

ABSTRACT

DANGLEBEN, D. TIFFANY. Parent Advocacy Experiences in Black Families of Children with Autism. (Under the direction of Dr. Kate Norwalk).

Autism spectrum disorder is a widely prevalent neurological disorder classified by areas of need in communication and social interaction, as well as restricted and repetitive patterns of behaviors and interests (American Psychiatric Association, 2013). There is an abundance of literature on autism and autism services; however, the research primarily focuses on White families from middle class backgrounds. Additionally, existing literature often conflates race and socioeconomic status, suggesting that any disparities in access to autism services is due to a limitation in economic resource. Not only does this narrative limit the reader's ability to grasp the nuances between race and disability, but it can also create space for misunderstanding (i.e., differential diagnosis and victim shaming). Emerging research suggests racial differences in the acquisition of an autism diagnosis and access to autism services are strongly related to social barriers such as implicit bias and cultural divergence, as well as lack of understanding about autism.

For Black families specifically, these factors have been identified as barriers when receiving an autism diagnosis and/or accessing autism services (Pearson, 2015). These findings raise concerns about the process practitioners follow when working with minoritized children suspected of having autism. Previous research has found that primary care physicians have more difficulty identifying symptoms of autism in Latino and Black children than in White children (Zuckerman et al., 2013). When analyzing facilitators to parents accessing autism services, research identifies advocacy as an effective tool (Pearson & Meadan, 2018); however, there is limited research that specifically focuses on Black families of children with autism and their

advocacy experiences. The present study fills this gap by examining: (a) advocacy among a sample of Black families of children with autism, and (b) Black parents' experiences accessing autism services. This qualitative study adds to the literature on Black families' experience with advocacy, while shifting away from the existing narrative that socioeconomic status is the main and/or only factor that affects their experiences. Further implications from the findings are also discussed.

Parent Advocacy Experiences in Black Families of Children with Autism

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CHAPTER 1

Autism spectrum disorder (ASD), also referred to as autism, is widely prevalent in the United States and other countries. According to the U.S. Centers for Disease Control and Prevention, 1 in 54 children is diagnosed with autism in the United States (Center for Disease Control and Prevention, 2021). Currently, there is no cure for autism; however, families of children with autism utilize a number of services to treat associated symptoms. These commonly used services, which include behavior management programs, early intensive behavioral interventions, speech therapy, and occupational therapy, have yielded positive results in pre-school and elementary-aged populations on a range of outcomes (Peters-Scheffer et al., 2011; Reichow, 2012; Case-Smith & Bryan, 1999; Aldred et al., 2004; and Wong & Kwan, 2010). Additionally, some research suggests that children who receive services at an earlier age have better outcomes, including improvement in their IQ, adaptive behavior, and other behaviors associated with their autism diagnosis (Dawson et al., 2010); as such, it is imperative that children with autism receive appropriate services as soon as possible to treat their related symptoms. This is also important to highlight because children can be diagnosed with autism as early as 2 years old, and those receiving early intervention services have shown significant increases in IQ and behavior compared to same aged children with autism who did not receive early intervention.

Unfortunately, past scholarship suggests that families of color often have less access to autism-related services than White families of children with autism (Irvin et al., 2012; Liptak et al., 2008; Thomas et al., 2007; Gourdine et al., 2011). Notably, Irvin et al. (2012) found that within their study, Hispanic children with autism received fewer in-school occupational and speech language therapy services compared to White children. Furthermore, Thomas and

colleagues (2007) found that Black families of children with autism utilized the services of a case manager, psychologist, developmental pediatrician, and sensory integration specialist to a lesser extent than their White counterparts. Socioeconomic status has been identified as one barrier that disproportionately affects access to services for families of color, and prior research has often conflated these two sociodemographic factors (Liptak et al., 2008); however, further research suggests that higher family income may not necessarily lead to an increased use of autism services for families of color and highlights additional barriers that can impact their access to services. More specifically, emerging research on the interactions between Black families and child practitioners emphasize an area of cultural divergence.

Cultural Divergence

Cultural divergence can be described as a barrier between parents of color and medical professionals that can hinder or prolong Black families of children with autism from receiving an autism diagnosis and accessing needed services (Pearson, 2015). These barriers can manifest themselves in various ways; however, they tend to consistently involve implicit bias and a limited understanding of autism (Gourdine et al., 2011; Pearson & Meadan, 2018; Stahmer et al., 2019). For instance, Stahmer et al. (2019) conducted a qualitative study to understand the perspectives of Black, Hispanic/Latinx, and Korean families and their service providers on the barriers to obtaining an autism diagnosis. The authors found that across racial and ethnic groups, families identified the following barriers: (1) limited understanding of autism, (2) misdiagnosis, and (3) dismissive behavior. Specifically, all caregivers noted that their child's healthcare professional had a poor understanding of autism, and many parents reported that their child's initial diagnosis was incorrect. Black caregivers specifically reported their child being misdiagnosed with externalizing disorders, such as ADHD. Furthermore, many caregivers

expressed that their delay in diagnosis was related to the child's provider minimizing parental concerns and felt this was related to their race or culture. For example, one Black mother reported that a medical provider blamed her child's behavior on her parenting style and refused to refer her for a diagnostic evaluation. These findings raise concerns about the process practitioners follow when working with children of color suspected of having autism.

Further evidence of cultural divergence comes from research with healthcare providers. Zuckerman et al. (2013) surveyed 267 primary care pediatricians (PCPs) in California to assess their developmental screening practices for autism, attitudes towards autism identification, and barriers to autism identification for their patients. Although the focus of this study was on autism identification in Latinx children, the authors examined differences in PCP reports for Latinx, Black, and White families. The majority of PCPs reported having more difficulty identifying symptoms of autism in Latinx and Black children than in White children. Additionally, the majority of PCPs reported that in comparison to parents of White children, parents of Latinx and Black children had less knowledge of autism. Similar findings were reported by Pearson and Meadan (2018) who identified a lack of parental knowledge of child development and disability as a barrier to receiving a diagnosis.

Advocacy as a Facilitator to Accessing Services

Limited research suggests that advocacy (i.e., advocating for school services) may serve to combat some of the barriers that impede Black families' access to services (Pearson & Meadan, 2018). Advocacy can be defined as the action of speaking and acting on behalf of another person or group of people to bring attention to their needs, strengths, and preferences (Wolfensberger, 1977). When a parent advocates for their child, they are seeking the best outcome for their child's individual needs. According to Trainor (2010) there are four types of

parent advocates: intuitive, disability expert, strategist, and agents of systemic change. Intuitive advocates rely on their personal knowledge of their child to advocate for services. Disability experts use their knowledge on the type of disability their child has to advocate for services. This type of parent advocate gathers information about the disability from doctors, organizations, and websites. Strategist advocates rely on their special education rights, as well as their personal knowledge about their child to effectively advocate. Finally, agents of systemic change push for educational and special education reform for all children.

What advocacy can look like

In addition to different types of parent advocates, *how* parents advocate can vary. Parents employ a variety of strategies and approaches to advocate for their child, such as increasing their knowledge about the special education process and parental rights (Zaretsky, 2004; Burke et al., 2018), and communicating with school professionals and utilizing community resources (Wilson, 2013; Stanley, 2015). Whereas some parents feel comfortable being an advocate, others might seek the help of a professional advocate to meet their child's needs. Goldman et al. (2020) evaluated the perceptions of caregivers who requested advocacy support to “understand why, for whom, when, and where the advocacy services were needed” (p. 158). They found that the most common reasons caregivers requested an advocate were to attend an individualized education plan meeting with them, if there was a disagreement on the amount or type of services, supports and accommodations provided for their child, and when they were seeking information and wanted to learn more about their rights. Notably, using a sample of 33 graduates of a special education advocacy training program, Burke and Goldman (2016) conducted a qualitative study examining the advocacy process that special education advocates use when working with families. They found that in addition to participating in IEP meetings (e.g., providing emotional

support and asking direct questions to school personnel), advocates also engaged in empowerment and knowledge sharing with parents by explaining special education rights to parents, providing guidance on choosing appropriate service options, and referring them to parent training and disability agencies to learn more about their rights.

Why parents advocate

Parents and parental figures engage in advocacy for several reasons; however, most parents of children with a disability, regardless of race/ethnicity, advocate to acquire proper services for their child. Burke and Hodapp (2016) conducted a national study that assessed factors explaining why parents advocate within the school system. Within a predominantly White sample ($n = 84\%$), they found that parents of children with severe behaviors and/or learning disabilities, autism, and health impairments advocated more than parents whose child did not have these needs. Additionally, they found that increased parental advocacy was strongly correlated with less satisfaction with services, a poor parent-school partnership, and parents' educational attainment. Specifically, parents with higher education advocated more for their child.

Black Parental Advocacy

In one of the few studies that have examined the advocacy experiences of Black parents of children with disabilities, Stanley (2015) found that Black mothers engaged in both individual and collective forms of advocacy. Individual advocacy was described as parents demonstrating efforts and decision-making skills on behalf of their child (e.g., using intuitive advocacy to educate school staff about their child's disability). By contrast, collective advocacy was described as when parents advocated for the needs of their children together (e.g., meeting with a large group of parents and teachers to protest a decision to close the alternative school their

children were attending). They also found that some mothers sought advice from their child's pediatrician and other providers before their child started school or when their child was experiencing academic difficulties. Pearson and Meadan (2018) also explored the perceived factors and facilitators that impede early diagnosis and access to services for Black children with autism. They found advocacy to be a facilitator in parents' access to autism services, specifically when parents communicated their child's needs during IEP meetings.

Social capital is another tool a Black parent can use in conjunction with advocacy to effectively navigate through social barriers. Social capital can include having a network, especially a network of parents which can give Black parents the opportunity to gain more knowledge about the school, its system, and potential partners to argue a disservice (Lareau & Horvat, 1999; Horvat et al., 2003). Within a sample of Black and White middle-class, working-class, and "poor" families (e.g., determined based on 'social class' and residence of public school), Horvat et al. (2003) assessed how social capital is used when issues arise in school. They argue that differences in networks and parental interaction with school personnel are due to differences in social class, not race. They found that Black and White middle-class mothers have little to no differences in the way they advocate for their child, nor in their ability to tap into resources when necessary; however, they also acknowledged that Black mothers had more "childrearing tasks" because they were aware of the possibility that their child could be subjugated to "racial discrimination and insensitivity on the part of officials," and discussed with other Black parents the need for more Black teachers in the school district (Horvat, 1999, p. 343).

Given the disparities in access to autism services for families of color, as well as the potential for parental advocacy to serve as a facilitator for accessing services, understanding the

advocacy experiences of Black parents is crucial. It can be argued that because of racism, Black parents have additional reasons to advocate for their child that makes advocacy amongst Black and White parents different. Although middle-class Black mothers have the education and social capital to advocate for their child in a way that is digestible for school officials (to whom are mostly White), it does not discount their experience having to advocate for their child as a result of racism. Black parents' awareness of racism, both personal and academic, is a factor that affects their relationship with educators and schools (Wilson, 2019).

Racism and its Effect on Black Parental Advocacy

As a community, Black people have a long-standing history of experiencing racialized educational exclusion (i.e., not being allowed to read, write, or attend public schools until after the Civil War) and educational inequities (i.e., separate but not equal education laws) in the United States. Racism continues to permeate the public school system, allowing for Black children to face discriminatory practices, which are often based on the subjective opinion of school officials. Although the *Brown v. Board of Education* Supreme Court ruling declared separate but equal educational laws unconstitutional, unequal practices were only reformed and now take the shape of inequities in school funding, higher rates of suspension and expulsion, and disproportionate rates of Black children in special education (Solis, 2021; Chapman, 2013; Shollenberger, 2015; Farkas et al., 2020; Connor et al., 2019). Black parents have a history of advocacy which includes protesting to improve the resources and standards their children are given (Cooper, 2009). For example, Yull et al. (2018) conducted a study on a Parent Mentor Program with four Black mothers of high school aged children in Rivertown, New York. Parents expressed that prior to participating in the program, they felt unwelcomed at their child's school and advocated for their child who experienced racialized disciplinary practices.

Additionally, Black parents advocate to be seen as caregivers. Previous research examining parental perceptions of the school system note a common misconception – Black parents do not care about their child’s education (Lavizzo, 2016; Marchand, 2019). Lavizzo (2016) conducted a qualitative study in Oakland, California examining Black parents’ concept of parental engagement, the effects of race and social class on parents’ engagement in their child’s education, and how school personnel encourage and/or challenge Black parent engagement. They found that educators blamed Black parents, Black culture, and low parental education on student outcomes. Roughly 35% of respondents affirmed that student problems are a result of parents not valuing education in their home. Another 29% identified as neutral or unsure on the topic. This perception is especially dangerous to the foundation of relationship building with Black families as well as the emotional and physical safety of students in schools. When teachers hold negative views about their Black students and their parents, this can discourage parents from wanting to work with them and/or have their child attend that particular school. Notably, when exploring the motivational factors for Black parents who homeschool their child, Ray (2015) discovered that amongst the conventional reasons for homeschooling (i.e., religious/home values, develop a stronger relationship with their child, and academic success) additional reasons were provided that are race related. For example, nearly 40% of Black parents said they want to give their child more instruction on African American/Black culture and history. Approximately, another 20% of participants reported having a desire to avoid racism in public schools as a motivator. Choosing an appropriate learning environment (i.e., a school or alternative option) is a form of parent advocacy. As it pertains to Black families, Black parents also consider the values of the school and its educators because of the negative ramifications racism will have on their children.

Current Study

Although there is an extensive amount of literature on autism, the majority of the information focuses on the experiences of White middle-class families – subsequently othering the experiences of Black families of children with autism. Additionally, as a result of using an economic lens to rationalize differences in parental attainment of autism services, previous research created a narrative that contributed to victim-blaming and differential diagnosis. Emerging literature suggests differences are due to social factors such as cultural divergence and proposed that parental advocacy is a facilitator in combating social barriers. Exploring the experiences of this specific Black population can allow professionals who work closely with them (i.e., pediatricians, service providers, and school officials) the opportunity to check their biases and provide better care and service to Black children on the spectrum. Few researchers have conducted studies on advocacy that focus on autism and Black families, specifically. This study fills this gap by using an exclusive sample of Black families of children with autism and exploring the parental experience of navigating through social barriers to advocate for their child. Therefore, the purpose of this study was to: (a) examine advocacy among a sample of Black families of children with autism, and (b) explore Black parents' experiences accessing autism services. This qualitative methods study was guided by the following research questions:

1. How do Black parents of children with autism describe their experiences advocating for services?
2. To what extent do Black parents of children with autism perceive their advocacy efforts as effective?

Reflexivity

I conducted this research with purpose and intentionality. I took it as an opportunity to tell a side of a story that has not been told before. As I delved into the literature on advocacy, autism, and Black families, I quickly noticed the academy lacked representation and understanding of Black families of children with autism. My goal was to shed light on the realities of this specific population, from their point of view, and allow readers the opportunity to understand and empathize with a situation that might be foreign to them.

My personal, academic, and employment background is closely related to this study. Therefore, throughout the process of literature review, coding and analysis, I was cognizant of not putting my voice and experiences before my participants. Like many of the mothers who were interviewed, I identify as a Black woman who is a caretaker of a young Black boy on the spectrum. Prior to beginning my doctoral journey, I studied Psychology with a dual minor in Africana Studies and Women Studies. As an applied behavior analysis teaching assistant, I worked directly with Black and Hispanic families of children with or suspected of having autism. As a result, I have extensive knowledge of how difficult it is for Black families to navigate educational and medical systems due to implicit bias and lack of knowledge about disability. In spite of my background, I would be remiss to not acknowledge the potential effect my graduate education has on my understanding of Black families. I am currently enrolled in a school psychology doctoral program at a predominantly White institution, which would provide me a historical White perspective on disparities in the Black community. To help combat this potential barrier, my research uses an interdisciplinary (Psychological, Educational, and Critical Race) approach to explore and analyze the advocacy experiences of Black families accessing autism

services for their child. This paper incorporates language and thought from multiple lenses to describe advocacy experiences within the Black community.

To ensure accuracy in coding, I chose an emergent coding approach. This required me to review an entire transcript to identify arising themes across participants. This approach is complementary to Black individuals who engage in oral accounts such as semi-structured interviews. Historically, oral tradition has been an important form of communication and the passing down of information within the Black diaspora. Turner (1990) noted that oral history traditionally measures time based on memorable events rather than specific dates. Taking this into account, it is possible that I would be limiting participants' voices if I engaged in a priori coding or only assessed the responses from specific questions. In other words, I was able to obtain the most information about participants' experiences with advocacy by reviewing the entire interview of each participant. Although this process is more time consuming, it was the best option in giving participants the opportunity to tell their story.

CHAPTER 2

This study utilized a qualitative research design. Within qualitative design, the researcher aims to explore and understand groups of people who are experiencing a social issue (Creswell & Creswell, 2018). Qualitative design has various methodologies; however, there are five main approaches of qualitative research: (a) narrative research, (b) phenomenology, (c) grounded theory, (d) ethnography, and (e) case studies (Creswell & Plano, 2018). Grounded theory was used as the methodological framework for this study. Grounded theory is distinct from other approaches in that its intent is to use the collected data to develop a theory explaining the social issue (Creswell, 2013). The purpose of this current study was to (a) use qualitative data to assess

advocacy and parental experience in accessing services, and (b) identify parent perception on the effectiveness of their advocacy.

Sample/Participants

The sample included a subset of data collected from the FACES Needs Assessment survey and semi-structured interview. The FACES data were collected in 2018. The present study consists of an exclusive sample of parents of Black children aged 2 to 26 with a primary diagnosis of autism. The final sample for this current study includes 12 parents (100% female). Participants reported wide-ranging annual household income that spanned from \$14k to \$113k. Parental education levels included: some high school ($n = 1$), Associate's degree ($n = 2$), some college ($n = 2$), Bachelor's degree ($n = 1$), and Master's degree ($n = 6$).

Measures

Semi-structured Interviews

The semi-structured interview consisted of 14 open ended items that inquired about the needs of the child, parents' experience with advocating for that child, and their recommendations for other parents and service providers. A sample of the interview questions can be found in Figure 1. The full interview protocol can be found in Appendix A.

Figure 1.
Interview Protocol Sample Items

Individual Interview Protocol

Please tell me about their abilities and areas of need.

Please tell me about your experiences with advocating on your child's behalf.

- a. How would you describe your "advocacy style?"
- b. How has your knowledge of autism impacted your ability to advocate?
- c. How has your knowledge of special education laws impacted your ability to advocate?

Procedure

Once the parent study was approved by the North Carolina State University Institutional Review Board (IRB), the principal investigator (Dr. Jamie Pearson) advertised the study at locations that target the population of interest. Using paper and electronic flyers, this study was advertised at the following organizations and locations: (a) the Psychoeducational Clinic at NC State University, (b) The Autism Society of North Carolina, (c) The Autism Program of Illinois, (d) the Chicagoland Autism Connection, (e) Easter Seals, (f) the UNC-Chapel Hill TEACCH program and affiliates, (g) early childhood and early intervention centers, (h) healthcare providers, (i) and community support groups across the east coast and midwestern United States. Parents who expressed interest in participating in the study contacted Dr. Pearson. Dr. Pearson then followed up with interested parents via email or phone call to provide them with detailed information about the study. Following this correspondence, those still interested in participating in the study arranged for a place and time convenient for them to complete the semi-structured interview.

Data Collection

Participants completed a 10-minute sociodemographic survey questionnaire that also collected data on the number of autism services participants utilize. The survey was distributed and submitted online via Google Forms. Following the completion of the survey, participants were interviewed, and all interviews were audio recorded by either a FACES graduate research assistant or Dr. Pearson. The interviewer began the approximately hour-long interview process by first describing the purpose of the interview according to the interview protocol. Participants were informed that audio recording was required for participation in the study and that video-recording the interview was optional. All audio recorded interviews were transcribed, and all identifying information in the transcriptions was redacted. All data from this study were

collected and accessed by members of the FACES team. Following the completion of the study, participants were compensated in the form of a \$50 gift card. Lastly, participants received a resource backpack that included parenting literature, and children's books about autism.

Data Analysis

Data Analysis

As described by Rossman and Rallis (2012), coding is the process of extracting segments of writing (i.e., sentences or paragraphs) into categories. Coded categories are often labeled with terms used by the participant (Creswell & Creswell, 2018). To understand participants' experiences with advocacy, the researcher used the qualitative analytic strategy known as thematic analysis (often referred to as thematic coding) to identify and categorize participant responses in the semi-structured interview. Thematic analysis differs from other analytic methods (e.g., interpretive phenomenological analysis, grounded theory, thematic decomposition analysis). Although these alternative approaches are useful in seeking patterns in qualitative data, their specific purposes are less fitting for the current study. For example, interpretive phenomenological analysis and grounded theory seek patterns within the data. Interpretive phenomenological analysis gives precedence to participants' experiences and seeks to understand their everyday reality in order to gain more understanding of the phenomenon in question. The goal of grounded theory is to create a plausible and useful theory that explains the phenomena within the data (Braun & Clarke, 2006). Additionally, thematic decomposition analysis examines patterns throughout an entire data set. Although thematic analysis is capable of assessing themes in an entire dataset, it also possesses the flexibility to assess themes that are of importance to the research question(s). The themes of this study will be guided by the proposed research questions.

Additionally, thematic analysis is not dependent on epistemology or theory. Instead, it is flexible and can provide a more complex account of the data (Braun & Clarke, 2006).

The validity and reliability of thematic coding can be established in multiple ways. Creswell and Creswell (2018) offer readers eight validity strategies for qualitative data. To ensure validity within this study, the researcher utilized two of those recommended strategies, as they are most applicable to this study. First, the researcher performed triangulation by extracting multiple segments of data that support the declaration of an identified theme (Braun & Clarke, 2006; Creswell & Creswell, 2018). Second, the researcher underwent reflexivity to identify how their background (gender, culture, history, and socioeconomic origin) can affect the interpretation of their findings. Due to a personal and professional background as a Black woman, an older sibling to a person on the spectrum, and her work with toddlers and families of color on the spectrum, the researcher has a higher probability of engaging in confirmation bias when creating themes from the data. The researcher considered member checking which will require her to take a final report of the identified themes to the participants so they can determine the accuracy of the information. The researcher did not undergo member checking because they are using secondary data and was not a part of the parent study.

Gibbs (2007) suggests four qualitative reliability procedures. Two techniques to ensure reliability were employed in this study. First, the researcher checked transcripts to ensure there were no mistakes in the transcriptions. Second, researcher cross-checked codes by entering into an intercoder agreement. An intercoder agreement calls for two or more coders to agree on the codes being used for the passages within the text. The remaining two strategies are not applicable to this study because they involve working within a team and having multiple coders.

CHAPTER 3

Advocacy Experience

To address Research Question 1, the interviewer asked participants open-ended questions such as, (1) Please tell me about your experiences with advocating on your child's behalf, (2) Describe your "advocacy style", (3) How has your knowledge of autism impacted your ability to advocate, and (4) How has your knowledge of special education laws impacted your ability to advocate? The following section describes the salient themes surrounding the advocacy experiences of Black families when attaining autism services. A visual of the qualitative data can be found below in Figure 2.

Advocacy Style

Eleven parents recounted how they advocated for their Black child with autism. Parental advocacy style can be described as an acknowledgement of various techniques employed when parents respond to a social or academic barrier. Within this study, parents advocated for their child in multiple settings and utilized two main approaches – passive and assertive.

Passive Advocacy. When parents utilize an indirect form of communicating to express grievances or educate others, they are using a passive advocacy approach. Passive advocacy can be modeled when writing letters and utilizing social media when engaging with childcare facilities, family members, and friends. One parent shared how she used social media to educate others about autism and how autism affects her son. She said, "I share a lot about X - if he's had a challenging day, [and] what that looks like. If he's had, you know, just the bomb day, I'll share that on Facebook." She further stated,

300 people can see X had a great therapy session because he did X, Y, and Z. And that'll spark the conversation of, 'What is OT?' I said, 'Oh yeah, it's just this and that and the other.' And so those things have really helped me to make the impact. – (Participant 25)

Assertive Advocacy. When working with medical and school professionals, some parents recalled taking an assertive approach to overcome barriers. As a Black woman, being assertive can produce negative outcomes due to racial and gender biases that lead to the misinterpretation of assertion as aggression. However, one parent noted the importance of being assertive in a “professional way,” and alluded to the positive outcome that could come from this kind of advocacy approach. She said, “I feel like if I don't try... then guess what, we're not going to get the services we need for him.” - (Participant 22)

The assertive approach was demonstrated in another parent's recollection of their advocacy experience. This parent recalled engaging with medical professionals when trying to get her son an autism diagnosis. Frustrated with her concerns being taken lightly, she asserted, “I literally went to a doctor's office and just went off. I went full like ghetto mode.” She further explained to the doctors,

You're here to help my son, to help my family and you're not doing that. You have a medical degree for reason. I'm here. I'm telling you that something is wrong with my son, and you're not listening. I need you to wake the f*ck up, pay attention and help me help my son because this sh*t right here not working for us. – (Participant 30)

It's important to note that advocacy is not dichotomous. Rather, like autism, advocacy exists on a spectrum. Parents can utilize passive or assertive techniques at any given time. One parent referenced her advocacy style when engaging with the school system. She noted that a part of her advocacy style is having a positive mindset; however, she will check in, “drive by in a

minute, observe and all of those things.” - (Participant 10). Here, the parent expressed her overall advocacy style as passive; however, if needed, she will use more assertive approaches (i.e., coming to the school and observing the classroom) if that will help her child have a better educational experience.

Reasons Why Parents Advocate

Parental advocacy can be found across races, economic status and between neurodivergent and neurotypical families. However, reasons why parents advocate can vary. Within this study, social-cultural factors that required parents to advocate more for their Black child on the spectrum were identified. The factors, Black culture and dissatisfaction, were intertwined with race, culturally specific ideologies in the Black community, and the educational and medical institutions.

Black Culture. Some ideologies within the Black community surrounding religion, child rearing practices, and disability were discussed as creating an adverse relationship between parents and their family members. Parents identified Black culture as challenging and playing a distinctive role in their advocacy and familial relations. Some parents explained that their family’s mentality and limited understanding of autism has negatively impacted their relationship. In some cases, the disconnect elicited a fear response in parents.

Religiosity, specifically Christianity, is interwoven in the belief system and daily operations of the Black community. It is not uncommon to hear members of the Black community describe a child with a disability as a gift from God. It is also assumed that the individual with a disability will be being taken care of by members of their family. However, the positive treatment towards that individual typically does not extend to understanding that person’s specific needs due to their disability.

For example, one parent shared how her mother views her son's autism diagnosis. She said, "My mother feels that it's a spiritual thing and God will work it out and she feels like he shouldn't have a labeling 'cause there's no such thing as autism. He's just developing at a different pace." - (Participant 22) Another parent recalled her mother sharing a similar sentiment about her son on the spectrum. She described her mother's mentality and the Black culture as, "It's just, you know, 'Oh that's X, you know, he's our special boy, that kind of thing. You know, it's kind of how the culture is down there.'" – (Participant 25)

Furthermore, the lack of understanding and acceptance of an autism diagnosis can elicit fear in some parents. In response to the fear, some parents chose to not have their child around their family members. This is done to protect their child from any perceived harm and serves as a passive form of advocacy. For example, one parent recalled not letting her daughter stay with family members out of fear for her child's safety. She stated,

I'm scared they're going to spank her or fuss at her a lot or just not understand that she's not responding to you because she's just not going to respond to you but she's not potty trained because she's not, she's not able to be potty trained yet. – (Participant 29)

The disconnect in autism awareness created a distant relationship between the participant, her daughter, and her family.

Education is another possible response to fear. One parent described having to educate her family on helpful ways to interact with her son and the importance of them knowing the difference between some neurodivergent children and typical developing children. She acknowledged that typical child rearing social norms and expectations in the Black community do not apply to children on the spectrum – specifically, her son. She said:

It's okay if he goes in the kitchen and gets a pot lid... It's okay. Because I guess traditionally even in African American communities, almost like you can't, you set a lot of parameters and rules around what children can and can't do. And with children on a spectrum, all of that goes out the window on most of it. They definitely need consistency and structure. But if you think you're gonna make a child do something they don't want to do. And now on the spectrum, they gonna show you real quick. Not today, not tomorrow.

– (Participant 10)

Furthermore, one parent noted having to educate herself on the best ways to engage with her son and not leaning on disciplinary actions she experienced in her childhood. She shared, I had to learn that I can't or not that I can't, that I shouldn't pop him because he can't communicate in the same way. Right. That was a process. I'm from the school if you act up, you getting lit up, like you're not listening. Okay, I can show you better than I can tell you. – (Participant 30)

While educating herself and advocating for her son, this mother found herself making a difficult decision in her marriage. She chose to advocate for her son over remaining married to her husband who, at the time, was not supportive of their son's autism diagnosis. She told her husband, "If you can't be there to advocate for your own son, this is my deal breaker, I can't do this." She further shared the negative impact culture and religion had on her husband:

My husband is West African. He's from Senegal and in their culture where they live, they don't know about autism. What I tried to explain to him is, I'm quite sure you do have it there. You just didn't know what it looked like and you don't have the resources there to be able to diagnose that and then treat them right. So, his thing is God will take care of it. Extremely religious. And don't worry about it. - (Participant 30)

Dissatisfaction. Some parents expressed being dissatisfied with their child's school (i.e., principals, IEP staff, school counselors, and teachers) and the services (e.g., therapies and medical examinations) their child received. Dissatisfaction with services can be described as moments when parents expressed the services their child was receiving as not helpful. This discontent resulted in them advocating more for their child on the spectrum.

Dissatisfaction with Schools. As reported by parents, negative interactions with the school and teachers placed parents in a position to provide even greater advocacy for their child. When discussing her experiences with the school, one mom perceived her child's principal as "racist" and "not helpful". She explained her son made an inappropriate remark related to gun violence which was addressed in an in-person meeting with the principal. Both parties agreed that his behavior was due to his diagnosis; however, the principal withheld sharing her decision to proceed with further actions such as calling the police. The parent recalled the police coming to her home the next day. She further shared that her husband answered the door and was interrogated by the officer because the principal provided the police with incorrect and racially biased information – describing the family as "a broken home", with "no father" and "on welfare." As a result, the parent now engages in passive advocacy with the school. She reported since the incident she seeks outside help for her son and does not go to the school. – (Participant 27)

Another parent described her decision to remove her child from a school because she noticed drastic changes in her son's behavior. She alluded that the change in her son's behavior could be due to the school mistreating him (e.g., locking him in a dark room or closet). She stated, "he went from a happy, really happy jovial, smiling, happy little five-year-old to this squeamish, terrified, afraid, crying little boy." – (Participant 26)

Another parent shared her hardships working with the special education team at her son's middle school. She felt her son's IEP team did not have his best interests. At IEP meetings she recalled addressing his failing grades and inquired about ways to support his learning. However, she did not receive the support she was looking for. She stated, "It wasn't a good seventh grade team. Nobody really seemed to care or acknowledged that 'Hey, this guy's failing.'" She later shared the team did not make an effort to inform her about the resources available to her son. She said:

I found out here at the end of the year, there was an autism resource teacher at a middle school... And nobody at this last meeting in May, said, 'Oh, we have such. You might want to talk to her. We'll make sure you can get her contact information.' Nobody ever sent it. I gave up because it's the last, you know, this is the last week. They said, 'We're going to talk to the principal to try to talk about what to do with the IEP.' No one came through with anything... We've never had her at any of the IEP meetings. I didn't even know she existed there. But she's an autism specialist and no one, no one said that. –

(Participant 31)

Dissatisfaction with Services. Parents recounted having to be vocal about their discontent with the services their child was receiving. For example, one parent shared she was disappointed in the lack of care that some service providers give. She felt "bamboozled" by "the amount of people who don't know that services are available." She went on to explain, "How many providers fail us on a regular basis. We have so many providers that help us and lift us up but there are a lot that don't." She further described her child's speech therapist as not helpful. She also highlighted her advocacy style when explaining her decision to get a new speech therapist for her son. She said, "One thing about me is, I'm very vocal. I don't bite my tongue, I mean

[what] I say, I say what I mean, but I do it all respectfully as possible.” – (Participant 30). This parent then went on to describe the new therapist as “okay in the beginning and then she kind of fell off”. She found herself having to advocate for her son again. She recalled having a sit down with the therapist and having a “conversation with her” where she shared her “feelings with her and where [she] was in that moment”. From that conversation, they “came to an understanding and things have been good since.”

Another parent noted that her child does not see the same provider at the clinic they frequent. As a result, she felt like she was “having the same conversation every time” with the medical providers when her daughter had a wellness visit. The parent further explained that the repeated conversations surrounded informing providers on how to effectively interact with her child and alluded to the providers not having knowledge on working with patients with autism. She recounted, “she's probably not going to just let you look in her ears and it's just like they ... they don't know [how] to examine her” and “they do the ASQ every time.” She further recalled an exchange with a medical professional saying,

Why are we doing this? She's not going to be on target. I don't see why we're doing this or do y'all have a modified one because this right here is unnecessarily, this is wasting 10 minutes out of my life to fill this out. – (Participant 29)

Some parents noted that their child’s medical professional lacked adequate autism knowledge which includes not utilizing best practices when engaging with children on the spectrum. Therefore, some parents educated medical professionals on the best ways to engage with their neurodivergent child. One parent recalled frequently having to explain to her daughter’s pediatrician that her child is nonverbal, and the techniques used with neurotypical

children will not work on her daughter. She further described a time at the hospital where she gave instructions to doctors on the best way to insert an IV into her daughter's arm. She shared,

I always have to tell them it's going to take more than one person to do [it], because you have to hold her hand... It's going to take more than one person. I need you to get another person cause it's going to take more than one. And once you get it in, you need to, you know, tape it and put the board under her so that she won't pull it out. – (Participant 32)

Effectiveness of Advocacy

Participants were asked if they perceive their advocacy efforts to be effective. Effective parental advocacy can be defined as the successful procurement of a service or improved treatment for their child as a result of engaging in passive or assertive advocacy. In an example of effective advocacy, one parent described her experience with getting her three-year-old son an autism diagnosis. After experiencing a delay in diagnosis by her son's pediatrician, she sought help from other providers in her area who specialize in autism and brain development. She recalled telling two providers her "sob story" and advocated for a diagnosis by saying, "I told them I need this, I want this, I don't care what I have to do. If you have a last-minute cancellation. Call me. I will drop everything." Shortly after, her son was diagnosed and started receiving ABA services. – (Participant 30). When responding to the interview question, "Do you feel like your advocacy efforts have been effective?", 45% ($n=5$) said yes, 36% ($n=4$) said somewhat, and 18% ($n=2$) said no.

Parents who perceived their advocacy efforts to be somewhat effective or not effective at all expressed being successful in some areas. There were additional barriers, such as knowledge of autism, and systemic and cultural issues within the school (e.g., school resources and parent/teacher relationships) that affected their perception and acquisition of services.

Parental Knowledge of Autism. One of the most salient factors found in effective advocacy is knowledge (e.g., knowledge of autism, autism services, and the special education system). Knowledge can be acquired from various sources such as workshops, friends and family, support groups, and parental internet research. One parent shared her willingness to learn more about autism, noting that it will make her a better advocate for her son:

I just feel like there is a lot out there that I really am not knowledgeable about and I need to look more into it so I can really get those services that would be beneficial to X. I really want to be much more knowledgeable of it and really research, I mean purchase books and everything. And I just want to read them and see what's out there. I want to go to more support groups. So, I can be able to advocate stronger. - (Participant 22)

Although this parent has limited knowledge about autism, she perceives her advocacy efforts to be somewhat effective. Pertaining to her son's educational experience, she recalled "being heard" when talking "to his teachers about effective tools to use based on what his therapist said". She further shared, "So I feel like when I talk to them about it, you know they implement some of the concerns." - (Participant 22). However, regarding her advocacy efforts with her family, she said, "Sometimes. I've noticed they've tried to kind of meet us where we are and help a little bit, but it's going to take time, 'cause I feel like they're still in the grief process."

Systemic and Cultural Barriers in the School. Some public schools are limited by the resources they are afforded due to the economic status of their district. For example, one parent expressed that her son's school is "very responsive" and that she has a "direct connection with his principal." She went on to share she is "a member of the PAAC, parents of African American children" which is a "group at his [her son's] elementary school that supports the advocacy efforts for all African children in the school, not just ones with disabilities." Despite having a

positive relationship and strong engagement with her son's school, this parent feels that her advocacy is "received by what they can do within their ability, but not necessarily what [she] really want[s]." The effectiveness of her advocacy is directly impacted by the resources afforded to the school. – (Participant 33)

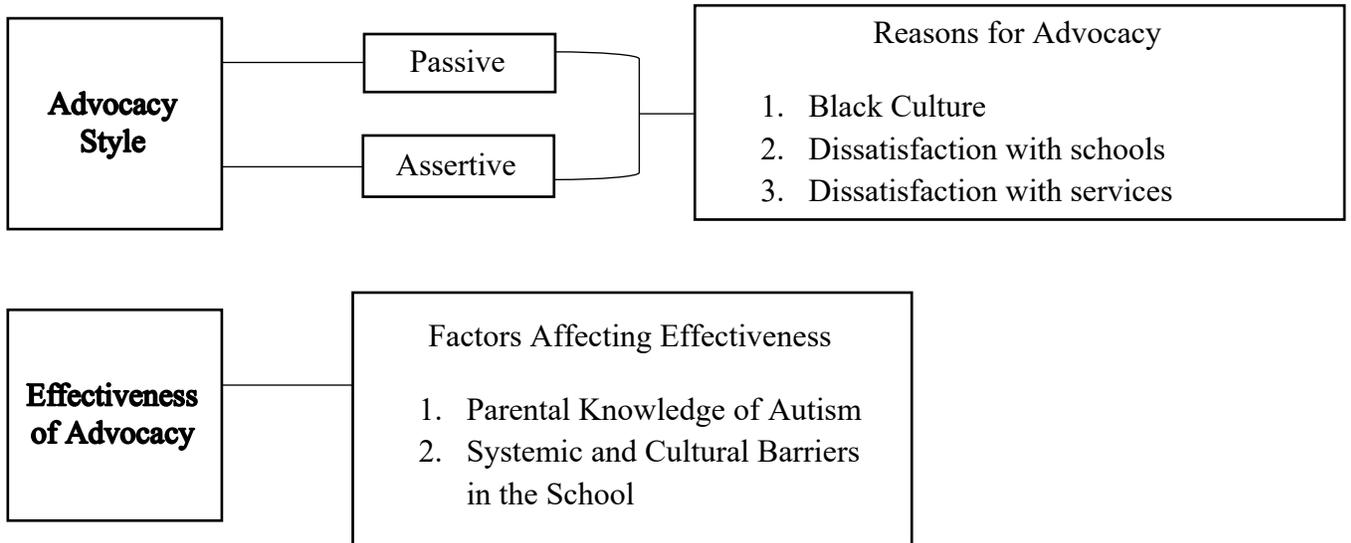
In another instance, one parent describes her son's school climate as a barrier to his educational success. Specifically, this parent describes poor communication between herself and her son's fourth grade teacher. She said:

I don't know what he's learned all year. I would say all year long, his teachers had been... saying no homework policy, but then they started a homework policy where he would do one problem a night. He couldn't remember to bring the homework book home. -

(Participant 31)

She further described a shift in his homework policy, despite having an IEP. She shared that at the end of the school year, "They sent homework home and it was eight problems. They send a review sheet home and it's eight, seven, eight problems a night. The first night I spent three hours helping X get through those problems." - (Participant 31)

Figure 2.
Findings



CHAPTER 4

The purpose of this study was to examine the advocacy experiences of Black families of children with autism and their access to autism services. Past research has largely focused on the experiences of White middle-class families; by focusing on an exclusive sample of Black families, this study gave a historically excluded group an opportunity to speak for themselves. The narratives shared by the parent participants serve as a critical step in highlighting racial disparities in access to autism services and serve as counter narratives to the inferences often made in previous literature that racial differences in service acquisition are mainly due to income disparities (Irvin et al., 2012; Liptak et al., 2008; Thomas et al., 2007; Gourdine et al., 2011). The findings support the premise that racism/racial bias and lack of understanding of autism play a role in the advocacy experiences (i.e., reasons why Black families advocate) of Black parents, and thus makes their experiences different than that of White families.

Since its scholarly inception, autism has been correlated to Whiteness. In the mid 1900s, researchers and medical professionals began to theorize the cause of autism, and many adopted and propelled the psychogenic theory that the parenting style of the mother was to blame for a child's atypical behaviors. Specifically, this theory claimed that mothers of children with autism were emotionally distant to their child (Cook & Willmerdinger, 2015), and thus the term "refrigerator mother" was created. Child psychiatrist Dr. Leo Kanner further described refrigerator mothers as Anglo-Saxon or Jewish, successful in their careers, and highly intellectual (Kanner, 1943). Researchers and medical professionals explicitly blamed the disorder on intelligent White women and also implicitly made associations to class. The initial explanation and inclusion criteria for autism therefore excluded Black families and low-income households, leaving room for implicit bias. Recent research on Black and ethnic minority parents' experiences accessing an autism diagnosis reveals not much has changed in the medical field as some parents note that doctors presumed the cause of autistic symptoms in their child was a result of their culture, specifically Black culture and stereotypes about Black males (Stahmer et al., 2019). As the findings of the current study suggest, these ongoing misconceptions have contributed to cultural divergence between Black families and service providers and created additional challenges and barriers to parental advocacy for Black parents of children with autism. These findings are described in greater detail in the following sections.

Style of Advocacy

Participants in this study engaged in two styles of advocacy, passive and assertive, although examples of passive advocacy were reported less frequently than those of assertive advocacy. More parents recounted having experienced direct/in-person advocacy interactions with primary care physicians and school personnel as opposed to engaging in indirect forms of

advocacy (i.e., writing letters). Many parents of children with disabilities, regardless of race/ethnicity, use assertive forms of advocacy because they believe that without them, their child's quality of education would decrease (Lalvani, 2012). This may be particularly true of Black parents, as research has highlighted inequities in the effectiveness of parental advocacy based on race and socioeconomic status (Ong-Dean, 2009). As such, Black parents may feel the need to engage in assertive advocacy to ensure that their voices are heard.

Parents in this study also alluded to the discomfort and racial bias that assertive advocacy can create; however, they also noted the importance of engaging in assertive advocacy. This finding highlights the need for Black parents to push past the racial discomfort that assertive advocacy may cause them in order to do what is best for their child. For many Black parents, assertive advocacy ensures their voices are heard and increases the opportunity for positive change for their child. Although not surprising, this finding also highlights that Black parents are hyperaware of racial stereotypes and presumptions about their racial community (Lareau & Horvat, 1999; Wilson, 2019). When you are Black, no matter how elevated your social status may be, you are still aware of the possibility of discrimination and unfair treatment that White families might not be aware of because they are historically not disenfranchised. Recognition of racial differences, potential discord due to racial biases, and how these factors can affect parent/school relationships and a child's education is documented in previous literature (Wilson, 2019; Yull et al., 2018; Lavizzo, 2016; Ray, 2015). Lavizzo (2016) confirms what Black parents already presume is being thought about them and their culture; that Black parents and Black culture do not perpetuate and support Black excellence and success. Rather, school personnel assume both concepts work together to *enable* student problems. As a result of this lack of understanding, many Black parents are selective in which schools their child attends and, if

afforded the privilege, choose to have their child homeschooled (Ray, 2015). As noted in this current study, one parent engaged in assertive advocacy by choosing to remove their child from a school after noticing drastic changes in her son's mood and behaviors.

Reasons for Advocacy

Parents' reasons for engaging in advocacy fell into two main categories. The first was dissonance between their goals and the ideologies of the Black community. Parents expressed discord between themselves and some members of their family because of religious beliefs and childrearing practices. Namely, parents shared that some immediate family members believed that God would cure their child of autism. The belief that God would cure their child of autism also rejects seeking help from providers and understanding how autism affects their child. Consequently, parents of children with autism had a negative relationship with their family members who adopted this belief. Additionally, parents expressed being fearful of leaving their child with an older family member, such as the child's grandparent, because of the child rearing practices they employ and their lack of understanding of how autism makes their child different from a typically developing child (Pearson & Meadan, 2018). In response to this disconnect, some parents chose to educate their relatives on what autism is and how it affects their child; others chose to distance themselves from their relatives, and one parent noted that she temporarily left her husband to fully commit to their son's progression.

This finding is unique to the Black community but not surprising based on previous literature on religiosity and stigma in the Black community surrounding mental illness. Research has found higher levels of mistrust of mental health systems (Snowden, 2001) and negative attitudes toward, and low perceived efficacy of, treatments (Nikerson et al., 1994). Additionally, the Black community often associates mental illness with concepts like trauma, oppression,

having a weak relationship with God, and demonic possession (Matthew et al., 2006). This previous research helps contextualize the current study's findings and clarifies the connection between mental illness and religiosity. It could be inferred that the Black community assumes that having a child with a disorder such as autism is a test of faith; however, research within the last ten years suggests a shift in views related to mental health and treatment within the Black community. Young Black women are more willing to seek mental health services than young and older Black men and women (Conner et al., 2009; Ward et al., 2013). This shift may help explain the dissonance amongst generations of families related to understanding autism and seeking treatment for the disorder.

The second category of reasons that parents advocate was related to being dissatisfied with services given to their child. Parents recounted experiences where their child's school personnel and/or service providers fell short in providing adequate care. Negative experiences within the school are intertwined with racism, racial bias (Yull et al., 2018; Lavizzo, 2016; Marchand, 2019), and lack of care and proper instruction for a child on the spectrum. Though not unfamiliar, in one instance a parent shared that her son's school acted in an inappropriate manner and used dog whistle politics to negatively portray her family. From this instance this parent decided not to engage in assertive advocacy with her son's school. This is yet another example of how Black parents want to be active participants in their child's education, but the school system deters them from participating (Lavizzo, 2016).

Parents also expressed dissatisfaction with services providers. Many recounted having to switch service providers because they were not doing their best when working with their child and or being dissatisfied with their lack of communication. Namely, one parent noted that service providers could have done a better job explaining what services are available. As it pertains to

medical professionals, parents noticed that the physicians they interacted with appeared to lack a good understanding of autism and how to work with children with autism (Gourdine et al., 2011; Pearson & Meadan, 2018; Stahmer et al., 2019).

Perception of the Effectiveness of Advocacy

Finally, parents' perceptions of the effectiveness of their advocacy efforts were influenced by additional barriers such as their own lack of knowledge about autism, as well as systemic and cultural barriers within the school system. One parent noted that having more knowledge about autism can improve their ability to advocate for their child. By contrast, another parent noted that although she has limited knowledge of autism, she perceived her advocacy efforts to be somewhat effective due to feeling like her opinions and suggestions were taken seriously and used when making decisions for her son. In another instance, a parent noted that her advocacy efforts are limited to the resources the school is afforded. Although the school is receptive to the changes she wants to make, they make amendments where they can. Conversely, another parent noted that her son's school lacks appropriate communication skills and as a result, there is a disconnect between what is expected of her son based on his IEP and what is required of him in the classroom. These findings differ from previous studies assessing the effectiveness of parental advocacy, especially when comparing the data to White families. Notably, Wright and Taylor (2014) found that parents ($n = 79\%$ White) identified their advocacy efforts as effective and highly effective in micro settings (i.e., schools and medical clinics).

Limitations and Implications for Future Research

The results of this study should be interpreted in light of some limitations. First, this study utilized secondary interview data with Black families of children with autism. To ensure the reliability and validity of the study were maintained, the researcher performed triangulation

and underwent reflexivity. Additionally, the researcher reviewed the interview transcripts prior to coding, and was involved in an intercoder agreement to ensure the reliability of emergent themes. However, she did not undergo member checking because she was not a part of the parent study. Therefore, the researcher did not provide participants with a final report or sections with their quotes to confirm the accuracy of the description. Despite this, the validity of the study remains strong. Second, the size and characteristics of the participant sample may limit the generalizability of the findings. This sample was made up of Black mothers from urban and suburban settings. This may limit our understanding of the Black parental advocacy experience, as this study did not collect the perspectives of fathers or parents from rural areas. Finally, this study excluded the perceptions of educators and healthcare professionals. Incorporating their perspective when engaging with Black families of children with autism or suspected of having autism would be monumental as it would provide the opportunity to compare perceptions.

Despite these limitations, this study provides valuable insight into the advocacy experiences of Black families of children with autism. Through interview data, this study highlighted reasons why these parents advocate for their child and what advocacy looks like for them. Additionally, it shed light on an aspect of advocacy that is unique to the Black community – the stigma and lack of knowledge about mental health and disability. Future studies can consider the following suggestions: (a) include a larger sample size, (b) utilize participants from rural counties in North Carolina, (c) be inclusive of participants from other states, and (d) undergo member checking. Additionally, future research can consider working with a small population of medical professionals in an autism identification intervention, specific to Black and other minoritized families. The intervention can work to have professionals gain knowledge

about autism, differentiate autism from other developmental disorders, address implicit bias, and identify available resources in the community such as early Intervention.

Implications for Educational and Medical Professionals

The themes identified in this study have direct implications for primary care physicians, related service providers, and educational professionals. Parents identified a number of barriers to advocating and accessing adequate services for their child, including perceived racial bias, a lack of practitioner knowledge around working with children with ASD, and poor communication. It is critical for practitioners to participate in training and ongoing professional development courses to learn more about autism, with a focus on increasing physician's comfortability in recognizing signs of autism in Black children, knowing differential developmental and neurological diagnoses, and teaching ways to engage with children on the spectrum. Additionally, it can inform physicians about other resources in their community such as Early Intervention, developmental, neurological, and psychological clinics that specialize in autism identification if they need consultation or would like to refer their family to another helpful resource. Furthermore, medical professionals should review their protocol when working with clients that have different racial and ethnic backgrounds than their own. This can include acknowledging and examining their own biases that may influence diagnostic decision-making and engaging in training that emphasizes cultural humility and responsiveness. When engaging with parents, medical professionals need to be aware of cultural and familial factors such as stigma around autism and receptiveness to services. Finally, medical professionals need to make concerted efforts to educate communities about developmental milestones, things to consider if these milestones are not being met, the signs and symptoms of autism, and options for assessment and intervention.

The present findings also have important implications for educational professionals. School districts should provide their faculty and staff with implicit bias training that is inclusive of and specific to the populations of children and families they are working with. Additionally, it is important for faculty and staff to make an effort to get to know their Black students' parents and communicate with them frequently about student successes as well as areas of growth. These conversations should be balanced and focus on building a strong parent-school relationship. Lastly, it is important to develop a collaborative community partnership. This can include a line of communication between parents, early intervention staff and their child's primary care physician and school.

APPENDIX

Individual Interview Protocol

Please tell me about your family and your child with autism.

Please tell me about their abilities and areas of need.

Please tell me about your experiences with advocating on your child's behalf.

- a. How would you describe your "advocacy style"?
- b. How has your knowledge of autism impacted your ability to advocate?
- c. How has your knowledge of special education laws impacted your ability to advocate?

What have you advocated for?

- a. Time or place for services?
- b. Additional services?
- c. One-on-one services?
- d. Specific strategies?

Do you feel like your advocacy efforts have been effective?

- a. Has your child benefited after you advocated?
- b. Has your family benefited after you advocated?

How do you think educators, healthcare providers, and service providers perceive your advocacy efforts?

- a. Do you think your race plays a role?
- b. Do you think your communication style plays a role?
- c. What tools or resources do you feel would help you to be a stronger advocate?

Please discuss your advocacy efforts as they relate to gaining access to the following services:

- a. Schools of choice
- b. Funding/healthcare
- c. Transportation
- d. Waivers
- e. Waiting lists

Have you ever participated in an advocacy or empowerment training in the past?

- a. If yes, which program?

- b. Would you say that program has had an impact on your current advocacy efforts?
 - 1. If so, how?
- c. Would you say that program has had an impact on your current access to services?
 - 1. If so, how?
- d. What else did you find beneficial about this program?
- e. Would you participate in this type of program again?

What resources, information, or supports do you think would help you better support your child with autism and your family?

- a. Do you know how to access those supports?
- b. If not, what do you think is creating a barrier?

What recommendations do you have for other African American parents of children with autism who are working to navigate access to services?

What recommendations do you have for educators to better serve the needs of African American children with ASD?

What recommendations do you have for service providers to better serve the needs of African American children with ASD?

What recommendations do you have for healthcare providers to better serve the needs of African American children with ASD?

Is there anything else you would like to add?

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