that siblings viewed their relationships as positive and joyful. Similar to research in childhood and adolescence, there are mixed results regarding whether siblings of individuals with disabilities have poorer well-being. However, research involving adult sibling relationships have different motivations within the literature and focuses less on positive or negative impact and more on closeness and support in preparation of possible caregiving (Atkin & Tozer, 2014; Burke, Fish, & Lawton, 2015; Davys, Mitchell, & Haigh, 2015; Tozer & Atkin, 2015). As siblings start to get older, support needs change and so do the people providing those supports. The conversations

transition to how the typically developing sibling can support the sibling with the disability once parents are no longer able to provide care (Arnold, Heller, & Kramer, 2012).

Several studies examined perceptions of closeness in the sibling relationship. Siblings who felt closer to their brothers and sisters were more likely to anticipate their future caregiving responsibilities (Burke et al., 2012). Rosetti and Hall (2015) found that the siblings without disabilities felt close to their sibling and noted feelings of joy, guilt, frustration, and stress. Some siblings hoped for improvements in the relationship while others accepted their current status (Rosetti & Hall, 2015). Barriers to the relationship included time together, distance, and the sibling's diagnostic type or severity (Orsmond & Seltzer, 2007b; Rosetti & Hall, 2015). One of the limitations within the literature is the reliance on the sibling to provide information regarding the relationship without including the sibling with the disability (Meltzer & Kramer, 2015). This gap in the literature will be addressed in the current study by including both siblings throughout the data collection and analysis process.

Tozer and Atkin described how siblings developed relationships in adulthood independent of their parents (2015). They included expression of affection, loyalty, and protectiveness towards siblings, but there was also some resentment and emotional issues from the past (Tozer & Atkin, 2015). This is helpful in thinking about how relationships evolve over time. In some other reflections on the past, Tozer, Atkin, and Wenham (2013) noted that typically developing siblings recalled their parents' stress growing up and their attempts to maintain normality, but also noted closeness in the current relationship and a lifelong bond between the siblings. McGraw and Walker (2007) explored perceptions of women specifically and how they viewed their roles. They found that women stressed the importance of their sister

being normal, emphasized opportunities for moral enhancement for themselves, and minimized their own personal sacrifices.

Atkin and Tozer (2014) explored conceptualizations of adult sibling roles and found that relationships were characterized by acceptance of the responsibility of care and sense of duty, protection, and support. Davys, Mitchell, and Haigh (2015) explored future planning for siblings with disabilities and determined that there was an understanding of caregiving expectations among siblings or acceptance of the likelihood that the typically developing sibling would be responsible for care. Some siblings expect to assume total responsibility in domains ranging from financial and legal to interactions with service systems (Burke et al., 2012). Siblings also struggle against policy for the support of their sibling with the disability and often experience barriers when they do take on the responsibility of support (Arnold, Heller, & Kramer 2012; Atkin & Tozer, 2014). Tozer and Atkin (2015) found that siblings had a strong sense of obligation and commitment, but experienced lack of inclusion from service providers. Tozer, Atkin, and Wenham (2013) also note barriers for siblings when dealing with service providers. Even with some of the barriers from service providers, typically developing siblings seemed to still have major roles in the lives of their siblings with disabilities.

African American Families

One of the most common themes in family-focused disability research is the impact of having a child with a disability on parents' well-being and mental health. In an examination of negative impact on mothers by having a child with a disability, researchers determined that ethnicity played a major role in predicting negative impact across African American and White participants with African American mothers reporting lower levels of perceived negative impact than White mothers (Bishop et al., 2007). When comparing education levels, Carr & Lloyd

(2012) also found that mothers of adolescents ages nine to fourteen reported lower levels of negative impact than White mothers. African American mothers were also more likely to report feelings of gratification and intimacy and fewer feelings of burden and conflict than White mothers when caring for their adult child with a disability and were more likely to keep their family member in the home (Valentine et al., 1998).

In a longitudinal study of African American and White mothers, Carr & Lloyd (2012) determined that mothers reported higher negative impact when their child had higher amounts of behavior problems. African American children also received less hours of individual treatment to assist with behaviors than White children in the sample, but still reported more positive impact (Carr & Lloyd, 2012). Many factors contribute to the impact on parental well-being, but these findings suggest that the impact varies based on diagnosis, number of behaviors, and race/ethnicity. Both African American and Latina mothers differed from White mothers, suggesting that there are possible protective factors for families of differing ethnic groups (Blacher & Baker, 2007).

In terms of overall mental health, African American and Latina mothers were more likely to have less favorable mental health functioning and children with autism were also more likely to have a mother with less favorable mental health and higher stress levels (Zablotsky, Bradshaw, & Stuart, 2013), so while mothers may report more satisfaction and less burden than White mothers, there is some factor impacting mental health and stress levels. While each of the studies set out to understand related, yet different phenomena, there were multiple articles that highlighted the role of social support and communication both within the family and outside of the family. Evans, Feit, & Trent explored African American parents' attitudes about their child's disability and early intervention services and found that parental social support was a positive

influence on their attitudes (2016). Similarly, believing in functional support, dependence on emotional support, and community support contributed to resilience in families (McCue, 2011).

Extended family support such as intergenerational support from grandparents was also an important factor and was related to better adjustment in adolescents (Frison, Wallander, & Brown, 1998; McCue, 2011). Ha, Greenberg, and Seltzer (2011) determined that negative consequences of having a child with a disability was significantly reduced when parents had positive support from family. Additionally, they concluded that the families are no more psychologically stressed than African American parents without a child with a disability (Ha et al., 2011). Interestingly, father involvement was cited as a form of support in families, even though the article claims to focus on parents as a unit and noted significant involvement from both parents (Evans et al., 2016). Resilience in African American families was found to be related to open communication and shared decision-making practices within families (McCue, 2011).

Another theme within the literature revolves around beliefs and values relating to identity and culture within African American families. Addressing cultural differences have been cited as one of the most prominent challenges for families within the disability literature (Harry, 2008; Burkett, Morris, Manning-Courtney, Anthony, & Shambley-Ebron, 2015; Zionts, Zionts, Harrison, & Bellinger, 2003). Some of the beliefs that arose as a part of a study that explored resilience in low-income African American mothers of adults with disabilities included a strong sense of group identity, clear organizational hierarchy, and an ethic of sharing responsibility (McCue, 2011). A study exploring African American mothers' narratives of raising a child with special needs focused mainly on the mothers' beliefs about their roles as caregivers and advocates for their children with disabilities (Jacobs, Lawlor, & Mattingly, 2011). Aligning with

some of the beliefs from McCue (2011), Jacobs, Lawlor and Mattingly (2011) described mothers' experiences of discrimination based on race, embracing stereotypes to advocate for their child, and the desire to be recognized as a Black mother rather than just a mother. They also note the desire to push back on stereotypes and generalizations regarding the growth of their children based on what is expected within the general population and push for others to see their children as unique and capable (Jacobs et al., 2011).

In examining the relationship between cultural factors and maladjustment in African American adolescents, ethnic identification was found to be related to fewer externalizing problems as was church support (Frison, Wallender, & Browne, 1988). One reoccurring theme is the importance of spiritual practices within the family (Evans, Feit, & Trent, 2016; Frison et al., 1998; McCue, 2011; Terhune, 2005). Evans, Feit, and Trent discussed the importance of positive parental spiritual connection on the parents' attitude toward disability (2016). Parents who were more spiritual had a more positive view of their adult child, and in some cases, saw their child as their primary purpose for living (Terhune, 2005). Each of these studies emphasizes the value in recognizing the racialized experiences of families while also considering the importance of their spiritual and religious beliefs.

Experiences with available resources was another theme that arose in the literature focusing on African American families. The previously mentioned ethnic and cultural considerations impact families' experiences with resources in how they seek, secure, and utilize services to the benefit of their child and family. One major barrier for parents is the comprehension and knowledge of resources (Evans et al., 2016). When securing care or other resources for the child, mothers have noted their concern with allegations of racial discrimination, stereotyping, lack of overall cultural awareness, and blaming parents for child

behaviors (Frison et al., 1998; Jacobs et al., 2011; Zionts, Zionts, Harrison, & Bellinger, 2003). While there is a large amount of literature discussing families' experiences with services and supports, it is important to mention here, as most of the studies that focus on within-family experiences often extend to their interactions and struggles with some aspect of the service and education system in connection with race/ethnicity.

African American families evidently have unique experiences in terms of having a family member with a disability. While very limited in number, the include studies demonstrate a need for research that considers the ethnic, racial, and cultural influences of their experiences in addition to understanding some of the challenges the family may face as a result of having a family member with a disability. African American families derive different meanings from their experiences (Frison, Wallender, & Brown, 1998; Gourdine et al., 2011; Ha et al., 2011; Jacobs et al., 2001; McCue, 2011; Zionts, Zionts, Harrison, & Bellinger, 2003) and are impacted differently than what has been demonstrated in the extant literature, but the importance of social support, ethnic identity, and appropriate resources have been consistent throughout the research.

Gender

The study also focuses on gender within families, but there is limited research that addresses gender differences. Some studies have focused specifically on caregiving roles, concluding that women and girls participate in more caregiving responsibilities above and beyond their male siblings, but few studies have explored experiences unique to women. One of the major themes relating to gender has been examining differences based on biological sex within and among families of children with intellectual and developmental disabilities (Ormond & Seltzer, 2007; Smith & Elder, 2010). The examination of gender in disability research is often embedded in the comparison between boys and girls and are not even considered before the age

of six (Einfeld, Gray, Ellis, Taffe, Emerson, Tonge, & Horstead, 2010). The common path of gender inquiry is typically based on the individual/medical model of disability. For example, 60% of all people with intellectual disabilities are male (Wilson, Parmenter, Stancliffe, Shuttleworth, & Parker, 2010) while 1 in 4 children with autism spectrum disorders specifically, are boys (Baio, 2012; Wilson et al., 2010). Similarly, researchers have also tested gender effects on behaviors and found that adult males with intellectual disability had higher frequency of repetitive and restricted behaviors (Hattier, Matson, Tureck, & Horovitz, 2011).

While most of the literature uses sex and gender interchangeably, it is important to note that the two are not mutually exclusive. Looking at the differences by sex while understanding ways in which bodies have been gendered and marginalized centers the conversation around how a person has been situated in society and how they may situate themselves (Stubblefield, 2007; Taylor, 2015). These examinations rarely extend to understanding gender as an aspect of identity. Studies in education have demonstrated that gendered identities do play a role in the experiences of people with disabilities (Banks and Hughes, 2013; Petersen, 2009).

Gender has been used as a moderator or mediator of maternal stress but results of this interaction were either not reported or the results were insignificant (Hoffman, Sweeney, Hodge, Lopez-Wagner, and Loone, 2009; Ingersoll & Hambrick, 2011; Lee, 2009; Pottie & Ingram, 2008). It is important to note that these studies have an unequal distribution with boys typically outweighing the participation of girls, possibly skewing the data. Zablotsky, Bradshaw, and Stuart (2013), however, did note that mothers with male children were more likely to experience higher levels of stress. Other trends within family research examine the impact of a person's disability and gender and how it may affect their relationship with a typically developing sibling (Ormond & Seltzer, 2007; Smith & Elder, 2010). While sibling disability research tends to be

gender neutral in its findings (McGraw & Walker, 2007), this neutrality changes when considering siblings as caregivers. This research typically favors female siblings as providing more caregiving support or foreseeing the female sibling assuming caregiving responsibilities in the future (Burke, Taylor, Urbano, & Hodapp, 2012; McGraw & Walker, 2007). The research rarely explores the experiences of the child or adult with the disability. There is an opportunity to further explore experiences that may be unique to gender.

Theoretical Framework

Social constructionism is concerned with meaning and understanding as the central feature of human activities, which is helpful in understanding how families view their kin and their interactions (Berger & Luckmann, 1991; Lock & Strong, 2010). It also posits that meaning and understanding have their beginnings in social interaction. Symbolically based language is a facet of this theory that plays a major role in how people are perceived in the larger society (Lock & Strong, 2010; Perkins, 2013). Disability, race, and gender are all social constructs that have developed meaning over time, but through interaction and interpretation of what is considered "normal" some identities within each construct have been subjugated to inferior status (Stubblefield, 2007; 2009).

Many disability studies researchers would argue that the line between ability and disability is arbitrary and relies on the notion of something else being normative (Annamma et al., 2013; Stubblefield, 2009). Stubblefield (2009) states "To say that intellect is socially constructed is not to say that there are no differences in cognitive development. But just as we have come to understand that we do not derive attributions of race straightforwardly from skin color or other physical differentia, unmediated by our socially constructed perception of these characteristics, so we do not derive attributions of intellect straightforwardly from cognitive

skills, unmediated by our socially constructed approaches to measuring them" (p.534). For this study exploring the experiences of families from a social constructionist paradigm, special attention is placed on the role of language. The study focuses on interactions both within the family and with larger society, and the meanings the family members derive from those interactions regarding race, gender, and disability as an intersection of identities.

Intersectionality Informed Dis/Crit Theory

Dis/ability critical race theory (Dis/Crit) attempts to address the intersection between race and disability and provide a theory to guide those connections (Annamma, Connor, & Ferri, 2013). Scientists have used perceptions of lower intelligence and inferiority to justify segregation and inequitable treatment (Annamma et al., 2013; Rushton & Jensen, 2005; Stubblefield, 2009; Taylor, 2015). Intelligence was used to dehumanize people of color (Annamma et al., 2013; Stubblefield, 2009; Taylor, 2015). Annamma et al. (2013) posited that the legacy of historical beliefs about race and ability, which were based on white supremacy, have become intertwined in ways that continue into present day.

With influences from both critical race theory and disability studies, Annamma et al. (2013) have developed a new theoretical framework. Tenets of Dis/Crit are as follows:

(1) DisCrit focuses on ways that the forces of racism and ableism circulate interdependently, often in neutralized and invisible ways, to uphold notions of normalcy.
(2) DisCrit values multidimensional identities and troubles singular notions of identity such as race or dis/ability or class or gender or sexuality, and so on.
(3) DisCrit emphasizes the social constructions of race and ability and yet recognizes the material and psychological impacts of being labeled as raced or dis/abled, which sets one outside of the western cultural norms.

(4) DisCrit privileges voices of marginalized populations, traditionally not acknowledged within research.

(5) DisCrit considers legal and historical aspects of dis/ability and race and how both have been used separately and together to deny the rights of some citizens.

(6) DisCrit recognizes whiteness and ability as property and that gains for people labeled with dis/abilities have largely been made as the result of interest convergence of white, middle-class citizens.

(7) DisCrit requires activism and supports all forms of resistance.

This framework is specifically aimed to address race and disability and will serve as the primary framework for this study.

Intersectionality. Intersectionality has become more prevalent framework for research in recent years as researchers are beginning to understand that identities are not merely additive (Bowleg, 2008; Cho, Crenshaw, & McCall, 2013; Collins, 1991; Crenshaw, 1989; Few-Demo, 2014; MacKinnon, 2013). Intersectionality also recognizes categories that may be privileged versus subordinated as well as those that are static or fixed versus dynamic and contextual (Cho et al., 2013). Similar to disability studies, intersectionality is concerned with structural and institutional power rather than solely identity (Cho et al., 2013; Collins, 1991; Crenshaw, 1989; Few-Demo, 2014). Thus, intersectionality studies represent three sets of engagements: 1) applications of intersectional framework or investigations of intersectional dynamics, 2) discursive debates about the scope and content of intersectionality as a theoretical and methodological paradigm, and 3) the political interventions employing an intersectional lens (Cho et al., 2013).

It is important to note that intersectionality as a framework that grew out of Black feminist thought continues to uphold a centrality of Black women's experiences as it attempts to address social power among other marginalized groups (Cho et al., 2013; Collins, 1991;

Crenshaw, 1989). There continues to be tensions set around intersectionality's capacity to do any work other than to call attention to the particularities of Black women (Cho et al., 2013). However, intersectionality is not merely about the experience of particular groups. As Cho et al. (2013) make explicit, intersectionality is a way of thinking that emphasizes what it does rather than what it is. Few-Demo, (2014) describes it as a theoretical framework that guides methodological considerations and data interpretation. It does not merely provide a description of experiences, but rather a methodological paradigm (Few-Demo, 2014; MacKinnon, 2013).

Intersectionality Informed Dis/Crit Theory. Dis/Crit theory in its current state is intersectional in nature as it focuses on the entanglement of two identities (Annamma et al., 2013). However, intersectionality incorporates an aspect that focuses specifically on the marginalization of Black women (Cho et al., 2013; Collins, 1991; Crenshaw, 1989). As critical race theory has traditionally centered Black men (Crenshaw, 1989), intersectionality will inform dis/crit theory throughout the analysis of this study to highlight gender differences among the participants and the marginalization that is specific to Black women. Intersectionality will enhance the tenets of dis/crit theory to include marginalization specific to Black women. This study will examine historical influences on Black women's identities and experiences and how the sisters experience their Black womanhood in today's social context, including how these influences interact with the concept of dis/ability and social relationships.

Ecosystemic Family Resilience Framework

This study will utilize an ecosystemic family resilience framework to understand how the various systems within and surrounding the family impact one another (Waller, 2001; Walsh, 2002; 2016). This framework is grounded in family systems theory (Broderick, 1979) and combines developmental and ecological systems perspectives (Bronfenbrenner, 1979). Family

systems theory emphasizes the various subsystems within the family, but the current study extends beyond the family system (Broderick, 1979). The ecosystemic family resilience framework considers the multigenerational family influence as well as community, political, and sociocultural impacts on the family and the individual (Walsh, 2002; 2016). This framework also speaks to power, privilege and systems that influence marginalization and oppression (Walsh, 2002; 2016).

The combination of the ecosystemic resilience framework and intersectionality will position the study to focus on both intra-family process and larger social context simultaneously. Intersectionality as a framework investigates converging identities and not only views each separately in relation to the whole, but understands the whole is a different experience entirely (Cho et al., 2013; Crenshaw, 1991; Few-Demo, 2014; MacKinnon, 2013). As a heuristic term that focuses on dynamics of difference and solidarities of sameness in the context of antidiscrimination and social movement politics (Cho et al., 2013), intersectionality is appropriate for the exploration of race, gender, and disability in conjunction with dis/crit theory. Additionally, due to the history of race and dominant discourse in this society, the discussion will center on Black women experiences with an understanding that other races and ethnicities may demonstrate similarities as well as differences based on their social identities, orientations, and historical experiences. Additionally, with the lack of current research in this area for Black/African American families, it is important to critically examine and challenge the possible reasons for the difficulties experienced by families, as well as the barriers to positive experiences with the service and education system and the lack of inclusion in research. This study will attempt to explore some of those challenges while opening a platform for the family to share multiple aspects of their experience.

CHAPTER III

METHODOLOGY

Introduction

This study used qualitative methods to evaluate how Black American siblings interact with one another and their communities of influence in the context of gender and race when one sibling is on the autism spectrum. To learn more about this, I conducted an in-depth case study of a family with two sisters, one of whom has Asperger's Syndrome.

The study consisted of three methods of data collection. The first was in-person, semi-structured interviews which I conducted with the sisters individually and in dyads, their mother, and one of the sister's husband. The second was participant observation which was a community outing to observe their interactions. The final method was a Photo-voice project, which is a data collection method consisting of taking photographs of places and things that represent their community for later explanation and discussion.

Rationale for Qualitative Methods

The current study is concerned with understanding how societal discourses and systems of oppression regarding disability interplay with discrimination and marginalization based on race and gender. Black American families of people with disabilities have been under studied in the disability studies and critical race studies fields. Therefore, there is a limited understanding of how systems influencing race and dis/ability affect Black American families and people with disabilities based on these intersecting identities. Due to the limited literature available, this study required a more in-depth exploratory approach to examine the real-world situations that

participants experience and allow those experiences to unfold naturally (Patton, 2015). Because there is such a dearth of knowledge in this area, an exploratory qualitative approach is an appropriate starting point for this area of family-focused disability research.

I chose a case study design for this study because it allows for a deepened level of inquiry and supports complexity when attempting to understand activity within important circumstances (Creswell, 2013; Merriam & Tisdell, 2016; Stake, 1995; 2006; 2010). The unit of analysis is the sibling relationship. Circumstances in this case include being a Black American woman with a disability or a Black American woman with a sibling with a disability, as well as the sibling relationship itself. Case analysis involves organizing the multiple methods of data collection for in-depth study and comparison which are holistic and case sensitive (Merriam & Tisdell, 2016; Patton, 2015; Stake, 1995; 2006; 2010). Case study also focuses on understanding actions, processes, patterns, and problems through interpretation and narratives (Merriam & Tisdell, 2016; Stake, 1995; 2006; 2010). Being transparent, flexible, and diligent in ensuring that the complexities of the case are presented appropriately was imperative to contributing applicable, appropriate, genuine awareness of the world as it is being studied.

Inclusive Methodology

Research in the disability field has typically relied on information from parents, particularly mothers, or typically developing siblings. Very rarely are the children or adults with disabilities interviewed or included in the research (Barton, 2005; Bigby, Frawley, & Ramcharan, 2014; Meltzer & Kramer, 2015; Richardson & Jordan, 2017). In the majority of sibling research, the focus has been on the effects of having a sibling with a disability rather than focusing primarily on the relationship itself (Meltzer & Kramer, 2015). There is an emerging movement within the disability studies field that has acknowledged this gap (Barton, 2005;

Bigby et al., 2014; Meltzer & Kramer, 2015; Munger & Mertens, 2011; Richardson & Jordan, 2017). More researchers are beginning to explore the value of incorporating the voice of the person with the disability (Barton, 2005; Bigby et al., 2014; Caldwell, 2014; Meltzer & Kramer, 2015; Munger & Mertens, 2011, Nicholson, Colyer, & Cooper, 2013, Nind & Vinha 2012; Richardson & Jordan, 2017). From a social model perspective, excluding the person with the disability from the research further contributes to the marginalization of people with disabilities (Barton, 2005; Meltzer & Kramer, 2015; Munger & Mertens, 2011; Oliver, 1992; Richardson & Jordan, 2017). Prescribing to a social model perspective, this study will include the adult sibling with the disability in every stage of the data collection process. This study is unique in that it will be one of the first to examine sibling relationships in Black American families while also incorporating the voice of the person with the disability.

Subjectivities Statement

I identify as a Black, heterosexual, questioning Christian woman who is typically abled in both mind and body. My most salient identity is that of a Black woman. This is the lens through which I see most of the world. My perceptions are predominately shaped by my experiences of marginalization and oppression as a Black woman. These experiences help to shape my understanding of intersectionality from a personal place, but also challenges me to explore my own privilege in the areas that are not marginalized identities in this social context, i.e. ability, religion, sexual orientation. When conducting research on the intersection of race, gender, and disability, it has been very important for me to recognize that I am both an insider and an outsider in different ways. I am an insider in that I identify as a Black American woman, but I am an outsider relating to the experiences of siblings where one has a disability. There were also class differences between me and the participants. When sharing the experiences of these

siblings, it is important that I recognize my position as an outsider and continuously examine my perception of my status as an insider as not to inappropriately assume that the participants' experiences mirror my own. Rather, utilizing my insider status to help make meaning only when I have critically examined the context of their experience.

Research Questions

The study focused on how race and gender intersect with disability within the relationships of adult Black American siblings. The main questions that this study will examine are as follows:

1. How do two Black American siblings interact and support one another when one sibling has Asperger's Syndrome?
2. How have two Black American siblings been socialized within their families and neighborhoods based on race, disability, and gender?
3. How have two Black American siblings experienced race, disability, and gender as social constructs in the US?

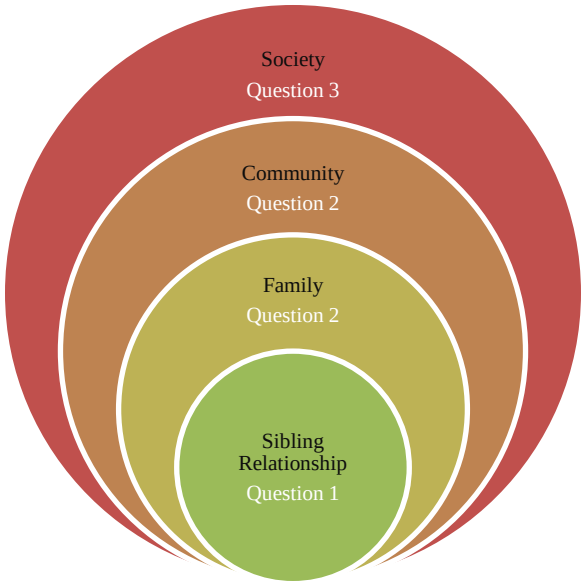

Figure 1. Research Questions and Focus

Research Design/Methods

Sampling Strategies

Criterion sampling (Patton, 2015) was used to recruit families through disability service agencies such as the Arc, sibling support networks such as the Sibling Leadership Network, disability advocacy offices such as the Georgia Advocacy Office, and contacts from previous research involvement. Participants were also recruited through social media and other sibling related support groups and events in order to reach the entire southeast region. After attending multiple conferences, speaking to siblings, and sharing information in various Facebook groups, I completed recruitment by contacting participants with past research study involvement. Following screening, one family agreed to participate.

Participants

As demonstrated through the review of literature, there is a gap in literature relating specifically to siblings in Black American families. To better understand the relationships between siblings in Black American families when one person has a developmental disability, this study included two same-gender sisters, their mother, and the spouse of the older sister. In order to be included in the study, participants had to be female sibling dyads, one of whom had to have a developmental disability. Same-gender siblings were preferred to limit effects relating to gender differences for this study.

There was no specific disability identified in the original recruitment. Due to regional and cultural differences on basis of race and gender, both siblings had to identify as Black or African American and have lived in the southeast region of U.S. at least half their lives. Participants were required to be between the ages of 18 to 35 with no more than a five-year age gap between them. Through recruitment, I identified one family that met the criteria from previous involvement in

another research study. I reached out to the participant (Samaria) and asked if she and her family would be interested. After writing a letter to the family with the information, which was shared by Samaria, the family agreed to participate. The information regarding the final participants is below in Table 1. Participants chose their own pseudonyms for the study, which is how they will be identified throughout the study.

Table 1

Participant Demographic Information

Name	Age	Marital Status	Education	Ability	Relationship
Michelle	28	Never Married	Master's in Progress	Asperger's Syndrome Gifted	Sister
Samaria	32	Married	Ph.D.	Gifted	Sister
Ethel	N/D	Married	High School	N/D	Mother
Miles	33	Married	Ph.D.	N/D	Samaria's Husband

Procedures Involved

Data collection took place in the participants' homes for two of the interviews and in a restaurant during the other interview. Informed consent forms (Appendix A) were provided and verbally explained to each participant prior to the beginning of the study. Each participant was given a paper copy to sign and a copy to keep for their records. During the first interview, the participants chose a location for the second set of interviews, which would also serve as a participant observation activity. I interviewed each of the sisters individually first, then together as a dyad. The Photovoice (Agarwal, Moya, Yasui, & Seymour, 2015; Harley, Hunn, Elliot, & Canfield, 2015; Wang & Redwood-Jones, 2010) project was introduced at this time as well.

They were instructed on how to conduct the Photovoice project and a timeframe to send the photos. After the conclusion of the dyadic interview, I interviewed their mother for the first time.

The second set of interviews took place in a restaurant near one of the sister's home. The interview began by discussing the Photovoice project photos. During this entire interaction, I also observed each of the sisters and their interactions with each other as well as their interactions and behaviors within the restaurant. They also discussed their second round of Photovoice photos, which focused more heavily on photos related to their identities as Black women. I also interviewed their mother for a second time following the dyadic interview and included a wrap-up conversation with all three of the women. The final interview was with the older sibling's husband Miles to gain and additional perspective into the family's experience. See Appendix C for the list of interview questions. All the interviews were audio recorded and conducted in person. The final step in the data collection process was inviting the participants to review and discuss the findings to ensure that they appropriately reflected their experiences.

Type of Qualitative Design

The first method of data collection for this study was semi-structured interviewing using a dyadic interviewing method. Dyadic interviewing has most frequently been used to examine couplehood (Eisikovits & Koren, 2010), but can be useful as an accommodation for people with intellectual and developmental disabilities (Caldwell, 2014). However, joint interviews may be seen as a problematic as they raise concerns regarding facilitated responses to suppress the voices of people with disabilities from a critical disability studies perspective (Caldwell, 2014). Joint interviews are appropriate in this context in that the study is focusing on the relationship between the two siblings. While independence is emphasized within the disabilities field,

disabled feminist scholars have acknowledged the benefits of dyadic interviewing and the importance of interdependent social relationships (Caldwell, 2014).

Because this study focuses on the sibling relationship as the unit of analysis, this methodology is appropriate for exploring this relationship in a family of a person with a disability for the reasons listed above. Individual interviews in addition to the dyadic interviews allow the participants to share their own perspective without forgoing the dyadic responses of the shared narrative (Caldwell, 2014; Eisikovits, 2010). Therefore, each pair of siblings were interviewed a total of three times together following an initial individual interview. Following Caldwell's (2014) dyadic interviewing structure for people with mild to moderate disability, the interview structure is a three-stage process in addition to the actual interview questions themselves. Because Michelle does not have an intellectual disability, the additional accommodation of a support person is not necessary. The original descriptions of the dyadic framework are listed below with some adaptations specific to this study. See Figure 2 for the adapted purposes for the sibling dyads. The purpose of interviewing the parent was to provide additional perspective for the sibling relationship from a family member that was close enough to the relationship to provide in-depth insight without being part of the sibling relationship itself. The additional perspective of one of the sister's husband was also included to provide outside perspective that would be different from someone who grew up within their family.

Participant observation. Participant observation as a data collection method aids in understanding, in context, the people who participate in activities and the meanings of what is observed from the perspectives of those being observed (Patton, 2015; Stake, 2010). The participant observer has the opportunity to discover things that others may not have access to (Patton, 2015). Being fully engaged in the experience involves simultaneous document analysis,

interviewing, observation, and introspection (Patton, 2015). The participants had the opportunity to choose an appropriate activity for the observation that balances interaction and engagement, but also confidentiality of the participants. They chose a restaurant in their town, which limited confidentiality, but also allowed for us all to blend in with the surroundings. I also observed interactions within the homes. As the researcher, I interacted with the siblings as an equal participant, engaging in general conversation about their experiences within their community while also observing.

Photovoice. Photovoice was developed and used with women in rural China with three major theoretical understandings: 1) every human being is capable of looking at the world critically in dialogical encounters with others; 2) feminist perspective on how power accrues to those who have a voice, set language, make history, and participate in decisions; and 3) photography as a way of thinking about how ordinary people could use the camera for social change (Wang & Redwood-Jones, 2001). Harley, Hunn, Elliot, and Canfield (2015) posited that social science researchers must consider utilizing research methodologies that are culturally sensitive and culturally appropriate for African Americans. They claim that Photovoice qualifies because it meets that standard as a participatory method (Harley et al., 2015). They also state that "Photovoice is consistent with the Afrocentric Paradigm and the Social Constructivist Perspective because of its emphasis on enabling oppressed populations to define reality for themselves" (Harley et al., 2015, p. 35).

Agarwal, Moya, Yasui, and Seymour (2015) utilized this method as an appropriate method for marginalized groups and used it to study college students with disabilities in inclusive education. Jurkowksi and Paul-Ward (2007) also utilized this method for people with disabilities. Wang (2006) provides nine steps for developing a Photovoice project. All of the steps were not

used in the current study, as they did not reflect the purpose of this study or were not needed. For example, step 9 was to put the photos on display for viewing. Only steps relevant to this study are listed below:

1. Decide on the focus of the social issue or construct to be examined by research participants. Social issues or concerns may include access to health care, community violence, barriers to accessing community resources etc. In this case, race, gender and disability were the social issues.
2. Obtain informed consent and meet all institutional review board requirements.
3. Facilitate a discussion regarding photovoice ethics with research participants. Participants were instructed NOT to take photos of people, only places and things that were meaningful to them.
4. Provide a timeframe for participants to take pictures and send to researcher. Participants were given two to three weeks between interviews.
5. Discuss with research participants their photographs and identify themes. The three-step process included selecting photographs, storytelling, and codifying themes.

Each sister was instructed to take photos with her phone and send to the researcher via Google drive or email prior to interview two and three. For the first set of photos, they were instructed to photograph things that represented themselves and their identities. For the second set of photographs, they were instructed to photograph things that represented their families and culture. During the outing for dyadic interview two, the participants and I discussed each of their first set of photos prior to the actual interview. Prior to dyadic interview three, we discussed each of their second set of photos.

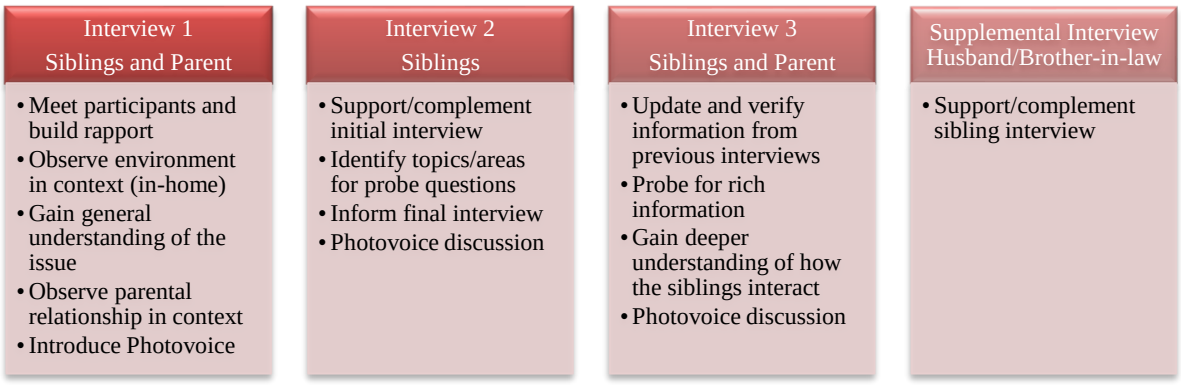

Figure 2. Methods and Procedure

Setting

Interview number one took place in the parents' home in Baton Rouge, LA. Interview number two, community observation, and the Photovoice project were all conducted at a chosen restaurant in New Orleans, LA. Interview number three was conducted in the older sister's home in New Orleans, LA. The interview with the brother-in-law was conducted by phone.

Data Management

Data is stored on a password-protected computer and jump drive and names of participants were changed to pseudonyms in the transcription. The jump drive is kept in a locked box. Data is also stored with the data analysis software, Nvivo. Participants chose their own pseudonyms which are used in all documents for analysis. No identifying information is associated with actual names of participants.

Data Analysis

Interviews were transcribed verbatim to ensure accuracy in analysis. Data analysis consisted of critical thematic analysis (Guest, MacQueen, & Namey, 2012) using Nvivo software. I paid specific attention to issues relating to race, gender, disability, and any aspect of these intersections and interactions or influences of dominant culture. Nvivo has the ability to store transcripts, audio files, and photographs to facilitate analysis of multiple types of data. Nvivo was used to create codes based on common themes among the different types of data. Context sensitivity was considered to place findings in social, historical, and temporal contexts for the purpose of extrapolating patterns for transferability (Patton, 2015).

As the focus of this study was two Black women's experiences through a critical lens, which in nature are intersectional due to being Black and woman, I paid particular attention to factors that involved their understandings of themselves and others in racial and gendered

contexts. Utilizing an intersectional disability critical race allowed for me to recognize coded language relating to their identities as well as identify experiences that critical literature has demonstrated to be connected to certain groups (Reynolds-Dobbs, Thomas, & Harrison, 2008; Stephens & Phillips, 2003; Woods-Giscombe, 2010). For example, the idea of the "strong Black woman" has been established in Black feminist literature (Reynolds-Dobbs, Thomas, & Harrison, 2008; Stephens & Phillips, 2003; Woods-Giscombe, 2010). I also focused on their interactions, both expressed and observed, to provide additional context into their relationship dynamics. Throughout the duration of the study, field notes were used to capture the observations relating to behavior and interactional dynamics and used to inform the following subsequent interviews. I also utilized a journal to document thoughts and emotions that arose through the interview process. The journal aided in developing additional questions and determining what to focus on through the process.

With the aid of the field notes, analysis was an ongoing process. There were established "base questions" for all three interviews, but interviews one and two were followed by a review of the transcripts and the field notes to inform additional questions for interviews two and three. Once a full draft of the findings section was complete, I provided all the participants with a copy and scheduled a meeting to discuss. I utilized memos (Saldana, 2013) throughout the analytical process, in conjunction with the journal, to capture any reflections on aspects of the data that sparked questions that I could not yet answer or reflected some aspect of my own experience. The memos aided in recognizing areas for additional inquiry and aspects that have not yet been explored in the literature. They also helped to determine the focus on clinical implications and limits of this particular study.

Coding

Interviews, field notes, and Photovoice were coded using a three-step process that was then supported by observational field notes (Saldana, 2013). The first round of coding included a review of each interview while *simultaneous, descriptive, and values* codes were all used through a process of chunking the data (Saldana, 2013). During this round, I coded each interview separately with their unique themes and created codes based on conversation regarding different aspects of their identities (i.e. Black womanhood, or disability, or Blackness). The second round involved finding commonalities among the various codes within each interview and creating codes for information that was not already sorted into an identity-based code. The final round of coding organized the codes into four broad themes that included information from multiple interviews and/or multiple participants and addressed the research questions.

During the coding process, the photos from the Photovoice were reviewed visually first, in an attempt to understand what was present in the photo and to make connections to the existing codes. I then reviewed the transcript from the conversation regarding the photo to determine how the sisters described what was happening in the photo. The findings noted the sisters' interpretations of the photos and their purposes for choosing the subject of the photographs. These interpretations were categorized into the existing themes.

Validity

Validity refers to the extent to which the findings match reality (Lincoln & Guba, 1986; Merriam & Tisdell, 2016). Triangulation is the main form of validation for this study (Merriam & Tisdell, 2016; Patton, 2015; Stake, 2006). Triangulation begins with the various methods of data collection (interviews, Photovoice, and participant observation). Dyadic interviewing itself has been considered a form of triangulation (Caldwell, 2014; Eisikovits and Koren, 2010).

Additional triangulation of findings occurs by including interviews with the mother of the siblings and husband/brother-in-law. Including the person with the disability also served as a validation method by reflecting the lived experience of the sibling with the disability and producing first-hand knowledge (Caldwell, 2014). At the conclusion of data collection during the data analysis process, member checking served as the final method of validation with the participants to ensure that the data collection is interpreted to reflect the participants' experiences (Merriam & Tisdell, 2016). I facilitated a conversation with all the participants through video conference, shared my findings with them, allowed them to share feedback and requested for them to share any issues they had with what was presented. They were all in agreement that the findings represented their family and their experiences.

Dependability

Reliability is purposed to examine the extent to which research findings can be replicated (Merriam & Tisdell, 2016). However, this was not the purpose of this study. The purpose of this study was to understand, in depth, the particular experiences of one family as a starting point of inquiry into a broader understanding of family relationships. Therefore, this study does not have a purpose of replicating results. Instead, Lincoln & Guba's (1986) concepts of dependability or consistency are more appropriate here in terms of whether the results are consistent with the data collected (Merriam & Tisdell, 2016). The use of multiple methods of data collection, member checking, and triangulation contribute to the dependability of the results (Merriam & Tisdell, 2016). There is also an audit trail which is a detailed log of how data were collected, categories were derived, and decisions were made (Lincoln & Guba, 1985; Merriam & Tisdell, 2016). In addition, I used field notes during the process and a journal following the interviews to further strengthen the dependability of the findings.

Trustworthiness

Major concerns with trustworthiness in this study arise in the ethical considerations of the data collection. Because this study involves a population of individuals designated as a vulnerable population by the institutional review board (IRB), there are several considerations that affect the trustworthiness of this study. The first is the consideration of how well the participant with the disability understands the research process and consent, and the reliability of responses. Caldwell (2014) addresses this challenge in connection with dyadic interviewing. Because the sibling in this study does not also have an accompanying intellectual disability, precautions relating to consent were not needed.

Conclusion

This chapter discussed the research design for this study. This study is innovative in many ways and addresses a major gap in the disability studies literature. Using an inclusive, in-depth case approach to understanding these families, this study focuses on a specialized group within the disability research field, Black American siblings, and explores their experiences using a critical paradigm. The study uses dyadic interviewing, Photovoice, and participant observation as data collection methods and a three-round coding system. The trustworthiness and rigor of the data was assessed using triangulation and member checking. Disability studies researchers have focused separately on each of the constructs addressed in this study, but not as one intersectional experience. This study serves as a starting point for inquiry that advances our understanding of a diverse pool of families, fosters a more inclusive society, and provides the most effective, appropriate, supports for all people. Because the study includes a small sample of one family, there is limited generalizability. However, the goal of the study is not to generalize,

but to gain an in-depth understanding of the family's experience as a start to developing more studies that increase knowledge regarding this population.

CHAPTER IV

FINDINGS

Introduction

The findings for this study addressed issues across multiple domains including the sibling relationship, family and community experiences, and sociocultural perspectives. Through analysis, the various methods, including interviews, observation, and Photovoice project, contributed to the emergence of themes. The findings will begin with vignettes and descriptions of the case, the two sisters, and will follow with the descriptions of each theme. Descriptions of the themes relating to the case will be outlined using information from interviews, and then supported by field notes and the discussion of the photographs from the Photovoice project. The following themes emerged through analysis and relate directly to the research questions: 1) strong sibling bond; 2) the influence of extended family values and kinship; 3) the struggle of Black womanhood; and 4) varied perceptions of Black families and disability.

This study focused solely on the experiences of Black American women. In recent years, there has been an influx of messages relating to the importance of confidence and strength for Black women. This has included and relied heavily on media influence through television, music, art, books, or social media and meme culture. In order to capture some of the ways Black women may translate messages through these media, some of the relevant quotes, sayings, and references from Black women will be included to supplement the findings section to help convey the spirit and essence of the messages. These quotes or sayings were chosen by the researcher after analyzing and developing themes. The quotes did not influence the analytic process.

Samaria

"*I define joy as a sustained sense of well-being and internal peace-connection to what matters*." -Oprah Winfrey

Samaria Richard, Ph.D. is a 32-year-old Black woman, wife, mother of two young children, and college professor. Samaria's interview was conducted first at the initial meeting. She was welcoming and hospitable prior to beginning the interview. After beginning the interview, she started by describing herself in the ways that are most salient for her at this point in time. By Samaria's expression, she identifies in two main categories: motherhood and career. Samaria is a new mom with two small children, 2 years and 5 months old, and has been married for eight years. Her motherhood journey began around the same time as her career. Samaria is a university professor at a prominent historically Black university. Samaria explained:

> When I started at Louisiana HBCU, I was just beginning the 3rd trimester of my pregnancy with my first child, my son who will be 2 in November and Lord help me, that has been one of the most-biggest learning experiences of my life.

Samaria has only experienced being a professor while becoming a mother and vice versa. She continued:

> I also have a baby whose going on 5 months. I got pregnant with her my 2nd school year so it's just been like this merge of career and motherhood both beginning at the same time which has been really interesting.

She mentioned support she received from her department and how that has also shaped some of her experience as a professor thus far. Many of her coworkers are also Black women of faith, so Samaria found value in having women who she believed to share similar identities and experiences relating to motherhood and being a Black woman.

She went on to talk about how her role as a wife has also moved quickly with the various experiences. She made reference to a quote that she felt was meaningful to her current process,

"it's like, women are thought of as mere reproductive beings, right, but that's like, true, but there's other parts...I think of sisterhood, I think of people who nurture, I do think of motherhood." Samaria discussed some of the things she has learned through these new experiences and how being a mother and professor have influenced who she is and who she wants to be going forward through growth and self-reflection. In her photograph choices, she chose pictures of some books she is currently reading for self-growth and a picture of her breast pump. She included these photos to capture the status of her motherhood as well as her career. She expressed a desire for an outlet that is not connected to her status of wife, mother, or career woman as part of her journey. This idea will be reflected in many ways through the findings from subsequent interviews.

Michelle

"*Now keep in mind that I'm an artist and I'm sensitive about my sh*t"*-Erykah Badu

Michelle's interview was conducted immediately after Samaria's. When I arrived, Michelle was still getting ready, so our initial meeting took place at the start of the interview. Samaria introduced us prior to beginning, but this was the first time we had spoken. Michelle seemed shy and reserved upon the beginning of the interview. This was not the case with Samaria's interview, as we had known each other prior to the study due to her previous research involvement. Michelle was also somewhat fidgety, constantly touching her hair, which consisted of freshly untwisted two-strand twists (commonly referred to as a twist out by Black American women). The interview began much the same way as Samaria's by describing some of the current stages and experiences that are most salient to who she is now. Michelle started by describing her age, race, and career. Specifically, she stated, "Well, I'm 28 years old, African

American female living at home with my parents. I work full-time at the library and I've been going to grad school part-time and it's tough, but…that's just a little about me."

Michelle is studying librarian information science in graduate school. Michelle described her typical day which included work for eight hours, a grocery run occasionally, and a visit to the coffee shop to do homework before venturing back home to relax for the evening. She also discussed some of her work relationships as well as other relationships outside of the family, which she preferred to keep as strictly coworker relationships. She expressed, "It's not like I hang out with them or anything. At one point I did, but with school and all, trying to be more social with my coworkers…it's not in my interests." Other relationships such as friendships were similar in that they were few in number and Michelle preferred to engage with few people on minimal basis. She described some of her own interests, "Well, when I'm not at work or when I'm not doing any school work, I like to draw, I like to paint, watch my favorite tv shows, I like to eat, I like to sleep. If I'm up to it, I like to shop, browse the internet. Those type of things." Her undergraduate degree was in fine arts. During the Photovoice project, Michelle shared some of her work as well as some things that spoke to her artistic side, such as a picture of a floral arrangement and one of her knitting projects. Michelle also talked about some photography she did. Samaria commented on Michelle's photo, "I really like the butterfly picture the most because I think it's so interesting how you don't see her face, but you see more of her than actually what she was trying to capture." Art seemed to be a major part of her identity.

Strong Sibling Bond

(Research Question 1)

The first set of interviews with the sisters and their mother, Ethel, was primarily positioned to address the first research question: How do two Black American siblings interact

and support one another when one sibling has a developmental disability? The sisters were interviewed individually, then together, followed by Ethel's individual interview. Being that Ethel is their mother and significant influence in their lives, she was also most appropriately suited to share her intentions as a parent and clarity regarding some of the values and beliefs Samaria and Michelle expressed. Because the interviews with Ethel were conducted to provide clarity and support for Michelle and Samaria's interviews, findings from the interviews are combined.

During the first dyadic interview, the sisters shared some of their childhood memories. This conversation is included, like the individual vignettes, to provide a broad picture of their sibling experience. They shared experiences that reminded them of each other's personalities and experiences that demonstrated aspects of their relationship, as well as their family values and relational dynamics. This theme will be followed by challenges, differences, and characteristics of the relationship. Within that theme are subthemes including guidance, support, and desires for more closeness. This section addressed their perceptions of their relationship and characteristics of the relationship. Many of these experiences were supported by the Photovoice project and field notes from the various interviews.

Memorable Experiences Through the Years

One of the first things mentioned was family vacations and reunions and the value of those experiences within their family. Michelle discussed a family trip to a summer program she was a part of one year. Samaria and Miles met them at the summer camp location, as they were in graduate school at the time. Michelle shared a story:

> I was in the dorms at the school and the other work-study and I were there, we were chilling on the porch and then out of nowhere I see this black thing coming on the road so slowly. I was like – I couldn't put it – I couldn't say, oh my gosh, look y'all, there's a bear. I was like, "Look behind you!" and everybody busted inside.

They discussed a celebratory trip to New York when they were both graduating; Michelle from high school and Samaria from undergraduate. During the Photovoice project discussion, they shared pictures from both of the experiences, demonstrating the stories they had told previously. In one of the photos, it showed Michelle in front of their lodging during the family trip. In another photo, Michelle and Samaria were together during their New York graduation trip. To them, both of these photos represented family supporting them in their endeavors.

They went on to talk about their family dog, Oreo, who was a little black and white dog who lived outside because their dad was not an inside dog kind of person, per the sisters' explanation. When their parents were not home, they would let Oreo into the house. Both sisters exclaimed "Get out here dog!" demonstrating how their father would react when he discovered the dog indoors. They also had a family bird. They told a story of when Michelle pretended to be the mama bird and sat on the bird. Michelle had killed the bird and was disciplined because of it. She playfully and simply, "I didn't know." Samaria goes on to describe the incident:

> Broke his neck and she's like, Dad, something's wrong with the bird. And he comes back like holding the bird, oh my gosh is he ok. Like holding the bird. And I'm over here crying like "my only friend" (laughter) "why she killed my friend" (demonstrating crying). It was like, you know, like someone really – it was a bird because you know I was a little kid. Yeah. She sprayed another bird with some cleaner called Fantastic.

The explanation of the incident was filled with laughter and dialogue between the sisters.

They each went on to discuss other memories that ranged from Samaria knocking Michelle's tooth loose during a pillow fight to Michelle joking about how Samaria would take her along when meeting boys during teenage years. Michelle was also the maid of honor in Samaria's wedding to Miles. Samaria discussed a time after her first child, Kahlil, was born where Michelle came to help her while getting adjusted to caring for an infant.

> Samaria: Remember when you spent the night after I had Kahlil, God bless her. I was a new mom and like oh man, my chest was so sore and I'm like, what is going on with this breastfeeding and she was like bringing me hot towels and putting them on my chest and like, you okay, and he would cry and she would bust in like you need help, what's going on, what's going on. And even when like if we were spending the night here and so it just was really like – it was sweet to see her like I'm an auntie and I'm on the scene if you need help. And I'm like, I don't really know what I'm doing. But she wanted to be hands on. Just I mean it's the simple moments.

Through these stories, they are outlining the various ways they banter with one another, conspire against others in the family for a little mischief, and support one another. In reflecting on these various stories Samaria added:

> I think, we can laugh really heartily on like very dumb simple stuff. I'm trying to remember. I mean, it doesn't take much and so that's like – she refreshes my soul in that way, it's just like lighthearted, I know she's not superficial or critical of me –

In telling a story about Samaria trying to connect her with a guy, Michelle interjected about Samaria being like a third parent or matchmaker and some of the roles Samaria has played in her life. These roles will be discussed further later in the findings. To sum up their reflections on their family memories Samaria added:

> I would say, just laughter and silly stuff and memories of gatherings and interacting with cousins or just being here and doing random stuff like –I think we were just happy at home and whatever. But yeah, just her being her and growing up like that's my sister.

Both sisters seemed to enjoy reminiscing and reflecting on some of the times that they enjoyed each other's company, supported one another, or simply joked around and had a good time. Based on these stories, it appeared that those times were abundant. Based on the stories they told regarding family vacations and childhood pets, their relationship was representative of what one would call a "normal" sibling relationship. It was filled with joy, laughter, and some playful banter between siblings. Within the discussion, they briefly touched on some of the dynamics within their relationship specifically. Those dynamics will be discussed in the following section further detail.

Perceptions of the Sibling Relationship

A significant portion of the interviews involved the sisters describing how the other is different in some way. Samaria described Michelle as having social difficulties relating to her disability, or special needs as Samaria described them. She also described herself as more extroverted and Michelle as more introverted. I also observed this dynamic while meeting them at the family home as well as the restaurant. Michelle was more reserved, often looking away or fidgeting with her hair, while Samaria's posture and conversation were relaxed and outgoing. This could also be attributed to the fact that Samaria and I had already interacted while Michelle and I had not I observed this again in the restaurant during the second interview, as Samaria came in and gave me a hug, eager to get started, while Michelle said hello, but was pulled into the conversation, as she did not initiate. During the interview, there were moments when Michelle took time to draw and create art during the interview, which was later included in the Photovoice project. This was both an observational representation of how Michelle was engaging in the restaurant when she was not being interviewed and a visual representation of her artistic talents. She chose to include the drawing in the photovoice project after the interview concluded. At the restaurant, Samaria mostly watched as Michelle interacted with the waitress, but she did interject when she felt Michelle needed assistance. Much of their dynamic was reflected in their interactions in the different spaces, and they were well aware of their differences.

Samaria felt that she was more self-driven, motivated, and independent as the oldest and often played the role of a third parent or encourager for Michelle. She seemed to feel that her sister was capable of doing more than her parents may have allowed, and through their sibling relationship she observed things that her parents may not have seen. Samaria also noted

Michelle's ability as an artist, citing Michelle's previous art displays at one the museums. This story was also accompanied by some playful banter as Samaria joked:

> I was in high school. It was a magnet school. We didn't really have no sports. I lettered in art. And then the artist comes behind me and the art teacher is like, oh, I thought you was good until I met your sister, you ain't nothing. (All burst into laughter) That's okay, I'm used to it. She's always been artistic. She's had art and child displays at the museum, I was just used to being like, I'm okay, but she's the prodigy. It's okay. I'm the dancer, she's not.

While playful, Samaria had somewhat accepted that Michelle was more artistic, but wanted it to be known that she also had gifts that Michelle did not.

Michelle often described herself and Samaria in a polarizing way of Samaria being the outgoing social butterfly and herself as, "the nerd, the geek, the person who likes to read comics that are not even American." She also spoke of Samaria's many friendships and the longevity of some of the relationships, describing Samaria as socially graceful. She stated:

> But you have a really close group of friends that really stuck with you. Me, I've only stayed in touch with like maybe one or two people since middle school and high school and that's it. Some friends I've had to let go because they were into things that – or into these influences and I was like, no, no, no. I feel that Samaria has known people since school and high school and she's, like I said, very socially [affable]-is that the– I'm trying to think of the word…Yes. You – there's something about Samaria that once she makes a friend, she always keeps the friend. Me, it's kind of harder to do that.

She went on to discuss some of her challenges with maintaining friendships, some beyond her control and some by choice. Ethel echoed some of the sentiments. One of the first statements Ethel made was:

> Because Michelle has some Asperger, she doesn't reach out to Samaria as much as Samaria reaches back to her. I often want to tell her, "call your sister. Text your sister." But I realize that that doesn't, you know, that doesn't make it any different for Michelle so, I can tell Samaria to reach out to Michelle etc. etc. and she will, you know. But they have a good relationship.

Ethel was forthcoming with her beliefs regarding some of Michelle's challenges. She expressed feeling that Michelle having Asperger's inhibited Michelle in many ways whether through her

relationship with her sister or friends outside of the family. Ethel noted her desires for Michelle to reach out to Samaria more or be the type of aunt who would pick up Kahlil and Maile and take them places. She also recognized that Samaria wanted those things as well, but expressed that she has accepted Michelle for how she prefers to engage.

Ethel also noted various personality and social differences between Samaria and Michelle. Similar to their own descriptions, Ethel described Samaria as more social and independent. Starting from early childhood, Ethel noticed differences between Samaria and Michelle. She expressed, “I knew all along that there was something different about Michelle, but I could not put my finger on it.” There was a family member in another state who noticed differences as well and suggested Ethel have Michelle tested. On the contrary, she described how Samaria did things early. Ethel added, “Michelle use to just point at stuff when she wanted something. She didn’t talk until later, she didn’t walk until later.” When Michelle was tested, they reported that she had difficulties with expressive and receptive language. She also noted that Michelle was very intelligent and gifted. She spent time in both the special education program and the gifted education program. Even with Michelle’s challenges, Ethel expressed, “she's exceed my expectations in some things and that’s made me very, very happy. Very happy.”

During the conversation, Samaria talked about their experiences while in school and how they may have been similar. In school specifically, Samaria mentioned some of the challenges her sister faced that may have been similar to her own. She stated, “I feel like – it’s a similar struggle, but it’s different, like we both were in ‘special’ education but it was for different reasons, like she's brilliant but she has some social challenges, she had some developmental challenges…” From Samaria’s perspective, their experiences were similar in that neither were a part of the mainstream experiences in their schools. She went on to say of Michelle, “it looked

differently, like she's always been artistically genius and very genius in other subjects as well. She just procrastinates and gets overwhelmed and then like implodes because like 'I'm so stressed, you can't rush an artist.'"

Michelle interjected by saying: "I guess – that's something else that I struggle with, procrast – and I've been doing research and wondering, do people with Asperger's have a tendency to procrastinate and is that a mental problem or is it just…" At this point, Samaria and Michelle started to show more of the non-verbal dynamics within their relationship. When Michelle made the above statement, Samaria interjected with statements like "being human" in response to her tendency to procrastinate and "But I think she tried, like she tried" in response to her effort to try and socialize more. This was a trend throughout the interview of Samaria showing her support through normalization and validation of Michelle's effort. Michelle had a moment when she decided to share how she felt about their differences:

> So – but if, sometimes I wonder if it were really like that, like sometimes – I have a – and this is a bit of a confession, I sometimes compare myself to Samaria and, you know, we go to the same schools, we went to the same college, but we're still different, we might be sisters, but we're still different kinds of people and sometimes I wonder does mom and dad love one more than the other and if so, why? But I have since learned that that's not the case it's just we're different ...

Overall, both sisters seem to have areas that they appreciate about one another, and areas where they desire to be more like their sister such as more outgoing or more willing to think outside the box. They went on to discuss how these differing interests, experiences, and personalities impacted their sibling relationship through the years. While there were some challenges and desires for more closeness, Samaria described some of their commonalities and times when she felt close to Michelle. For example:

> We have really corny jokes and laugh and most of it's directed at my mom or mocking my dad, so but yeah it's definitely umm that and she always finds some like random Youtube video. I mean she's quirky, she's different, but I appreciate that about her. Just

> like her doing her which is different than how I do me, but yeah…Eat, we both like Asian food, shopping, and then if we can find like something we can agree upon on tv.

Samaria expressed being proud of Michelle for the growth that she has shown through the years. Being proud of the sister with the disability overcoming challenges is a common theme in sibling literature. Sisters have expressed underestimating their sisters due to their disability (Richardson & Stoneman, under review) and recognizing the effort it takes to overcome some challenges. This concept was present in Samaria and Michelle's relationship as well. Samaria also described Michelle as a really great artist -which turned out to be a very important part of Michelle's identity- and generally spoke very highly of her sister. While there may be a desire to have a closer sibling bond, she was able to discuss ways in which they are able to spend quality time, enjoy each other's company, and appreciate each other's differences. In all the ways they described the dynamics within their relationship, the most significant were desires for more closeness, guidance within the relationship, and support. Each of these dynamics are described in more detail below.

Desires for more closeness. When asked about her sister and their relationship, Samaria described her perception of some of the challenges of having a close sibling relationship. She stated:

> Well like growing up and knowing that she had special needs if you will or just some challenges and her personality, it was like I have a sister, but it's kind of like, she ain't really feeling me so it's kind of like, it was kind of lonely sometimes. Then being the eldest it's like, if she do something, it's your fault because you didn't tell her better and all this foolishness. And I remember like wanting to be closer to her and even now, but I know like, now I'm comfortable with where we are and not pushing things.

Samaria mentioned several times that she found it difficult to have a strong sibling relationship with her Michelle due to Michelle's social challenge. When asked her perspective on how close she feels her relationship with Samaria is currently, Michelle stated:

> It's not like I'm considering one an outcast and the other room the special child who's favored by her parents, it's not like Jacob and Esau if that's what you mean. (Laughter) – I'm just saying, it's not like that, you know, it's not like Cain and Abel either, I'm just saying. If I knew we were like Jacob and Esau I would say, but no, thank God, it's not that bad.

During Michelle's individual interview, she expressed her own challenges with developing a strong sibling relationship

> So I learned about Asperger's and people with Asperger's are just socially clumsy for lack of a better word. We are…We're so interested in different things that other people don't necessarily… Thank you (in response to me handing her tissues). It's like, the things she likes are not things I like and the things I like, well, I don't know if she likes that. And, I just feel like…you're in the world, but you're not really a part of it. Like you are always surrounded in a bubble that no one else can penetrate.

This moment was unexpected because Michelle was being very transparent and open with her emotions with me, someone who is essentially a stranger.

When asked if Samaria knew she felt that way, Michelle responded, "She knows… well, the bubble part I don't think she knows." She believed that Samaria would want to penetrate the bubble and understand her more, but she did not believe it was possible. Michelle expressed:

> She could be beside it, but not the one to pop it, like, to put it in a better phrase, I feel like an alien. I came from a different world, a different planet and I look like a human, I talk like a human, I was born from a human, but I still feel like I don't belong.

It was clear that this was a very emotional topic for Michelle. She went on to say that she believed their relationship dynamic was her fault because of her social difficulties. She described steps that she could take to improve the relationship which included things like taking more time off work and being willing to drive to see Samaria or talking more often. I asked if she would be willing to share those feelings with her sister in the dyadic interview and she agreed. Interestingly, Ethel described Michelle's social life as, "just in a bubble kind of, you know. In a bubble." Michelle also described herself as being in a bubble. Neither of them had discussed that feeling to that point, so it was interesting that they used the same phrasing.

Throughout the interview, Michelle seemed to take on the responsibility for the dynamics within the sibling relationship. For example, she stated:

> I think, the reason why we're not as close is because I put myself in my own world where I enjoyed my things. She talked about video games, she's not a video game person. If I had known that as a kid maybe I would have, I don't know, spent more time with her on the phone or in the kitchen or shopping. It might have made me uncomfortable, but if I knew that growing up this was going to be – it would have helped, then I might have taken a bit of more time, but I guess I get so absorbed into what I like that I don't think about, you know, the bigger things that matter more.

Samaria, however, described the reasons why she believes their relationship is the way it is. Samaria spoke multiple times of allowing Michelle to lead the way in the relationship. She stated:

> I'm respectful of where she is because growing up I did used to want, oh, the sisters who like fight but then they make up and then they play house together and they do all these things. We hung out, but it was definitely one of those where we know that we like different things and also, we're like four years apart.

Sibling relationships in families of people with disabilities have been describing as less conflictual (Orsmond & Seltzer, 2007a; Stoneman, 2005; Taunt & Hastings, 2002), which is supported by the dynamic within Michelle and Samaria's relationship. This assertion was accompanied by a comparison to their friends' sibling relationship and noting how their relationship was different. Their perception of their sibling relationship was also influenced by what they had observed from their mother's relationships with her sisters. Samaria and Michelle described how close their aunts and mother are because of the culture where they grew up and how they on the phone on a regular basis. While there was comparison to other relationships, Samaria appeared to recognize and understand that relationships can be different. While there seemed to be some desire to experience some of the experiences of their friends, they accepted their status for their own relationship.

Samaria also discussed how her husband coming along helped the cultivate their relationship. He offered guidance relating to her role as the "third parent" and how that may be impacting their sisterhood:

> Samaria: …I think when he came, it helped cultivate our relationship-it helped cultivate our relationship more because he would be like, you know, I know you love your sister, but don't talk to her in that tone. If you really want her to open up to you, do – so he would give me some advice like how to be a better sister and not being more of her like overbearing parent.

During the interview with Miles, he also recounted these conversations. He expressed that he recognized how Michelle would respond to Samaria when she would say things a certain way and felt that he should say something. Early on in the relationship, he admitted that he did not fully understand their dynamic and chose to stay out of the relationship, but as the relationship between him and Samaria became more serious, he felt compelled to offer feedback, particularly as he was learning more about relationships through counseling training. He also began to develop his own relationship with Michelle over time as he learned more about her and how to communicate with her. According to Miles, it took a while for her to warm up to him and for him to understand her disability and how it impacts how she socializes.

Samaria's relationship with Miles continued and they are now married with two children. Michelle discussed how Samaria having children helped her to feel closer to Samaria. Michelle would also make stuffed animals for them. They began to talk to about that experience:

> Samaria: But yeah, and even like I said when I had my kids and just the fact that she wanted to make stuff for them and that she wanted to be hands-on and different things and like over the summer we were at our family reunion and like she heard Kahlil cutting up, she knocked on the door, hey, everything okay? You need help? I'm like, come in. Kahlil, go with Tee Tee, just go. Just – bye.

> Michelle: Yeah, it's funny because her family is helping me to be closer to her, it's like I get to hang out with Miles before they had kids and when they do have kids, it's like, okay Kahlil, I'm still learning about you but let's hang out. I made him a bear and I made

> Maile a fox and what's funny, both of them have scarves, the animals I made, they both have scarves. I'm just saying.

Surprisingly to Samaria, Michelle would help with the babies when they were on family vacations. During the Photovoice project, they shared photographs from a vacation. The photographs included pictures with cousins and the babies. To the sisters, this was another representation of the closeness of their family and their willingness to come together and spend time with one another.

Some of the challenges with feeling close to one another were related to their physical distance from one another. However, they both seemed to believe that the distance should not be a factor because it is such a small distance. At this time, the moment from the individual interview with Michelle reemerged. She was able to tell Samaria how she felt about their relationship. Michelle expressed:

> Okay, well I feel like our relationship could be better. I know that we just live an hour away, just an hour and a half drive, but sometimes I feel like travelling even that distance can be a bit much for me so when I think about, you know, all this time that I could have at least picked up the phone and called you or sometimes on a day like this, I get off from work and then it's a new day and I'm off and I'm like, I don't feel like doing anything, I'll just stay in bed, this bed is so comfortable, but that's time that I could be using to spend time with my family in New Orleans.

Samaria expressed that she had similar sentiments regarding their distance and her desire to spend more time with Michelle. In response to Michelle's comment above, Samaria expressed:

> I've always felt like – and this is not from me being like prideful, but I always felt like I was a safe space for you so you didn't have to fake with me, so if you feel like you do have to fake with me, I'm sorry that you feel that way, cause you don't. Like I think if anyone has understood you, it's been me because I've always like been there, literally seeing you grow.

Samaria went on to discuss how during childhood, she was the only one who could understand Michelle and helped to communicate with others. She was shocked to know that Michelle did not

feel as close as Samaria believed she was. She also stated how she wanted to give Michelle space and respect her bubble. Michelle seemed to appreciate the response.

She went on to express some of the ways she desires to participate with Samaria and her family, including spending more time and helping financially. Michelle talked about a book she read regarding Asperger's and how it helped her to understand herself. This conversation led to Michelle realizing that she preferred things over people. She ended her statement by saying to Samaria, "Maybe that's why I almost ignored my sister and I feel terrible, terrible about it. I'm sorry." To which Samaria responded, "No, no, don't feel sorry, because I knew you had other interests and that's alright – I mean, I think too it made me more independent." Samaria also expressed that she was grateful to have her sister because childhood may have been lonely without Michelle.

While they both desired to have a closer relationship, there was still a strong sense of closeness and bond between them, whether through their interaction during the interview or their descriptions of their relationship through the years. It was clear that they loved and cared for one another and enjoyed each other's company. From inside jokes to a mutual understanding and respect of their differences, there were strengths in the relationship. They each noted ways they could act differently to foster more closeness between them and things they want to change going forward, such as more frequent visits, sleepovers, and more frequent texts, which Michelle prefers rather than calling on the phone. Michelle stated that she could listen to audiobooks to help her through the drive. They both recognized that they desire to have a closer relationship.

During the entire interviews, they talked more with each other than with the interviewer, so their dynamic was reflected through their short conversations. I observed the differences in their personalities, Michelle being more reserved and Samaria more outgoing. However, there

was a level of comfort and openness between the two of them that somewhat felt like I was not there at times. Michelle was very open and engaged in the conversation and over time, their different ways of expressing themselves and telling their stories almost masked their social differences. There were times when Samaria would be telling a story and Michelle would make a statement or Michelle would be telling a story and Samaria would ask her a question or they would finish each other's stories. They would ask each other questions for clarity on a situation.

There were multiple stories where they would rely on each other's memories for the story or finish the story for their sister as they laughed. This seemed to be a typical dynamic for them, as they confirmed that it was their way of interacting. There were many impactful, emotional conversations during the interview. It seemed that both sisters were ready for these conversations and desired to have a closer relationship, but there was not yet a space for the conversation. This could possibly be related to Michelle's disability in that she may not be forthcoming with her feelings, and Samaria's decision to let Michelle lead the way in their relationship. However, they both seemed to want to share their feelings and needed the opportunity.

Like many sibling pairs that include a person on the autism spectrum, there are challenges within the relationship (Orsmond & Seltzer, 2007a; Tomeny et al., 2012). These challenges are often in the form of social difficulties and behavioral challenges (Estes et al., 2009; Orsmond & Seltzer, 2007a; Seymour et al., 2013; Zablotsky et al., 2013). The sisters in this study shared similar insights and experiences within their relationship, but the challenges mentioned were primarily social rather than behavioral. Consistent with the current literature (Rosetti & Hall, 2015), the biggest issue regarding their relationship was desiring to be closer one another. Because adults with disabilities often require support throughout the lifespan, relationship closeness is a common area of inquiry within the disability literature (Atkin &

Tozer, 2014; Davys et al., 2015; Tozer & Atkin, 2015). Like other sibling relationships when one sibling has a form of autism, barriers to the relationship include time together, distance, and diagnosis (Orsmond & Seltzer, 2007b; Rosetti & Hall, 2015), which in this case is Asperger's which specifically impacts social and emotional relationship functioning (American Psychiatric Association, 2013).

Both sisters discussed some of their personal challenges with their relationship. They often discussed their sister's personality as drastically different than their own, which they seemed to view as a barrier within their relationship. For example, Michelle would describe herself as a nerd who liked different things than Samaria, so they did not spend time doing combined activities. Samaria was described as more of a social butterfly with many friends while Michelle had few friends, which she preferred. However, the preference for limited social connection did not extend to the relationship with Samaria. Rather, Michelle expressed desire to feel closer to Samaria. This portion of the interview was emotional for Michelle, displaying how important having a relationship with her sister was to her.

Samaria mentioned several times that she hoped for the type of relationship she observed her peers having. Samaria perceived those relationships to be more desirable based on the amount of time spent together and types of activities those siblings would do together. When recounting their childhood, both sisters noted that they would see other sisters fighting and admitted to not having that dynamic. According to Kaminsky and Dewey (2001), it is common for siblings of children on the autism spectrum to have less conflict and competition. However, Michelle and Samaria did not necessarily view the conflict as a negative aspect of the relationship but rather a normal aspect of relationship between sisters.

While both sisters expressed satisfaction in their relationship, they also expressed difficulty finding ways to connect. Michelle admittedly struggled with reaching out to her sister Samaria and Samaria had settled on allowing Michelle to determine their level of interaction. However, it seemed that the decision to maintain the status quo contributed to the distance rather than creating comfort, as intended. They reported experiencing changes throughout the research process. During the follow-up portion of the second interview, Michelle and Samaria reported things that they had already begun doing to improve their relationship and foster more closeness between them including planned overnight visits and more frequent contact. The desire was already present, but neither knew nor understood how much their sister desired to improve the relationship. Being able to have an open dialogue about their desires for the relationship led them to a better understanding of the type of relationship each sister wanted and allowed them to figure out solutions to help obtain that level of contact.

Guidance. The second subtheme to emerge regarding the relationship between Michelle and Samaria was the idea of Samaria being like a third parent to Michelle. The types of advice ranged from tips about dating to assistance with school and career. Samaria's guidance ranged from subtle reminders to blatant directions on how to do things. During school years, Samaria was able to get Michelle to do things or take direction in ways their parents could not. The "third parent" status was somewhat driven by their mom soliciting Samaria's help at times or encouraging Samaria to check in on Michelle. In her individual interview, Ethel stated, "if Michelle needs Samaria, needs anything, she's there for her. As a matter of fact, she's like our first go-to person when something with Michelle comes up as far as socialization or even education." When it came to school, both Samaria and their parents were trying to get Michelle

to take her time and move at her own pace. In Michelle making the decision to go back to school for her master's, Samaria urged:

> I was telling her, like please – I've been in school long enough, please don't just do school because you feel like you have to. Do some soul searching, find out why grad school would – what would it do for you, because – you understand, like it's not the kind of thing, oh, it's the universal experience, like no, it's uh uh, just do something else.

Because Samaria had already completed both her master's and doctorate, she felt that she had enough experience to help guide Michelle. For this reason, Samaria experienced some angst when Michelle did not come to her for help with an essay she wrote for school. She expressed:

> But when she did go back to school, I was salty because my mom was like, you should read her essay, it's so good, and she didn't send it to me. And I'm like, but I'm a professor, why wouldn't you send me – and it was like, respectfully, like I can understand she wanted to do this her way and I was proud that she did send me a few other things that she did for school and I was like, yay.

Michelle did not appear to have known that bothered Samaria, but she assured her that she was not intentionally trying to leave her out. They discussed a few times Michelle had difficulty in school and Samaria attempted to offer guidance with coursework and process-related issues.

They also discussed dating and Samaria's mission to connect Michelle with a partner. There was a point during Samaria's wedding festivities where she and her husband Miles sat Michelle down to talk about how to start dating. That advice included opening herself up to be more social, which Michelle admits is difficult for her.

> Samaria: Oh, when I was getting married, my bridal shower, I could tell that she was in a funk, like one, it's a social setting, and two, she was in a funk. And so like after the bridal shower, I'm like, what's going on? And you're like, oh, no offense, I am happy for you and Miles, but I can't help but wonder if I'll ever have my own day one day. And so, we ended up having like a relationship session with me, Miles, and her, it was like, well, if you want to be in a relationship, you kind of got to be available to people, you kind of have to be vulnerable, you have to share your time and your space, think about just starting with having friends. You can't just jump into having a relationship, like if you're in a relationship, are you going to want to be bothered with them? Like, no, I'm taking a nap right now.

They recently talked about a man at Michelle's church recently who Samaria thought would be a match for Michelle. Samaria described him as bright and quirky. Michelle and Samaria had a brief conversation about this during the interview. Michelle mentioned that she had gone to the movies with the guy but had not told Samaria. This was another example of a time that Samaria felt left out, but again, Michelle let her know that it was not intentional. Michelle did not automatically think to share the information. It seemed as though Samaria placed more emphasis on sharing individual experiences than Michelle may have, but it also did not seem that Michelle trusted Samaria any less or did not want to be transparent.

Michelle would also like to move out on her own soon. Samaria and her mom have encouraged Michelle to make sure she is financially secure enough before taking on that responsibility. Samaria suggested a roommate or waiting until she has finished paying for her car. Samaria also used her own experience of being on her own and wishing she could move home to help guide Michelle to making the best decision for herself. In response, Michelle concluded, "I've realized now that, yes, rent, is too much for one person to handle and I already have a car note, I'm already trying to pay for school, so I'm thinking maybe I should stay here for a while longer." Relating to the idea that Michelle was trying to keep up with others around her, Samaria continuously encouraged Michelle not to try to do things the same way as she did. Michelle confirmed that she does compare herself to Samaria and what she has or does and uses it as a benchmark to what she should be doing. Samaria expressed to Michelle:

> Yeah, don't feel bad for being who you are, I know you're – we're both still growing in that and I think that's one thing I've tried to be transparent, from your vantage point, it may seem like I'm all that and a bag of chips which is a very kind compliment, but let me tell you, I am not. And try to just be transparent.

It appeared that Michelle values her sister's advice and guidance when given. There were not many times when either sister mentioned any contention or resistance relating to Samaria sharing her own wisdom through her experience.

The guidance, however, was not one-sided. Michelle also offered advice and support to Samaria in other areas. The main area they spoke about related to hair and both of their natural hair journeys. "Going natural" refers to the choice that Black women make to no longer use chemicals to straighten our hair and is often an emotional and challenging time for Black women. Samaria had been natural longer than Michelle, but Michelle had taken more time to learn about her hair and try new things. Now she is able to share tips with Samaria on how to better care for her hair. Michelle took the time to learn more and is more meticulous with her hair care regime and that is something she and Samaria can share and is valued within their relationship. Shared experiences and mutual advice are not areas that are often discussed in disability literature. There is an assumption that siblings' experiences are drastically different and having little mutual ground. That was not the case for these sisters. They shared many experiences and offered guidance and advice in various situations. The same could be said about support, which is described in the next section.

Support. Support between the sisters was major focal point. This included material ways they support one another, but also expressions of emotional support both during and outside the interview. For Michelle, supporting her sister Samaria meant providing postpartum support such as helping Samaria when she had her first baby. Michelle would bring hot towels during breastfeeding sessions or spend the night with Samaria so that she could be there to help with the baby if needed. This gesture was special to Samaria because Michelle had little to no experience with babies and did not enjoy children. However, when Samaria needed her, she offered to be

there. Michelle stated, “If I could, I would be her babysitter and if I could, I would take her kids the library while she gets her hair done, gets her nails done, get her pedicure done.” Samaria responded with, “oh, that would be a dream.” Michelle made things for the children as well. Michelle also served as the maid of honor for Samaria’s wedding.

Samaria’s support of Michelle came in the form of being there for special moments for Michelle, such as her trip to camp. Samaria and Miles drove from another state to be there with her and the family for that experience. Outside of the support through various acts of service, they also supported each other emotionally. Samaria spoke several times about encouraging Michelle to be herself and embrace her differences. She went on to say:

> But yeah, so just like I recognize your uniquenesses and our similarities but also our differences and I'm at a point – I had to let that go a long time ago, so just know that if there's anyone you should feel safe with, it should be family, but it should definitely be me because as your older sister, I've seen and I maybe remember some stuff that you don’t remember, so if you want to be vulnerable and do more, I'll support you in that, but I'm not going to force you in that.

She mentioned several times how smart Michelle is and how much she believes in her. When Michelle expressed interest in moving out of the family home, Samaria encouraged their parents to let her try. Samaria expressed to them how much she believed in Michelle and offered to help her sister during the process, and so they started looking for a potential apartment. Michelle mentioned that Samaria would make up songs to make the process more fun. Making up chants was another memory for them that signified their bond and was something that only they understood. Although Michelle decided not to move out at that time, a decision also influenced by her sister’s guidance, Samaria was there to support Michelle and encourage her to try the things she wanted to experience.

Through the interactions I observed, it was clear that Samaria’s presence made Michelle more comfortable. For example, Michelle mentioned previously that she struggled with

trichotillomania. During the final interview, Samaria would give Michelle gentle reminders to stop touching her hair. There was a point in the interview where Samaria had to leave the room. Michelle's fidgeting and hair touching increased significantly while her sister was outside the room. Her level of eye contact changed, and she was shifting her body more frequently. All of these behavioral changes decreased once Samaria returned. Her sister makes her more comfortable.

There was a powerful moment at the end of the first interview where Samaria told a story about a very difficult time during college. Samaria made a painful decision that affected her tremendously.

> Samaria: For some reason, I confided in her of all people, right? The introvert, like "why are you telling me" – but she, in that moment, I just was like, I couldn't take the guilt anymore and we were riding down a street down here I think and she was like – I was like, I feel like I need to tell mama … I'm like confiding in her about something so intimate not knowing how emotionally she'll respond and she was there for me in that moment and I've always cherished the fact that you were there for me in that moment… I'm sorry. (Grabbing tissues) … But yeah, so even though she may – even though you may feel like you don't have a lot to offer or a lot to give, there have been specific time points where, without a shadow of a doubt, you were there for me. So, be confident and courageous in that, that you were – you were there for me when I needed you and I didn't even know that you would come through.

Samaria continued by expressing how proud she is of Michelle and all that she has accomplished despite her challenges. Michelle responded in that moment:

> Thank you. And I guess I should say – it is weird kind of seeing my sister as the trailblazer of the family… But to know that my sister is not pushing me to follow in her footsteps but to try and be the person that I would want to be, it means a lot because we hear stories about these families who push other family members to conform and it's heartbreaking, but this family is not like that and I'm glad to know that my sister is not trying to make me be someone that I don't want to be…And you're understanding about where I am, where I was, and where I'm trying to go and I don't know what it would be like if I didn't have that kind of support. Thank you.

This moment was extremely powerful because this was the first time Samaria had shared her feelings with Michelle regarding their relationship. It was a moment that could not be

completely captured through words itself, but there was an emotional breakthrough between the sisters. It was an extremely emotional moment for both sisters and aspects of their relationship became clear that had not previously been revealed to one another. This moment also demonstrated something that is not often expressed in the literature. Support was not simply about caregiving. Both of the sisters were expressing and demonstrating a mutual emotional and moral support rather than a unidirectional type of support. Because of challenges with building relationships for people with Asperger's, it is not common to consider emotional support within relationships. Support in disability-related sibling research is not groundbreaking in and of itself, as it is one of the most commonly researched areas, but support looked very different between these sisters. It had little to do with caregiving or needing support external to their relationship. Their support was solely about supporting one another through the many stages of life, which is more typical than not. This is an area of growth for researchers when studying sibling relationships in families of people with disabilities.

The Influence of Extended Family Values and Kinship

(Research Question 2)

The next section focuses on the sisters' experiences within their families and communities beyond their relationship with one another and was positioned to address research question number two. This included examining influences on the sisters' identity development both while growing up and currently. The top themes from this interview included extended family influence, importance of faith, and the superwoman complex. Each of these themes will be explained in further detail in subsequent sections.

Extended Family Influence

A major influence on the sisters' upbringing and many of their experience in adulthood either involve or center around their extended family. Many of their memories involved events like family reunions or family vacations with their cousins. They discussed some of their family traditions on both sides of their parents' families. Another family tradition they shared was going to the Bayou Classic each year, which is the football game held on Thanksgiving weekend between Southern University and Grambling University. Attending historically black colleges and universities (HBCU's) was also a legacy within their family, so much so that Samaria decided to become a professor at one. Michelle recounted a recent experience at their Tucker family reunion where their cousin Janice began to cry when speaking about family:

> You know, she was explaining, while some of us are here today, a lot of people weren't there because they passed away from cancer or they passed away from Alzheimer's or- And so, she – just becoming a mom, being a wife, hosting this – I think it kind of opened her eyes as to who is here, what generation is here, what generation is no longer here, those who are, you know, and just the overall family legacy. So, dad just shared his heart and his feelings and I was like oh my God.

This moment was also special to them because their father was described as not being an emotional person, so him showing that emotion around the extended family was meaningful. They described the closeness within their family and the value of the family bond. Because their family members were spread across the country, there were many places to visit on vacation. Locations included Texas, Mississippi, Gulf Shores, Florida, and DC, to name a few. They shared some of the photos from those experiences during the Photovoice conversation.

Photos of them with their cousins were referenced several times because they displayed multiple parts of their family, particularly Black women, and included multiple generations with Maile included. In discussing the family reunions, Michelle mentioned a family of sisters, their cousins from the Marnier family, whom Michelle adores. During a family reunion one year, they

were not present. Michelle expressed, “I was so upset, so devastated.” Samaria interjected, “because that like to her, they were… if they weren’t there, then it wasn’t a family thing.” To Michelle, a piece of the family was missing if they were not in attendance. They mentioned these sisters many more times during the interview. They also planned girls’ trips for the women in the family. When their grandmother died, Samaria remembered feeling the importance of getting the women in the family together when possible, so they went Florida last year. Some of the photos from that trip are included in the Photovoice project, along with photos of the Marnier sisters. Being intentional about involving multiple generations within the family in their events was common for their family.

Multi-generational influence. Samaria and Michelle recounted memories of staying with their grandmothers, eating mayonnaise sandwiches and watching The Young and the Restless, a long-standing soap opera. Samaria told a story of a time Michelle received a whooping from their grandfather for disobeying his rules and their father got upset with their grandfather:

> Samaria: And he was mad that my grandpa, my grandpa whooped Michelle. He was like, he whooped you behind a coke? And I'm like, mind you, no one else drank the Coke, Michelle was the one who drank the Coke, we all got the memo, we all remember the stories of getting whoopings when – everybody getting a whooping even though only one person did something wrong. And he was like, you don’t whoop a kid over a Coke and my mom said, but it was the principle and the principle was, he told her not to…

There was a point where Michelle and Samaria’s paternal grandmother was sick and she moved in with their family. Samaria expressed that, at the time, they did not understand what was going on, but now recognize as an adult the importance of taking care of family. Along those lines, there was a cousin who was displaced due to hurricane Katrina and he came to move in with their family as well. Michelle stated, “we’re pretty close because of that.” Samaria added, “he was like the brother we didn’t have and he used to be so silly as a boy though.”

Samaria and Michelle's mother Ethel has five sisters and they have a close relationship according to the Samaria and Michelle, verified by Ethel. They shared a photo of their mother with all her sisters during the Photovoice discussion. Each of their aunts have different talents or play different roles in their lives. For example, one of their aunts is skilled at doing hair, so she would braid and "perm" everyone's hair in the family. There is another aunt who is into thrifting, and so she shares that hobby with others in the family. Two of their aunts are twins, who Samaria described as having very different personalities:

> One is very strong and assertive and the other one is more like nurturing and emotional kind of thing. And so, the aunt who was the ex-con that can braid hair and do all that, she was the big sister and the baby sitter for the strong independent twin, the baby twin. And then my mom took in the more nurturing, more cuddly soft-hearted twin. Does that make sense? So, it's like –

Based on Samaria's description, two of the older sisters helped to raise two of the younger sisters to be similar in personality to themselves. The aunt that their mother, Ethel, took in actually lives in the home with their mother and father currently. Michelle described this aunt as knowing how to cook, clean, and give good advice. Samaria added that her aunt is also fashionable and gives Samaria hand-me-down shoes. She concluded her description of the aunts by saying, "she would be my vote for replacement" if one was ever needed. Samaria described their mom as the matriarch of the family:

> In her family as – so there's an older sister that has a different dad and she was raised with her dad's side, so my mom was like the oldest sister. So, she's like the matriarch, I'm in financial trouble, so and so in jail, so and so is beating on me, I'm leaving him. She's the go-to for emotional – my cousin that's in Angola, he calls her more than he calls his own mom.

Michelle agreed. She went on to talk about how where she feels she belongs within the two sides of the family. Michelle shared:

> Sometimes I feel more like a Toussan than a Toussaint. I'm supposed to be a black woman in Louisiana, but mmm, I don't feel like a Toussaint today. I might be at this

> family reunion, but that don’t mean anything. I sometimes feel like I'm not old enough to be in the Tucker family, because all of the cousins are older than me by a decade and I'm like, my cousins are older than me by a decade or at least four or five years, there's something wrong, I'm the baby.

Michelle seemed to find it difficult to find a connection to the family in some ways due to her own differences, whether those differences be age or not feeling connected to her perception of what a Louisiana Black woman should be.

Fictive kin. Extended family did not end with aunts and cousins through blood. Samaria and Michelle also included their aunts and uncles by marriage and discussed some of the ways they have influenced their family. Church community was also included in their definition of extended family. Some of the church community also lived in their neighborhood, so they could connect outside of church. Samaria stated, “So we would like just be between each other’s houses and playing and growing up together and it was almost like having more brothers and sisters.” Michelle talked about still being close to some of those friends to this day. Michelle mentioned that, if anything were to happen to her parents, she would want to go with the Rinehart family down the street because she has known them all her life.

During Ethel’s interviews, she also discussed her beliefs and values as well as extended family relationships. As already established in the dyadic interviews, extended family is important to the Tuckers. Ethel has five sisters and has a close bond with her sisters. In addition to her own sisters, she also mentions the relationships she has with her in-laws. Her sister-in-law is the person who helped guide Ethel through the process of adjusting to having a child on the autism spectrum. In the dyadic interviews, Michelle and Samaria talked about their family reunions and mentioned a story about the Marnier sisters. Ethel also told this story and described how upset Michelle was after finding out the sisters would not be at the family reunion. This

story, in both instances, demonstrates how important their extended family bonds are to them. The women in their family were also exemplars in different ways. Ethel described:

> My family, being a woman. I would say, especially from his side of the family, he had two sisters, very strong women. Independent. They were educators, professionals. So they had role models, they always knew they were going to college, there was no question about that. I have five sisters and we're all very, very close and so – and I have a lot of nieces, so I would say, you know, we all got along as women. I got along with my in-laws. I don't believe in that gossip and chatty kind of stuff.

There were several other stories that Ethel mentioned demonstrating the role and importance of extended family in their lives. While not explicitly stated, extended family play a major part in the sustainability and socialization within the Tucker family.

Extended family was a highly important part of their family experience. Not only did the family play material roles such as babysitting and helping around the house, the members of the family helped shape how they viewed the world and themselves. Whether through practices of faith or the day-to-day living of their experiences as Black women, their grandparents, aunts, uncles, cousins, and church family had some level of influence and both Samaria and Michelle value that influence on their own lives and their responsibilities as extended family members to others. This view of extended family is unique in disability studies because extended family is typically viewed as support. In this study, extended family played a major role in identity development and overall family experience instead of solely relating to the disability.

Family values. Ethel discussed some of the values she hoped to instill in Michelle and Samaria. One of their family values was respect. The idea of respecting your mother and father was important in their family. Ethel also stressed her husband's role in making sure their daughters respected her as their mother. She told a story of how Michelle made a statement while they were watching television, which Mr. Tucker perceived as a lack of respect. According to Ethel:

> Something on television and I was trying to figure out a commercial and I was like, why would they make a commercial like that and then it came to me, it had something to do with our judgment and how we would handle that commercial. And she said, "mom, maybe they're testing your ignorance." And she didn't mean my ignorance, she meant general, people's ignorance. And he said, "don't say that to your mama." And I'm like, "Michelle, it's okay," because he's very protective of me and the way they talk to me, but my children and I are friends.

In that case, Ethel demonstrated the importance of respect in how her children speak to her, but also her and her husband's differences in perception regarding how the children showed respect or disrespect in this example. She went on to say, "we are friends. I used to tell them when they were little, 'I'm your friend, but-' you'll have to ask them, they'll know how it went because I've forgotten it." As Michelle and Samaria have gotten older, Ethel seemed to have transformed her perception of how they should show her respect. After she remembered, the saying was, "oh, you don't have to like me, just do what I say. That's what I told them. You don't have to like me, just do what I say. So that was something that I would remind them of here and there." However, as adults, they are more friends now than when they were children and therefore, have more freedom in the types of conversations they have and how they have them, according to Ethel. This dynamic was observed in their interaction during the home visits. I noted the balance of power in the relationship when their mother was around. They joked with one another, but there seemed to still be an understanding of how they should talk to her during conversation and they also listened to their mother's directives.

Some of Ethel's other values related specifically to race and ethnicity. Ethel discussed the importance of exposing her children to different cultures and types of people. She stated that she always taught them not to be prejudiced. Of her own experience, she said, "I worked in a predominantly white culture and I believe it was good for me, I've been challenged, people have questioned how I know what I know and so forth and so on." As previously mentioned, both

Samaria and Michelle were in gifted programs. Because of their programs, they were around children from different ethnic groups. This meant that they exposed to diversity throughout their school careers according to Ethel. She viewed this as a positive thing because they could relate to different people and function in different settings. However, she also stressed the value of them being exposed to blackness. Like Samaria and Michelle, she spoke about the family tradition of historically Black colleges and universities and other traditions grounded in their blackness. For Ethel, she believed it was important for her children to have diverse experiences to be able to learn things that they may not be exposed to in their own culture, but to also be proud of who they are.

Faith

As mentioned briefly above, their Christian faith is also central to who they are and many of their experiences within their community growing up. Their church family was also considered extended family, so they spent a lot of their time there. Their faith was heavily influenced by their mother's teachings and modeling. Samaria and Michelle discussed the importance of attending church growing up. It was expected and required that they go to church every Sunday. Ethel was also their Sunday School teacher, so she made sure they were there. Samaria reflected on a moment her mother had a few years regarding her faith and her identity as a Black woman:

> Samaria: I do remember the night after Obama got elected, her having some – I don't know, maybe this is a signature Black woman experience, where you're having to cry about why am I Black, why I am a woman, all of these different things and you're lamenting and it's just because you've hit a wall of frustration and you have to vent. So, it's almost like this Harriet Tubman experience, but she was like, well first of all, I raised you to fear the Lord and, you know, Christ comes before whatever race and whatever gender, like, so whatever he says is how we should frame things, like let's not get so caught up in – because she was like, I work in corporate America and I was the only black and she's a lighter skinned black, but she would kind of like say, kind of her – the

> way that she dealt with things was from more of like a – I'm going to use my faith as like a coping mechanism…

Samaria mentioned several times how much her faith is central to who she is as a woman and as a mother. Much of her journey of self-reflection and growth is intertwined with getting closer to God. Samaria is a part of the dance ministry at her church. During her pastor's appreciation celebration, she did a worship dance during the ceremony. She expressed how she has learned recently just how much she loves dance.

Michelle revealed that she witnessed Samaria worshipping the night before, even though Samaria did not see her. Samaria asked Michelle to tell her more about what she saw. Michelle expressed that even in her worship, it was obvious how much the movement meant to her and how that was also an important part of her practice of her faith. Michelle spoke of her own experience and some of the ways she felt God moving in her life right now. She expressed:

> I believe the Lord is especially trying to prick my heart right now because I took piano classes, middle school and high school, college, I had to turn that off, but there was this man who was a PK, sees the gift in me and is like, Michelle, why don't you play something because you need to develop the gift, you need to develop.

For Michelle, she was starting to feel a pull to serve her in through her own gifts, which in this case is the piano. Michelle described Jesus as a "very good provider." Jokingly, Samaria stated, "you can tell by now we all about Jesus." Samaria added, "there are various parts of our identity and honestly it's like, without that very fundamental part of our lives, I don't know life would be much…" Michelle interjects, "I don't know what it would be…" Samaria continues, "much more confusing and hectic and frustrating." It was clear that Jesus and their faith practices related to serving Jesus were a major part of their identities and how they viewed their experiences and the world around them.

Ethel spoke explicitly of the importance of instilling the value of the Christian faith in her daughters. She expressed, “they've been in the church all their lives and I'm so grateful that I didn’t have to coerce them to go to church and they paid tithes off their little allowances and everything.” She told stories of their childhood in church. Ethel mentioned stressing the importance of remaining a virgin prior to marriage. In the Christian faith, abstaining from sex is an important teaching, which Ethel wanted her daughters to follow. Ethel shared her hopes and desires for the relationship between her daughters and the values she hoped to instill in them as women. Their faith is paramount to their values and identities. Ethel concluded with, “I want my girls to be well-rounded and trust God for all this other stuff in life. And I guess that’s it” and based on the interviews with Michelle and Samaria, Ethel succeeded.

Superwomen

The final subtheme related directly to the sisters’ identities as Black women. According to Beauboeuf-Lafontant (2003) and Harris-Lacewell (2001) as referenced in Woods-Giscombe (2010), “The concept of Superwoman developed partially as a result of African American women’s efforts to counteract negative societal characterizations of African American womanhood (such as “Mammy,” “Jezebel,” and “Welfare Queen”) and to highlight unsung attributes that developed and continue to exist despite oppression and adversity” (p. 669). This concept arose many times during this study. During this interview, it was most commonly related to how Samaria and Michelle perceived their mother and her sisters. The terms “superwoman” was actually brought up about by Samaria, who studies the concept through her own work as a professor.

Of course, the first superwoman they identified was Ethel. They described the many ways she modeled that concept through the years. They discussed her cooking and how she was known

for her gumbo, her pecan candy, and her pralines. Michelle added, “sweet potato pie, peach cobbler.” Samaria agreed and began to think about her own cooking and what could be her defining dish. According to Samaria and Michelle, you cannot be a really Louisiana Black woman without knowing how to make some of those signature dishes. Samaria remembered observing her mom taking care of them while also being in the corporate world. Becoming a mother herself, Samaria expressed some of the things she has come to understand as a result of her new status as a mother. She shared:

> Yeah, so just even like, you know, and now as a mom like I realize that she was doing something that the people before her weren’t doing, she was doing the corporate thing and like I will call her sometimes, like “oh my gosh, God bless you.” We had a different age gap and her mom was in town to help her out more than she is able to help me, but I'm like, “God, there were times you didn’t get to do stuff you wanted to because whatever, and then you had like your career you were trying to do…”

Michelle joined in:

> Think about it, mom is mom, mom is a wife, mom is a Sunday school teacher, when it’s SIMC, which is just a big church conference, she's a teacher over there. She's a leader in the children’s ministry. She…does a lot.

Their mother continues to play the role of caretaker in the family as well. They gave several examples of her caring for multiple members of the family while also caring for her own and working in corporate America. The giving of self they displayed did not end with their immediate family. She also took care of her sister’s son at one point. The trend did not end with their mother. It extended to her sisters as well. In Samaria’s individual interview, she was discussing self-care and looking at her mother and aunts. She shared:

> So, there’s definitely a universal struggle of women as sisters I think. But then it’s just kind of like coloring that from a black woman’s perspective, I think of being superwoman…I know…I thought I was looking at my mom and aunts like (gesturing pointing at each of them) superwomen, superwoman, superwoman, calm down, calm down, calm down, and didn’t realize that I had definitely pick up on that you know.

Michelle chimed in:

> Yeah, it's like they take care of everybody else except themselves and I'm like, mom, you need to sit down and take a break. Dad tells her all the time, "honey, why don't you sit down." "No, I'm not -."

Both Michelle and Samaria had picked up on the tendency of the women in their lives to over do it in a sense.

In discussing their mother and their aunts, they mentioned some of the effects of being superwoman. Samaria stated:

> I mean, at a certain age you felt like they were invincible, they could do everything, but then as you got older, you realized how much they went through, how much they were still going through. And how much life had weathered them to the point where they probably should take a break or ask for help, but that they don't always do that. And being like, that ain't healthy. You over here trying to run my house but you ain't all together yourself.

For their mother, Michelle conjectured, "Because ever since they had a sibling, my mom would have to be another mother." This statement was in response to Samaria stating, "They don't know how to sit down, they don't know how to not do and not…" What followed was a very powerful statement. Without really thinking, Samaria said, "I think, like for them, doing is their being-you know what I mean? I'm going to marinate on that, like doing is their being. To be here means I have to do. I don't know how to not do."

Both Samaria and Michelle began to push back on this idea of being superwoman. Relating to their mother's superwoman status, Samaria shared a conversation where her mother was questioning her purpose in life, to which Samaria and Michelle began to engage in a dialogue:

> Samaria: Because I'm like, yeah, you are like hands down the most servant-hearted person that I know. But, I think one thing that we're learning now is that to be a good servant, you have to take care of yourself and learn how to give yourself some nurturance to nurture other people well.

> Michelle: You sacrifice your time and energy for other people but when are you going to take care of yourself?
>
> Samaria: Yeah, because you can't give out of empty.
>
> Michelle: Yeah, and you can't give if you're broken.

In thinking about the importance of taking care of oneself and not giving if you are broken, the conversation shifted to Samaria's own attempts to break the cycle for herself. During the individual interview, Samaria referenced several experiences that have influenced her journey of growth. She spoke of examining her current habits and means of self-care to determine what felt more nurturing to her growth and a woman. She mentioned several books she is currently reading such as *The Slow Professor* for work and *Boundaries: How to Save, Know How to Say Yes and Take Control of Your Life* for church. Also, during the individual interview, Samaria shared:

> Spring 2016 when I was coming out of like a post-partum anxiety, funk, and I was just like 'I can say no' so I think like there's this univer…like there is this universal thing with women like, "who am I? Can I say no to everybody and not be selfish?" you know "can I nurture me?" And not always feeling like we're allowed to do that or like that's ok. (Inaudible laughter) But yeah.

During the Photovoice discussion, she shared photos of some of the books she has been reading and some of the places she has been going to clear to her mind. One of the pictures was of a fountain outside of a museum near her home. This fountain represented calm and peace for Samaria.

There was also reference to modeling that she picked from the women in her family and how her Black womanhood colored the experience of self-exploration and growth. She expressed:

> So, there's definitely a universal struggle of women as sisters I think. But then it's just kind of like coloring that from a Black woman's perspective, I think of being superwoman…I know…I thought I was looking at my mom and aunts like (gesturing

> pointing at each of them) superwomen, superwoman, superwoman, calm down, calm down, calm down, and didn't realize that I had definitely pick up on that you know. So now, like, hanging that cape up. (laughter)[Searching] for some wholeness.

Samaria also expressed this sentiment from her experience as a professor and understanding some of the health implications of trying to do and be everything. Many factors contribute to this tendency to overwork or over-dedicate their time and energy. These factors can include upbringing and family dynamics as well as expectations from the outside world. By observing this concept of the superwoman in practice through the women in her family, Samaria discussed her decision to take her own cape off during her individual interview. She recognized that the behavior was not healthy nor sustainable and wanted to break generational curses. Michelle responded differently. While she agreed that the women in the family needed to take better care of themselves and would often overexert themselves, being less independent (by living with her parents) led her to feeling like she was outside of the family experience. So, even though being a superwoman was not seen as a positive thing in the eyes of either of the sisters, there was still a need to feel like she belonged and could share that experience.

The main purpose of the second interview was to explore the sisters' experiences within their immediate family as well as their extended family and community. The majority of their experiences were positive, providing a sense of support and grounding in many ways. They discussed the importance of their family to their identities as the roles of their extended and fictive kin. Additionally, they discussed their experiences, perceptions and critiques of the Black women in their lives. This included the examples in their families and the perceived dangers of over-committing to the strong Black woman trope. These ideas are expanded in interview three and discussed more broadly from a societal perspective.

Again, this concept of extended family is not unique in disability literature. However, how it is discussed is different. Michelle was not referred to as an outsider or someone who they had to figure out how to accommodate. Extended family was not present simply to serve as social support for the parents of caregiving support. This is likely because Michelle is independent and does not require much support, but this is still a missing area in the literature in terms of understanding what function extended family does and could serve for families of people with disabilities. Extended family in the Tucker family played a major role in the sisters' development and were involved in many of their defining experiences. The same goes for faith and family values. Those areas are pertinent to their development and how they view and experience the world around them.

The Struggle of Black Womanhood

(Research Questions 2 and 3)

Much of the discussion about their identities and how they experience the world related to their identities as Black women. The researcher asked how they chose to identify, and they both agreed that they identify as Black women. During the first round of interviews, they discussed some of their challenges while growing up relating to their Black girl/womanhood. In school, Michelle mentioned multiple times feeling like she is not the typical Black female because her interests and ways of interacting are different. She mentioned several times that she describes herself as a Black nerd and identifies with other nerds. However, both sisters seemed to share the idea that they did not fit into their perception of the typical Black girl/woman that they interacted with through their years. Before discussing those experiences, it is important to fully define their interpretation of the "typical Black female."

Typical Black Female Defined

The discussion regarding the typical Black woman began in the first interviews with Michelle and Samaria describing their school experiences. The typical Black girl was described as "miss hip-hop" wearing the latest fashions, knowing the latest dances, and engaging in similar activities as other students. The idea of the strong Black woman or superwoman also emerged again. Samaria proclaimed that Black women just get up and go because that is how things are and have always been historically and presently. They discussed the idea that Black women are strong, independent, and capable of taking care of themselves without the support of others. Michelle wondered how women who ascribe to the independent Black woman narrative incorporated men into their narrative. She asked:

> "I am a strong, independent, Black woman who don't need no man?" Who is to say you don't need a man? Are you saying you don't need a father to be in your life? Are you saying that you don't need some type of male role model in your life, like we need to appreciate both sexes and we need to appreciate all ages and all figures and include them in our life because it's just going to be healthier and wholesome versus excluding them. So, when I say – I mean, there is something attractive about independence in the black woman in that she can do so much by herself, but that's not healthy.

So, Michelle shared similar sentiments, recognizing that being strong may have consequences for Black women such as declining mental and physical health.

In later interviews, when asked to describe the stereotypical Black woman, Michelle stated, "the ghetto mom, the hoochie mom" and Samaria chimed in, "like the welfare queen, like that one?" Michelle expressed her concern and dislike for the specific stereotypes "welfare queen" and "Jezebel" or "hoochie mama." Samaria added multigenerational representations of women such as pictures of mothers and grandmothers. She added another trope, mammie. Samaria stated, "…a mammie, because I'm like, do we have to say she's Black? A mammie holding a white child in a family photo being like, oh look, there's a family, and Mammie." This

trope is also in line with the superwoman, caring for another family and then having to go back home and care for your own. Additional images included a Black woman rolling her neck; being loud and angry. Some physical images they discussed when thinking about Black women included natural hair and afros, big lips and features that many people would associate with Blackness.

Similar to Samaria, Michelle also drew from her work experience to discuss her perceptions of and experiences as a Black woman. At her job, she gets to see and meet different people from "all walks of life." She described:

> I get to see Black women who are mothers who are either married or they might be single for whatever reason, so I get to see a variety of them…I get to see the very defensive women, I get to see the defensive mother who is hardworking and I get to see the stereotypical Black woman.

She went on to say:

> They come in the library looking like this [referring to her own clothes worn around the house] or worse, they'll-yeah, with a bonnet. It's like, why are you – who taught you that you could go into a public place looking any kind of way, revealing your body in any kind of way, and not to say that they're not – it's not to say that they're worthless and trash, no, they have to work and contribute to society as much as I do, it's just sometimes I wonder how does the Black woman start to deviate from the stereotype… how do you get to women like Michelle Obama, how do you get to women like Condoleezza Rice or even Rosa Parks. We – you've got so many kinds of Black women, it's like how did we get to these stereotypes and when – what does it take to dispel all of that.

Many of their perceptions of Black womanhood related to stereotypes, but they were not all negative. Samaria mentioned, "so I think of like, you know, just a continuum of negative images and also like nurturing Black excellence, Black girl magic, Black girls rock, you know, like that kind of stuff too." While various images came to mind when thinking about representations of Black women, Samaria in particular acknowledged that a person may be multiple things at different times. Both sisters identified stereotypes relating to Black women, but their perceptions and decisions about conforming to or rejecting those stereotypes varied.

Samaria recognized that Black women's identities are fluid and may differ depending on the situation. She was also aware that perceptions are not always valid or fully representative of the person. Michelle was more likely to reject the stereotype for herself. She did not feel like she fit into the mold of the typical Black woman, so she did not necessarily see herself in those stereotypes. The following will discuss ways the sisters either embrace or reject certain aspects of Black womanhood in their own lives.

Samaria and Michelle's Black womanhood

Samaria believed that the various representations of Black womanhood, whether stereotypical or culturally relevant, were fluid and could be lived at different times. She stated:

> And it's just like the different things that I wear that represent who I am and my different roles and responsibilities. So, like if you catch me after about 7:00pm, I've got on slippers and pajamas and may have a boob hanging out and I'm running behind somebody, right? But, on Fridays I wear jeans to kind of show that, hey, it's Friday, I can be relaxed or whatever or be at a conference in a little bit, so I try to make sure – so I think of me in different settings being a chameleon of sorts.

While Samaria described herself as a chameleon, fitting into different stereotypical roles at different times, Michelle felt less connected to the experience of being a Black woman. She expressed, "Well, I'm – like I say, I just think of myself as being very deviated, deviant from – I don't know what society would call the normal Black women, like in my case I think of myself as a Black nerd." The "Black nerd" did not fit the mold of the typical Black woman, and thus, was considered inferior or outside the norm in Michelle's eyes.

Relating to some of the stereotypes above, the sisters either accepted or rejected the stereotypes for themselves. For example, Samaria related her perspective back to image portrayal and her role as a professor, particularly a professor at a historically Black university. She stated:

> I think because I'm a professor at a HBCU and young Black women is who I teach on a regular basis, I know that I'm a role model whether I want to be or not, that I'm viewed as such, and so I'm very – I try to be intentional about how I carry myself, how welcoming I

> am, how warm I am in some instances, how firm I am in other instances. How I am when I represent the university at an event or, you know, just being very intentional and thoughtful about what I project.

As a Black woman, Samaria believed it was important to portray a polished image to the young women she taught on a daily basis. This image also went beyond dress, but to also attitude and ways of interacting with others. She did not want to be viewed as the "angry Black woman" or the "ghetto hoochie mama" for example, and instead wanted her students to view her as a polished, professional, which did not fit the previous descriptions described in the stereotypes. She went on to say, "So even though there are sometimes when I'm running to daycare that I look a little ratchet and I'm like no one would know or have any idea that I have a Ph.D." This statement suggested that there is a tension between how she may dress while running errands in more comfortable clothing and her status as a woman with a doctoral degree. However, she also expressed some frustration with being concerned about her image and how others may perceive Black women in general if she decides not to dress in what she deems appropriate for a professor on some days.

The superwoman narrative was another that Samaria had begun to challenge for herself. Samaria discussed some of her work for a recent conference that brought churches into the conversation about the health of Black women. She was creating a PowerPoint for the conference and put a picture of Rosie the Riveter, but a Black version. As she was creating this slide, she reflected:

> I think that even if you try to resist being the strong Black woman, that depending on how you were raised and your culture, it hops on you. Like the tendency to do too much, the tendency to not take care of yourself but try to do stuff for everybody and everything.

A large part of Samaria's understanding of the impacts of being "superwoman" comes from her educational experience and career in public health, but she has also experienced the weight of the

superwoman narrative for herself. She talked about feeling weak sometimes and trying to make that an appropriate conversation for women to have. She also mentioned previously that she has decided to take her cape off to care for herself, recognizing the possible negative impacts. For example, Samaria discussed the weathering effect of not prioritizing healthy eating or sleeping habits and preventive health. She stated, "so carrying it all emotionally, mentally, spiritually is leading to women carrying it all physically with obesity and diabetes and other chronic disease." While being strong can be necessary and appropriate, it is not sustainable, particularly as it relates to mental health.

Black Woman with Asperger's. Michelle's perspective regarding her Black womanhood was primarily related to her experience as a Black woman on the autism spectrum. As previously mentioned, Michelle identifies herself as a Black nerd and often feels like she does not fit in with other Black women. When speaking about her experience as a Black woman, being on the spectrum was a major impact. Michelle described herself in various ways, but geeky and nerdy were the most prominent. Michelle said of herself:

> – smart and awkward, I hung out with the geek/nerdy people who like Japanese culture and anime. I'm with that group. So, I also think of myself – well, you don't always see – recognize a picture of autistic people, but you know that it's an issue that's prevalent in today's world. Because we're so thoughtful about diverse people, we are thoughtful about inclusion, we're mindful of these things and so you can't recognize autism until you see the person, until you get to know that person, and so Samaria used a good word of being a chameleon, I'm sort of trying to be a chameleon, but at the same time, I know that I am unique, I know that I'm fearfully and wonderfully made, and you just have to get to know me to understand what makes me, me.

Samaria chimed in, "so me and my husband have a joke about Michelle, that she's an artist and no one understands an artist, right? It's like, I'm an artist, you wouldn't understand." Michelle described some of her social challenges and how they impact her relationships:

> I'm just reminded that not only has it been challenging socially, but it's also been a benefit of sorts. Like I have reason to believe that because I've had Asperger's, my social

> challenges have kind of shielded me away from the dangers of being social. Like I – there's something about the club that I don't like, there's something about the atmosphere and the loud noises, total darkness or these weird lights and special effects, because I'm on the spectrum, I don't know if that's why I kind of stayed away from that or if I just stepped into the club one night and thought, oh my goodness, I can't be in here. I guess my senses, my sensory were just going red flag, red code, all over my head, so I was like, you know what, I can't do this, y'all go right ahead.

Michelle mentioned several times that she did not enjoy some of the same activities that a "typical Black woman" might, so in this statement, she recognized for herself that having Asperger's made it easier for her to stay away from activities she did not enjoy. Michelle seemed to have an awareness of her likes and dislikes and felt comfortable in the current status of her social life. Samaria added that she was proud of Michelle for trying different things, but also recognized her preferences and limitations. During the interview, there was a conversation regarding dating. Michelle was concerned that her disability makes it difficult for her to date and find a partner. She went on to say:

> And sometimes I wonder if I'm so independent or is it independence or is it just shyness or reclusiveness that keeps me away from a relationship, it's not that I can't be social, it's just that I guess right now I don't see myself needing a man, I want to be in a relationship, but perhaps the reason I'm single right now is because I don't get out there as much, I don't present myself to a lot of people, I have different interests, I have different needs, I have different – I'm just a different woman.

Based on previous interviews, dating was a recurring conversation. Michelle showed some interest in dating and sought advice from Samaria and Miles, but she expressed that she may not yet be ready to begin a relationship. She also believed that the "typical Black man" would not be interested in her because of her differences and interests.

The conversation including stereotypes about Black women touched on Michelle's perceptions of her proximity to the experience of being a Black woman. The superwoman or strong Black woman concept was prevalent in all the interviews. This stereotype or concept was one that Michelle did not feel she fit into. She stated, "I just don't see myself – I am strong, but

I'm not independent either if that makes sense because I have this disability, I'm going to need help." It has been established that there is an idea that Black women have to be strong and push through adversity, but Michelle expressed the feeling that she did not fit into that idea because of the supports she may need due to her disability. She went on to speak about the many benefits of her own experiences with therapy and medications. She expressed:

> Well, looking back now, in retrospect, I would have had a hard time if I had not been given the help that I've received. Of course I was always wondering why the short bus, mom, why can't I be on the long bus like everybody else. She knew that I would have been bullied and I would not have been able to handle that if I'd gotten on the long bus without help. She knew that there were some developmental, cognitive needs that had to be addressed in a special ed program and so if I were put in the crowd of normal kids, would I have been able to progress educatively like everybody else, probably not…If I had not received all of this help, where would I be today? I don't know – I don't want to know at this point.

She also criticized the tendency for Black people to shy away from help and support when needed, recognizing the benefits and needs for support within the Black community. She later stated:

> It's helped me to – well, it just helps – it reminds me that my gosh, I'm different, that I'm – and it reminds me that disabilities and challenges are going to affect all kinds of people and while African American society doesn't really want to deal with weaknesses and challenges, we're going to struggle with them anyway.

Michelle recognized and strongly believe that Black people will deal with challenges and weaknesses, it is important to seek support when needed.

Through the interview process, each of the women, including Ethel, mentioned several times that they did not feel like they have experienced what it means to be a Black woman. While the definitions of Black womanhood that were given were mostly based on stereotypes, the women felt like they were either missing something or like they were being restricted by the limited definitions of Black womanhood. Samaria mentioned some of the ways she felt she limited herself to activities that were stereotypically Black, such as going to clubs and dancing

the latest popular dances to prove that she was smart and Black. She had the opportunity to study abroad while in school but did not explore the possibility. She expressed remorse with not being more like Michelle in exploring different activities. Samaria worried that she had missed out on experiences that could have broadened her own world view. Michelle, on the other hand, wanted to do activities like study abroad, but was deterred by her parents' refusal. They worried that she would not communicate enough because of her lack of desire to socialize or keep in constant contact with others.

Michelle consistently stated that she feels like she is not the typical Black woman because of her different ways of socializing and different interests. Additionally, she did not feel like she fit into the superwoman or strong Black woman stereotype, so again she could not relate. Ethel also mentioned in both of her interviews that she felt that she was not right for this study because she could not relate to the experiences of discrimination due to being a Black woman or experiencing poverty and other previously mentioned stereotypes. However, each of them still felt that their experiences were valid and confidently identified as Black women. Their societal definitions of Black womanhood and their own experiences of Black womanhood were linked, and one did inform the other, but there was still some tension between their descriptions of themselves and the societal descriptions. These definitions are based on historical representations and stereotypes created through the oppression of Black woman, so it is not surprising that these definitions continue to impact the women's perceptions of themselves. Yet, the women continued to battle those stereotypes and work to define their Black womanhood in ways that felt authentic for them.

Varied Perceptions of Black Families and Disability

(Research Question 3)

The final theme addresses Samaria and Michelle's perceptions of the culture of Black families and Black families experiencing disability. The questions regarding this theme was positioned to address research question three to address sociocultural influences on their identities as a Black family with a family member on the autism spectrum. Aspects of the conversation addressed their beliefs regarding Black families in general as well as Black families relating to disability. This theme is addressed in two sections including Blackness and Disability and Blackness. While these categories do overlap because of disability being a natural part of the experiences of Black families, aspects of the discussion emerged in one category or the other.

Blackness

In the initial interview, the women were asked how they identify racially, ethnically, and/or culturally, and they stated African American or Black. "Black" was the term they decided on ultimately. They were also asked in that interview what being Black meant to them. The answers included things like soul, hair, food, and having dark skin. When asked the same question during this third interview, however, the first statement was "to be marginalized." Michelle stated:

> To be almost [be defensive] of your heritage, oh, Black is inferior, Black is this, it's like who is to say that Black is not beautiful and who is to say that we don't have something valuable to offer to our world, so I'm mindful of that.

Michelle went on to talk about prejudice against Black people and her pride when she sees Black people doing well in the world. Samaria reflected on some of the challenges of being Black by stating:

> I also feel like there are sometimes when you're just like, ugh, I don't want to be the flag bearer for the race today, I don't want to feel like I'm the ambassador or the spokesperson

> for Black people, Black women, for just women sometimes. You know, it's just like – but when we're born, we were not given an orientation on welcome to being Black in America.

She went on to share her feelings about representing her race and having a heightened awareness in situations where she may feel like the "token" or the only Black person. She felt a sense of obligation to do well because of how her performance may impact the opportunity for another. She also explained how some people may feel threatened by the next Black person taking their spot as the token, so some people do not desire to create more opportunities out of fear that it will negatively impact their position. Samaria added that Black people come in a variety of hues from deep "blue black" as she described it, to really fair, so she thinks about colorism in the Black community. Michelle called the fairer complexion "high yellow." In a previous interview, Samaria mentioned that her mom was a lighter skinned Black person, so that came with a different experience than someone who may have been darker skinned.

Michelle also discussed some challenges within the Black community, one of which relates to seeking help when needed. From her own experience of therapy, she recognized the value in seeking professional help and support, but also believed that Black people as a group look down on therapy. Samaria added as a remark on how others view therapy, "it's weak. You know that, you're a therapist…It's weak…or it's white. And that makes us look better, right, if we say that that's a white thing and they are a weaker people than us because we're so strong." She referenced the idea of pulling yourself up by your bootstraps in terms of mental health, which means to help yourself out of difficult situations. People often believe that they should keep moving regardless of their challenges and ignore any type of pain they may experience because pain is a "normal" part of life. Because it is perceived as a normal part of life, people often do not seek support when needed. Strength and resilience were both an effect of historical

trauma and a detriment to current mental and physical health. Additionally, when mental health supports are presented, Samaria and Michelle felt that efforts rarely include Black people. Samaria mentioned how the face of mental illness is typically not Black, so that also creates a barrier of representation.

Samaria discussed some racial disparities relating to health, as this is her career field. She referenced the opioid public health crisis and the shift in focus for the government for substance use issues. She expressed:

> It's like people have been having substance abuse issues for a while, it may not have been opioids, it may have been crack, but now that the cup of tea of the day or the cup du jour soup du jour is opioid and who uses that? Who abuses prescription pain killers is a certain group then it's a public health crisis and it's like, we've had public health crises level of other things but no one seemed to care or throw money at it, but I think when the face of an issue, whether it's mental illness, disability, physical, mental, if the face is seen as white, then we can maybe rally some troops around it which is unfortunate because even if you're trying to raise awareness in your own community about how it affects your own community, it may be hard to champion that.

Samaria seemed to feel passionate about this issue. Michelle did not have much to add to this particular part of the conversation, but she did seem to be in agreement with her sister on some the disparity issues relating to health.

An interesting addition to the conversation was a discussion on meme culture in the Black community and how people communicate shared experiences through memes. According to the dictionary, a meme is a humorous image, video, or piece of text that is copied and spread rapidly by internet users. From the discussion on memes, Michelle and Samaria began discussing the differences between Black churches and white churches, as faith is an important part of their lives. The meme showed a picture of Black people in church praising while white people were straight-faced and sitting. Michelle remarked:

> Yeah, it's a stereotypical explanation of the different cultures and I'm like, I've been to a white church and no, they're not sitting down looking all solemn and pitiful and stuff, no.

> They had different style music than us, so they're not going to always have an organ in the background. And then, something else I think about, negro spirituals, so it's like – there are some hymns that both church bodies are going to have, some other songs you would associate with the white people church.

From her perspective, another hallmark of being Black was the church experience. She also acknowledged that the stereotypes about church are not always accurate, as with any stereotype.

The last part of the conversation relating to their identity as Black people involved their views on some of the current events regarding advocacy and activism for Black people. They were asked broadly about their feelings regarding the current social and political climate. Samaria started by referencing a recent event where Representative Fredrica Wilson spoke on behalf of the family whose husband and father was killed in the Niger ambush. Samaria expressed her dislike for the way the media tried to taint her image because they did not like how she spoke to and about the current president. She had similar sentiments for the treatment of football player Colin Kaepernick and his decision to take a knew during the singing of the national anthem to protest police brutality as well as sports analyst Jemele Hill's suspension due to her remarks regarding the president. Samaria said:

> Jemele is a sports analyst, like a black female sports analyst and she knows her stuff, she can beat you back and forth with some information and the president didn't like something she said so was calling for her to be suspended.

Michelle added, "they have every right." She went on to say, "This is a democracy, it is not an aristocracy, it is not a monarchy and I'm glad it's not anarchy either, but people have a right to do what they do so long as it's peaceful." They also referenced former President Barack Obama and their perceived differences between him and the current president. Similar to Samaria's thoughts about perception and image and the importance of representation for Black people, both Samaria and Michelle expressed the importance of former president Obama being more respectful in his

speech, well-rounded, well-studied and having a multicultural perspective; none of which they believe the current president exemplifies.

This segment of the interview touched several issues relating to their experiences and perceptions of being Black. From stereotypical representations of Blackness and history of marginalization to health disparities and current social issues, the women had strong opinions about the challenges relating to being Black in America. They also discussed challenges within the Black community and ways some of the histories affect Black people's perceptions of themselves. There was some reference to perceptions of disability in the Black community. This intersection will be explored further in the following section.

Disability and Blackness

Along the lines of seeking support for mental health, seeking support for disabilities was another area the sisters felt was a challenge for Black people. Although Michelle is on the autism spectrum, when speaking about autism and their perceptions and experiences of autism, the following conversion ensued:

> Samaria: Initially hearing the word autism, I think of a little white boy.
>
> Michelle: Yes, a white boy.
>
> Samaria: I think that's the poster child of autism, honestly, like maybe a little boy like five – between five and ten and having done case management with kids with disabilities, that was – my clients that had autism were usually white males. I think they may just be better at getting it screened or they're better at advocating for it, but yeah, that's – so as far as like the spectrum, I think of a little white – not to say that I know, our cousin –

The representation of autism, to them, was typically a young white boy, which Michelle is not and has never been. Neither being on the spectrum herself nor having a male cousin on the spectrum changed the perception of who they think of when they think of autism. Additionally, the dominant picture regarding disabilities in general was someone with a physical disability

rather than a mental or developmental disability, according to Michelle. She stated, “I think more about physical disabilities than mental and developmental ones. I think about the kid in the wheelchair or somebody who needs crutches, usually that’s what I think about.” Michelle went on to tell a story about a Black family who visits her job at the library. The mother often brings her child who is in a wheelchair or may bring all of her children. Michelle was in awe of how the mother managed to get herself and her child with a wheelchair to the library multiple times per month. She continued:

> …you don’t always hear the word disabilities and think about minorities because if they advocated on television, you just see a lot of white males and in some cases, white females. So I think when people think about minorities, they think about people who are healthy but they just happen to be from a different culture versus disability. I don’t know, perhaps it’s a cultural thing, perhaps it’s a white people society thing, I don't know, it’s just been ingrained to us to think about some little white boy who is autistic and gifted and yeah.

From Michelle’s perspective, one of the reasons Black people do not seek support is due to lack of representation and not being able to see themselves in the experience, which she was able to relate to in multiple ways from her own experience. Samaria this was similar to how people perceive mental health. Black people do not want to be perceived as weak or needing help and from her perspective, disability falls into that category for some people. Michelle had been in therapy for as long as she could remember and recognized the value and importance of seeking services.

Conclusion

This chapter discussed the findings from the interviews, Photovoice project, and observations with the sisters. The themes that emerge include perceptions of the sibling relationship, extended family influence, Black womanhood, and Black families and disability. The themes discussed several areas that should be considered in disability literature regarding

families of people on the autism spectrum. The sibling relationship was a source of support for both sisters but did not come without challenges. Extended family has played a major role in the lives of this family through emotional and material support as well as identity development. Black womanhood is a source of both pride and pain as Black women continue to be restricted by societal definitions. Black families and people with disabilities are impacted by discourses that position Black families as underrepresented in the disability community. While these themes cannot capture the entirety of these sisters' or this family's experience, they provided a platform to begin conversations that may not have been previously discussed as well as an impetus for understanding possible areas for more study.

Through this study, the research was able to gain a better understanding of how the sisters perceive themselves and their relationship as well as how they perceive themselves in the context of their intersecting identities. They are both Black woman on differing ends the spectrum of ability, yet they have many similarities in the ways they have experienced those identities. Michelle is on the autism spectrum, having Asperger's Syndrome, as well as being gifted. Samaria was also considered gifted, but more socially graceful. These attributes impact both the way they interact with one another as well as the way they interact with the world around them. They have both had some challenges relating to those identities and experiences.

CHAPTER V

DISCUSSION

Introduction

This study focused on the sibling relationship between two Black American sisters, one with Asperger's Syndrome, and their experiences and perceptions of being Black women in the United States of America. The purpose of the study was to explore three questions relating to their experiences: 1) How do two Black American siblings interact and support one another when one sibling has Asperger's Syndrome; 2) How have two Black American siblings been socialized within their families and neighborhoods on the basis of race, disability, and gender; and 3) How have two Black American siblings experienced race, disability, and gender as social constructs in the US? The researcher aimed to answer these questions using multiple methods of data collection from multiple sources. The sisters were interviewed individually and together over a series of three interviews, their mother was interviewed twice, and Samaria's husband Miles once. The researcher accompanied the sisters on a lunch outing observation, and used the Photovoice method (Agarwal, Moya, Yasui, & Seymour, 2015; Harley, Hunn, Elliot, & Canfield, 2015; Wang & Redwood-Jones, 2010). Each of these methods provided a different type of information to develop a clearer picture of the sisters' experiences, perceptions, and interactions. The first set of interviews were purposed to address research question number one, the second set of interviews addressed question number two, and the third set of interviews addressed question number three. However, throughout the process, the themes proved to overlap and entangle

across interviews and experiences. Ethel's interviews and Miles's interview, as well as the observation and Photovoice were utilized to triangulate the data throughout the research process.

Intersectional Identities

One of the main purposes of this study was to explore the sisters' perceptions and experiences of being Black women and how that influences their identities within the larger sociocultural context. The researcher explored each sister's perceptions of their Blackness, womanhood, and dis/ability and their impact on how she interacts and makes meaning of the world around her. Each of these aspects of their identities influenced a different part of their individual and family experiences. Being Black and being woman are identities that are not easily disentangled. For many women, it is not at all possible to separate the identities in individual categories as the identities are intersectional, rather than additive (Bowleg, 2008; Cho, Crenshaw, & McCall, 2013; Collins, 1991; Crenshaw, 1989; Few-Demo, 2014; MacKinnon, 2013). Dis/Crit also challenges singular notions of identities but focuses specifically on disability and race (Annamma et al., 2013). While both sisters do not identify as having a disability, both of their identities were somewhere on the spectrums of ability and social aptitudes. The different nuances of their experiences will be explained in different configurations (i.e. Black woman, disability), recognizing that the experiences are not fully separate.

Black Womanhood

The sisters' identities as Black women was the most dominant theme throughout the interview process. The same applies to the interviews with their mother. Their experiences being Black women were influenced by many factors including experiences in school, modeling by family members, and societal stereotypes. Samaria and Michelle's definitions differed slightly when describing themselves versus describing their perceptions of Black women in general.

However, their perceptions of themselves were influenced by those societal stereotypes in several ways.

Black women have been portrayed in many different ways throughout history since arriving in the United States, yet those ways are limited to a few categories. Some of the most common are the mammy, the angry Black woman, the whore or Jezebel, single baby mama, and the overachieving Superwoman (Stephens & Phillips, 2003; Reynolds-Dobbs, Thomas, & Harrison, 2008; Woods-Giscombe, 2010). Michelle and Samaria described Ms. Hip Hop and Superwoman. Ms. Hip Hop is the girl who has all the latest fashions and does all the latest dances. She has many friends and is a part of the "in crowd." This was a description neither of them felt like they fit. On the other hand, the Superwoman was a description that was prevalent in their lives.

"I'm a strong Black woman and I cannot be intimidated"-Congressman Maxine Waters

Superwoman. Throughout U.S. history, Black women have worked inside and outside their homes to care for their families. The idea that Black women can work tirelessly without rest or support has been prevalent throughout history (Stephens & Phillips, 2003; Reynolds-Dobbs et al., 2008; Woods-Giscombe, 2010) and has been well-documented in the literature. Researchers and Black women themselves recognize the mental, emotional, and physical toll this mindset takes in the lives of Black women. In this study, Michelle and Samaria continuously described their own experiences with the superwoman narrative. They described their mother and their aunts as superwomen, who despite working hard in their careers also attempt to take care of everyone else inside and outside their homes.

During the interviews, there was a conversation around rejecting stereotypes and narratives in which the sisters felt they did not fit. For this particular narrative, they saw

themselves rejecting this narrative for different reasons. Samaria started to recognize for herself that this was something she was beginning to enact herself. She did not want to continue on this path, considering she has a vast understanding of the impact of the superwoman narrative in the lives of Black women, so she made a conscious decision to take to start caring for herself by creating boundaries and participating in activities that she felt contributed to her growth as a woman. Michelle, however, rejected the stereotype for a different reason.

Michelle did not feel that she fit into the narrative of being a superwoman. One of the traits of the superwoman is that she is strong and independent. Because of Michelle's disability, she expressed that she did not feel strong or independent, and therefore could not be a superwoman, thus not fitting in with other Black women including the women in her own family. The idea of being a strong Black woman or "superwoman" has been prevalent in the narratives of many Black women and can be deadly in extreme cases. As demonstrated by Michelle and Samaria, the superwoman narrative can impact women with and without diagnosed disabilities. While assessing mental health and other issues impacting people on the autism spectrum, this narrative may be an important one to consider for Black women on the spectrum specifically.

"If I didn't define myself for myself, I would be crunched into other people's fantasies for me and eaten alive." - Audre Lorde

The mold of Black womanhood. The was another theme across all three of the women's interviews. Michelle, Samaria, and their mother Ethel all expressed feeling like they were not Black enough or that they were not the typical Black woman. Michelle's reasoning was because of the types of things she enjoyed like Japanese culture, video games, different music, movies, and television, and her overall different ways of socializing. Samaria felt this way because of her gifted student status and being labeled as "talking white" while in school. Ethel's reasoning

related to her lack of experience with discrimination on her job or not experiencing single motherhood, low-income status, or other experiences associated with stereotypical Black womanhood.

For each of the women, they did not necessarily speak negatively of women who may fit those stereotypes, but rather acknowledged them and assessed for themselves where they felt they fit into the stereotypes. Because they did not fit into the stereotypes, they did not feel included in the experience of typical Black womanhood. In school, "Ms. Hip Hop" was the standard of what it meant to be Black for the sisters. Michelle distanced herself from that particular group while Samaria figured out how to conform. In some ways, Samaria's social aptitudes, as Michelle described them, helped her to fit in with that particular mold of Black woman and thus, to feel connected. However, she also expressed some regret for trying to fit in rather than finding and embracing experiences outside of what would be deemed for typical Black women.

Black women have been prescribed limited options for identity from the beginning of our history in the U.S. (Stephens & Phillips, 2003; Reynolds-Dobss et al., 2008; Woods-Giscombe, 2010). White women have the range to be many things, to have many different interests, personalities, and expressions. There can be hundreds of narratives at any different time. Black women have only a few to choose from (Mammy, superwoman, Jezebel or freak, gold diggers, welfare queen) and if she does not fit into one of those categories, people are not sure how to interact with her both among other Black women and society in general (Stephens & Phillips, 2003; Reynolds-Dobss et al., 2008; Woods-Giscombe, 2010).

Chimamanda Ngozi Adichie speaks of the *Danger of a Single Story* (Adichie, 2009). It is the idea that our lives consist of many different stories and ways of being, but once we only have

access to one type of story, and we expect people to fit into that story, there is a risk of misunderstanding people, and thus categorizing them in ways that can be dangerous. In this family, that danger is demonstrated. Each of the women expressed that feeling of not belonging on varying levels, but the person that was affected the most was Michelle. Because of her Asperger's, she did not adjust to the mold of the typical Black woman. In some ways, this was a benefit to Michelle because she was able to experience different things, but it also impacted her mental health and social relationships. Being a Black woman with Asperger's presented many challenges for her relating to her social life, but the connection to her Black womanhood and other Black women was prevalent. To focus on issues relating to Michelle's experience of being a Black woman on the spectrum, the next section will address themes that affected her specifically.

"Again and again, you will find that the answer to the aforementioned question, now unspoken, 'What does autism have to with race?' is a gentle, but resounding, "Everything."- Morenike Giwa Onaiwu

Black Woman with Asperger's

All three women in the study share their identities as Black women, but only Michelle also experiences the impact of a third marginalized identity. Being on the autism spectrum creates a unique perspective and experience from her mother and sister. As previously mentioned, feeling like she was not the typical Black woman was prevalent for Michelle, but there were other aspects of her experience that her mother and sister did not share and that are often ignored in disability and autism literature. Some of those aspects of Michelle's experience included the emotional impact of being a Black woman on the spectrum, issues with dating, and

career. Something else that was mentioned was parenting. Each of these aspects have remained virtually unexplored in the literature, particularly for Black women.

Emotional impact. During Michelle's individual interview, one of the first things she expressed was feeling like she is in a bubble that no one can penetrate. She mentioned feeling like an alien. This is a sentiment that many people with Asperger's express to some degree (Brown, Ashkenazy, & Onaiwu, 2017). This feeling is exacerbated by being a part of multiple marginalized groups. For Michelle, that is being Black and being a woman. For others, that is being of other ethnic groups, sexual orientations, socioeconomic statuses, or religious minorities (Brown et al., 2017). The anthology published by Brown, Ashkenazy, and Onaiwu (2017) shares experiences through the voices of people from multiple ethnic groups on the autism spectrum. According to the authors of this book, race has everything to do with autism. From diagnosis, to education, to dating and relationships in adulthood, race impacts the experiences of people on the autism spectrum. However, research focuses on behavioral issues and friendships (Estes, Munson, Dawson, Koehler, Zhou, & Abbott, 2009; Orsmond & Seltzer, 2007; Seymour, Giallo, & Jellet, 2013; Zablotsky, Bradshaw, & Stewart, 2013). Michelle demonstrates that there are other experiences to consider that are more normative than atypical.

Dating. One of the issues of dating for Michelle was feeling like the typical Black man would not want to date her because she is not the typical Black woman. She also is not interested in the typical Black man for the same reasons she does not fit the mold; many of the men she meets fit the mold rather than being different, like her. When considering dating for people with Asperger's the intersection of racial differences could play a role and therefore should be considered in research. Sibling and parenting roles in preparing for dating should also be considered, as their attitudes and advice can also influence the dating experience.

Parenting. Parenting is rarely an experience that is discussed positively for people on the autism spectrum, regardless of independence of functional capacity to care for a child. For this family, parenting was something that was a hope for Michelle. Michelle did not mention parenting for herself, as she was still working on dating, but it was a hope for her sister and mom, who were willing to support her if needed. Samaria and Ethel mentioned several times that Michelle was not good with children growing up, but as she has become more experienced with her niece and nephew, she was beginning to become more comfortable. While it is not necessary for Michelle to have or to even want children, it is still an important conversation to think about for people on the autism spectrum. For people who do choose to parent, it is important to consider how families can support and what conversations need to be had during adolescence and young adulthood to help prepare people on the spectrum rather than avoiding the conversation altogether.

Being a Black woman on the spectrum is a unique experience that has seen little exploration in the disability studies field. Being on the spectrum can affect people in many ways, including identity, social and family relationships, education, and vocation. All of these areas are also impacted by being Black and being a woman. However, the intersection of these identities receives little to no attention. In this family, being a Black woman on the spectrum impacted her mental health, dating life, educational experiences, sibling relationship, and self-concept. While she continues to thrive, she also continues to need support, which she expressed has benefited her tremendously and she does not know where she would be without it. There are many other people who do not have that same support because families and services providers alike may not understand the impact of how these identities interact for people on the spectrum. Researchers and families could benefit from some education and awareness regarding this issue.

Disability and Black Families

Disability research involving Black families is limited. As established in the review of literature, the majority of existing research has concluded that Black families in particular experience less burden and stress relating to having a family member with a disability than white families (Carr & Lloyd, 2012; Jacobs et al., 2011; Valentine, McDermott, & Anderson, 1998). It has also been determined that Black families experience discrimination in both the educational system and service provider systems (Jacobs et al, 2011). Beyond that information, little is known about Black families with a member with a disability and fewer studies focusing on the autism spectrum and Asperger's Syndrome. In the Tucker family, the stress of caregiving and burden did not enter the narrative at all. Additionally, according to Ethel their family did not experience any discrimination related to being Black.

Most of their narrative regarding their family involved how close they were or wanted to be within the immediate family or their extended family. The challenges they mentioned did involve Michelle's disability, but the disability was not centralized as a burden. It was viewed more as only one part of their family narrative. They discussed their family traditions and the importance of family trips. They discussed their relationships with their aunts and uncles. They discussed their careers and relationships outside the family. Their experiences were very similar to those of many other families. They did, however, have perspectives about disability in Black families that may provide some insight into some of the challenges and barriers to support for Black families.

Lack of representation. Michelle described the face of autism as a white boy approximately ten years old. When thinking about the autism spectrum, the focus is typically on children. However, Black people are often misdiagnosed or underdiagnosed with autism and

thus, do not receive supports until later if at all (Mandell, Wiggins, Carpenter, Daniels, DiGulseppi, Durkin, Giarelli, Morrier, Nicholas, Pinto-Martin, Shattuck, Thomas, Yeargin-Allsopp, & Kirby, 2009). Children are therefore place in alternative education or receive other disciplinary action rather than diagnosis of autism and the support that accompanies the diagnosis. In women, autism can be misdiagnosed as depression or anxiety because there is still little knowledge regarding how autism presents in women (Begeer, Sander, Mandell, Wijnker-Holmes, Venderbosch, Rem, Stekelenburg, & Koot, 2013). Conversely, if Black families perceive autism to be a thing that only white families experience, they are much less likely to believe that their child is on the spectrum. Michelle was assessed for autism because her aunt is an educator who is experienced in special education. If it were not for her recommendation, Michelle may not have been diagnosed and may not have received the supports she received.

As an adult Black woman, she does not fit the typical picture of autism. When someone cannot see themselves in experience, it is difficult to develop a strong sense of self. This is something that Michelle struggles with. She does not feel that she fits in with Black women, but she also does not see herself in the picture of autism. The way autism is depicted needs to expand beyond a 10-year-old white boy to include children and adults from various backgrounds and genders.

Narrative of strength and resilience. Another contributing factor to the barriers to supports for Black people is the historical influence of narratives about Black people. In the discussion with Michelle and Samaria, they mentioned that Black people do not want to seem weak or admit to having challenges. One of the dominant narratives regarding being Black is that of strength and resilience. Black people have endured the middle passage, slavery, reconstruction, Jim Crow, and modern racism and discrimination. Being strong is a matter of

survival. In some cases, acknowledging that a child has a disability may be viewed as weakness. Parents want to believe that their children are strong and resilient and having autism, from their perspective goes against that idea. The ecosystemic perspective takes a strengths and resilience-based approach to understanding families (Walsh, 2002; 2016). This includes considering larger systems of supports and influence that impact systems of power and oppression (Walsh, 2002; 2016). Because of racism and a long history of marginalization, strength and resilience were/are necessary for survival. However, many of the ways people adapted have started to have negative impacts on mental health and well-being.

While strength and resilience are adaptive qualities, in some cases, they can be counterproductive. One of the challenges is for families to be open to acknowledging vulnerabilities and asking for assistance. Another challenge is the belief that having a disability is a weakness rather than a matter of difference and diversity. Michelle stated in the interviews that families need to acknowledge that they have weaknesses because everybody has them. Everyone needs support at some point whether it be mental, emotional, or physical support. Black families in general need the space to have differences and diverse experiences that include strength and resilience, but also room for vulnerability when it happens.

Centuries of enduring pain and oppression are not to be criticized in and of themselves, but the systems that only allow one type of experience should be. Families have had to focus on survival for so long that it may be difficult to seek support from the very systems that contribute to their oppression. With so many stories from families who experienced discrimination in the educational and service systems, it is no wonder families are reluctant to seek support. These systems must examine critically the ideas and ideologies that contribute to the disparities within the system and provide support that considers the diversity in family experiences and for people

with diverse backgrounds. Within the Black community, people must allow themselves the room to be vulnerable and have space for areas that may be different from the norm. Until the system of disability itself transforms to something that is more equitable and displays more than one type of person, people will continue to lack the types of support that are needed and have access in ways that are appropriate for families that are not white and middle class.

According to Dis/Crit, racism and ableism circulate interdependently in neutralized ways to uphold notions of normalcy (Annamma et al., 2013). Michelle, Samaria, and Ethel were all impacted by ideals of what are considered "normal" or "typical" based on their surroundings. Ableism, racism, and sexism consider constructs of dis/ability, race, and gender as systems rather than one particular identity. Histories of marginalization relating to each of these concepts intersect as an experience all its own (Bowleg, 2008; Cho, Crenshaw, & McCall, 2013; Collins, 1991; Crenshaw, 1989; Few-Demo, 2014; MacKinnon, 2013). All of the women felt some aspect of their ability was scrutinized or marginalized by the dominant group and each of them felt like they did not fit the mold of the typical Black woman. Researchers and practitioners must problematize notions of any one type or way of being and challenge the idea of "normal" within each of these categories as well as across intersectional identities and experiences.

I am My Sister's Keeper: Sibling Relationship

Sibling relationships in families of people with developmental disabilities have an established record of importance (Arnold, Heller, & Kramer, 2012; Orsmond & Seltzer, 2007a; Smith & Elder, 2010; Stoneman, 2001; Stoneman, 2005). Sisterhood in the Black community is also an important aspect of Black women's lives (Bryant-Davis, 2013), but the connection to sisterhood between the two communities has not yet been made. Siblings in general are some of the first friends in childhood and the longest lasting relationships through the lifespan (Orsmond

& Seltzer, 2007a; Smith & Elder, 2010; Stoneman, 2001; Stoneman, 2005). Sibling relationships can provide additional caregiving within the family, support, friendship, and guidance. However, for people on the autism spectrum, developing and maintaining relationships is a challenge which can also affect sibling bonds. The current study sought to explore one family's sibling bond between the sisters in the family, one of whom is on the autism spectrum. During their interviews, the sisters shared their perceptions of one another, their perceptions of their relationship, and desires for their relationship. The findings included challenges within the relationship, support for one another, and closeness within the relationship. An additional aspect to their relationship was connecting through their experiences as Black women. In the current literature, the concept of support is widespread, but not in the ways it was discussed in this study.

Support

"Is solace anywhere more comforting than that in the arms of a sister?" -Alice Walker

Studies involving families of people with autism have often focused on support and quality of life (Bishop, Richler, Cain, & Lloyd, 2007; Cohen, Holloway, Domínguez-Pareto, Kuppermann, 2014; Evans, Feit, & Trent, 2016; McCue, 2011). According to the literature, sibling relationships in families of people with autism are likely to be positive, nurturing and satisfying (Orsmond & Seltzer, 2007a; Stoneman, 2005; Taunt & Hastings, 2002). This was also the case for Michelle and Samaria. While the sisters placed a great deal of emphasis on their desire for more closeness, they also described high levels of support within the relationship. For them support came in many forms, including Samaria driving to meet Michelle at her camp, helping one another with hair, serving as the maid of honor in Samaria's wedding, and being there emotionally through difficult times. As mentioned, caregiving is a major theme within the literature and typically serves as the measure for support in sibling relationships, specifically for

adults (Arnold et al., 2012; Atkin & Tozer, 2014; Davys et al., 2015; Tozer & Atkin, 2015). When not relating to the sibling relationship itself, support is researched as something necessary to help the typically developing sibling to cope and does not include the sibling with a disability at all.

There have been many opportunities throughout their lives to demonstrate support for one another. According to the sisters, the other comes through even when not expected. Because of some of Michelle's challenges, Samaria did not expect Michelle to support her in that way, but Michelle was able to fulfill the supportive sister role when it mattered. Samaria also described and demonstrated during the interview support of Michelle's differences whether through her social difficulties or different interests. Samaria and Michelle described various times where Samaria supported Michelle in a decision or a new activity. Samaria also told stories of times when Michelle supported her both in college with a difficult experience and as a new mom.

Atkin and Tozer (2014) concluded that adult sibling relationships were characterized by acceptance of responsibility of care and a sense of duty, protection, and support. This was found to be true with Samaria and Michelle. Both sisters agreed that they would be there to support one another through different life changes and events. Samaria also seemed comfortable in her role as the designated "third parent." However, caregiving was discussed minimally, as Michelle is mostly independent. The type of support Samaria discussed included helping with children if Michelle decided to become a mother and being a source of sound advice when it came to big decisions. The support in their relationship was mutual rather than one-directional. Within the literature, sibling support is often discussed in the form of caregiving or other forms of material support. Seldom do researchers explore or discuss emotional support or the type of mutual support mentioned here. Siblings on the autism spectrum can engage in a sibling relationship that

is bidirectionally nurturing, supportive, and satisfying, as with other sibling relationships. I recognize that this dynamic is dependent on the social and communication styles of the person on the spectrum, but in focusing on Asperger's specifically, this is a gap in the literature and area for further examination to fully understand how to support siblings in adulthood.

Guidance

Another theme within this study was guidance from experience. This theme was more one-sided than support. Because Samaria was older, there were several instances where she had experiences that Michelle had not. For example, school was a major area for guidance from Samaria. Because Samaria has already completed a master's and doctoral degree, she often provides feedback and input to Michelle regarding her educational process as she pursues her master's degree. Their family has deemed Samaria as the third parent. Samaria and Michelle's mom often leans on Samaria to discuss issues with Michelle because Michelle is more likely to receive the feedback from Samaria.

Michelle also sought guidance from Samaria and Samaria's husband, Miles, regarding dating. Michelle has some desire to date and has had conversations with them regarding how to go about the process of dating. Michelle also sought guidance from Samaria in other areas such as finances and housing. This is another area of research within disability studies that is rarely explored. Because people with disabilities may require support, caregiving is the main area of focus rather than ways siblings connect through their experiences. It is common for older siblings to share their experiences and learning with younger siblings. However, when discussing sibling relationship quality in families of people with disabilities, this topic is not discussed.

It is possible that this topic is not discussed because of the perception that caregiving support takes priority. It is important, however, to recognize the value in sharing mutual

experiences. Additionally, many adults with developmental disabilities have minimal support needs, but there is still limited understanding of how to foster closer relationships outside of support. The belief that adults with disabilities' lives are drastically different from their typically developing siblings also contributes to the idea that siblings cannot benefit from sharing experiences and providing guidance to younger siblings (or to older siblings who have not yet experienced some things a younger sibling may have). There is an opportunity to better understand the role of shared experiences in improving relationship quality within sibling relationships of adults with disabilities.

Connecting Through Identity as Black Women

The sisters in the study did not explicitly discuss their identities as Black women as related to their sibling relationship previously, but there were some interesting observations to come up through the interview process. They each described their own identities as Black women in different ways. Michelle described herself as being a Black nerd. Samaria did not give herself one specific label but described her Black womanhood through her characteristics of strength, intelligence, natural hair, motherhood, and education. However, during the interview, there was a mutual discussion regarding each of their proximity to Black womanhood as they experienced it. For instance, each of them discussed feeling like they did not fit into the mold of a stereotypical Black woman, Michelle for her quirkiness and Samaria for her giftedness, although Michelle was also gifted.

The typical Black girl was described as "miss hip-hop" wearing the most recent fashions, being able to dance, and being in the "in-crowd." Throughout school, they each had experiences where they felt they did not fit in. However, they responded in different ways. Michelle decided to shy away the "typical Black girl" crowd while Samaria found ways to assimilate such as

through dancing. This did not seem to be a conversation they had prior to their interviews, so this was another instance where the interview itself created a sense of connection. They were able to discuss the ways in which they both felt they were not a part of the typical Black woman experience.

Another way they connected that is unique to their identities as Black women is through their hair. “Going natural” in the Black women community is seen as a deeply meaningful personal and political choice (Thompson, 2009a, 2009b). For many Black women, hair has been both a source of pride and a source of shame (Thompson, 2009a; 2009b). For Samaria and Michelle, deciding to go natural was another connecting experience for the sisters. Samaria went natural first, then Michelle, but Michelle often provided tips to Samaria on how to maintain her hair. This conversation also came up in the interviews with Samaria doting over Michelle’s hair. There continued to be mentions of hair throughout the interviews both within their relationship and in reference to extended family members. Their experiences as Black women seemed to be as much of a source of bonding as the support and guidance within their relationship, sometimes intersecting. Racial identity has not yet been explored in study of sibling relationships and disability but could possibly lead to more in-depth understanding and possible areas of intervention for siblings of different racial and ethnic groups.

The dominant narrative for families of people with disabilities have supported the idea siblings of children and adults with developmental disabilities are burdened and negatively affect psychologically. However, siblings with developmental disabilities are also believed to have a positive impact on their typically developing sibling (Taunt & Hastings, 2002). While there was some evidence to support this idea in the study, it was not a dominant theme. Samaria mentioned being more sensitive to others’ differences, but it was not necessarily because of her sister. This

study did not support the idea that siblings are burdened, but rather experience some challenges with closeness. Additionally, these siblings felt supported by one another and leaned on one another for major events and experiences in life. Their relationship was also influenced by their identities as Black women. Their relationship can be characterized as nurturing, supportive, and satisfying with some room for improvement.

Extended Family and Intergenerational Influences

In autism and family research, studies involving the extended family typically explore the extended family members' role in social support and caregiving of the child or family member with autism. For the Tuckers, extended family provided support in many ways, some relating to Michelle's disability, but mostly not. Extended family support was a function of family values rather than material need. Extended family members, such as aunts, also played a major role in identity development for Samaria and Michelle. In Black families, extended family and fictive kin have a long-established history of relevance and permanence (Chatters, Taylor, & Jayakody, 1994; Stewart, 2007) While things have shifted over time in the levels of cohesion within a community, extended-family including multiple generations, aunts and uncles, cousins, and close family friends were typically a major part of a family's experience providing social support, child care, and other forms of support such as transportation and sometimes even housing. People who are not related by blood may be considered family (Chatters, Taylor, & Jayakody, 1994; Stewart, 2007). For this reason, the presence of extended family support for Black families within the disability literature is not surprising, nor is it unique to families of people with disabilities.

Many studies have posited that families of people with disabilities rely on extended family to function (Frison, Wallander, & Brown, 1998; Ha, Greenberg, and Seltzer, 2011;

McCue, 2011). While this is important to note, it is not surprising considering the historical and cultural understandings of how Black families have survived dating back to slavery. Extended family support would exist with or without the child having a disability. Therefore, rather than merely observing that extended family support exists, this study focused on how the support functioned for this family and what areas the support influenced. Having an understanding of how the extended family is involved with the family of interest will help to better focus the inquiry regarding extended family and fictive kin and how the support can continue to contribute to the growth of families with a member with a disability. Rather than encouraging the presence of something that already exists, researchers can figure out how to involve and utilize the bond of extended family and fictive kin.

One thing that continuously surfaced throughout the interviews was the value of family reunions for Samaria and Michelle. Both of their parents' families hosted family reunions, which were central to their bonding time with their extended family. So much so that Michelle was extremely upset when some of her favorite cousins could not make it to the family reunion one year. Family trips were another activity was seemed important to their extended family bonding. In the research, there is little about how family members with disabilities are integrated into these experiences. Much of the literature focuses on behavioral issues that may prevent family members from doing special activities like going on trips. However, for people with disabilities who may not have behavioral difficulties, there is little understanding about the family experience or the person with the disability's experience. For Michelle, family reunions were both enjoyable and central, but also created some feelings of being out of place. Having such a strong family that included lots of social activities and strong identities as Black women was a source of anxiety and led to a feeling of lack of belonging for Michelle. So, for people with

Asperger's Syndrome specifically, the presence of the extended family as a support is relevant, but there also needs to be and understanding of the person's experience while participating in such activities. For people with Asperger's from different cultural backgrounds, this should be an area of further interest.

Community and Faith

The Tucker family identifies as Christian and made clear the importance of their faith to their family experience. The sisters and their mom all mentioned several times how faith played a role in their family experience. They told stories about their involvement in church and different experiences they had through the years. They are all still involved in church in some major capacity. Other studies have discussed the importance of faith to families of color who have children with disabilities. There has been no clear acknowledgment of how to involve faith in the support of families. Churches are often a major source of support for families, but families have also acknowledged that churches are not always helpful when it comes to issues relating to disability (Evans, Feit, & Trent, 2016; Frison et al., 1998; McCue, 2011; Terhune, 2005). There is another opportunity for service providers and families to partner with churches to provide better education and support so that churches can be a better support to the community members that may have family members with disabilities.

Family Modeling and the "Superwoman" Complex

"*All the women in me are tired*"- Nayyirah Waheed

Not only did the Tucker family speak highly of their extended family influence, they spoke of it often. This included their aunts and uncles, cousins, church community, and friends from down the street, to name a few. These people had a role and shaped the women's experiences and identity in many ways. Identity development and family values that contribute to

the individual and family development are rarely discussed in the literature within this context. It has been established that Black families experience less burden and stress relating to family members with disability, so other family dynamics should be explored. Whether that is family cohesion, family quality of life, conflict, problem-solving or other family issues, family values are also important to explore. Family values are often passed down through generations, which means family members outside of the immediate family will also display similar values. For example, Michelle and Samaria often talked about their aunts' influence in their lives and the traits that modeled through family interactions. While their mother was their primary influence, their observations of their aunt reinforced and solidified some of the messaging.

The most dominant message the sisters discussed was what they called the "superwoman" complex. This was the idea that Black women are supposed to be superwoman, doing and being everything to everyone with little regard for their own well-being. Samaria and Michelle responded to this phenomenon differently. Samaria recognized that she sees herself in that mold and made the decision to reject or break away from it. Conversely, Michelle was unable to see herself in the mold because she felt she did not fit due to her disability. This aspect of the family experience had a major impact of Michelle's self-concept. Within the literature, there is no exploration of family influence on identity, but for this family and possibly other families in more collectivist cultures, extended family impact may be of increased importance. The impact that her extended family modeling had on identity and self-concept impacted Michelle's mental health and required additional support. This is an area for further inquiry.

"Caring for myself is not self-indulgence, it is self-preservation, and that is an act of political warfare."-Audre Lorde

Methodological Benefits of Multiple Methods of Inquiry

This study utilized multiple data collection methods over time, in different settings from multiple people within the family. There were three sets of interviews at different time points across the period of two months. During those interviews, Michelle, Samaria, and their mother were interviewed separately and together (Caldwell, 2014; Eisikovits, 2010). They participated in an action research project called Photovoice (Harley et al., 2015; Wang & Redwood-Jones, 2001) and were observed during a lunchtime interview (Patton, 2015; Stake, 2010). To date, this is the first study of its kind in Disability Studies. This study design provided several benefits that no one method could provide on its own.

The interview portion included individual and dyadic interviews that built on one another throughout the process (Caldwell, 2014). During the first interview, I met with each of the sisters individually to introduce myself and allow them to get to know me and create a sense of comfort prior to the dyadic interview. I had already spoken with Samaria before this study so we were acquainted, but this study was my first time meeting Michelle. This interview provided each sister the time to share some thoughts about themselves and their relationship with their sister without their sister hearing those thoughts. If there were points that I felt would be helpful to share in the dyadic interview, I received permission to open that dialogue when we were all together.

The dyadic interview as a method was valuable in this study, as it provided me with the opportunity to see them interact through the interviews to deepen the case study inquiry (Caldwell, 2014; Merriam & Tisdell, 2016). It allowed me to see the nuances of their communication styles. This approach supported a systems approach to supporting families and translated into the research process (Broderick & Smith, 1979; Walsh, 2002; 2016). I also

became a part of the conversation rather than just an interviewer (Sprague, 2016). They would tell me stories and laugh with one another. As a Black woman myself, there were times where they would assess my own shared experiences. This seemed to increase the level of comfort and trust along the way. One of the goals of this study was to create space where the women felt comfortable, safe, and connected throughout the research process.

Interview two was conducted during lunch at a local restaurant in New Orleans. The sisters arrived, and we exchanged hugs and stories about our journeys there that day. They shared their conversation on the car ride over, which consisted of developing an idea for a children's book about being different. This was an idea that was prompted by the first set of interviews. They discussed some of the things they had noticed about their relationship since the last interview. We were all able to reflect on those changes and how they see their relationship progressing going forward. Another aspect of this experience was connecting through food. We discussed our meals and they made suggestions to me as a non-Louisiana native. Being in this setting allowed me to see how each them interact with the staff and the environment of being a public place.

The third interview was conducted in Samaria's home rather than their parents' home, so I was able to observe the different dynamic of the two homes. I witnessed Samaria attempting to assert her power in her home, although unsuccessful as her mother swiftly re-asserted her own as the mother. It was the small exchanges such as that one that provided additional insight that I otherwise would not have had access to if they were not in their familiar settings and if they did not feel comfortable with me as a researcher. This speaks to the importance of the researcher as an instrument. While it may not necessary for a researcher to share the same racial identity, in this case, it was helpful to the subject matter.

The addition of Photovoice (Harley et al., 2015; Wang & Redwood-Jones, 2001) allowed me to see their worlds through their eyes. They were able to capture moments as they were happening day to day during the interview process. Some things they could speak to but having a photo to complete that picture was invaluable. For example, the pictures of Samaria's nightstand that included her breast pump and books she is currently reading, or Michelle's knitting photo at work. These additions provide context and bring these experiences to life. There were times when the sisters would include a photograph that was directly related to the conversations we had been having in the previous interviews and other photos would reflect something additional. Through the analysis, the sisters' interpretations were the primary source of information, but there is also the possibility of interpreting the photos without the participants' interpretations as influence. Analysis could include the participants' and researcher's interpretations of the photographs for further meaning-making. Additionally, when two people are describing the same experience, there may be difference. Having a photograph of the experience can help bring clarity to the different ways of describing the same experience.

Overall, the different methods provided different pieces to a very complex puzzle (Caldwell, 2014; Harley et al., 2015; Patton, 2016; Stake, 2010; Wang & Redwood-Jones, 2001). The individual interviews allowed for the sisters to share some feelings that they had not yet accessed or were not yet ready to share. The dyadic interviews added additional perspective to the individual interviews and allowed for interaction between the sisters. Those interviews allowed for and created some emotional experiences that would not have been possible in individual interviews. The additional interview from their mom and Miles provided additional clarity around experiences they had during childhood and adulthood and the parents' influence of aspects of their experiences. The interview at the restaurant allowed for observation of both

sisters in a social setting outside the comfort of their homes. The Photovoice provided a means for the sisters to capture and share moments in real time and provide support and context for some of the experiences they shared during the interviews.

Samaria and Michelle mentioned several times how the research process itself was therapeutic for them. After each interview, they would express how much they were impacted by having a space to talk about their relationship. The value of "in the moment" interactions between the sisters were immeasurable. One of the most powerful moments of the entire study was during the first interview when Samaria and Michelle shared their feelings about being there one another. Without the interviews, there is no way to know if these conversations would have happened, and thus, whether they would have experienced the growth they reported through the study. This therapeutic value of the interview process speaks to the importance of a space to discuss relationship. Siblings need a space to not only process their feelings, but to have conversation with one another. This space for siblings is currently limited. One of the challenges of this study is figuring out how to translate this experience from interviews as intervention for siblings in different settings. There is power in conversation, but it is possible that people do not know or realize that their relationships can grow. Samaria and Michelle admitted that they both wanted to be closer but had not spoken to one another about their desires. These sisters cannot be the only siblings to feel this way. One of the main goals of this study is exploring how to create more closeness for siblings. A space for conversation could be a start whether through research or practice, but preferably both.

Conclusion

This case study is a representation of two Black women sister's experiences relating to ability, social aptitudes, and their Black womanhood. Their stories are filled with faith, gratitude,

support, empathy, love, and joy. This dissertation represents the complexity of relationships between individuals and the many influences that impact their relationship. Their story is unique within the literature, but it is likely not unique in our society, yet their stories have not been told or studied.

This study set out to address sibling relationships, family and community influences, and sociocultural issues relating to Black womanhood in a Black family with a member on the autism spectrum. This is a broad topic that required an in-depth exploration of their lives. The larger purpose of this study was to cast a wide net to capture aspects of their experience that have not yet been addressed in the literature. As mentioned continuously throughout the study, the information regarding Black families and disability is limited to one line of inquiry: how burdened are families who have a child with a disability? The study demonstrated that the narrative for families that included a member with a disability are not simply burdened by their family member. While families may experience some burden or challenges, there is still much to learn about this population of families. This family's narrative was very complex involving multiple facets of experiences across their lifespan that included life transitions, continued education, career, dating, artistry, travel, and family traditions.

Through this study, the researcher discovered new ways of exploring family relationships when there is a family member with a disability. This included considering the mutuality of support in relationships rather than a bi-directional assessment, expanding our understanding of the role of extended family in Black families, and considering how intersectional identities impact mental health and self-concept for people on the autism spectrum. An additional area to consider is the lack of representation for people of color in disability advocacy and the impact on family outcomes. Researchers and practitioners must consider the impact of historical influences

on identity and perceptions of people of color as well. This includes how researchers perceive people of color-Black people in particular- and how Black people may perceive themselves based on historical messaging. These perceptions impact the dominant narratives which in turn affect the types of support people seek.

Clinical Implications

Through the interview process, the sisters consistently expressed how therapeutic the interview process was for their relationship. The aim of the dyadic interviews was to help create dialogue and provide multiple perspectives rather than individualized perspectives. This process speaks to the importance of a family systems approach.

Family systems approach. The family mentioned how well Michelle did after participating in therapy, but they did not think to include the entire family in the process. This thinking is still very common within families as well as some professionals. Treating the family member who is identified as having the problem is believed to be the proper approach, but the field of family therapy was grown out of systems thinking and built on the idea that any change in one member affects change in the whole system (Broderick & Smith, 1979). Treating one person is only helpful insofar as no one else is involved with the person, which is typically not the case. Therapy is still seen as an individualized process, but the systemic approach can be much effective with multiple family members involved in the process, as also evidenced through this study. Rather than focusing interventions on the person with the disability, families would benefit from a systemic family therapy approach. Disability is not something to be fixed, therefore it would be helpful for all family members to discuss and work through issues they have relating to their personal family experiences. In addition, the systematic influences of race, gender, and dis/ability should be included in treatment approaches.

Individual support. Another aspect to consider is the mental health of people on the autism spectrum. The majority of research addresses parents or siblings of people with disabilities. Rarely are people with disabilities included when thinking about who might be distressed. The field focuses heavily on families of children and adults with high support needs because parents and siblings may experience more distress within these families, but this focus neglects to recognize people who may have less support needs or considered "higher functioning" because they do not affect stress levels of the people around them as much, but people do not then consider that the person themselves may be in distress. Researchers and clinicians alike much consider the experiences and challenges of the entire family and not just focus on how one person is harming another. How they support everyone within the family is also valuable and necessary.

Limitations

The main limitation of this study is the lack of generalizability. The study focused on one family and therefore was not meant to represent any one group's full experience. The family was also middle class with high levels of formal education. Families of lower socioeconomic status and less formal education may not share this family's experiences or perspectives. The study also focused purposefully on Black families, thus the information is not generalizable to other racial or ethnic groups, as they are also U.S. born and may share different cultural influences. However, the differences that were found suggest that other groups may also experience differences in their family experience. The study also focused on women/sisters and may suggest differences for men/brothers or mixed gender sibling dyads. Experiences relating to identity was a major focus for this study and would manifest differently for men. The number of children in the family could also have an impact.

The type of disability also plays a role in the family's experience. The researcher recognizes that Michelle was highly independent with minimal support needs. The family's experiences could range tremendously depending on the characteristics of the family member with a disability. Additionally, the sample was not randomized and was recruited through prior participation in a similar study. This study was meant to serve as a starting point for inquiry to suggest possible areas to address when working with families of different backgrounds. The study provided insight into this family's experience and offered perspective on possible ways to better support families and shift the way that we examine and explore families' challenges as well as ways they thrive.

Recommendations for Future Research

This study demonstrated that there is an opportunity to expand the way we do research with families of people with disabilities, specifically on the autism spectrum. While there are many considerations to make when working with Black families based on the findings of this study, the major recommendations can be applied more broadly. The first is to consider including the person with a disability in the research. Much of the disability research excludes the person's voice from inquiry and thus misses out on a valuable perspective. Michelle having the opportunity to share her feelings and perceptions led to some valuable moments in the interviews as well as transformative experiences outside the interviews. Excluding the person from the research process reinforces the idea that people with disabilities should not heard and their needs are not important.

The second recommendation is for research and practice that utilizes a family systems approach. The dyadic format of interviewing provided data and information that would not have been accessed through individual interviewing. For practitioners, the family systems approach

already has an established record of value (Broderick & Smith, 1979). Focusing on impact of one person on another is only helpful if there is also a reciprocal understanding because relationships are not linear. Transitioning this thinking to disability community supports will help families to function as a unit rather than focusing on any one person at a given time. The extended family could also be valuable in this process for families where extended members play a major role in the family.

For sibling relationships specifically, research should begin examining relationship characteristics beyond caregiving. While caregiving is extremely important to consider for families of people with disabilities, it does not exist in a vacuum. Michelle and Samaria demonstrated that caregiving was not a major aspect of their relationship. Closeness may look different for siblings when one of them of the spectrum, but it is not simply caregiving. It can also be mutual support through life stages, shared experiences, or identity-based experiences such as challenges related to being a Black woman in the workplace.

Finally, research should consider more critically the impact of intersectional identities. Whether it is family identity or individual identity, it plays a role in family functioning and the types of supports families receive or do not receive. Cultural influences can shift a family's experience tremendously in ways we do not yet understand. Many people on the spectrum with intersectional racial identities are screaming for someone to see and hear them. Autism is not colorblind and should not be treated as such. Ignoring aspects of someone's experience can lead to mental health issues, health disparities, disparities in diagnosis, and social exclusion to name a few. The research has consistently demonstrated that people of color's experiences are different. It is past time that those differences go beyond acknowledgment and people are given a voice to speak truth to multiple types of power.

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APPENDICES

APPENDIX A

CONSENT FORM

I am My Sister's Keeper: A Critical Case Analysis Sisterhood, Black Womanhood, and Asperger's Syndrome in a Black Family

Researcher's Statement
I am asking you to take part in a research study for my doctoral dissertation. Before you decide to participate in this study, it is important that you understand why the research is being done and what it will involve. This form is designed to give you the information about the study so you can decide whether to be in the study or not. Please take the time to read the following information carefully. Please ask the researcher if there is anything that is not clear or if you need more information. When all your questions have been answered, you can decide if you want to be in the study or not. This process is called "informed consent." A copy of this form will be given to you. This research is conducted under the supervision of Dr. Zolinda Stoneman. If there are any questions or concerns that cannot be answered by the research, please feel free to contact her.

Doctoral Advisor: Zolinda Stoneman, Ph.D., zo@uga.edu, 706-542-4827

Purpose of the Study
The purpose of this study is to explore the experiences of African American siblings related to race and gender when one sibling has an intellectual disability. This study aims to better understand how siblings interact with one another and how they have been socialized regarding race and gender. This study aims to seek the perspective of Black/African American men and women.

Study Procedures
If you agree to participate, you will be asked to …

- Answer a series of questions that will be delivered by the interviewer. These questions will involve inquiries about your childhood, relationship with your sibling, and issues regarding culture/race.
- The interviews will last approximately 90 minutes.
    - Questions that may be asked include, but are not limited to:
      How would you describe your current relationship with your sibling?
      How involved are you now in your sibling's life?
      Do you currently have responsibilities for your sibling's care?
      How often do you see your sibling? How much time do you spend together?
- Interviews will be video and audio recorded.

- The photovoice portion will occur over a period of 3 months
- The participant activity will take approximately 3 hours

Risks and discomforts

- Answering questions regarding your relationship, both past and present, has the potential to cause emotional discomfort or stress.
- If any discomfort occurs, you are free to refrain from answering the question or you may withdraw your participation at any time.

Benefits

- Participation in this program will help aid in understanding relationships of siblings involving a person with an intellectual disability. Helping in this process can be rewarding for participants as they will have first-hand in contributing to this knowledge base.
- Understanding these relationships will aid in creating more effective and applicable programs for siblings in clinical and educational settings.

Incentives for participation

You will receive a meal with each interview. The research will provide lunch or dinner at the beginning of each meeting.

Audio Recording

Audio recording will be used to ensure accuracy of the information that is shared during the interviews and observation. The interviews will be transcribed word for word as they are spoken once the interviews are completed. The audio recordings will be destroyed after they are transcribed.

All participants' names and places will be changed to pseudonyms and any identifiable information will be omitted from any data that may be seen by anyone other than the researchers. Data will be recorded and filed separately for each interview. A coding system will be assigned to each participant interview. All data will be stored in locked cabinets and password protected. Researchers will not release identifiable results of the study to anyone other than individuals working on the project without your written consent unless required by law.

Please provide initials below if you agree to have this interview recorded or not. You may still participate in this study even if you are not willing to have the interview recorded.

_____I am willing to have this interview audio recorded.
_____I am willing to have this interview video recorded.
_____I do not want to have this interview audio recorded.
_____I do not want to have this interview video recorded.

Taking part is voluntary

Your involvement in the study is voluntary. If you decide to stop or withdraw from the study, the information/data collected from or about you up to the point of your withdrawal will be kept as part of the study and may continue to be analyzed.

If you have questions
The main researcher conducting this study is Shaquinta Richardson. Please ask any questions you have prior to beginning of the study. If you have questions later, you may contact *Shaquinta Richardson at sllrich@uga.edu*. If you have any questions or concerns regarding your rights as a research participant in this study, you may contact the Institutional Review Board (IRB) Chairperson at 706.542.3199 or irb@uga.edu.

Research Subject's Consent to Participate in Research:
To voluntarily agree to take part in this study, you must sign on the line below. Your signature below indicates that you have read or had read to you this entire consent form, and have had all of your questions answered.

_____	_____	_____
Name of Researcher	Signature	Date
_____	_____	_____
Name of Participant	Signature	Date
_____	_____	_____
Name of Participant	Signature	Date

Please sign both copies, keep one and return one to the researcher.

APPENDIX B

DEMOGRAPHIC INFORMATION

Sibling Birth Date (w/disability):_____

Sibling's Birth Date (w/o disability): _____

Gender of siblings:_____ **Race/Ethnicity**:_____

Number of siblings in the family:_____

Number of siblings with intellectual/developmental disability:_____

Sibling 1 Relationship Status: Married Divorced Separated Never Married Other

Sibling 2 Relationship Status: Married Divorced Separated Never Married Other

Are your parents: Married Divorced Separated Never Married Other

Sibling 1 Education Level: Some High School High School College Graduate School

Sibling 2 Education Bevel: Some High School High School College Graduate School

Sibling 1 Occupation:_____ **Sibling 2 Occupation**:_____

Sibling 1 Income: Under $10,000 $10,000-$19,000 $20,000-$29,000 $30,000-$39,000 $40,000-$49,000 $50,000-$59,000 $60,000-$69,000 $70,000-$79,000 $80,000 and over

Sibling 2 Income: Under $10,000 $10,000-$19,000 $20,000-$29,000 $30,000-$39,000 $40,000-$49,000 $50,000-$59,000 $60,000-$69,000 $70,000-$79,000 $80,000 and over

Please check the item(s) that most accurately describe most recent diagnosis (sibling with disability):

_____Autism _____Intellectual Disability/Mental retardation _____Down Syndrome _____Physical disability _____Language delay _____Visual impairment _____Hearing impairment _____Fragile X _____Other-Please describe_____

APPENDIX C

INTERVIEW QUESTIONS

Interview One: Sibling Relationship (Introductory)

Individual Questions

(Following an introduction about myself)

1. Tell me a little about yourself.
2. What are some of your favorite things to do?
3. Who are some of your favorite people?
4. What do you do during the day? Work, school, etc.
5. What are some of your favorite things about your sibling?
6. What are some of your favorite things to do with your sibling?
7. When I say the word ability, what does that mean to you?
8. When I say the word disability, what does that mean to you?
9. When I say the word Black, what does that mean to you?
10. When I say the word woman, what does that mean to you?

Dyadic Questions

1. What are some of your favorite things about each other?
2. Tell me about some of your favorite times together.
3. Tell me about some of your favorite memories from childhood.
4. How did you interact during school?
5. Tell me about your friendships.
6. How would you describe your relationship now?
7. How much time do you spend together now?

8. What types of things do you do together?
9. How do you feel about your relationship when you were growing up?
10. How do you feel about your relationship now?
11. Were there people who supported you when you were growing up?
12. What is a favorite story of you and your sibling?
13. What support does your sibling provide you? Describe a situation that your sibling was ‘‘there’’ for you…
14. What kind of support do you provide your sibling? Why? Are you involved in advocacy organizations, for instance?
15. What would you say has been the best/hardest part of growing up with your brother or sister? Why?
16. How do you see your relationship in the future?

Parent Questions

1. How does your family identify?
2. How did you teach your children about being Black?
3. What types of things do you think about when you think about being Black?
4. What traditions, rituals, or practices does your family engage in related to being Black?
5. How did you teach your children about being a wo/man?
6. What types of things do you think about when you think about being a wo/man?
7. What traditions, rituals, or practices does your family engage in related to being a wo/man?
8. What experiences have you had in your community related to being Black?
9. What experiences have you had in your community related to being a wo/man?
10. What experiences have you had in your community related to being a Black wo/man?
11. How do you believe you prepared your children for experiences related to their gender and race?
12. Was this different for one sibling from the other?
13. What experiences have you had in your community related to dis/ability?
14. What are your thoughts on being a Black wo/man with a disability?
15. Have you had conversations relating to this topic?
16. How do you believe you prepared your children for experiences related to disability?

Interview Two: Family & Community

Dyadic Questions: Siblings

Interview 1 Follow-up Questions

1. So what have you noticed since our first interview? Anything different? Things that have come up for you?
2. How did you two talk about relationships, dating, and other things relating to being a woman? What were those conversations growing up?
3. There was mention of therapy. Can you talk about that experience?
4. There was some talk about school. Did either of you experience bullying? How did you handle that?

Interview 2 questions

5. How does your family identify?
6. How did your parents teach you about being Black?
7. What types of things do you think about when you think about being a Black family?
8. What traditions, rituals, or practices does your family engage in related to being Black?
9. How did your parents teach about being a wo/man?
10. What types of things do you think about when you think about being a wo/man?
11. What traditions, rituals, or practices does your family engage in related to being a wo/man?
12. Tell me more about your aunts and seeing them as superwomen.
13. What experiences have you had in your community related to being Black?
14. What experiences have you had in your community related to being a wo/man?
15. What experiences have you had in your community related to being a Black wo/man?
16. Have you two ever discussed things related to being Black or being a wo/man?

17. Were there people outside of your family you could talk to?
18. Can you recall a time you were treated poorly by someone else based on your race and/or gender?
19. Can you tell me more about Black nerd problems?
20. How did your parents teach you about dis/ability?
21. What types of things do you think about when you think about ability or having a disability?
22. What experiences have you had in your community related to dis/ability?
23. What experiences have you had in your community related to being a Black wo/man with a disability?
24. Have you had conversations relating to disability?

    *****If dad was not mentioned much, ask more about dad.
25. Were there people outside of your family you could talk to?
26. Can you recall a time you were treated poorly by someone else based
27. What kind of supports would you have liked to have growing up and or now?
28. What would you like to see in advocacy for people with disabilities?

Interview Three: Society

Dyadic Questions: Siblings

1. What have been some of your experiences related to race, disability and gender?
2. What does it mean to be Black?
3. What does it mean to be a wo/man?
4. What is ability to you?
5. What is disability to you?
6. When you think about being Black and being a wo/man, what does it mean to be a Black wo/man?
7. What are some symbols or images you believe have represented Black women?
8. What are some symbols that represent you as a Black woman?
9. How did your parents teach you about being a Black wo/man?
10. What are your thoughts on being a Black wo/man with a disability?
11. How did your parents teach you about being a Black wo/man and ability?
12. With things that are currently happening in the media, have you had conversations around these issues? (i.e. shootings, police brutality) Ex. Colin Kaepernick. Jemelle Hill

Parent

1. What does it mean to be Black?
2. What does it mean to be a wo/man?
3. What is ability to you?
4. What is disability to you?
5. When you think about being Black and being a wo/man, what does it mean to be a Black wo/man?
6. What are some symbols or images you believe have represented Black women?
7. What are some symbols that represent you as a Black woman?
8. There was mention of being a strong black woman. How do you feel you modeled that for them?
9. With things that are currently happening in the media, have you had conversations around these issues? (i.e. shootings, police brutality) Ex. Colin Kaepernick. Jemelle Hill

Brother-in Law Questions:

1. Tell me about your earliest memory of meeting your sister-in-law?
2. What types of things did you notice about their relationship?
3. How would you describe your relationship with your sister-in-law?
4. How do you all interact when you are all together?
5. There was a conversation around you helping Tyra with their relationship. Can you tell me what you were noticing that led you to provide some insight?
6. When you started to have children, what thoughts and feelings came to mind in thinking about your children and their sibling relationship?
7. What is ability to you?
8. What is disability?