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Understanding African American Mothers' Perceptions of the Effectiveness of Autism-Related Services for Their Autistic Children in Rural Communities

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Walden University
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Abstract

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MPhil, Walden University, 2019

MMFT, Trevecca Nazarene University, 2011

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Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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Abstract

This study aimed to address the gap in the literature related to understanding African American mothers' perceptions of the effectiveness of the available services provided to their children diagnosed with autism living in rural communities. The theoretical framework used for this study is the racial formation theory as a lens for completing this study. The research question explored African American mothers' perceptions of the effectiveness of autism-related services provided to their children with autism in rural communities. The research design chosen for this study is a generic qualitative design using semi-structured interviews for data collection from 10 African American mothers of autistic children who reside in rural communities across the United States. The data from the interviews, field notes, and demographic information forms were analyzed using content analysis using open and selective coding. Four themes emerged from the data analysis that provided a deeper understanding of ten African American mother's perceptions of the autism-related services provided to their children (a) speech therapy and school are effective; (b) being black living in rural impacts the quality of care; (c) education and research; and (d) advocacy matters for children. Implications of this study could be helpful for scholar-practitioners, researchers, and other human service providers by providing new insight and knowledge about African American mothers' perceptions of the effectiveness of available services within rural communities and if race or geography impacts their perception.

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Dedication

I dedicate my dissertation to the special people who have played a pivotal role in my dissertation journey. I first dedicate this study to my parents—Bobby and Lillie Treadway. Your love, prayers, encouragement, and continued support have been appreciated during this journey. I also dedicate my dissertation to my sister—Dr. Jessica Treadway. Sharing our dissertation journeys at Walden University has been a unique and connected experience. I am grateful to have shared this journey with you and to have your support. I also dedicate my study to the memory of my maternal grandmother—Ms. Johnnie Mae Currie. You started this journey with me, and I have now completed it. Your affirmations, love, and support continue to push me forward. I also dedicate this study to my co-workers, colleagues, and clients for their genuine support. Finally, this study is dedicated to every African American mother who tirelessly advocates, nurtures, and supports their children diagnosed with autism. Your labor of love is honored and appreciated.

Acknowledgments

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Dr. Gloria Billingsley, I appreciate your support and guidance as my dissertation committee member throughout this journey. Thank you so much for your feedback and for providing your knowledge and connection to autism. I am so grateful to have an African American professor and scholar as part of my dissertation committee. You are much appreciated!

I am sending a special thank you to the beautiful African American mothers who participated in this study. Thank you for dedicating time to share your experiences and stories. Without your contributions, this study would not be possible.

I thank God, my parents, sister, ancestors, and support system for their support and love during my journey to earning my doctorate. Thank you abundantly!

Table of Contents

List of Tables

List of Figures

Chapter 1: Introduction to the Study

Introduction

Researchers reported in 2020 that less than 30% of the autism spectrum disorder (ASD) research studies capture the experiences and perspectives of Black families and other ethnically diverse groups who have a child with autism spectrum disorder (Shaia et al., 2020). This generic qualitative research study seeks to understand African American mothers' perception of the effectiveness of services available to their children diagnosed with autism spectrum disorder living in some rural communities of the United States. A study conducted by Mello et al. (2016) in the southeastern region of the U.S. with 415 caregivers of children with ASD living in rural and non-rural communities compared their experiences accessing care for their children. Of the participants, only 101 of the caregivers lived in rural areas. Of the caregivers living in rural communities, only two participants were African American caregivers with children with autism in Tennessee (Mello et al., 2016).

This generic qualitative study contributes to the current body of autism research to offer insight into African American mothers' perceptions of service effectiveness for their children diagnosed with autism in rural communities. Moreover, another study showed that African American mothers reported experiencing racial discrimination when seeking and receiving services for their sons diagnosed with autism, negatively impacting their experiences with effective services (Lovelace et al., 2018). Another study revealed that African American parents living in urban areas felt the providers lacked empathy for their child's needs and judged their parenting styles and traditions, contributing to disengagement with their children’s services (Burkett et al., 2017). La Roche et al. (2018) discussed how providers and clinicians lack cultural competence to treat non-white people, thus negatively impacting their ability to effectively serve black and brown autistic children more than autistic white children. Even though there is some research on African American mothers’ perceptions of services in urban/suburban communities, there is limited research on African American mothers’ perceptions of the services provided to their children diagnosed with an autism spectrum disorder in rural communities.

Background

Previous autism-related studies recognized and identified that rural communities lack appropriate and effective services for children diagnosed with autism spectrum-related disorders; however, most studies explore and examine the lack of services for White non-Hispanic participants without minimal representation from African American participants (Broder-Fingert et al., 2018; Donohue et al., 2019). Even though autism-related research in rural communities consists of primarily white participants, researchers explore African American participants’ perspectives and experiences with services for their children with autism in urban communities. Graves (2017) recruited African American mothers living in public housing in an urban community to explore their children’s help-seeking behaviors for mental health services. Moreover, Graves (2017) found that barriers such as stigma, poverty, the mother’s experience with mental health, and perceptions of mental healthcare contributed to them using or not using services for their children. In addition, mothers showed ambivalence to starting recommended treatment due to cultural beliefs, mistrust of mental health providers, and concerns with side effects. Antezana et al. (2017) identified the barriers in rural communities related to ASD screening, diagnosis, and intervention trends. Mello et al. (2016) compared the accessibility and quality of services for children with autism spectrum disorder (ASD) living in rural and non-rural communities. The data showed that rural families did not implement behavior support services and parent support groups, traveled long distances and times to get services, and had lower perceived service effectiveness (Mello et al. (2016). Robertson (2016) conducted a study that explored African American parents' efficacy and acceptability of implementing a parent-based intervention for their children diagnosed with autism.

Broder-Fingert et al. (2013) discovered that children diagnosed with autism who are African American underutilized specialty psychiatric and psychological services to treat autism compared to Caucasian children. Strunk et al. (2014) conducted a phenomenological study to explore the challenges parents experiences getting treatment for their adolescent children diagnosed with autism and identified a theme of needing assistance regarding various aspects of treatment (i.e., medication, resources). Heitzman-Powell et al. (2014) acknowledged the limited access to specialized services for youth with autism and suggested implementing telemedicine technologies to make ABA more accessible. Longtin and Principe (2016) compared the poverty level and awareness of evidence-based treatment for children with autism of African American parents. Parents living below the federal poverty line are less aware of evidence-based treatment for their children with autism. Speed (2013) conducted a qualitative study that explored the lived experiences of African Americans accessing mental health treatment in rural communities.

Problem Statement

The research problem identified for this study is understanding African American mothers' perceptions of the effectiveness of available services provided to their children diagnosed with autism living in rural communities. Previous studies reported how mothers of children diagnosed with autism experience higher levels of psychological and emotional distress than mothers of children with no disabilities and mothers of children with other non-autism-related disabilities (Burkett et al., 2017; Reed et al., 2017). Parenting a child with autism increases the likelihood of declining mothers' physical and mental well-being (Ramdinmawii et al., 2017; Reed et al., 2017). Also, higher familial disruptions negatively impact the autistic child's social and educational progress (Ramdinmawii et al., 2017; Reed et al., 2017). According to Strunk et al. (2014), mothers of children and adolescents with autism spectrum disorders identified inadequate behavioral and healthcare services to treat autism-related issues as the primary cause of parental stress. Unfortunately, mothers living in rural communities experience more difficulty accessing specialized services to treat their children with autism due to the limited availability of such services (Antezana et al., 2017; Heitzman-Powell et al., 2014; Mello et al., 2016; Robertson, 2016; Strunk et al., 2014).

Current research shows that African American mothers of different socioeconomic backgrounds in urban areas have been dissatisfied with services for their children with autism due to racial and cultural biases (Graves, 2017; Lovelace et al., 2018). Also, another researcher reported that living in rural areas decreases access to mental health services for African American families (Mello et al., 2016). According to Lovelace et al. (2018) and La Roche et al. (2018), African American mothers experience a unique challenge in finding effective services for their children due to race issues. In one study, African American mothers reported experiencing racial discrimination when seeking and receiving services for their sons diagnosed with autism, thus negatively impacting their experiences with effective services (Lovelace et al., 2018). Another study discussed how providers and clinicians lack the cultural competence to treat diverse ethnic and racial minorities, negatively impacting their ability to effectively serve minority children with autism compared to White children with autism (La Roche et al., 2018). Some researchers highlighted how culturally biased practices prevent families living with autism from receiving satisfactory autism services and mental health care within the African American community (Broder-Fingert et al., 2018; Nguyen et al., 2016). As previously mentioned, studies in this section explored African American mothers' perceptions of service effectiveness in urban locations. However, I found a gap in the literature related to studies exploring African American mothers' perceptions of the effectiveness of services available to their children diagnosed with an autism spectrum disorder in rural communities. This study seeks to address this gap in the literature by exploring African American mothers' perceptions of the effectiveness of services available to their children with autism in rural communities.

Purpose of the Study

This study aimed to understand African American mothers' perception of the effectiveness of available services to their children diagnosed with autism spectrum disorder living in rural communities in the U.S. A generic qualitative research design using in-depth interviews was used to understand the mother's perceptions. This study sparked interest based on my exploration of autism research on African American children and families in a rural context. Even though autism research is growing related to the African American community (Shaia et al., 2020), there is a lack of research on the phenomenon of interest.

The insight gained from this study could bring awareness to this underserved population's issues or unique experiences so that clinicians and providers can better serve them. Also, this study will contribute to the growing body of autism research on ethnic and racially diverse populations. Also, this insight may provoke more research on this population and provide opportunities for practitioners to improve their practices.

Research Question

What are African American mothers' perceptions of the effectiveness of autism-related services provided to their children with autism in rural communities?

Theoretical Framework

The racial formation theory provides the theoretical framework for this study as it acknowledges expressly how race influences and impacts the lives of individuals in the United States (Omi et al., 2014). According to Cheng (2014) and Cohen (2019), the racial formation theory acknowledges that race goes beyond nationality or ethnicity but views race as a multifaceted concept consisting of a social structure and cultural representation. Omi and Winant, the creators of the racial formation theory, created the term racial project, which interprets and explains multidimensions associated with race by including the influence of social, political, and economic factors (Jacobson, 2015; Tewolde, 2019). This theory's development evolved to provide awareness of the diversity within U.S. society. Social scientists failed to acknowledge how race impacts various social, political, and economic contexts by using racial projects to give meaning to these experiences (Golash-Boza, 2013). The racial formation theory drives this study by providing the foundation for understanding the perceptions of African American mothers in the multiple social contexts of being black mothers and living in rural communities.

Nature of the Study

The rationale for selecting a generic qualitative approach for this study is that it allows researchers to understand how people interpret, construct, and make meaning from their experiences and world (Kahlke, 2014; Ravitch & Carl, 2016). For this study, I will seek to understand African American mothers' perceptions of the effectiveness of services provided to their children with autism in a few rural communities using in-depth semi-structured interviews. The in-depth interviews allowed me to develop themes, categories, and codes revealed by the participants' experiences (Kahlke, 2014; Stewart, 2016). I will utilize data from participant interviews, observing participants during interviews, journaling, analytic memos, and field notes to ensure data triangulation. Since this study focused on a specific population residing in one location, I used purposive criterion sampling to recruit participants. Purposive criterion sampling works best for this study because it allows me to obtain a wealth of data about a phenomenon surrounding a specific population of people who live in a particular location (Duan et al., 2015; Patton, 2002; Ravitch & Carl, 2016). This sampling strategy allows me to get information-rich data from individuals who meet a specific criterion (i.e., African American mothers of autistic children) who are knowledgeable about a particular phenomenon (effectiveness of services in rural communities) with limited resources (Benoot et al., 2016; Duan et al., 2015; Palinkas et al., 2015).

Definitions

Autism Spectrum Disorder (ASD): The Diagnostic and Statistical Manual of Mental Disorders (DSM–5; American Psychiatric Association, 2013) defines autism spectrum disorder (ASD) as a neurodevelopmental disorder characterized by persistent deficits in social communication and interaction. Some difficulties include engaging in back-and-forth conversation, noticing and interpreting other people's verbal and nonverbal cues, and initiating and maintaining social relationships. Also, other symptoms include restricted and repetitive behaviors, interests, or activities such as hand flapping, body spinning, or other stereotyped motor behaviors; another example is having very specific and limited interests, sensory hypo-sensitivities, or hypersensitivities.

African American: African American refers to a person of African ancestral origins who self-identifies or is identified by others as African American (Agyemang et al., 2005). The term African American dates back to the 1920s and has been used most in the USA since the 1970s (Agyemang et al., 2005). Most African Americans in the USA originated from sub-Saharan Africa, so the term is not applied to Africans from northern

African countries such as Morocco (Agyemang et al., 2005). Most African Americans are descendants of persons brought to the Americas as slaves (distant ancestry) between the 17th and 19th centuries (distant ancestry). Such people differ from others from Africa or the Caribbean in the 20th and 21st centuries (recent ancestry) regarding culture, language, migration history, and health. These differences are often ignored (Agyemang et al., 2005).

Rural Communities: Rural communities are non-metro areas with a population of under 50,000 (Ennis, 2018). Rural communities can be categorized as exceptionally rural areas (under 5,000 inhabitants), rural areas (between 5,000 and 10,000), and mid-rural areas (between 10,000 and 20,000) (Kruger, 2017).

Medical Mistrust: According to Griffith et al. (2021), medical mistrust is "a general sense of unease or suspicion toward someone or something that is predicated either on the notion that the provider or healthcare entity may not act in the patient's best interest, and they may actively work against the patient. Mistrust may originate from distinct historical experiences linked to group identity, personal experience, vicarious experiences, and oral histories (p.2)."

Autism Disparities: Factors that negatively impact children's access to early assessment, diagnosis, and therapeutic interventions include racial, ethnic, and socioeconomic disparities (Singh et al., 2019).

Diagnostic Disparity: Children of diverse racial groups are diagnosed later than white children, which delays their access to early interventions and services. Another aspect of diagnostic disparity includes the misdiagnosis of children as well. Factors contributing to diagnostic disparities include inadequate access to healthcare, clinician prejudices and biases, and parent interpretations and report of symptoms (Donohue et al., 2019).

Racial Disparities: Racial disparities are unfair differences contributed by racism and discrimination within the health care system that impact black, indigenous, and people of color (BIPOC). Racial disparities include limited access to mental and physical health services, poor quality of care, and misdiagnosis (Perzichilli, 2020).

Applied Behavioral Analysis (ABA): ABA is an evidence-based treatment for children with ASD, which consists of techniques used to facilitate desired learning and behavior that is highly effective (Carson et al., 2021; Hazen et al., 2018).

Cultural Competence: Patient-centered care given by health care systems and professionals is responsive and respectful to patients' cultural perceptions and experiences, including the patients' and families' preferences, values, cultural traditions, language, and socioeconomic status (Stubbe, 2020).

Cultural Competence Education: Training specifically for healthcare professionals that educates them on culturally sensitive practices. Cross-cultural communication improves cultural competency, increasing patient involvement and adherence to treatment and leading to a higher quality of care and better health outcomes (Kennedy et al., 2007).

Ethnicity means belonging to a specific social group with a common national or cultural tradition (Tromans, 2020).

Ethnic Group: People sharing commonalities and experiences in areas such as diet, religion, migration experience, language, education, and health behaviors (Tromans, 2020).

Assumptions

The primary assumption of this study is that African American mothers will express dissatisfaction with the effectiveness of the available services in rural communities. This assumption is based on the previous research presented in the problem statement about African American mothers experiencing dissatisfaction with the available services. However, I have not found research that addresses this assumption about African American mothers' perception of the effectiveness of the services.

Scope and Delimitations

The scope of this study focuses on African American mothers' perception of the effectiveness of services for their children diagnosed with autism living in rural communities. I interviewed African American mothers with biological children diagnosed with autism and no other developmental disorder. The mothers must have been the primary caregiver and were present when their child received services for autism. Therefore, other ethnic groups, mothers, or other caretakers were excluded. The population selected for this study was delimited from a rural county in the U.S. There is a potential for transferability in this study with other ethnic groups and African American mothers or parents living in different regions in the U.S.

Limitations

Potential limitations of this generic qualitative design include issues with the sample sizes and validity (generalization) (Schreier, 2018). Qualitative studies such as this have small sample sizes due to the nature of the data collection, which consists of obtaining information-rich data associated with the phenomenon of interest (Galvin, 2015 & Malterud et al., 2016). The sample size and criteria for my study do not generalize to the broader population. As a result of the small sample sizes, I used purposive criterion sampling to select participants for this study. Even though purposive criterion sampling allows for in-depth data and is often used in different qualitative research designs, it does not allow for random sampling like quantitative research studies.

There is a limitation as it relates to the specifications of the participants. For example, the participants must have been African American mothers raising children with ASD in rural communities in the rural U.S. African American mothers living in rural communities in the U.S. with children diagnosed with autism perceptions and experiences may not reflect other parents of different ethnic or racial groups experiencing the same phenomenon. My sample is from more than one rural community, which may help increase the representation of African American mothers with autistic children in other geographical locations. Not including other caregivers, fathers, and guardians of African American children with autism may limit the depth of data related to the phenomenon of interest.

Human error and researcher bias may limit the study of any research study. I acknowledge the potential for bias and error as a researcher. Some factors impact my positionality: I am an African American woman living in a rural community, just like the participants. I also acknowledge that my experience working with families with autism as a therapist may influence my perception and assumptions of the study's data. During the data collection, I will utilize reflexive strategies such as journaling and analytic memos. Ravitch and Carl (2016) emphasized that they are vital at minimizing researcher bias by not assuming the data outcome based on my experiences serving families with autism in rural communities. I will practice and maintain self-awareness, not enforce or share my personal beliefs and experiences that may influence participants' outcomes (Sanjari et al., 2014). To ensure this research study is trustworthy and credible, I will use member checking by confirming with the participants that I captured their experiences accurately and consulting with my dissertation chair throughout the process. I will also use data triangulation by incorporating field notes and multiple analysis triangulation to ensure credibility, trustworthiness, and quality, which will be further explained in Chapter 3.

Significance

This generic qualitative study contributes to the current body of autism research by providing insight into this underserved population's possible issues or unique experiences. This insight may provoke more research on this population and provide opportunities for practitioners to improve their practices. A previous study revealed that only two percent of African American families living in the rural region where the study took place reported seeking services for their children with autism (Mello et al., 2016). Moreover, another study showed that African American mothers reported experiencing racial discrimination when seeking and receiving services for their sons diagnosed with autism, thus negatively impacting their experiences with effective services (Lovelace et al., 2018). Another study revealed that African American parents felt the providers lacked empathy for their child’s needs and judged their parenting styles and traditions, contributing to disengagement with their children’s services (Burkett et al., 2017). Another study discussed how providers and clinicians lack cultural competence to treat ethnic and racial minorities, thus negatively impacting their ability to effectively serve minority children with autism more than White children with autism (La Roche et al., 2018). I found no research that shares African American mothers’ perceptions of the services provided to their children diagnosed with an autism spectrum disorder in rural communities.

Social change aims to eradicate systems of discrimination and oppression that inhibit specific groups of people from experiencing equity and freedom in all aspects of life (Yob and Brewer, 2015). African American mothers represent a population that historically and presently experiences discrimination based on race and gender (Graves, 2017; La Roche et al., 2018). This research contributes to social change research by sharing data from an underrepresented and traditionally oppressed group, which sheds light on their unique perceptions. Scholar-practitioners, researchers, and other human service providers may gain new insight and knowledge from African American mothers’ perceptions of the effectiveness of available services within rural communities and whether race or geography impacts their perception. As a result of the insight gained, practitioners can assist rural mental health agencies and other human and social service organizations in creating changes in their organizations' structure by implementing culturally sensitive strategies and approaches to improve the effectiveness of their services. Also, this study provides an opportunity for advocacy research because it gives a voice to a population typically silenced by society (Yob & Brewer, 2015). This research provides a platform for researchers, scholars, and practitioners to hear these women's voices. Practitioners, researchers, and other entities may find the data from this study valuable. These entities could promote awareness and advocate the needs of rural African American families impacted by autism to local and state governments, which may aid in allocating funding for training and helping professionals provide culturally sensitive services for these families. Schools in rural communities may find the data beneficial to implementing school-based behavioral services when working with African American youth with autism.

Summary

This chapter included the purpose of this study, which was to explore African American mothers' perception of the effectiveness of autism-specific services available to their autistic children in rural communities. This chapter also presented a literature synthesis that sets a foundation to address the phenomenon of interest. The literature presented critical components to this study: African American parents raising an autistic child; African American mothers' experiences with accessing mental health; treatment and services for children diagnosed with autism; and challenges the African American community encounters with mental services in general.

In Chapter 2, I present an extensive literature review on the topic. Chapter 3 described the qualitative methodology used to address the research question and conduct this study. The chapter also focuses on the instruments and procedures utilized to conduct this study. Chapter 4 provides the analysis and data collection method. Chapter 5 overviews the research and discusses the results and the study’s implications.

Chapter 2: Literature Review

Introduction

The research problem identified for this study focuses on understanding African American mothers’ perception of the effectiveness of the accessible services provided to their children diagnosed with autism living in rural communities. This generic qualitative research study seeks to understand African American mothers’ perception of the effectiveness of services available to their children diagnosed with autism spectrum disorder living in some rural communities in the United States. In one study, researchers discussed how African American parents experienced low-quality services and limited access to quality services to meet their autistic children’s needs (Broder-Fingert et al., 2013).

Previous autism-related studies recognized that rural communities lack appropriate and effective services for children diagnosed with autism spectrum-related disorders. However, most studies explore and examine the lack of services from White non-Hispanic participants without minimal representation from African American participants. Even though autism-related research in rural communities consists primarily of white participants, researchers explore African American participants’ perspectives and experiences with services for children with autism in urban communities. This study addresses the identified gap in the research literature that focuses on African American mothers’ perception of the services provided to their children diagnosed with autism spectrum disorders.

I share my literature search strategy in the first section of this literature review. Then, I provide the theoretical framework for this study. I then present a synthesis of the literature reviewed for the study, which includes an overview of autism, types of autism treatments and services, parental stressors associated with raising children with autism, disparities associated with autism-related services in rural communities, and African American parents' perceptions of services used to treat autism. Also, I will justify utilizing a generical qualitative design to answer the research question for this study.

Literature Search Strategy

The search strategies to support this literature review included detailed searches using Walden University's research databases, such as Thoreau, PsychARTICLES, PsycINFO, SocINDEX, Scholarworks, ProQuest Dissertations & Theses Global, and Walden University dissertations and theses. Also, the search included all EBSCOhost databases and ProQuest. The Google Scholar search engine and the National Center for Biotechnology Information database were utilized to find additional articles for this literature review. In addition to using the listed scholarly databases, articles were pulled from Google Scholar before being cross-referenced with the listed databases to ensure that the journal articles were peer-reviewed, such as Sage Journals and Sage Premier. These databases and university dissertations provided a plethora of scholarly peer-reviewed resources that aided in completing a thorough review of the currently available literature. I searched from 2016 through 2021 for recent literature and from 1900 to 2016 for historical references to inform the study. In order to broaden the search of articles for this literature review, I used the following terms and term combinations: *autism*, *rural* *communities, mental health, African American families, African American mothers, autism and mothers of autistic children, African American children, the prevalence of autism and minorities, autism treatment, Applied behavioral analysis, accessibility of autism treatment, mental health disparities, coping with autism, stigma,* and *qualitative studies on African American parents and autism*.

Theoretical Foundation

Chapter 1 introduced the racial formation theory as the theoretical framework for this study. Sociologists Michael Omi and Howard Winant introduced the racial formation theory in their book *Racial Formation in the United States* in 1986 (Omi et al., 2014). Since 1986, three editions of *Racial Formation in the United States* have been published (Omi et al., 2014). This theory's evolution as a leading racial theory in sociology, psychology, religion, and anthropology contributes to defining the role of race during the latter half of the twentieth century and the beginning of the twenty-first century to the present day in the United States. Created as a response to the reductionist theories that simplified race as an epiphenomenon of class, ethnicity, or nation, the racial formation theory has reshaped the study of race (Alumkal, 2004).

As previously mentioned, Omi and Winant, the originators of the racial formation theory, present a multifaceted, comprehensive assessment of how race in the United States is not just based on phenotype and biology but how society, politics, and culture influences how a person is perceived and treated (Crawford et al., 2007; Omi et al. 2014). This theoretical framework introduces concepts that expand the understanding of race in the United States. Omi and Winant first introduce racialization, emphasizing how a person's looks (i.e., skin tone, hair texture) impacts how others categorize, perceive, and treat them. They present the term *racial project*, which interprets and explains multidimensions associated with race by including social, political, and economic factors (Omi et al., 2014; Jacobson, 2015). According to Cheng (2014) and Cohen (2017), the racial formation theory acknowledges that race goes beyond nationality or ethnicity to view race as a multifaceted concept consisting of a social structure and cultural representation. This theory's development provides awareness of the diversity within U.S. society. Social scientists failed to acknowledge how race impacts various social, political, and economic contexts by using racial projects to give meaning to these experiences (Golash-Boza, 2013). Omi et al. (2014) define racial formation as "the sociohistorical process by which racial categories are created, inhabited, transformed, and destroyed." They attempt to chart a middle course between two extremes. The first extreme is an "essentialist" formulation that views race as "a matter of innate characteristics, of which skin color and other physical attributes provide only the most obvious, and in some respects most superficial, indicators" (Omi et al., 2014). The other extreme is a view that trivializes the race category, arguing that race will disappear if we ignore it since it is a social construction. This latter view ignores how race has deeply structured Western civilization for the last 500 years. The racial formation theory drives this study by providing the foundation for understanding African American mothers' perceptions of black mothers' multiple social contexts and living in rural communities. Ultimately, this study provides insight into individuals' experiences of a specific race that acknowledges the totality of their racial experiences within the context of their social structure and cultural representation in society.

Literature Review Related to Key Variables and Concepts

This section of the literature review provides a synthesis of the literature reviewed for this study. A detailed analysis of the literature provides an overview of autism, the variation of services used to treat autism, parental stressors associated with raising children with autism, disparities associated with autism-related services in rural communities, disparities impacting African American children with autism, and African American parents' perceptions of services used to treat autism. Also, I will justify utilizing a generical qualitative design to answer the research question for this study.

Overview of Autism

Autism Spectrum Disorder (ASD) is a complex, lifelong, biological, neurodevelopmental brain disorder characterized by two core behavioral symptoms: impairments in social communication and restricted/repetitive behaviors (Eissa et al., 2018; Monz et al., 2019). ASD presents with core deficits in communication, social participation, behavior, and sensory processing, ultimately affecting an individual's social interaction and communication (Bölte et al., 2018). With this disorder, the core symptoms can be observed for three years and last for the person's life (Eissa et al., 2018). Autism, unlike many other illnesses, diseases, or impairments, does not present with consistent characteristics, attributes, or symptoms.

According to Morales-Hidalgo et al. (2018), ASD attributes range from mild and capable of functioning within society to severe, presenting with low cognitive or language abilities. Noticeably, the presented symptoms and severity tend to change over the person's lifespan, creating difficulty in successfully functioning in various settings and delaying diagnosis (Morales-Hidalgo et al., 2018). A myriad of symptoms and behaviors manifest in ASD persons. To be diagnosed with ASD, they must demonstrate deficits primarily in social communication and interaction and exhibit restricted, repetitive behaviors, interests, and activities. Also specified in the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5) are further criteria for such symptoms to have been present during early development and not due to global developmental delays or intellectual disability (Malik-Soni et al., 2021). The above-described symptomology for ASD should significantly impair occupational, social, and overall functioning. Appendix F provides a table of the five diagnostic criteria for autism according to the DSM-5. In addition, Appendix G includes a table that notes a range of symptoms associated with ASD. Appendix H has a table listing the severity levels for autism spectrum disorder.

Historical Introduction to Autism

In 1911, psychiatrist Eugene Bleuler documented the first description of autism by identifying detachment behaviors from reality, like the symptoms of schizophrenia that cause issues with difficulty or impossibility of communicating (Alves et al., 2020). Years later, in 1943, psychiatrist Leo Kanner published a study where he used autism to diagnose eleven children with "infantile autism" who had presented with behavioral characteristics of the inability to engage and establish relationships with others socially (Alves et al., 2020). In addition to social impairment, the children could not create emotional connections and displayed higher resistance to changes in their environments (Alves et al., 2020). In his observations of the children, Kanner also noticed extreme complications in using language to communicate thoughts, feelings, and understanding of verbal and nonverbal cues (Alves et al., 2020). A year later, in his study, Hans Asperger, a Viennese pediatrician, described children with some characteristics like autism who exhibited challenges in social communication with peers but also exhibited earlier language development than those who met autism (Mintz, 2017). Also, Dr. Asperger noticed these children were above normal to exceptional intelligence and had noticeably restricted interests. Children with these milder, higher-functioning forms of autism were later diagnosed with Asperger's Syndrome, named after Dr. Hans Asperger (Duffy et al., 2019; Mintz, 2017). However, the most recent version of the Diagnostic and Statistical Manual of Mental Disorders DSM has removed this diagnosis and is under the umbrella of ASD (American Psychiatric Association, 2013).

ASD is prevalent in individuals of various racial and socioeconomic groups, diagnosed in 1 in 68 children, and noted to occur five times more frequently in boys in the United States (Baio J. et al., 2018). According to Alves et al. (2020), ASD has become a high priority for scientists and health care providers and has also attracted public attention because of the reported increase in its prevalence (Sheldrick and Kao et al., 2018; Eissa et al.,2018; Xu et al., 2018). The global prevalence of individuals with an ASD diagnosis is remarkably high, and estimations show an expected increase in the global prevalence from one in 160 children with ASD (Malik-Soni et al., 2021).

The American Psychiatric Association (APA) published new diagnostic criteria for ASD in the revised DSM-5 to clarify the diagnosis of ASD (APA, 2013). In the DSM's previous edition DSM-IV-TR, individuals were diagnosed with the following four disorders: Autistic Disorder, Asperger's Disorder, Childhood Disintegrative Disorder, or Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) (American Psychiatric Association, 2000). With the updated DSM-5, changes eliminated sub-classifications under the autism spectrum and allowed for one uniform diagnosis of ASD (APA, 2013). PDD-NOS and Asperger's Disorder were removed and merged under the ASD class. The most recent DSM-5 now includes one diagnostic category for ASD, reclassifying other related conditions (APA, 2013). Genetic and neurodevelopmental disorders like Rett Syndrome and Fragile X exhibit deficits in early speech-language development and different disorders from autism spectrum disorders (Roche et al., 2018). Additionally, individuals who do not meet the criteria for ASD and have challenges using verbal and nonverbal communication receive a Social Communication Disorder diagnosis (APA, 2013). Medical and other professionals must consider the most appropriate diagnosis by which an individual exhibits the above-noted symptomology and whether ASD or a better-suited disorder.

The Variation of Services Used to Treat Autism

Due to the complexity of autism spectrum disorders, various treatments help reduce the disorder's symptoms. Treatments for autism fall into two major categories: behavioral treatments and medication treatments (Jenabi et al., 2019; Xu et al., 2019). However, Hazen et al. (2018) also include Dietary Approaches and

Complementary and Alternative Medicine in the list of treatments for autism. Even though various medications and behavioral treatment approaches exist, no treatment modality cures ASD. Because the developmental levels and symptoms vary substantially in children with ASD, no specific treatment method is considered universally significant for individuals with ASD (Brandl et al., 2020; Hong et al., 2017). Often families who receive ASD services come for multiple visits with many interdisciplinary providers such as physicians, psychologists, and speech and language pathologists (Antezana et al., 2017; Hazen et al., 2018). For example, children and their families frequently attend an initial diagnostic appointment with a medical or psychological provider. After a diagnosis, providers often refer children for further comprehensive assessments related to their cognitive (with neuropsychologists), language (with speech and language pathologists), and physical (with occupational and physical therapists) needs. Based on the child’s specific needs, behavioral therapy referrals include applied behavioral analysis and psychotherapy (Azad, 2019; Carson et al., 2021; LaRoche et al., 2018). Due to advancements in technology and the flexible nature of various behavioral treatments, the accessibility of services is provided in various settings such as schools, remote/telehealth, homes, and communities (Azano et al., 2017; Azad et al., 2019). Behavioral learning methods use focused behavior modification techniques to influence behavior change. In traditional behavioral interventions for autism, the targets reduce unwanted (often repetitive or assumed non-socially functional) behaviors and increase identified social behaviors (Goldman et al., 2018; LaRoche et al., 2018).

Medication Treatment

A significant component of autism treatment involves medication, also called drug therapy (Eissa et al., 2018). Drug therapy helps minimize stereotypic behaviors associated with autism and treats common comorbid disorders that impact individuals with autism, such as sleep, neurological, and gastrointestinal disorders (Hazen et al., 2018; Masi et al., 2017). Even though medications relieve ASD symptoms, researchers and scientists emphasize that medications do not cure autism (DeFilippis et al., 2016; Eissa et al., 2018). Medical providers often prescribe psychotropic medications to treat autism symptoms (Hong et al., 2020; Hong et al., 2017). Psychotropic medications primarily treat mental illnesses such as bipolar disorder, depression, anxiety, attention deficit hyperactivity disorder, and psychotic disorders (Carson et al., 2021; Hazen et al., 2018). Drug therapy treats behavioral symptoms: hyperactivity, inattention, impulsivity, aggression, outbursts, self-injury, obsessive-compulsive, rigidity, repetitive behaviors, anxiety, depression, and sleep disorders (Eissa et al., 2018; Jenabi et al., 2019; Xu, 2019). In addition to managing symptoms such as high energy levels, inability to focus, anxiety and depression, behavioral reactivity, and self-injury, medication treatment also helps with secondary symptoms of autism, such as seizures (Hazen et al., 2018; Hong et al., 2017).

Several medications help reduce aggressive behaviors such as self-injury, temper tantrums, physical aggression, and irritability. Three significant classes include antipsychotics, antiepileptics, and antihypertensives (DeFilippis et al., 2016; Hong et al., 2017). The other classes of drugs used to treat autism include antidepressants, ADHD medications (stimulants and non-stimulant), anticholinergics, mood stabilizers, anxiolytics, and sedatives/hypnotics (Hong et al., 2017; Jenabi et al., 2019). One of the primary classes of medications prescribed to treat autism falls under antipsychotics. Antipsychotics are unique in ASD treatment due to two drugs in this class called risperidone and aripiprazole (Eissa et al., 2018; Yu et al., 2020). Only risperidone and aripiprazole received FDA approval for treating the behavioral symptoms associated with ASD (Madden et al., 2017; Masi et al., 2017; Yu et al., 2020). These medications treat psychotic symptoms such as hallucinations and delusional thinking, and mental health disorders such as schizophrenia and schizoaffective disorder. However, antipsychotic medications also help control aggression, self-injurious behaviors, hyperactivity, impulsivity, oppositionality, and repetitive behaviors caused by ASD (Madden, 2017; Strunk et al., 2014). Even though antipsychotics historically focused on treating psychotic disorders, there is no connection between ASD and psychosis (Eissa et al., 2018; Hazen et al., 2018).

Antiepileptic medications treat seizures and epilepsy, and since children with autism experience seizure disorders, it is one of the primary treatments for ASD (Kao et al., 2018). One study found that roughly 12% of children with autism have epilepsy, and by the time they reach adolescence, 26% of them receive a diagnosis of epilepsy (Chepure et al., 2018). Also, antiepileptics help lessen explosive behaviors and aggression (Eissa et al., 2018). Additionally, the University of Missouri-Columbia (2016) discovered that the antihypertensive medication used to treat high blood pressure, Propranolol, showed signs of improving children's conversational and nonverbal skills with autism. Another study found that antihypertensive medications like clonidine and guanfacine help minimize hyperactivity, inattentiveness, impulsivity, and insomnia in children with ASD (Hazen et al., 2018; Wink et al., 2017). Also, medical providers combine antihypertensive medications with other medications to help children with autism (Wink et al., 2017; Xu et al., 2018). Antidepressants treat self-injurious and stereotypical behaviors of autism and other comorbidities such as seizures, insomnia, and depression (Eissa et al., 2018; Kao et al.., 2018). Even though studies show that drug therapy helps children and adults with autism, some researchers have found that medications from most drug classes show little to no impact on autism symptoms (Fung et al., 2016; Yu et al., 2020). Additionally, medications contribute to adverse side effects due to prolonged use of these drugs (Kao et al., 2018; Fung et al., 2016; Yu et al., 2020).

Behavioral Treatment

Doctors, neurologists, and other medical providers make referrals to licensed and certified providers who specialize in behavioral treatments in the realm of behavioral, psychological, educational, and skill-building interventions for children and adolescents diagnosed with ASD (Eissa et al., 2018; National Institute of Mental Health, 2018). Such treatments typically consist of highly structured and intensive interventions that involve parents, children with ASD, siblings, other family members, and other key players such as teachers, case managers, and others (Brandl et al., 2020; National Institute of Mental Health, 2018). Behavioral treatments include learning life skills necessary to live independently, reducing challenging behaviors, increasing or building upon strengths, and learning social, communication, and language skills (DeFilippis et al., 2016; Monz et al., 2019).

Applied Behavior Analysis

Applied Behavior Analysis (ABA) is one of the most used services for families of children with ASD (Carson et al., 2021; Mello et al., 2016). Based on applied behavior analysis principles, targeted and comprehensive behavioral treatment models aim to reinforce socially acceptable behaviors, decrease or eliminate undesirable behaviors, and regularly identify well-established treatments for ASD (DeFilippis et al., 2016; Schlinger, 2017). ABA is becoming more recognized among healthcare professionals and is used in many schools and treatment clinics (Singh et al., 2019; Zoder-Martell et al., 2016). ABA encourages positive and discouraging behaviors; the child's progress is tracked and measured. (Hazen et al. 2018; Schlinger, 2017). ABA is a treatment based on theories of learning and operant conditioning. It includes specific intervention targets coupled with positive reinforcement (verbal praise, tokens, or edible rewards), with the repetition of learning trials as a critical component (DeFilippis et al., 2016; Goldman et al., 2018). Early intensive behavioral intervention for children with ASD increases the potential to significantly affect developmental outcomes, particularly concerning behavior, adaptive skills, and communication (Schlinger, 2017). Behavior analysis consists of three separate but overlapping and related branches: the philosophical branch, called behaviorism or radical behaviorism; the primary research branch, the experimental analysis of behavior (EAB); and the applied branch, called ABA (Schlinger, 2017).

Occupational Therapy

Occupational therapists play a vital role in children with autism spectrum disorders. Occupational therapists liaise with patients and families by facilitating and coordinating care during inpatient admission for medical care, outpatient procedure, or diagnostic testing (Hazen et al., 2018). Occupational therapy teaches skills that help children live as independently as possible by alleviating sensory defensiveness and other symptoms of autism (Brauner, 2018). Some skills taught include learning to dress, eat, bathe/clean, and interact with others. Also, children learn coping strategies and self-soothing (Hazen et al., 2018).

Social Skills Training

Social skills training is a highly requested service by a parent due to a social deficit caused by autism. Parents often utilize these services so their children with autism can form lasting relationships and improve their interaction with their peers (Carson et al., 2021). Social skills training teaches children to interact with others, including conversation, problem-solving, social cues, and rules (Mintz, 2017).

Speech & Language Therapy

A common symptom associated with ASD includes complications with language and speech. Speech therapy helps improve communication skills by teaching children verbal communication skills using visual and physical aids ((Monz et al., 2019). Traditional approaches to mastering language tend not to work for children with ASD because teaching children with autism to speak will not fully transform their social behavior (Kao et al., 2018). Meaning the children need to learn how to use language to communicate in social interactions, which include (Goldman et al., 2018):

- They know how to hold a conversation.
- Thinking about what the other person in a conversation understands and believes.
- Improving awareness of other person’s meta-linguistic signals, such as facial expression, tone of voice, and body language
- Helping children heighten their awareness of assessing nonverbal cues and communication due to the predisposition of not noticing nonverbal language.

Speech and language therapists diagnose and treat language problems and speech disorders. Speech and language therapists work with nonverbal persons with autism (Kao et al., 2018).

Physical Therapy

Individuals with autism spectrum disorders benefit from using physical therapy if they have any of the following indicators: stiff or tight muscles; delayed in reaching motor skills milestones; difficulty with poor balance and coordination; difficulty navigating through their environment; posture abnormalities; muscle weakness; pain (Longtin et al., 2016; Kao et al., 2018). Also, physical therapy addresses co-morbidity issues for people with autism, such as musculoskeletal, podiatry, and other surgeries (Hazen et al., 2018).

Alternative Treatments and Interventions

With a rise in the use of alternative methods of alleviating symptoms of ASD, some parents, healthcare professionals, and other clinicians use and recommend alternate treatments outside the scope of behavioral and medical treatment modalities. These alternative treatment methods for ASD are complementary and alternative medicine

(CAM) (Owen-Smith et al., 2019). CAM treatments utilize no traditional medicine approaches incorporating specific products or services to minimize autism symptoms (Höfer et al., 2017). CAM treatments comprise special and restrictive diets (gluten-free, casein-free, sugar-free, lactose-free), vitamin therapy (vitamins C & D), and dietary supplements (omega-3 fatty acids, dimethylglycine) (Hazen et al., 2018). Another CAM includes chelation, another form of detoxification, a treatment to remove heavy metals from the body (Höfer et al., 2017). Many alternative treatments are not empirically proven effective; moreover, a review of chelation studies found evidence of no harm and no evidence to indicate that it effectively treats children with ASD (Owen-Smith et al., 2019). Some research shows that as many as one-third of parents of children with ASD may have tried CAM treatments (Hazen et al., 2018; Höfer et al., 2017). Up to ten percent of children are at risk of potentially dangerous treatment (Höfer et al., 2017).

African American Mistrust in the US Healthcare System: Historical Context

Research has found higher mistrust levels of mental healthcare services and other human services within African communities (Gemegah et al., 2020; Pearson et al., 2021; Robertson, 2016). Some of the significant factors that contribute to this mistrust of mental healthcare include African American historical factors associated with slavery and unethical treatment and experimentations, dissatisfaction with the quality of services provided, biases experienced with treatment providers, and the host of disparities African American face (Azad et al., 2019; Griffith et al., 2021). Throughout history, African Americans have tended to experience barriers to participating in medical research due to historical events that have caused a greater mistrust of the medical profession, including mental health (Lee et al., 2018; Speed, 2013; Kennedy et al., 2007). Researchers suggest that African Americans, especially those economically and educationally disadvantaged, have historically lacked trust in established health care systems due to the lack of resources (Brandl et al., 2020; Burkett et al., 2019; Lee et al., 2018).

The African American perceptions of fear and distrust in the healthcare system stem from long before personal healthcare choices and collaborative decision-making (Bailey, 2018; Shaia et al., 2020). The history of slavery, segregation, and racism created a system that negatively impacted African Americans' quality of care in medicine (Griffith et al., 2021; Tromans et al., 2020). Several studies have reflected the mistrust of health care providers and skepticism of the information provided by medical authority figures (Coffield et al., 2020; Griffith et al., 2021; Lee et al., 2018; Stahmer et al., 2019; Williams et al., 2019). Despite the absence of slavery, African American mothers experience unique forms of racism and segregation than previous generations (Burkett et al., 2017; Graves, 2017; Lovelace et al., 2018); however, the historical impact of slavery remains embedded in their minds as a constant reminder (Griffith et al., 2021; Kennedy et al. 2007; Lee et al., 2018). The United States healthcare system experimented with and used enslaved Africans and their descendant throughout its history (Shaia et al., 2020; Kennedy et al., 2007; Lee et al., 2018). African Americans received inhumane and unethical care that began mistrusting providers (Lee et al., 2018; Speed, 2013). The history of harmful interactions with healthcare providers presents itself because providers with limited cultural and historical awareness may perpetuate mistrust in the system (Coffield et al., 2020; Hazen et al., 2018; Williams et al., 2019). Mistrust significantly influences people’s decision-making skills and ability to utilize critical resources that work best for optimal health and wellness (Griffith et al., 2021; Pearson et al., 2020; Pearson et al., 202). Factoring trust helps improve health research, eradicate healthcare disparities, and achieve health equity (Burkett et al., 2017; Griffith et al., 2021). Nevertheless, efforts to build trust to increase healthcare utilization and research participation may have little effect on attitudes or behaviors rooted in distrust or mistrust (Griffith et al., 2021; Shaia et al., 2020; Tromans et al., 2020).

Tuskegee Syphilis Study

African descent people often harbor feelings of being medical test subjects due to previous medical exploitation within unethical studies, such as the well-documented Tuskegee Syphilis study (Brandl et al., 2020; Lee et al., 2018). Studies conducted on African Americans, like the Tuskegee Syphilis experiment, resulted in withholding medical treatments to African American men for over twenty years, which caused severe issues for the participants (Jaiswal et al., 2019; Pearson et al., 2020; Williamson et al., 2018). This experiment diminished trust in research with African Americans due to the loss of life and complications. According to Kennedy et al. (2007), the Tuskegee study signified racism in medicine and human research misconduct with African American participants. Researchers have noted difficulties in recruiting and retaining African Americans for research (Shaia et al., 2020; Williamson et al., 2018). History shows an underrepresentation of African Americans in research studies (Brandl et al., 2020; Jaiswal et al.,2019; Shaia et al., 2020). The lack of participation is prevalent when potential participants feel that the research is meaningless to them or their community

(Coffield et al., 2020; Hazen et al., 2018; Williams et al., 2019). Often, investigators researching African American communities are not of the same race (Hazen et al., 2018; Williams et al., 2019; Lee et al., 2018). This lack of familiarity and similarity often leads to continued mistrust.

Undoubtedly, The Tuskegee Study of Untreated Syphilis in the Negro Male holds the most nefarious example of unethical medical research (Griffith et al., 2021; Williamson et al., 2018; Pearson et al., 2020). Even though the United States Public Health Service study illustrating those concerns about medicine and public health's lack of trustworthiness are not unfounded, knowledge of the Syphilis Study and other unethical research studies is not solely responsible for African American patients' mistrust (Jaiswal et al.,2019; Griffith et al., 2021; Manning, 2020). In the Syphilis Study and many other instances of unethical medical research, part of the deception was that the research disguised and presented to patients as medical care, making it difficult for patients to view medical care outside of the context of medical research (Bonchek, 2021; Jaiswal et al.,2019; Lee et al., 2018). It also is noteworthy that the principal investigators of the Syphilis Study had strong reputations as physicians and researchers who had demonstrated commitment and concern regarding the health of "Negroes" and that the racial disparities in the prevalence of syphilis were due to poor social and economic status, not inherent racial susceptibility (Griffith et al., 2021; Manning, 2020).

Systemic Racism in Medicine

The experiences of African Americans with the US medical profession and public health system yield historical and present-day issues of mistrust while raising a complex quandary of how to rectify the issue (Lee et al., 2018; Manning, 2020; Williamson et al., 2018). African Americans perceive hospitals and other public health agencies as prejudiced due to systematic historical racism and modern-day systemic racism of American medical institutions and agencies (Gemegah et al., 2020; Lee et al., 2018). During the establishment of medical associations and schools in the antebellum era, African Americans were wielded as easy targets due to their poverty-stricken socioeconomic status (Bonchek, 2021; Jaiswal et al.,2019; Lee et al., 2018). As a result of these socioeconomic factors, the black community unwillingly provided black bodies for autopsy education and studies; quite often, medical institutions attained the black bodies by kidnapping them and withholding medical care for sick African American patients (Hua et al., 2018; Lee et al., 2018; Manning, 2020). To add more context to this phenomenon, early scientists and doctors in the US made scientific assumptions that spanned to the late 20th century that black bodies hold racial inferiority to white bodies (Hua et al., 2018; Lee et al., 2018; Williamson). The assumptions implied that the black race closely resembles non-human animals physiologically, which sparked various medical experiments performed on African Americans by public health agencies and medical societies (Gemegah et al., 2020; Lee et al., 2018; Williamson et al., 2018).

African Americans’ culture is collectivistic, with values of contributing to the community, honoring the elders, and prioritizing family (Hua et al., 2018; Williams et al., 2019). African Americans that live by traditional African American values, such as religious and cultural beliefs, actively engage in their community (Gemegah et al., 2020; Williams et al., 2019). Religion plays a fundamental and foundational role in the African

American community, with churches often serving at the epicenter of social movements and support (Jaiswal et al.,2019; Shaia et al., 2020; Tromans et al., 2020). These traditional elements contribute to the resiliency of African Americans' and their unique history in America compared to other ethnic groups stemming from systemic racism and slavery (Kennedy et al.,2007; Shaia et al., 2020). Without this knowledge and interest in African American culture, service providers devalue African American parents and their child's health concerns (Stewart, 2016; Williams et al., 2019). Consequently, they often perceive that medical professionals are biased against black families. In combination, these systems-level factors create a complex environment for promoting authentic engagement with families with marginalized identities in medical and educational settings (Shaia et al., 2020; Speed, 2013). Family factors such as cultural differences in the perception of child development and developmental disabilities may also reduce timely access to care (Burkett et al., 2017; Tromans et al., 2020).

Parental Stressors Associated with Raising Children with Autism

A critical factor that warrants attention when parenting a child with autism is the stress associated with parenting. Over the past decade, researchers explored and studied the impact of autism on parents caring for their children. Studies found that parents with autistic children experience more stress than parents with children with other disabilities (Azad et al., 2019; Masi et al., 2017; Reed et al., 2017; William et al., 2019). For example, parents of children diagnosed with ASD reported elevated objective and subjective burdens of parenting, more psychological distress, and a lack of social support (Ramdinmawii et al., 2017; Pearson, 2018; Picardi et al., 2018). Some objective burdens refer to parents' practical problems, including disrupted family relationships, constraints, limitations in social and leisure time, work functions, and financial hardships (Catillo et al., 2020; Donohue et al., 2019; Picardi et al., 2018). Subjective burdens are also called parents' psychological responses, including feelings of hopelessness, deferred dreams, expectations, depression; anxiety; and embarrassment in social situations (Picardi et al., 2018; Voliovitch et al., 2021).

In a systemic review and meta-ethnography of qualitative research, researchers identified four overarching barriers contributing to stressors and disparities connected to autism treatment: familial, cultural, and structural (Singh et al.,2019). Factors contributing to these barriers included limited knowledge of autism and resources, cultural stigmas, and beliefs about autism. Other studies reported that parents of autistic children experience higher psychological and emotional distress than parents of children with no disabilities and other non-autism-related disabilities (Burkett et al., 2017; Coher, 2017; Voliovitch et al., 2021). Another study collected data from a large insurance claims database to explore how many parents of children with ASD were diagnosed with depression; the parents of children with autism received a clinical diagnosis of depression two times more than parents with children without autism (Cohrs et al., 2017). When factoring in the typical responsibilities of parenting, such as providing food, safe shelter, physical care, and other factors that contribute to stress, parenting a child with autism increases the likelihood of a decline in parents' physical and mental wellbeing (Coher et al., 2017; Barroso et al., 2018). Higher familial disruptions negatively impact autistic children's social and educational progress (Ramdinmawii et al., 2017; Reed et al., 2017).

According to Strunk et al. (2014), parents of children and adolescents with autism spectrum disorders expressed that the primary cause of their parental stress is caused by inadequate behavioral and healthcare services to treat autism-related issues. It is also pertinent to highlight that parental stress negatively impacts children's wellbeing and progress (Ramdinmawii et al., 2017; Reed et al., 2017).

Singh et al. (2019) and Barroso et al. (2018) also confirmed higher rates of parental stress of parents with children diagnosed with ASD than the stress levels of parents of children without the disorder in their studies by systematic review and meta-analysis. In addition, the researchers explored the correlation between the severity and intensity of the behavioral symptoms in children with ASD and parenting stress versus other factors and other symptoms of the children with and without developmental delay (Barroso et al., 2018; Williams et al., 2019). In one instance, the study confirmed that the severity and intensity of a child's behavior significantly affect parental stress more than other factors, such as developmental delay (Azano et al., 2017; Brehm et al., 2021, Barroso et al., 2018). However, another study found that the severity of the child's symptoms did not impact parental stress but the lack of social support and poor coping skills (Voliovitch et al., 2021). Other researchers revealed that children with autism who exhibited both behavioral and cognitive deficits contributed to higher rates of parenting stress (Barroso et al., 2018; Hazen et al., 2018). Also, parents expressed experiencing more stress when their child had a co-occurring disorder with autism (Brehm et al., 2021). Barroso et al. (2018) highlighted in their mixed findings that children with ASD experience various symptoms and behavioral responses that differentially impact parenting stress (Barroso et al., 2018; William et al., 2019). Even though researchers acknowledge higher stress levels in parents of children with autism, newer research suggests that early treatment and intervention could remedy these issues (Estes et al., 2019; Ramdinmawii et al., 2017). In addition to early diagnosis and interventions, researchers deem it necessary to examine further how the stress of parents raising children with ASD is crucial to understanding all factors associated with higher levels of parenting stress (Azano et al., 2017; Hazen et al., 2018). Researchers acknowledged that further research should consider how demographical factors such as the children with autism, gender, age, race, and ethnicity influence the relationship between parents' stress and the severity of behavioral symptoms exhibited by their children (Castillo et al., 2020; Barroso et al.,2018).

African American Mothers' Stressors

A qualitative study of African American mothers reported that they face additional stressors to a higher degree due to experiences with structural racism, discrimination, unsafe neighborhoods, fewer financial resources, single-parent homes, and imprisonment (Lovelace et al., 2018). African American children and families experience subtle racism called racial microaggressions that insult, invalidate, or demean their experiences and identity (Hazen et al., 2018; Williams et al., 2019). These additional stressors, especially racism and discrimination, promote more anticipatory coping (i.e., taking steps to mitigate potential stressors) in African Americans (Graves,2017). Even with race-related stressors, one study found that African American mothers reported fewer issues surrounding their social, emotional, and physical wellbeing while caring for their children with autism than white mothers (Burkett et al., 2017). Historically, African Americans draw upon cultural strengths to cope with life and culturally specific stressors and rely on family and extended family networks for support (Assari, 2018). Religion, spirituality, and emotional support are essential in the African American community (Stewart, 2016). More research suggested that children with ASD experience more stress than parents of typically developing children and parents of children with other disabilities (Malik-Soni et al., 2021; Hayes et al., 2013). For African American families, stressors intensify when they experience poverty (Goldman et al., 2018).

For example, poverty lowers parents' engagement levels in training and support due to stressors related to experiencing poverty and affects the fidelity of continuing services, intervention effectiveness, and skill development (Goldman et al., 2018). These additional stressors associated with poverty, such as limited services available through public insurance, little money for transportation and childcare, and lack of flexible employment, might complicate and interfere with intervention effectiveness for families of children with ASD (Goldman et al., 2018; Singh et al., 2019). The topic of income, finance, and socioeconomic status appears to be a research theme exploring parental stress of African American families with mixed results. For instance, some studies on African American parents and autistic children fall within the low-income status (Bailey, 2018; Castillo et al., 2020). Concerning race, previous research has suggested that higher rates of stress among parents are often due to factors associated with low socioeconomic status, such as limited access to resources and services (Grave, 2017). Other studies indicate that African American parents, especially mothers, experience higher levels of education and have financial means (Lovelace et al., 2018; Pearson et al., 2018).

One study found no significant differences in parental stress among mothers from different racial and ethnic minority backgrounds (Barroso et al., 2018). Given the inconsistent findings in their research, Barroso et al. (2018) emphasized the need to examine the link between child race/ethnicity and parental stress. Other studies presented refuting results. Other researchers indicated that families of color and other ethnic groups, such as African Americans, encounter many unique stressors, including financial hardships, discrimination, and limited access to and knowledge of resources (Burkett et al., 2017; Donohue et al., 2019). These stressors lower parents' tolerance for child misbehavior and ultimately increase parenting stress levels (Graves, 2017; Hua et al., 2018). According to Barroso et al. (2018), no other demographic factors, such as children's age, race, and familial socioeconomic status, did not significantly differ in the parents who completed the parental stress measures tool. Although previous research suggests a decrease in parenting stress levels and behavior problems as children age, newer research discovered that the connection between these variables remains constant throughout childhood (Pearson et al., 2020; Shaia et al., 2020; Tromans et al., 2020).

Specific to African American families, a "cultural clash" between African American parents and the broader medical and education system has been recognized (Bailey., 2018; Goldman et al., 2018; Pearson et al., 2020), yet there is a lack of empirical research to identify evidence-based strategies to address these challenges. Some suggested strategies include developing better parent-professional partnerships where providers attain more precise knowledge, consideration, and interest in the values and cultural norms of African American families' backgrounds when planning interventions (Goldman et al., 2018; Tromans et al., 2020). Provider biases further confound the potential for inadequate cultural fit between children and families of color and the treatment and interventions specialized for autism. Inadequate cultural fit can relate to diverse interpretations of disability, different coping and interaction styles, and limited access to information (Magaña et al., 2015; Pearson et al., 2020), negatively impacting intervention effectiveness. If providers structure interventions according to each family's needs that align with their lifestyle, culture, and daily routines, these strategies could better equip African American parents to implement better skills and interventions (Azad et al., 2019; Estes et al., 2019; LaRoche et al. 2018).

According to some researchers, African American mothers experience unique challenges and stressors with parenting their children due to finding effective services for their children with autism and other issues (Manning, 2020; Shaia et al., 2020; Tromans et al., 2020). For example, one study highlighted a correlation between demographic elements such as a child's race and ethnicity and parental stress (Donohue et al., 2019). Researchers found that parents from non-white racial and ethnic backgrounds reported higher parenting stress rates due to socioeconomic status, limited resources, and access to services (Barroso et al., 2018). In one study, African American mothers reported experiencing racial discrimination when seeking and receiving services for their sons diagnosed with autism, negatively impacting their experiences with effective services (Lovelace et al., 2018). Another study discussed how providers and clinicians lack cultural competence to treat ethnic and racial minorities, negatively impacting their ability to effectively serve minority children with autism rather than White children with autism (La Roche et al., 2018). Some researchers highlighted how culturally biased practices prevent families living with autism from receiving and experiencing satisfaction with autism services and mental health care within the African American community (Broder-Fingert et al., 2018; Nguyen et al., 2016). However, no studies explore how race and geography influence African American mothers' perspectives on the effective services available to their children diagnosed with an autism spectrum disorder in rural communities. This study seeks to address this gap in the literature by exploring African American mothers' perspectives on the effectiveness of services available to their children with autism.

Disparities Associated with Autism-Related Services in Rural Communities

Rural communities face significant challenges regarding adequate screening, diagnostic, treatment, and support services for individuals with autism spectrum disorder (ASD) (Antezana et al., 2017; Mello et al., 2016; Speed, 2013). Regarding overall healthcare services that comprise behavioral and mental health treatment, rural communities lack adequate resources to serve those in need more than urban areas (Azano et al., 2017; Carson et al., 2021; Monz et al., 2019). In a systemic review of medical literature, Malik-Soni et al. (2021) reported that non-metropolitan areas experience a shortage of specialists and healthcare for autism, limiting parents from pursuing services due to the additional financial cost and time constraints of daily obligations coupled with traveling long distances. Other factors contributing to this resource deficit include the geographical distance between families and service providers, low dependence on healthcare professionals, and cultural characteristics that contribute to the diminished availability and utilization of services (Antezana, 2017; Doody et al., 2017; Mello et al., 2016). Parents in a southeastern state shared experiencing challenges of limited access to care, pointing to specific barriers that prevent adequate access to care and identifying primary concerns for children, including social skills, emotional regulation, and behavior management (Carson et al. 2021). Collectively all of these factors lead to risks for delayed ASD screening and diagnosis, yielding lower educational and functional outcomes (Antezana et al., 2017; Ennis, 2018).

Diagnosis and Treatment for ASD in Rural Communities

A consensus in data and medical science emphasizes the importance of early diagnosis and intervention for improving functional outcomes in children diagnosed with autism spectrum disorder (Darcy-Mahoney et al.,2016; Duffy et al., 2019; Antezana et al., 2017). However, rural communities suffer from early diagnosis and intervention for children with autism despite the similar prevalence ratios of ASD in both rural (0.9%) and urban (1.0%) (Azano et al., 2017; Ennis, 2018). One challenge that impacts early diagnosis and treatment for ASD in rural communities is the remoteness of many rural areas (Azano et al., 2017). Also, compared to the prevalence rates in urban communities, the researchers noted a lower occurrence of rural ASD rates in studies exploring geographical variation (Barroso et al., 2018). Azano et al. (2017) suggested that rural communities needed access to professionals to identify and treat children early. By having more accessibility to these trained providers and professionals, rural communities can address this significant initial step toward cultivating ongoing developmental growth for children with ASD (Barroso et al., 2018).

Compared to urban areas, children with ASD in rural cities and towns are more likely to experience a later diagnosis of autism due to the lack of geographical access to services (Azano et al., 2017). Even though some studies indicate urban areas have higher occurrences of ASD than rural areas, research acknowledges that the occurrences may differ due to rural areas having less access to autism-related services and treatments than urban areas (Azano et al., 2017; Doody et al., 2017). As a result of the geographical limitations, children with ASD encounter later diagnoses and implementation of treatment and supportive services to address the disorder in remote rural areas (Azano et al., 2017).

Low-resource rural communities face significant challenges regarding the availability of evidence-based services (Azano et al., 2017; Ennis, 2018). They are often disadvantaged in geographic proximity to care, particularly specialty care, facing challenges such as poverty, inadequate transportation, unemployment, and limited access to information technology, all of which contribute to diminished service utilization. Disparities contribute to inadequate screening, misdiagnosis, and under-treated children with autism. Unfortunately, parents in rural communities experience more difficulty accessing specialized services to treat their children due to limited availability (Antezana et al., 2017; Mello et al., 2016). For instance, parents living in rural communities expressed guilt and frustration regarding their incapacity to spend quality time with their spouses and other children due to the demands of caring for their child with ASD (Doody et al., 2017; Mello et al., 2016). Also, Parents verbalized their desire to connect with other parents and caregivers of children with autism and engage in meaningful, enjoyable activities with others in their community in similar situations to reduce the feelings of isolation that occur with parenting a child with autism (Doody et al., 2017).

Disparities Impacting African American Children with Autism

Pearson et al. (2020) eloquently stated, “When race and disability are combined, it is the axis of one oppression with another (p.305). This quote reflects the narrative shown in various research on African Americans and their disparities related to healthcare. Some researchers identified how race and disability are social construction issues that African American children and families face that yield unfavorable consequences to receiving help (Donohue et al., 2019; Williams et al., 2019). Due to these multifaceted social disadvantages, African Americans with disabilities such as autism experience disorders and systemic issues that fail to meet the person’s needs (Pearson et al., 2018; Tromans et al., 2020). Healthcare providers and other service providers serving African American children experience their own biases and judgments that impact their ability to serve (Bailey, 2018; Lovelace et al., 2018; Robertson, 2016). Physicians reported experiencing discomfort and anxiety with helping African American families and children due to the lack of exposure to treating them with disabilities such as autism which impacts how they help them (Pearson et al., 2018; Pearson et al., 2020; Pearson et al., 2021). Research shows that people who identify as African American overall experience worse health outcomes than White people in the US (Assari, 2018). Studies also show that African Americans’ racial health disparities begin before birth and continue throughout childhood to adulthood and old life (Assari, 2018; Bailey, 2018; Tromans et al., 2020). Unfortunately, the severity of disparities impacting the African American community impacts the overall mental health treatment for African American children, including the treatment for autism (Graves, 2017; Bailey, 2018; Pearson et al., 2021). A significant disparity impacting African American children with ASD revolves around the issue of misdiagnosis or late diagnosis (Papoudi et al., 2020; Williams, 2019; Stahmer et al., 2019). Studies show that African American children get diagnosed years later than white American children (La Roche et al., 2018; Nguyen et al., 2016; Stahmer et al., 2019). More recently, the Centers for Disease Control substantiated these findings and suggested that African American children are 30% less likely to receive an ASD diagnosis than white American children (Bailey, 2018; Williams et al., 2019). Not only do African American children get diagnosed later by approximately two years, but they also get misdiagnosed with conduct disorders or adjustment disorders (Lovelace et al., 2018). One study found that almost 50% of black children with autism receive the label intellectually disabled, and 25% of white children with autism receive the label intellectually disabled (Williams et al., 2019).

Substantial epidemiological research suggests that autism spectrum disorder (ASD) is a universal disorder that affects individuals from all racial, ethnic, and socioeconomic backgrounds (Maenner et al., 2020; Hua et al., 2018), yet ethnic minorities are often underdiagnosed and go without treatment (Tromans, 2020; Begeer et al., 2009). The Centers for Disease Control and Prevention (2019) data suggests that non-Hispanic White children are 30 percent more likely to be diagnosed with ASD than non-

Hispanic Black children. Almost half (48%) of Black children diagnosed with ASD also receive a diagnosis of intellectual disabled compared to only one quarter (25%) of White children with an ASD diagnosis. Even after a late diagnosis, African American children sometimes experience a delay in managing autism symptoms (Broder-Fingert et al., 2018; Coffield et al., 2020). The contributing factor to this problem involves providers who treat autism. One source reported dissatisfaction among patients and families with their providers' ability to treat autism, especially among African American and Latino families (Hazen et al., 2018; Shaia et al., 2020). Healthcare providers and professionals admit to not always utilizing culturally appropriate screenings and have admitted that it is more difficult to recognize symptoms and signs of ASD in African American and Latino children (Malik-Soni et al., 2021; Morales-Hidalgo et al., 2018; Shi et al., 2021). Given the diagnostic disparities among African American children with ASD, parents often face challenges regarding access to services and effective communication with providers (Griffith et al., 2021; Bailey, 2018). The three most common barriers African American families face in accessing these services include gaining accurate and timely diagnoses, socioeconomic status, and cultural dissonance between parents and providers (Longtin et al., 2016; Pearson et al., 2021).

One Autism and Developmental Disabilities Monitoring site covering 11 counties in middle Tennessee reported the prevalence of ASD in black-to-white children at a .9 to 1.0 ratio (Baio et al.,2018; Maenner et al.,2020). Therefore, the data showed no overall difference in ASD prevalence between black and white children aged eight years old; however, black children disparities exist in early evaluation and ASD diagnosis in those counties in Middle Tennessee (Maenner et al.,2020; Longtin et al., 2016). Several decades of research documented how race and ethnicity and other factors impacting black and other children of color, such as income and language barriers with autism spectrum disorder (ASD), are diagnosed later than white children (Papoudi et al., 2020; Burkett et al., 2017; Broder-Fingert et al., 2013). Families of these children experience more unbelievable struggles accessing services in the United States (Baio et al., 2018; Coffield et al., 2020). The delayed access to early diagnosis and interventions impacts child outcomes and family quality of life (Barroso et al., 2018; Malik-Soni et al., 2021). Children of color receive fewer evaluations overall and are less likely to be identified as having ASD despite displaying similar symptom profiles (Donohue et al., 2019; Nuygen et al., 2016; Assari et al., 2018). Structural factors in the service systems contribute to the disparities in access to quality care (Gemegah et al., 2020; et al., 2021). Providers often lack the resources, capacity, or mandate to disseminate information to under-represented groups (La Roche Stahmer et al., 2018; et al., 2019).

A study of 3615 participants, which consisted of 2935 white, 243 Hispanic, 188 African American, and 249 other identifying researchers, sought to explore the racial differences in specialty care services among children with autism spectrum disorder (Broder-Fingert et al., 2013). The specialty care services for autism treatment explored included neurologic, psychiatric, and gastrointestinal treatment (Hazen et al., 2018; Shaia et al., 2020). Based on the results, there was a significant difference in African American children’s uses of the services:

- African American children used GI and nutrition specialty services less than other participants.
- African American children showed lower rates of GI studies in colonoscopies, endoscopies, and stool studies.
- Regarding using providers in psychiatry and psychology, African American children ranked lower in receiving those.
- Compared to white children, African American children used neurological services, tests, and treatments such as EEG, brain MRI, sleep studies, and neuropsychiatric testing at a lower rate.

The researchers found a difference in the use of subspecialty services of participants based on race and ethnicity among children diagnosed with autism using treatments and procedures (Broder-Fingert et al., 2013). The researchers explained that their findings suggest that the differences in African American families’ services use are due to the presentation in symptoms, referral rates, and following through with referral appointments (Broder-Fingert et al., 2013).

Some researchers theorized that Black parents might emphasize children’s disruptive behaviors to healthcare providers (Shaia et al., 2020; Stahmer et al., 2019), contributing to the overdiagnosis of disruptive behavior disorders in Black children with ASD. Due to the over-diagnosing conduct disorder in Black children with ASD, researchers must investigate factors other than parent reports of symptoms, such as clinicians’ biased interpretation of symptoms as disruptive behavior in Black children with ASD (Bailey, 2018; Singh et al., 2019). Black parents report significantly fewer concerns about ASD, social interaction, and repetitive behavior than white families, even though race does not influence parent reports of non-ASD-related concerns such as disruptive behavior (Singh et al., 2019). These differences in developmental delay and ASD concerns may affect providers' reporting and subsequent diagnosis (Burkett et al., 2017; Goldman et al., 2018). Because of the stigmatization of ASD in many cultures, it may be more challenging for families of color to accept their children's diagnosis.

Consequently, this may delay efforts to seek social support and services. Black parents report resistance to the ASD diagnosis due to social stigma around mental health concerns (Graves, 2017; Manning, 2020; Williamson et al., 2018). Disparities may also be due to a lack of knowledge regarding ASD symptoms and treatment and limited available information specific to children of color (Hua et al., 2018; Magaña et al., 2015; Nguyen et al., 2016). For instance, being from a family of color or a low-income household has been associated with lower parental expectations of benefits from child therapy, lower caregiver engagement in services, and the belief that their child's condition is a mystery (Pearson et al., 2020; Pearson et al., 2021; Shi et al., 2021). Black parents report frustration regarding the scarcity of evidence on behavioral interventions' effectiveness for their children with ASD (Shi et al., 2021; Singh et al., 2019; Stahmer et al., 2019).

African American Parents' Perceptions of Services Used to Treat Autism

This study aims to get African American mothers' perceptions of treatment services for their children with autism in rural areas. However, I have yet to find many sources that share their perceptions. Evidence suggests that people of diverse sociocultural backgrounds, such as African Americans and other ethnic groups, perceive the causes, symptoms, and treatments of autism differently due to disparities in access to treatments and education (Castillo et al., 2020; Papoudi et al., 2020). Some researchers found that African American parents' perceptions of autism and the services used to treat the disorder differ in reporting their concerns (Pearson et al., 2018). For example, one study on children with ADHD compared Black parents' and White parents' perceptions based on their concerns and found that black parents reported fewer concerns with key symptoms of ADHD like hyperactivity in their children (Donohue et al., 2019; Shi et al., 2021). The study reported that African American parents acknowledged that they did not know the symptoms of ADHD compared to white parents (Catillo et al., 2020; Shi et al., 2021). Some studies compared African American and White parents' concerns with autism-related symptoms in their children (Reed et al., 2017; Papoudi et al., 2020). The study showed that despite their severity, African American parents reported few concerns with autism-related symptoms, which could negatively impact African American children getting the additional help they may need (Donohue et al., 2019; Papoudi et al., 2020). Researchers explored the perceptions, experiences, and needs of culturally diverse families of children with autism; the researchers confirmed that African American families' perceptions of autism are influenced by a frequently reported lack of knowledge of autism as well as experiences including social stigma and difficulties in having access to services (Pearson et al., 2020; Pearson et al., 2021; Papoudi et al., 2020). Other researchers explored the experiences and perceptions of support of African American children with ASD and their families (Pearson et al., 2020; Robertson, 2016). The researchers’ findings indicated two themes: (1) participants identified few facilitators to service access, and (2) both parents and healthcare providers perceived similar barriers and facilitators to early diagnoses and service access—implications for parents, healthcare providers, and educators (Pearson et al., 2020; Pearson et al., 2020).

Another study examined the lived experiences and perceptions of three African American mothers with sons diagnosed with ASD and identified prominent themes of each other’s experiences identifying racial identity’s impact on receiving medical treatment and educational support services (Lovelace et al., (2018). In other research studies, each mother’s experiences uncovered how covert and overt racial discrimination resulted in unfair or observable differences in how educational and medical professionals treated them and their children (Bailey, 2018; Lovelace et al., 2018; Reed et al., 2017). Even though their circumstances differed to some degree, each mother shared similar experiences of racial discrimination as they sought help from professionals who help with autism (Griffith et al., 2021; Lovelace et al., 2018; Williams et al., 2019). There was a consensus of experiencing more covert acts of racial discrimination shared by each of the mothers, such as how provider diminished their knowledge of the disorder and the lack of interest in providers and professionals helping their sons. In addition, each mother expressed hesitations in admitting how race contributed to the treatment she and her son received (Donohue et al., 2019; Lee et al., 2018).

In a few studies, I found that most researchers explored perceptions of African American mothers from urban metropolitan areas. However, I did find one qualitative study that explored African American mothers’ perceptions of the diagnosis and services for children with autism where mothers lived in urban and rural areas of a midwestern state; out of the 11 participants, three of the mothers lived in rural communities (La Roche et al., 2018; Pearson et al., 2018). The three mothers shared that living in rural communities poses extra barriers to accessing services such as ABA treatment for their children due to treatment availability and traveling a long distance to get help (Lovelace et al., 2018; Pearson et al., 2018). According to Lovelace et al. (2018) and La Roche et al. (2018), African American mothers experience a unique challenge in finding effective services for their children due to race issues. In one study, African American mothers reported experiencing racial discrimination when seeking and receiving services for their sons diagnosed with autism, negatively impacting their experiences with effective services (Lovelace et al., 2018). More specifically, black parents reported feeling "undervalued" by practitioners due to their lack of interest in understanding their children and culture (Stahmer et al., 2019). Another study also highlighted how providers and clinicians lack cultural competence to treat diverse ethnic and racial minorities, negatively impacting their ability to effectively serve minority children with autism more than White children with autism (La Roche et al., 2018; Morales-Hidalgo et al., 2018). Other researchers highlighted how culturally biased practices prevent families living with autism from receiving and experiencing satisfaction with the autism services and mental health care within the African American community (Broder-Fingert et al., 2018; Morales-Hidalgo et al., 2018; Nguyen et al., 2016). African American parents reported higher frustration levels with the validity of treatments for autism (Stahmer et al., 2019). Due to the growing body of qualitative research on African American children and families, there is an overall mistrust theme with treatment due to apparent provider bias against African American children and families (Bonchek, 2021; Griffith et al., 2021; Hua et al., 2018; Singh et al.,2019). For this study, I find it pertinent to provide context on the phenomena of mistrust in the African American community to add depth to the context of autism-focused treatment by African American parents, especially mothers.

Summary and Conclusions

Autism spectrum disorder continues to be discussed in medical and psychological research due to its complexities and impact on its lives (Carson et al., 2021; Panisi et al., 2021). This chapter provided an overview of autism, including diagnostic criteria, prevalence, and behavioral characteristics associated with ASD. I also provided a historical overview of ASD. In addition to specifying autism, I shared the disorder's treatment categories—medication and drug therapies, behavioral treatment, and alternative treatments. In assessing the multitude of treatments available to children and families impacted by autism spectrum disorders, I synthesized the literature on parental stress due to a body of research on the subject (Brehm et al., 2021; Carson et al., 2021; Coher, 2017; Jenabi et al. 2019; Singh et al., 2019). I share literature on the disparities in accessing these services in rural communities. I delved into how rural communities often lack adequate treatment services and resources for children and families with autism, leading to late diagnosis and treatment.

The next part of this literature review addresses the disparities impacting African American children and families accessing autism treatments and services and other disparities impacting this community. While addressing the disparities impacting the

African American communities related to autism services, I presented literature sharing African American parents’ perceptions of their children’s services in nonrural, urban areas. In highlighting African Americans’ perceptions of mental health and services for autism, I identified a theme of mistrust in the literature. As a result, this mistrust theme found it pertinent to share the literature on the United States healthcare system’s historical impact on African Americans that contributed to and sparked mistrust that stems from racism. Even though I presented current literature on the African American mother’s perception of services for their children with autism, I did not find current research on mothers’ perceptions of autism services in rural communities, specifically in the rural U.S. In the next chapter, I describe the methodology used in the study.

Chapter 3: Research Method

Introduction

This study applied a generic qualitative design to explore African American mothers’ perceptions of the effectiveness of services provided to their children with autism in rural communities. The study contributed to the existing literature on autism and African American mothers and children related to their perceptions of the effectiveness of services provided and offered to their children with autism. In Chapter 3, I provide the rationale and justification for choosing a generic qualitative design, a description of the research design, and a description of the role of the researcher within the study. I then introduce an overview of data collection methods, data analysis, sampling strategy and sampling size, trustworthiness issues, confidentiality, ethical procedures or concerns, and a description of the data collection and analysis process.

Research Design and Rationale

This generic qualitative study addressed the following research question: What are African American mothers’ perceptions of the effectiveness of autism-related services provided to their children with autism in rural communities? A qualitative research design was most suitable for this study because it allowed me to obtain in-depth information regarding the thoughts and perceptions of the participants. Qualitative research was selected over quantitative research because the focus of the research was the subjective perceptions of each participant. Qualitative research allows researchers to collect more in-depth information from participants on a process, event, or phenomenon.

I chose a generic qualitative approach for this study because it allows researchers to understand how people see, believe, and make meaning from specific experiences and their world (Kahlke, 2014; Ravitch & Carl, 2016). Percy et al. (2015) said a generic design is excellent for qualitative research, not intended for deeper inquiry, such as lived experiences or narratives. For this study, I sought to understand African American mothers' perceptions of the effectiveness of services provided to their children with autism in rural communities through in-depth interviews. The in-depth interviews allowed me to develop themes, categories, and codes shared by the participants' experiences (Kahlke, 2014; Stewart, 2016). Unlike the other foundational qualitative methodologies such as phenomenology, ethnography, grounded theory, and narrative inquiry, the generic methodology does not operate based on philosophical assumptions, which allowed me to focus specifically on gaining insight into the interest of my study (Kahlke, 2014).

I followed a generic qualitative approach design to provide a detailed description of the phenomenon under investigation. I selected this design because I am not using a more focused qualitative design such as phenomenology, grounded theory, or others that require more in-depth information (Percy et al., 2015). Caelli et al. (2003) wrote an article building upon other research on generic qualitative research by providing clarity on generic qualitative studies compared to other qualitative studies. Generic designs allow researchers to seek, discover, and understand a phenomenon, a process, or the perspectives and worldviews of the people involved (Patton, 2002). Generic studies combine compatible tools and methods from more than one established methodology

(Renate et al., 2014). Generic qualitative studies can draw on the strengths of established methodologies while keeping or preserving the flexibility that causes generic approaches to be attractive to researchers whose studies do not fall neatly within a specific established methodology (Renate et al., 2014). Generic studies seek to understand how people interpret, construct, or make meaning from their world and experiences (Renate et al., 2014). The generic study approach also helps researchers understand people and their behavior in a social, cultural, and economic context (Hazzan et al.,2014; Renate et al., 2014).

When considering this study, I explored different qualitative designs, including generic, ethnography, narrative, grounded theory, phenomenological, and case studies (Finlay, 2014). For this study, I considered the study's purpose: to explore African American mothers' perspectives on autism-related services provided to their children with autism in rural communities. After careful assessment, a generic qualitative design appropriately aligned with this study's purpose due to the design's flexibility to incorporate semi-structured interviewing without the need to delve deep into rich content. Other qualitative research designs incorporate a more structured, in-depth research study. This study used a generic qualitative design to explain the mother's perceptions of services. Other qualitative designs, such as grounded theory, case study, narrative study, ethnography, and phenomenology, provide a more in-depth understanding of research, such as participants' lived experiences (Dotimi, 2016). Even though the narrative design contributes to qualitative research by telling participants' stories, the design would not significantly understand this study's participants' perceptions (Clandinin et al., 2007). A case study design would not be the appropriate fit for this research study because a case study requires more participants and in-depth inquiry from the participants (Yin, 2009). Phenomenological designs aim to understand the lived experiences of individuals through in-depth interview questions and data analysis; however, this study explores the participants' perceptions of a specific experience.

Role of the Researcher

Ravitch et al. (2016) explained that the researcher is a crucial instrument in a qualitative study. The researcher's role is to conduct interviews for data collection and code for data. Positionality describes the researcher's identity and connectedness to the study and individual experiences that impact how the researcher will make sense of the study (Ravitch et al., 2016). As the researcher of this study, my role included maintaining objectivity throughout the process of data collection and data analysis. I prioritized self-awareness of my positionality. It was essential to consider conflicts of interest and biased situations (Merriam et al., 2016). Ravitch et al. (2016) explained that researchers should explore their positionality by utilizing reflexive strategies for notetaking and writing memos throughout the process. Reflexivity requires the researcher to identify their connectedness to the study and how their personal experiences make sense of it (Ravitch et al., 2016). Some factors that affect my positionality in this study include gender, location, and work experience as a provider for children with autism. Gender and race are factored into my awareness because I am an African American woman, just like the participants of this study. I also live in a rural community and have served as a clinician treating children diagnosed with autism. According to Ravitch et al. (2016), I must use reflexive strategies to ensure that I am not biased or make generalized assumptions regarding my data based on my experiences and perceptions of the services available to African American children living in rural communities.

Methodology

Participant Selection Logic

The participants had to be African American mothers of children diagnosed with autism who reside in rural communities in the United States. Since this study focused on a specific population residing in rural areas, purposive criterion sampling was used to recruit participants. Purposive criterion sampling worked best for this study because it allowed the researcher to obtain a wealth of data about a phenomenon surrounding a specific population of people who live in a particular location (Duan et al., 2015; Patton, 2002; Ravitch et al., 2016). This sampling strategy also allowed the researcher to get information-rich data from individuals who meet a specific criterion (i.e., African American mothers of autistic children) who are knowledgeable about a particular phenomenon (effectiveness of services in rural communities) with limited resources (Benoot et al., 2016; Duan et al., 2015; Palinkas et al., 2015).

This generic qualitative study had a specific criterion for participants in this study. The following list gives an explicit criterion for each participant:

1. Must self-identify as African American or Black.
2. Must be the mother of a child with a professional/clinical diagnosis of autism spectrum disorder.
3. The child must be under the age of 18.

4. The mother must be the children’s primary caregiver, and the child must live with the mother.
5. The participants must live in the rural U.S.
6. Must have access to a telephone, computer, and email.
7. Must be willing to be recorded by video/voice recorder.

The following criteria excluded participants from this study:

1. Does not speak English.
2. Mothers should be at least 18 years old.
3. Not self-identify as African American.
4. Does not have a child with ASD.
5. Does not live in a rural area.
6. No access to a telephone, computer, or email.
7. Refuse to be recorded by video/voice recorder.

This study’s recruitment and selection procedure involved purposeful criterion sampling. This sampling is a beneficial method due to its alignment with a qualitative research study and its value in investigating experiences associated with a group of people (Galvin, 2015; Malterud et al., 2016). Moreover, with this form of sampling procedure, participants comprehensively informed the research topic, question, and the phenomena under investigation since this study explored African American mothers’ perception of services provided to their children diagnosed with autism living in rural communities (Duan et al., 2015; Patton, 2002; Ravitch et al., 2016). The sampling procedure involved a purposive selection method of 10-20 participants who met the specific criterion specific to race, gender, and mothers living in rural communities in the U.S. to ensure data saturation. The data collection method involved semi-structured interviews with each participant with the researcher.

The participant recruitment was done through a social media flyer shared on the researcher's social media accounts (Facebook and LinkedIn). The flyer was shared on Facebook groups catered to mental health professionals, autism support groups, and autism research groups to broaden participant selections. The recruitment flyer (Appendix A) provided an overview of the study, my contact information, and the criteria for participant selection. The flyer encouraged prospective participants to contact me by the listed e-mail address. Once the participants expressed interest in participating, the researcher emailed a consent form and a link to the demographic form (via Google Form) to complete (Appendix B & C). Once the participant replied "I consent" to the consent form via email and completed their demographic form, I screened and selected participants that met the criteria to participate. I followed up with the participants via email to schedule a time for their interviews.

Once the potential participants responded to the email and shared their availability, I provided more background about the study, answered any questions, and sent Zoom links for their designated interview times with a meeting passcode. Ritchie et al. (2013) reported having a small sample size, typically 50 participants, while Galvin (2015) and Malterud et al. (2016) suggested using approximately 10 to 20 participants for studies using purposive sampling to ensure data saturation with a criterion sample that seeks specific race, gender, geographic location, and directly impacted by a phenomenon of interest. Therefore, I aimed to have 10 to 20 participants in this study.

Instrumentation

The data collection instrument for this study was the researcher. As the researcher, I played a vital component in this qualitative inquiry. According to Ritchie et al. (2013), the researcher is the primary data collection instrument and interpretation for qualitative research. In addition, the researcher is typically the instrument used to collect the preliminary data (Creswell, 2013). The researcher gathers data through observations, in-depth interviews, narratives, focus groups, and case studies (Denzin et al., 2013; Ravitch et al., 2016). Typically, qualitative researchers collect data in the participants' natural environments and settings where the phenomena occur to add depth and meaning to data interpretation (Denzin et al., 2013).

I utilized a self-developed interview protocol (Appendix D) for this study to receive participant data. I also used Zoom software to record the virtual interview and a backup audio recording device to record each interview. The interview protocol consisted of semi-structured interviews. To ensure data triangulation, I reviewed and considered all interview recordings and transcripts, participant demographic information, and field notes during the individual interviews. These multiple data sources were considered against each other to capture all aspects of the phenomenon described by the participants.

The semi-structured interviews provided sufficient data for the researcher to develop themes, categories, and codes shared by the participants' experiences (Kahlke, 2014; Stewart, 2016). The interview questions were beneficial due to flexibility and the opportunity for deeper content analysis. Qualitative interviews follow a schedule of guided questions and topics that allow discovery and exploration of the proposed case. Since I sought to understand African American mothers' perceptions of the effectiveness of services provided to their children with autism in rural communities in the United States, semi-structured interviews were the best format to gather sufficient data. The interviews allowed for in-depth data collection due to the nature of the open-ended questions and space to ask for more information based on the structure of the questions (please see Appendix D).

Procedures for Recruitment, Participation, and Data Collection

The data from this study were collected from various instruments: demographic form, semi-structured interviews, and field notes done during the interviews. The demographic form (Appendix B) provided pertinent data regarding the mother's age, race, the mother's code name for the study, age of the child, age of diagnosis, household size, education, career, and marital status. These forms were sent via email and were filled out electronically using Google Forms to make it easy for participants to fill out the required information. The study utilized semi-structured interviews to answer a series of open-ended questions to answer the research question for this study (Appendix D).

I was responsible for all data collection: creating interview questions/protocol, demographic forms, and field notes. In preparation for the interview, I emailed each participant a secure virtual meeting code the day before the interview and requested that they find a private space with limited chances of being interrupted or heard. Each participant had a unique meeting code. Virtual face-to-face interviews were provided to collect the interview data. The interviews were done one at a time by each participant. I designated enough time to gather and transcribe data between interviews. Since the goal was to interview 10-20 participants, I continued with each interview until data saturation or until she reached 20 participants.

I opted to do virtual interviews recorded by Zoom software and a backup audio recorder to ensure interviews were recorded if there were issues with Zoom software. During and after the interviews, I took field notes to capture her observations of the participants as an additional set of data that complements the interview. The notes helped me to develop a more comprehensive look at the data. These notes also provided the researcher's observation data, such as the mood and body language of the participants or any other pertinent information that potentially affected the interview data.

The Interview Protocol (Appendix D) provides a detailed structure of the interview process: introduction, interview, and debriefing (wrap-up). At the end of the interviews, each participant was thanked for volunteering to participate and providing data for the study. I also informed each participant that a copy of the summary of interpretations of interviews would be e-mailed to check accuracy. The participants were also informed that they could receive a copy of the study's findings by email if requested.

Data Analysis Plan

Data analysis required specific actions to assess and interpret data thoroughly. For my data analysis, I selected specific interview questions that helped facilitate adequate data, including observational data (observing participants' body language during interviews), to ensure a wealth of data to interpret (Creswell, 2013). The essential techniques used to analyze data from the interviews, field notes, and demographic information content analysis using open and selective coding (Patton, 2002; Saldaña, 2016). The researcher opted to use content analysis to analyze data for two reasons. Content analysis is an effective way to find recurring themes and categories in qualitative data. It is excellent to analyze interview transcripts, video and audio recordings, notes, images, and text documents (Patton, 2002; Schreier, 2014). The content analysis allowed me, as a researcher, to condense and organize large volumes of data without losing the context of data while exploring and analyzing data to interpret the data into themes (Mills et al., 2010). Coding is how qualitative researchers identify themes, concepts, events, and examples from the raw data collected from their study (Rubin & Rubin, 2012). Saldaña (2016) explained that a code is a word or simple phrase that captures meaning from qualitative data from audio, visual, written transcripts, and other sources used to collect data. The open coding was first condensed interview transcripts, field notes, and demographic form data into codes (Schreier, 2014). Then selective coding was done to categorize themes (Schreier, 2014).

The data analysis process of this study was completed after the data was collected after each interview. Each interview was transcribed. I used professional transcribing software to transcribe the interview data to ensure accuracy. After the interviews were transcribed, I listened to each interview while reading the transcripts to ensure that the transcript reflected what was said in the interview. If there were issues with the audio, I planned to email the transcript to each participant to clarify any inaudible elements of the transcript. The next step was coding. I reviewed each transcript and implemented open coding to condense the interview data into Excel spreadsheets. I then used selective coding to categorize codes into another spreadsheet and find themes from the categories.

I also used Computer Assisted Qualitative Data Analysis (CAQDAS) software to code the interview data. Coding software was selected because it offers many benefits to qualitative data analysis. For example, CAQDAS analyzes and organizes qualitative research data from various sources such as text, audio, images, and video (Allen, 2017). Also, CAQDAS analyzes raw data into categories and themes (Yakut et al., 2017). Allen (2017) highlighted that CAQDAS enhances the data’s credibility, reliability, and validity because the software’s functionality makes coding easier than manual coding (Allen, 2017; Predictive Analysis Today, 2016).

I also used CAQDAS software after the manual coding process after each interview. I uploaded my interview transcripts to the software for analysis. After processing the categories and codes through the software, I compiled the CAQDAS-coded data with the analyzed manual data. I interpreted themes from the codes.

Issues of Trustworthiness

Quality, trustworthiness, and credibility are sometimes used interchangeably to explain the validity of qualitative research (Patton, 2002; Ravitch et al., 2016). To ensure the validity of this qualitative research study, I addressed credibility, transferability, dependability, and confirmability. Qualitative research credibility provides an accurate interpretation or representation of the experiences of the participants (King et al., 2018; Patton, 2002). Ritchie et al. (2013) and King et al. (2018) both articulated that credibility is needed to establish the trustworthiness of qualitative research. The research design must be high quality to ensure that a qualitative study is trustworthy and credible. Rubin and Rubin (2012) explained that a quality research design involves selecting knowledgeable participants and having firsthand experiences that reflect the phenomenon of interest. This section discusses how I ensured trustworthiness in my study by sharing credibility, transferability, dependability, and confirmability strategies.

Credibility (internal validity):

Establishing credibility helped me as a researcher to increase the trustworthiness of my study (Anney, 2014). According to Patton (2015), credibility consists of the researcher assuring the information provided by the participants is accurate. Some strategies used to ensure credibility for this study included researcher reflexivity, data triangulation, and member checking. As the researcher of this study, I explored my positionality by utilizing reflexive strategies such as note-taking and writing memos throughout the process (Ravitch et al., 2016). These reflexive strategies provided opportunities to practice self-awareness as the researcher by identifying my connectedness to this study and considering how my biases and other personal experiences impact the study (Ravitch et al., 2016). Some factors I identified early in this study include my positionality. My positionality in this study comprises my gender, race, residence location, and work experiences as a provider for children with autism. Gender and race are factored together because I am an African American woman, just like each study participant. I also live in rural communities and have served in capacities that assisted in treating children diagnosed with autism. According to Ravitch and Carl

(2016), I have to use reflexive strategies to ensure that I am not biased or make generalized assumptions regarding my data based on my experiences and perceptions of the phenomenon of interest. I journaled and made memos during each phase of this study.

I provided each participant with a summary of their interview transcript to review the document's accuracy for member checking. If there were an issue with understanding the transcript, the participant would be asked to correct any errors found within the transcript. Every participant also confirmed that their information was accurate. I also used the triangulation method using coding software to cross-reference my interview transcript to verify my codes to see any alignment.

Transferability (external validity):

Transferability for this study would mean that the results of this study can be transferred into other studies in different contexts, settings, and using different populations (Anney, 2014). To improve transferability, I gave detailed, rich, and thick descriptions of this study's research setup, procedures, participants, and role as a researcher. Providing a thick description and information about this study better allows readers and other researchers to evaluate whether my findings are transferable to their own experiences, situations, and studies (Korstjens et al., 2018; Ritchie et al., 2013). Another strategy used to help with transferability in this study was purposive sampling. Purposive sampling allowed me to focus on a specific sample knowledgeable in effectively answering the research question for this study. As a result of this sampling, the participants provided greater in-depth findings than other probability sampling strategies (Anney, 2014; Shenton, 2004).

Dependability (the qualitative counterpart to reliability):

Dependability connects to the extent that qualitative research results are consistent and valid based on their ability to be replicated. I used memos to create an audit trail to ensure dependability, and member checking will also help (Korstjens et al., 2018; Shenton, 2004). The other documents used in the audit trail included the demographic form, my reflective journal content, the interview transcripts, audio/video recordings, and an evaluation of the data analysis process (Anney, 2014; Ghrayeb et al., 2011).

Confirmability (the qualitative counterpart to objectivity):

The first issue to address confirmability entailed maintaining neutrality throughout this study as the researcher. I monitored my internal dialog, biases, beliefs, and so forth to maintain an objective stance (Ghrayeb et al., 2011; Shenton, 2004). The two strategies that I used were an audit trail and reflexive strategies (Korstjens et al., 2018; Shenton, 2004).

Ethical Procedures

The participants of this study were vital contributors to this qualitative research because they provided the data needed for the phenomena of interest (Ritchie et al., 2013). Therefore, I took special precautions to protect and treat participants ethically as the researcher. My role as a researcher was not to harm the participants and to conduct myself ethically (Rubin et al., 2012). Qualitative research is unique because it is relational and interactive between the researcher and participants (Ravitch et al., 2016). The relational dynamic between the researcher and participant may present ethical dilemmas that the researcher should consider (Saldaña, 2016). Researchers must be aware of the potential ethical issues when participants share their personal beliefs and experiences (Sanjari et al., 2014). In order to monitor research ethics, there are systems established to assist researchers in protecting their participants and enforcing ethical behavior. Universities have institutional review boards (IRB) and ethics committees that regulate ethical conduct for qualitative research (Ravitch et al., 2016). Walden University has an IRB to ensure that each student researcher conducts ethical research.

In order to begin this study, I obtained approval from Walden University's institutional review board (IRB) by submitting my application. Once IRB approved this study, I began the recruitment process by posting my recruitment flyer on my professional social media sites (i.e., LinkedIn and Facebook). Once I got responses from potential participants, I emailed them the consent and demographic forms. The flyer had my contact information so potential participants could contact me (Appendix A). The consent form informed participants of the purpose of the study, my role, the participant's role, any potential risks, voluntary participation, and their right to withdraw from the study at any time (Appendix A). Their real names were not used in the study. Once the participants replied, "I consent" via email, I offered to schedule a time to speak with them to answer any questions. I also scheduled their virtual interview.

In order to protect the participants' identities, I allowed them to create a code name to use when I reported my data. The demographic form provided a space for the participants to place their names. During the interview, the participants had the option to turn off the screen during the interview recording. They had to show their faces to confirm racial identity before recording the interview if they opted not to be seen. The researcher also made sure that the virtual interview room was encrypted. All electronic and digital data was saved on an encrypted drive that required a password to secure the raw data collected from the participants during the research. The hard copy data collected from the research, such as notes, recordings, and personal information, was locked in a file cabinet in the researcher's home office to maintain security and confidentiality. The information saved on an audio recorder, notes, and the hard drive was saved for five years before shredding (Creswell, 2013).

Summary

This chapter provided a detailed description of the research design and rationale, the researcher's role, methodology, issues of trustworthiness, and ethical procedures for the study. This study aimed to gain awareness of American mothers' perception of the effectiveness of the services provided to their children diagnosed with autism living in rural communities. A generic qualitative design was used to conduct this research. The participants had to meet a specific criterion: African American has a biological child diagnosed with autism, the child must be under 18 years old, be African American, and reside in the rural U.S. Data collection was done using open-ended, semi-structured interviews. The instruments used to collect data included, Zoom software (video), an audio recorder, and note-taking. The data from the interview was electronically transcribed and verified by the participants, and the researcher manually coded the data for themes. I also used coding software to code transcripts to ensure correlation with her codes.

In Chapter 4, I present the results of this study about African American mothers' perceptions of the effectiveness of services provided to their child with autism while living in rural communities based on implementing the generic qualitative design. I address the setting of the study, participants' demographics, the data collection and analysis processes, evidence of trustworthiness, and a discussion of findings.

Chapter 4: Results

Introduction

This generic qualitative research study sought to understand African American mothers’ perception of the effectiveness of services available to their children diagnosed with autism spectrum disorder living in some rural communities in the U.S. The research question for this study is as follows:

R1: What are African American mothers’ perceptions of the effectiveness of autism-related services provided to their children with autism in rural communities?

Data were collected using a semi-structured interview protocol that consisted of 17 questions to facilitate interviews for this study. In this chapter, I provide an in-depth description of the study’s setting, demographics of the participants, data collection process, data analysis procedures, evidence of trustworthiness, the results, and a summary of Chapter 4.

Setting

The setting of each semi-structured interview was virtual via Zoom. Each member had to consent to participate in a virtual interview. A significant part of this study was recruiting participants from rural United States areas. According to the U.S. Department of Agriculture, the criterion for rural communities is a city or town with a population under 50,000 people and not identified as urban, metropolitan, or suburban. Participants were from the following states: Tennessee, California, Oklahoma, Georgia, New York, Michigan, and Illinois.

Demographics

For this study, I sought a specific demographic of participants: African American mothers of African American children diagnosed with autism living in rural communities. Ten African American women participated in this study. They varied in age, marital status, employment status, and education (see Table 1 below). Participants were asked to provide a code name to identify themselves in this study. Each participant provided their demographic information on a demographic form (see Appendix B) that I sent them. It also provided demographic information about their children (listed below in Table 2).

Table 1

Participants Demographics

Code Name	Age	State	Marital Status	Employment Status	Highest level of education completed
Lizbeth	33	California	Married	Part-Time	Bachelor’s Degree
Nina	34	Tennessee	Single	Full time	High School Diploma
CyCy	40	Oklahoma	Married	Not employed	Bachelor’s Degree
Sag girl	35	Tennessee	Married	Full time	Associate Degree
Erica	30	New York	Married	Part-Time	Bachelor’s Degree
Lisha	46	Georgia	Married	Part-Time	Master’s Degree
Pat	36	Michigan	Married	Full time	Bachelor’s Degree
Swayy	27	Tennessee	Single	Part-Time	High School Diploma
Young	28	Illinois	Married	Not Employed	High School Diploma
V9	25	New York	Married	Part-Time	GED

Table 2

Participants' Children's Demographics

Code Name	Child's Sex/Gender	Child's Current Age	Age Child Diagnosed with ASD
Lizbeth	Female	12	3
Nina	Male	8	4
Cycy	Male	12	3
Sag girl	Male	5	3
Erica	Female	7	2
Lisha	Female	13	2
Pat	Female	15	2
Swayy	Male	7	3
Young	Male	5	3
V9	Male	12	6

Data Collection

The recruiting period started at the beginning of June 2022 and ended at the end of July 2022. The recruitment efforts were made by posting digital flyers on various social media pages and groups on Facebook and my professional LinkedIn profile. More than 50 potential participants expressed interest in the study, and 10 met the criteria. Participants had to self-identify as African American or Black; be the mother of an African American child with a professional/clinical diagnosis of autism spectrum disorder; their child had to be under the age of 18; the mother must be the children's primary caregiver, and the child must live with the mother; the participants must live in the rural U.S.; have access to a telephone, computer, and email; and be willing to be recorded by video/voice recorder. Data collection was conducted using open-ended, semi-structured interviews. Those who were not eligible were informed of their ineligibility for the study via email. Eligible persons were provided consent forms via email and a link to fill out the virtual demographic form via Google Forms. Ten participants completed semi-structured interviews with 17 questions established by the researcher for the data collection process. The interviews were recorded using Zoom software and a backup audio recorder. Participants could stay on or off camera once they verified their racial and gender identity. I reserved 60 minutes for each interview. The actual interviews ranged from 15 to 60 minutes based on participant data. I collected data from the demographic forms of each participant (data from Tables 1 and 2).

Data Analysis

I used open and selective coding content analysis for the generic qualitative design to identify specific codes, categories, and themes that aligned with my theoretical framework and research question. I used three different transcription software to transcribe my data: Sonix, Meetgeek, and Colibri. After each interview was transcribed, I reviewed each transcript by listening to the audio file and making necessary changes to the transcripts. I organized each transcript’s data into an Excel spreadsheet for coding and used a QDA Miner Lite to organize my codes. Below is Appendix H; I organized the interview questions and participant responses to show how I began the data analysis. After structuring the interview and questions in Appendix H in Excel, I used open and selective coding to condense the interview questions and answers to generate codes for my data analysis. I then organized the codes into categories using a QDA Miner Lite. Appendix I shows all the codes and categories of this study. Once the codes were organized into categories, I used thematic analysis to identify themes from the data presented in this chapter’s result section.

Evidence of Trustworthiness

Credibility

I used researcher reflexivity, data triangulation, and member-checking strategies to establish credibility and increase my study's trustworthiness. Throughout the process, I explored and assessed my positionality by utilizing reflexive strategies such as note-taking, journaling, and writing memos (Ravitch et al., 2016). These reflexive strategies allowed me to practice self-awareness as the researcher by identifying my connectedness to this study and considering how my biases and other personal experiences impact the study (Ravitch et al., 2016). Significant factors that I identified early in this research process include my positionality in this study, which included my gender, race, residence location, and work experiences as a provider for children with autism. My gender and race were factored in because I am an African American woman, just like each study participant. I also have lived and presently live in rural communities and have served in capacities treating children diagnosed with autism. According to Ravitch and Carl (2016), using my identified reflexive strategies ensured that I checked my biases and processed my thoughts by not making generalized assumptions regarding my data based on my experiences and perceptions of the phenomenon of interest.

Instead of providing each participant with a copy of their interview transcript to review for member checking, I planned in Chapter 3. I opted to email a summary of my interpretation of their interviews to ensure I accurately captured their answers. Each participant was asked to review my summary to confirm if my interpretations were accurate and send any corrections or identify any errors found within the summary. Every participant was given a week to confirm or share corrections. My interpretations were considered accurate if the member did not respond within a week. I also used the triangulation method using coding software (QDA Miner Lite Lite) to cross-reference my interview transcript and verify my codes for alignment.

Transferability

To ensure the transferability of this study, I took steps so that the results could be transferred into other studies in different contexts and settings and using different populations (Anney, 2014). I gave detailed, rich, and thick descriptions of this study's research setup, procedures, participants, and role as a researcher. Providing a thick description and information about this study can better allow readers and other researchers to evaluate whether my findings are transferable to their own experiences, situations, and studies (Korstjens et al., 2018; Ritchie et al., 2013). Another strategy used to help with transferability in this study was purposive sampling. Purposive sampling allowed me to focus on a specific sample that would be knowledgeable about the topic and able to answer the research question for this study effectively. As a result of this sampling strategy, participants provided more significant in-depth information that yielded much data and insight (Anney, 2014; Shenton, 2004).

Dependability

Throughout the data collecting and analysis phases, I ensured dependability by using memos to create an audit trail and member checking (Korstjens et al., 2018; Shenton, 2004). The other documents used in the audit trail include the demographic form, my reflective journal content, the interview transcripts, audio/video recordings, and an evaluation of the data analysis process (Anney, 2014; Ghrayeb et al., 2011).

Confirmability

In Chapter 3, I identified that the first issue to address confirmability entailed maintaining neutrality throughout this study as the researcher, which means that I monitored my internal dialogue, biases, beliefs, and so forth to maintain an objective stance (Ghrayeb et al., 2011; Shenton, 2004). The two strategies that I used were an audit trail and reflexive strategies such as journaling, note-taking, and writing memos (Korstjens et al., 2018; Shenton, 2004).

Results

I identified four key themes from the data collected in this study. Due to a large amount of data, I made sure to ensure that the themes aligned with the research question of this study:

> R1: What are African American mothers’ perceptions of the effectiveness of autism-related services provided to their children with autism in rural communities?

After further reviewing the wealth of data, I identified specific categories of codes (Appendix I) that answered the research question. Four overarching themes stood out for me from the data, which are compiled into Table 3, that expressed the mothers’ perceptions of the effectiveness of services provided to their children: (1) speech therapy and school are effective; (2) being black living in rural impacts the quality of care; (3)

education and research impact the quality of care; and (4) advocacy matters for children.

Table 3 shows the codes from the themes that emerged.

Table 3

Thematic Analysis: Codes Organized by Themes

Themes	**Theme 1: Speech Therapy and School Are Effective**	**Theme 2: Being Black Living in Rural Impacts Quality of Care**	**Theme 3: Education and Research Impact Quality of Care**	**Theme 4: Advocacy Matters for Children**
Codes	Speech therapy Speech therapy	Delay in diagnosis	Research	I have to fight for my child
	School interventions and support	Discrimination	Self-study	Advocacy
	The school provides multiple services	Late school placement		I am their voice
		Inaccessible services		Mothers have to gauge environments due to safety concerns for their physical and emotional well-being
		Having African American teachers and school support		

Figure 1

Codes Used for Thematic Analysis

Theme 1: Speech Therapy and School Are Effective

In my exploration to see what services the mothers found most effective and helpful in treating and supporting their children, there was a consensus on speech therapy and school support services. During the data collection phase, I asked two questions about effective services offered to each participant's autistic child.

- What services do you feel are currently most helpful in helping your child manage autism symptoms?
    - Why do you feel that these services were most helpful?
- What effective services have you used in the past that have helped your child manage their ASD symptoms?
    - Why were those services effective?
    - Why were the services discontinued?

As a frame of reference, each mother revealed that their children were nonverbal before receiving speech therapy. I found that speech therapy was the most helpful service, both presently and in the past, for the participants' children. Also, the school's special education and preschool programs were helpful in many ways for both the children and the mothers.

For example, Participant Young shared, "…I have seen that my son has been able to improve in terms of his speech. I can also see that he's able to construct a sentence. And for me, this is something that I'm actually happy about it." Lisha's daughter has been receiving speech therapy in school, and her daughter was nonverbal for seven years. She shared her perspective on speech therapy: "I kind of went in hard on the front end, and I feel like I've got the benefits on the back end. So, she's doing really well now." She shared that due to her daughter being nonverbal for so long, the tone was a big issue, and speech therapy has been beneficial.

Participants Nina, Sag Girl, Swayy, and Lisha's children currently receive school speech therapy. These mothers also shared similar experiences that their children could go to preschools with special education programs that offered multiple services to their autistic children, including services that help autistic children, such as speech therapy, occupational therapy, and behavioral therapies. Lisha mentioned that she found the other services helpful, but she also acknowledged that speech therapy helps her daughter become verbal and be able to articulate how she feels. Lisha's daughter is now a part of a debate team. Swayy shared that she liked the preschool/elementary school program her son went to because, "they kept me updated with everything…[and] gave me more information, helped me out with the information that I had to so I could use it. I can use that information to help get more resources for myself." Ms. Swayy also shared that her son's current educational therapy teacher has been resourceful because she also has an autistic son.

Theme 2: Being Black Living in Rural Impacts Quality of Care

In collecting and analyzing data, I found another theme related to how being African American or Black impacts the quality or adequacy of care the participants and their children receive, which aligns with the theoretical framework. Omi et al. (2014) introduced the term *racial project* to explain how social structures (such as discrimination or segregation) intersecting with everyday experiences shape a person's identity and experiences. When factoring our participants' experiences with being African American mothers living in the rural United States, race impacts how they perceive their children's treatment. This theme highlighted the unique experiences of being black and living in rural communities for mothers with children with autism. The questions that I asked each participant that generated the data for this theme were as follows:

- How has living in rural communities impacted your child from receiving effective services?
- How does being African American impact, your child getting the help they need to manage their autism symptoms?

In response, Young shared that she experiences discrimination with services.

> There's a little bit of discrimination…I'm saying that because there's another friend of mine. He also seeks the same services, although he's Caucasian. So, for

> them, they were able to be connected to the resources that they wanted. But for us, yeah, it was so hard for us to get linked to these services.

Pat stated,

> It took a while before he got the diagnosis. And, also I think it caused delayed services because being a person of color does not make you quite a priority when you have such serious conditions. So, you're kind of sidelined when it comes to services like you don't get like the services quickly.

Lisha shared that her child being African American has made it a "fight" to get her everything that she needs. She also expressed that if she didn't fight and advocate for her daughter, her daughter would "get left to the wayside." Nina said, "Being African American. And, this time, it prolonged the inevitable. It prolonged a lot of things that should have been left to the wayside corrected." Nina expressed that it took almost three years for her son to get diagnosed. "My son was four and a half, almost five [when he was diagnosed], but I started the process at age two."

Sag Girl stated her perception of how race impacts her son in getting the help he needs. "I feel like it impacts it a lot… I am aware of things that go on around me in my community. I am a person that looks up statistics." She expressed that her town has a larger white population, and that specific activities and resources are only accessible to white children. "I feel like we get the short end of the stick, and we've left out because our children, even though they are autistic, they put this label on them." Swayy noted,

> I definitely feel like he doesn't get all the help that he could get. I feel like they just put him on the back burner and be like, 'Oh, I'll help you later on, like, I'll

> give you I'll give you this piece of information, but I won't give you all the information.

Lizabeth said,

> I think my race cause how people view you sometimes. Maybe someone might say like, 'You are maybe less of a mom because you should have done better'…People can start blaming you for the condition, and it can be really hard on you. Because like being a black woman who's living in rural areas, we really have to go to these to see these doctors. And, sometimes, in these offices, you might even face discrimination or racism. So, it can be harder.

Three mothers, Swayy, Sag Girl, and Nina, all experienced their sons getting misdiagnosed, which they feel was due to their children's race and lack of interest in exploring deeper.

Swayy shared that her child was being treated for hearing loss and deafness. Her son was nonverbal due to autism and was found to have perfect hearing. Sag Girl stated that before her son was diagnosed with autism, he was misdiagnosed with a speech impediment and was made to learn sign language with no success. After his nurse practitioner heard of this, she recommended that her son be screened for autism. Her son can now articulate sentences and express his feelings verbally. Nina shared that her son was black, and the community she was in was not as sensitive to black children that exhibited autistic symptoms. It took about three years for him to be officially diagnosed. Her son was labeled a "problem child" in his previous school. As I mentioned earlier, once he changed schools, the staff of predominantly black educators identified that he was on the autism spectrum and structured his IEP accordingly.

CyCy and Erica shared that being African American has not impacted their children’s getting help. As I mentioned earlier, CyCy shared that having African American providers serving her child and having a supportive and understanding community has been pivotal for her child. Also, Nina expressed that her experience with having African American educators in her son’s new school has been “a blessing.” She expressed, “They reach out to me all the time,” offering interventions and resources to help her son.

As it relates to living in rural communities, every mother has expressed challenges with living in rural areas. Pat mentioned, “I can say it kind of makes us like get delayed services because of the geographical distance.” Young mentioned that she had to discontinue seeing a psychologist due to travel and expenses. Erica shared her experiences of getting services in her rural town. “It has been time-consuming and stressful.” She expressed that balancing work and keeping up with her daughter’s medication management appointments and therapy sessions are overwhelming as her daughter is taking anti-anxiety medication and a stimulant which requires frequent medication appointments. CyCy shared that receiving services takes “a lot of time.”

Lisha shared that she found an excellent preschool program for her daughter but had to travel over two counties. The school program was free for children living in that county. Since she lives in another county, she had to pay out of pocket.

> I've had to, you know, travel to get her to services needed, and most people wouldn't be able to do that… Because I didn't live in the area, I had to pay out of pocket, and so I could only afford two days a week—half a day. You know, I had to take, you know, the minimal really just to try to get something. Preschool was available in my area, but it was substandard.

Sag Girl shared, "I just feel like that we need more resources. And, with the with the resources that we do have, they're probably doing the best that they can." V9 shared how she feels about getting help for her child in her town. "I just encountered various problems. I just felt physically exhausted. And the continuous supervision of my child. Just like emotional problems, just like such as sadness, worries, and distress." Lizabeth expressed,

> For example, living in rural areas and accessing the hospitals and services, the distance is very long. And also, so there are also like few qualified specialists in the rural area, and we have to work with their schedules and appointments. But, it is a challenge getting resources. Resources are not nearby. You really have to go for long distances for them and wait and book appointments and all these things. They usually consume a lot of time and even then, candidly, your child's treatment.

A primary concern for several mothers—V9, Nina, Lisha, Pat, Sag Girl, Swayy, Lizabeth, and Young- was that rural areas need more accessible services to help with early interventions and diagnosis.

The presence of black people impacted the mothers' experiences and perceptions of the services offered to their children. One mother shared her experience with black educators in the school system. Ms. Nina, an educator, shared that at the previous school that her son went to, "they were building pretty much a case against my son" due to any behavioral issue. As a result of this issue, she transferred him to the school where her mother works. After being transferred to a new school, they could identify that Ms. Nina's son had a speech delay and "autism on the Asperger's side."

> It's a blessing...To have an atmosphere led predominantly by African American women. Just having him in those atmospheres of people who truly care about him was a prayer of mine as well. I know that sometimes the extraordinary children world and be overlooked. So, the fact that I had so many people reach out to me, even when they transitioned with new people, they had the same energy.

She expressed that "they always had my son at the forefront of their mind" by sharing tools and resources that she could do at home.

It was important to note that one participant's (CyCy) response when asked the interview question—How does being African American impact your child getting the help they need to manage their autism symptoms? CyCy shared,

> Racism is not as impactful. It's quite low because we have neighbors who are African American. And also, the services where I get the services some of them, they're specialists are also African Americans...I think that was the most positive thing because they [non-black providers] really don't know how being in another environment, how, how that can impact my kid. But, I think having the African

> American people around him is quite safer because I’ve never had a good experience with living with the other community. So, I really think having around them [black providers] that’s the best thing.

Theme 3: Education and Research Impacts Quality of Care

The third theme is connected to the mothers’ perception that education and research impact the quality of care their child receives. Due to the content of the data surrounding this theme, I found two subthemes: *self-education and research impact the quality of care,* and *community education and research impact the quality of care*.

Subtheme 1: Self-Education and Research Impacts Quality of Care.

Six mothers emphasized the importance of educating themselves and doing their research has impacted their experiences with getting the proper care for their children. Nina expressed, “I’m grateful for the struggle. I really am. It forced me as a parent to do more reading and to do more research.” She went on to say,

> Always educate yourself. Take time out and read some things outside of what the school gives you, including your rights. I think that’s more important, so you know what you’re getting into when you go to those (school Individual Educational Plan) meetings.

Sag Girl shared that when her son was first diagnosed with autism, “I was ignorant about autistic children or autism.” She shared that before her son’s first appointment with a provider, she started doing her research.

> I started reading…I got the definition from the doctor, of course. But they didn’t do any justice. But when I started reading up on [autism] and doing my own

> research on it. And, I was like, ‘Oh my God, this is my child.’ I just knew it was my child, and it was hard for me to come to grips.

She went on to express how she did more studying between and after every appointment her son had to familiarize herself with the information she received. Lisha shared that her advocacy work for her daughter was vital due to her educating herself and doing her research.

> I did the research on the front end and read every book through my rights but for and. And I knew what barriers my daughter would face like I knew if she was a behavioral problem, that would be a problem.

Subtheme 2: Community Education and Research Impacts Quality of Care.

Mrs. Young and Mrs. Pat shared that there should be more awareness about autism in the community due to the stigma and lack of information about autism. Mrs. CyCy shared that people in rural areas should be “enlightened about special people. How much they are important to us and how much they should be treated properly… It’s a good thing that you do because most of the time, people have like misconceptions about autistic kids.” Young shared that having more education on accessing resources in rural areas is crucial. Swayy stated,

> My advice would be to educate yourself. Don’t wait around to let somebody else educate you like look up, look it up. Do research yourself. That way, you get a better understanding of it for yourself. It’s best to do your research and continue doing your own research. Even with the resources and stuff, it’s better to look it all up for yourself.

When asked to share any additional information she feels is essential to this study, Lizabeth cited,

> For me, I feel like in rural areas more specifically that there is the need to have the education of people on diseases and conditions like autism. I think that it is something that people take lightly, and it’s something that is critical and serious.

CyCy also shared her observation about how people in her community responded to her son being autistic. “I think he was quite discriminated a bit by kids and adults due to being different.” Despite experiencing this, she took this as an opportunity to educate the adults about her son so they could explain autism to their children. As a result of educating the neighbor, “there’s never been a struggle about that.”

Theme 4: Advocacy Matters for Children

Advocacy matters as it relates to the mothers getting the services for their children. When asked about their experiences, most mothers said they must fight for their children and be their voice. Ms. Swayy said, “…I have to fight for him. I have to be his; I have to be his voice. I have to be his voice. I have to. I have to be that guidance for him.” Ms. Nina shared about her experiences getting her son the help he needed, “So I’m grateful for the struggle because in that struggle I had some success. it forced me to do one more and change more and really be more of an advocate when it comes to my child’s learning…”. Ms. Nina later shared about her experiences getting help in her rural city, “It made me be more vocal when it came to his choices. It really prompted me for the advocacy because I’m realizing that a lot of young black women like myself are having the same issues of finding help.”

Ms. Lisha shared,

> Everything is a fight. That’s why I have become a master at advocating. And so, I definitely feel like, you know, as an African American child, she kind of just. You know would get left to the wayside if it wasn’t for my advocacy skills even to this day, even as high functioning as she is. For example, you know, I wanted her to participate in band in middle school. and you know, she had some what I would call minor issues, you know, kind of getting adjusted. initially their immediate response was just to pull her out for the school [band]. ‘Like oh, she can’t do it.’ ‘Maybe that’s too much’, but I’m like, ‘Well, maybe not.’ You know, she’s entitled to participate in extracurricular activities.

Summary

In this chapter, I presented the results of this study, which included the themes that emerged from the data collection and data analysis processes that answered the research question of this study:

R1: What are African American mothers’ perceptions of the effectiveness of autism-related services provided to their children with autism in rural communities?

All things considered, the findings show that the participants have similar and varied perceptions about the effectiveness of the services provided to their autistic children. For instance, every mother identified speech therapy and/or school support services (which includes speech therapy and other behavioral support) to be the most effective in helping their children overcome autism symptoms. Speech therapy and school resources and services have been pivotal in helping these African American mothers see progress in their children’s lives. As I mentioned earlier in this chapter, all the children had or still have issues with the nonverbal symptoms of autism. Some mothers reported that their children can communicate and express themselves now, which helps with social interactions with peers and adults. Nina credited the school her son attended for how they helped him with his speech. She shared that her son can now verbalize when he is not feeling well. She shared that she expressed to the teachers her need for support in teaching him how to communicate when he was sick due to having issues in the past with the child getting extremely ill with severe earaches. He did not exhibit any behavioral or verbal indications that he was not feeling well. Now, he can say “ouch” and use simple sentences to express his feelings. Swayy also shared that her son’s school has been the most resourceful in providing speech therapy, educational therapy, and information about community resources. School systems have been valuable and effective in providing multiple services.

Identifying other services that the mothers shared in their interviews is essential. For example, some current services that were helpful include behavioral therapy and psychotropic medication (Pat & Erica), occupational therapy (Young, Lisha & Cycy), and physical therapy (Lisha & Lizabeth). None of the mothers identified current services that are ineffective.

I also asked participants about previous ineffective services and treatments during the interviews. One mother (Cycy) shared that she previously tried chelation therapy to remove metal from her son’s body since it was a recommended treatment. She shared that she witnessed no changes in her son’s symptoms and that the treatment was expensive. Another mother (Young) mentioned that she joined a support group that was not helpful because the shared resources either did not follow up with her or were not beneficial. Lisha shared that she was referred to a care coordination service that provided basic parenting skills training that she did not need. Nina shared that the screening service offered to her child was not a great experience due to issues with follow-ups from the provider, and it took almost three years to diagnose her son.

I also found that having African American providers and educators proved beneficial to mothers getting the support they need for their children. To get the necessary services to help their children, mothers must be advocates for their children and do their research and self-study. There was an overwhelming response from the participants that being black and living in rural areas trying to access services for their autistic children has caused issues that impacted their child's delay in diagnosis. There was a misdiagnosis for several of the children, which caused them to receive services that did not treat the symptoms caused by autism. The mothers all expressed levels of ongoing emotional distress. Even one mother cried during her interview.

In Chapter 5, I interpret this study's findings and explain the limitations. I also present recommendations and implications from the results of this study. Finally, the chapter will end with closing thoughts and a conclusion.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

This study sought to understand African American mothers' perception of the effectiveness of autism-related services for their autistic children living in rural communities in the U.S. Current research shows that African American mothers in urban areas of different socioeconomic backgrounds have been dissatisfied with services for their children with autism due to racial and cultural biases (Graves, 2017; Lovelace et al., 2018). Also, another researcher reported that living in rural areas decreases access to mental health services for African American families (Mello et al., 2016). According to Lovelace et al. (2018) and La Roche et al. (2018), African American mothers experience a unique challenge in finding effective services for their children due to racial issues. In one study, African American mothers reported experiencing racial discrimination when seeking and receiving services for their sons diagnosed with autism, negatively impacting their experiences with effective services (Lovelace et al., 2018).

In Chapter 1, I cited studies that explored African American mothers' perceptions of the effectiveness of services provided in urban locations. I found a gap in the literature related to a lack of studies exploring African American mothers' perceptions of the effectiveness of services and treatments available to their children diagnosed with an autism spectrum disorder in rural communities. I used a generic qualitative research design to address this gap to explore African American mothers' perceptions of the effectiveness of services available to their autistic children in rural communities using the racial formation theory as the theoretical lens. Four key themes emerged from my finding: (1) speech therapy and school are effective; (2) being black living in rural impacts the quality of care; (3) education and research; and (4) advocacy matters for children.

Chapter 5 provides an interpretation of the findings presented in Chapter 4. Following my interpretation of the findings, I discuss the study's limitations and recommendations for further research. I then share the implications of positive social change and my conclusion of this study.

Interpretation of the Findings

The findings of this study confirm findings from the peer-reviewed literature explained in Chapter 2. Previous data highlighted that African Americans and other people of color perceive the causes, symptoms, and treatments of autism differently due to disparities in access to treatments and education (Castillo et al., 2020; Papoudi et al., 2020). To get a deeper understanding of the participants' perceptions of services offered to their children diagnosed with autism, I utilized the racial formation theory as a lens to acknowledge how racial identity has shaped and impacted the mother's perceptions of how effective or ineffective services have been for them and their children. In this study, participants expressed how difficult it has been to access quality care for their children living in rural communities. Also, some mothers brought up the lack of education on the disorder. Researchers explored the perceptions, experiences, and needs of culturally diverse families of children with autism; the researchers confirmed that African American families' perceptions of autism are influenced by a frequently reported lack of knowledge of autism as well as experiences including social stigma and difficulties in having access to services (Pearson et al., 2020; Pearson et al., 2021; Papoudi et al., 2020).

Some researchers found that African American parents' perceptions of autism and the services used to treat the disorder differed from white parents. They did not know the symptoms of autism compared to white parents (Catillo et al., 2020; Pearson et al., 2018; Shi et al., 2021). One participant shared, "I was ignorant of autism." Another said, "A parent of an autistic child, I don't know," and she shared that teachers "don't know." Other researchers explored the experiences and perceptions of support of African American children with ASD and their families (Pearson et al., 2020; Robertson, 2016). The researchers' findings indicated two themes: (1) participants identified few facilitators to access services, and (2) both parents and healthcare providers perceived similar barriers and facilitators to early diagnoses and service access, which has implications for parents, healthcare providers, and educators (Pearson et al., 2020).

Another study examined the lived experiences and perceptions of three African American mothers with sons diagnosed with ASD, identifying prominent themes of each mother's experiences of how racial identity impacts receiving medical treatment and educational support services (Lovelace et al., (2018). In this study, I presented findings that most mothers acknowledged how race had impacted their child's treatment. So, mothers mentioned that their children were "sidelined" for treatments and "targeted" in school settings. In other research studies, each mother's experiences uncovered those covert and overt acts of racial discrimination that resulted in unfair or observable differences in how educational and medical professionals treated them and their children

(Bailey, 2018; Lovelace et al., 2018; Reed et al., 2017). Even though their circumstances differed to some degree, each mother shared similar experiences of racial discrimination as they sought help from professionals who help with autism (Griffith et al., 2021; Lovelace et al., 2018; Williams et al., 2019). In addition, each mother hesitated in admitting how race contributed to the treatment she and her son received (Donohue et al., 2019; Lee et al., 2018). In this study, one mother even hesitantly acknowledged how being black in her town impacts access to community resources. The racial formation theory drives this study by providing the foundation for understanding the perceptions of African American mothers in the multiple social contexts of being black mothers and living in rural communities.

Limitations of the Study

The small sample size and sampling strategy are limitations to the trustworthiness of this generic qualitative study, partially due to the nature of the data collection, which consists of obtaining information-rich data associated with the phenomenon of interest. The sample size and criteria for my study did not generalize to the broader population, which led to me using purposive criterion sampling to select participants for this study. Even though purposive criterion sampling allows for in-depth data and is often used in different qualitative research designs, it does not allow for a random sample like quantitative research studies.

The participant criteria also have a limitation; the participants must be African American mothers raising children with ASD in rural communities in the rural U.S. The perceptions and experiences of African American mothers living in rural communities in the U.S. with autistic children may not reflect those of parents of different ethnic or racial groups experiencing the same phenomenon. My sample is from more than one rural community, which may have helped increase the representation of African American mothers with autistic children in other geographical locations. Another limitation of this study was not including other caregivers, fathers, and guardians of African American autistic children, which may have limited the depth of data related to the phenomenon of interest.

I also factored that human error, researcher bias, and my positionality limited this study. I utilized reflexive strategies such as journaling and analytic memos during the data collection and analysis process to help minimize researcher bias and positionality. I also practiced and maintained self-awareness to not enforce or share my personal beliefs and experiences that could have influenced participants' answers. I used member checking by confirming with the participants that I captured their experiences accurately, and I consulted with my dissertation chair throughout the process. I also used data triangulation by incorporating field notes and multiple analysis triangulation to ensure credibility, trustworthiness, and quality.

Recommendations

Future Research Recommendations

This study focused on better understanding African American mothers' perceptions of the effectiveness of services offered to their autistic children living in rural communities in the United States. Since the study was done specifically with African American mothers in rural communities with biological autistic children, further research can expand to African American fathers and other guardians of autistic African American children to gain their perceptions and experiences. Another opportunity to develop this study is to explore parents' perspectives of different ethnic groups, such as Asian and Hispanic populations, residing in rural areas. I received interest from autistic African American young adults participating during the recruitment process. Receiving information from autistic African American individuals could offer valuable information as they live each day with autism and receive services directly. Understanding their perceptions of services could provide insight into what they have found to be effective or ineffective.

During the data collection process, I asked questions and received extensive data not shared in this document's results sections. Even though the findings were not presented does not mean that it was not valuable. Participants also shared treatments and services that were not as effective for their children, such as chelation therapy and some programs offered in the schools and community. The mothers also provided recommendations about what could make their child's treatment experiences more practical such as better-trained providers, more community awareness of autism, and more accessible services.

Policy Recommendations

Participants shared recommendations that would improve their experiences living in their rural communities for their children, prompting some ideas for policy-making and reform. State and local governments could create policies prioritizing education and advocacy for African American children and their families, as several participants express the need for more education about autism in their communities. Local and state leaders could assist by creating initiatives with providers and healthcare organizations to offer more training to those who provide services for children with autism so that they can be better equipped to serve them. Also, governmental leaders and healthcare organizations can use this study's data to be more intentional about having equity policies in place that provide jobs and training to African Americans professionals who work with autistic children in education and healthcare since their presence is valuable to the children and families.

The rural education system has been extremely vital to all the mothers in this study. Even with the children and mothers' support, the mothers expressed that the schools have limited resources and trained staff. Other researchers highlighted how pivotal the educational system is in the lives of children with autism. However, schools in rural communities lack adequate resources and need professional development from school staff, and children with ASD have a higher risk of not receiving federally mandated education services (Antezana et al., 2017; Azano, 2017). Due to the disparities that rural communities face in conjunction with the cultural disparities in receiving adequate services for autistic African American children, policy reform concerning funding is needed to support schools in addressing the challenges that rural schools face with serving these children.

Implications

In Chapter 1, I shared that positive social change eradicates systems of discrimination and oppression that inhibit specific groups of people from experiencing equity and freedom in all aspects of life (Yob and Brewer, 2015). Historically and presently, African American mothers represent a population that experiences multiple aspects of discrimination due to race and gender (Graves, 2017; La Roche et al., 2018). This study contributes to the growing body of advocacy research by sharing African American mothers' perspectives on what services are helping their children diagnosed with autism, specifically in rural communities. My mission and hope are that this study gives voice to the experiences of a unique demographic that is not heavily represented in autism research.

Implications of this study could be helpful in several ways for scholar-practitioners, researchers, and human service providers providing treatment and services to African American autistic children. For scholar-practitioners, researchers, and human service providers, this study potentially provides new insight and knowledge about African American mothers' perceptions of the effectiveness of available services for their autistic children within rural communities. The insight and knowledge highlight how race and geography impact the participants' perceptions. I hope this study prompts more advocacy research for African American families, children, and individuals impacted by autism to bring awareness and be a voice to this demographic by sharing their stories, perspectives, and experiences in scholarly work. Researchers documented that African Americans are still underrepresented in autism research (Shaia et al., 2020). Shaia et al. (2020) found that African American parents want to participate in autism research that includes Black families and to have researchers who share the same racial identity or are culturally responsive to their race. As the researcher of this study, some of the participants expressed gratitude about sharing their stories and having an African American researcher. In addition to prompting more research for African Americans in autism research, I hope more African American researchers contribute to autism research.

The findings could help practitioners better serve and assist rural mental health agencies and other human and social service organizations in creating changes in their organizations' structure by implementing culturally sensitive strategies and approaches to improve the effectiveness of their services. For example, several mothers mentioned that their children being African American impacts their getting services that their white counterparts get. Schools and healthcare organizations could hire and train more African American educators and providers to serve African American children. Also, practitioners and others involved in autism-related services can allot space for cultural competency training to ensure that they are meeting the needs of all clients and patients with autism. Since speech therapy and school resources and services have been effective in helping the children of the participants, the findings can prompt more research and program evaluations of these services to help improve effectiveness and address barriers such as lack of resources and traveling long distances to get services.

Conclusion

This generic qualitative study addressed the gap in the literature that explores African American mothers' perceptions of the effectiveness of services provided to their autistic children living in rural communities across the United States. In this study, my finding revealed that African American mothers found that speech therapy and school support services have been the most effective for their children as they have helped them become verbal and socially expressive. Of course, mothers have found other services effective for specific issues that their children may have faced. For example, one mom shared that their child uses medication management to address anxiety and inattention. Another found seeing a psychologist helpful in giving her and her son a space to process emotions.

I also found that mothers have found that educating themselves and doing research has been helpful in their journey of getting help for their children. In this study, mothers shared that having African American providers and educators has positively enhanced their experiences with getting help for their children. Living in rural areas significantly impacts children getting the services they need, resulting in time being taken from work, traveling, and the cost of getting assistance. Adding to the challenges that rural communities bring with limited services and adequately trained professionals, mothers acknowledged how being black had impacted their children from getting help. Mothers shared how other children are prioritized, information on resources is withheld, and they feel and see racism and discrimination.

The purpose of this study was accomplished by providing insight into African American mothers' perceptions of the effectiveness of services for their autistic children living in rural communities. I hope that this research has shed more insight into African American families' experiences and children with autism in the rural US so that positive social change occurs for not only the participants and their children but all of the children and families who need support with autism.

References

Agyemang, C., Bhopal, R., & Bruijnzeels, M. (2005). Negro, Black, Black African, African Caribbean, African American, or what? Labeling African-origin populations in the health arena in the 21st century. *Journal of Epidemiology & Community Health*, *59*(12), 1014-1018. http://dx.doi.org/10.1136/jech.2005.035964

Allen, M. (2017). *The sage encyclopedia of communication research methods* (Vols. 1-4). Thousand Oaks, CA: SAGE Publications, Inc. https://dx.doi.org/10.4135/9781483381411

Alumkal, A. W. (2004). American evangelicalism in the post-civil rights era: A racial formation theory analysis. *Sociology of Religion*, *65*(3), 195-213. https://doi.org/10.2307/3712249

Alves, F. J., De Carvalho, E. A., Aguilar, J., De Brito, L. L., & Bastos, G. S. (2020). Applied behavior analysis for the treatment of autism: A systematic review of assistive technologies. IEEE Access, 8, 118664-118672. https://doi.org/10.1109/access.2020.3005296

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing. https://psycnet.apa.org/doi/10.1176/appi.books.9780890425596

Anney, V. N. (2014). Ensuring the quality of the findings of qualitative research: Looking at trustworthiness criteria. *Journal of emerging trends in educational research and policy studies*, *5*(2), 272-281. http://jeteraps.scholarlinkresearch.com/abstractview.php?id=19.

Antezana, L., Scarpa, A., Valdespino, A., Albright, J., & Richey, J. A. (2017). Rural trends in diagnosis and services for autism spectrum disorder. *Frontiers in Psychology*, *8*, 590. https://doi.org/10.3389/fpsyg.2017.00590

Assari, S. (2018). Health disparities due to diminished return among black Americans: Public policy solutions. Social Issues and Policy Review, 12(1), 112-145. https://doi.org/10.1111/sipr.12042

Autism PDD (n.d.) Common Medications to Treat Autism. https://www.autism-pdd.net/testdump/test1049.htm

Azad, G. F., Singh, V., Kalb, L., Pinkett-Davis, M., & Landa, R. (2019). Child and family characteristics that predict autism spectrum disorder specialty clinic appointment attendance and alignment with providers. *Journal of Autism and Developmental Disorders*, *49*(8), 3060–3072. https://doi.org/10.1007/s10803-019-04027-8

Azano, A. P., & Tackett, M. E. (2017). Perceptions of teachers and parents on the educational experiences of students with autism in a remote rural community. *Rural Educator*, *38*(3), 39-54. https://doi.org/10.35608/ruraled.v38i3.219

Bailey, S. (2018). *Asperger's Syndrome in African American children*. Scholar Works. https://scholarworks.waldenu.edu/dissertations/4834

Baio, J., Wiggins, L., Christensen, D. L., Maenner, M. J., Daniels, J., Warren, Z., ... & Durkin, M. S. (2018). Prevalence of autism spectrum disorder among children aged 8 years-autism and developmental disabilities monitoring network, 11 sites, United States, 2014. *MMWR Surveillance Summaries*, *67*(6), 1. https://doi.org/10.15585/mmwr.ss6706a1

Barroso, N. E., Mendez, L., Graziano, P. A., & Bagner, D. M. (2018). Parenting stress through the lens of different clinical groups: A systematic review & meta-analysis. *Journal of abnormal child psychology*, *46*(3), 449-461. https://doi.org/10.1007/s10802-017-0313-6

Begeer, S., El Bouk, S., Boussaid, W., Terwogt, M. M., & Koot, H. M. (2009). Underdiagnosis and referral bias of autism in ethnic minorities. Journal of autism and developmental disorders, 39(1), 142. https://doi.org/10.1007/s10803-008-0611-5

Benoot, C., Hannes, K., & Bilsen, J. (2016). The use of purposeful sampling in a qualitative evidence synthesis: A worked example on sexual adjustment to a cancer trajectory. *BMC medical research methodology*, *16*(1), 21. https://doi.org/10.1186/s12874-016-0114-6

Bölte, S., Girdler, S., & Marschik, P. B. (2019). The contribution of environmental exposure to the etiology of autism spectrum disorder. *Cellular and molecular life sciences : CMLS*, *76*(7), 1275-1297. https://doi.org/10.1007/s00018-018-2988-4

Brandl, E. J., Dietrich, N., Mell, N., Winkler, J. G., Gutwinski, S., Bretz, H. J., & Schouler-Ocak, M. (2020). Attitudes towards psychopharmacology and psychotherapy in psychiatric patients with and without migration background. *BMC Psychiatry*, *20*, 1-10. https://doi.org/10.1186/s12888-020-02585-1

Brehm, B., Schill, J., Rauh, R., Fleischhaker, C., & Biscaldi, M. (2021). Preliminary Evaluation of the FETASS Training for Parents of Children with Autism Spectrum Disorder: A Pilot Study. *Frontiers in Psychology*, *12*, 1406. https://doi.org/10.3389/fpsyg.2021.604851

Broder-Fingert, S., Shui, A., Pulcini, C. D., Kurowski, D., & Perrin, J. M. (2013). Racial and ethnic differences in subspecialty service use by children with autism. *Pediatrics*, peds-2012. https://doi.org/10.1542/peds.2012-3886

Broder-Fingert, S., Walls, M., Augustyn, M., Beidas, R., Mandell, D., Wiltsey-Stirman, S., Silverstein, M, & Feinberg, E. (2018). A hybrid type I randomized effectiveness-implementation trial of patient navigation to improve access to services for children with autism spectrum disorder. *BMC Psychiatry*, *18*(1), 79. https://doi.org/10.1186/s12888-018-1661-7

Burkett, K., Morris, E., Anthony, J., Shambley-Ebron, D., & Manning-Courtney, P. (2017). Parenting African American Children with Autism: The Influence of Respect and Faith in Mother, Father, Single-, and Two-Parent Care. *Journal of Transcultural Nursing*, *28*(5), 496-504. https://doi.org/10.1177/1043659616662316

Caelli, K., Ray, L., & Mill, J. (2003). ‘Clear as mud’: toward greater clarity in generic qualitative research. *International journal of qualitative methods*, *2*(2), 1-13. https://doi.org/10.1177/160940690300200201

Carson, T. B., Palacio, A. E., Hextall, S., & Guerrero, L. A. (2021). Therapy needs for children with autism in a rural, underserved island community. *Journal of Rural*

Mental Health, *45*(2), 129. https://psycnet.apa.org/doi/10.1037/rmh0000177

Castillo, A., Cohen, S. R., Miguel, J., & Warstadt, M. F. (2020). Perceptions of causes and common beliefs of autism spectrum disorder in the US. *Research in Autism Spectrum Disorders*, *70*, 101472. https://doi.org/10.1016/j.rasd.2019.101472

Centers for Disease Control and Prevention. (2019). Treatment and Intervention Services for Autism Spectrum Disorder. https://www.cdc.gov/ncbddd/autism/treatment.html

Cheng, Y. J. (2014). Bridging Immigration Research and Racial Formation Theory to Examine Contemporary Immigrant Identities. *Sociology Compass*, *8*(6), 745-754. https://doi.org/10.1111/soc4.12164

Chepure, A. H., Somaiya, M. P., Subramanyam, A. A., & Kamath, R. K. (2018). Epileptic Encephalopathy and Autism: A Complex Interplay. *Journal of pediatric neurosciences*, *13*(2), 273-275. https://doi.org/10.4103/jpn.JPN_172_17

Coffield, C. N., Harris, J. F., Janvier, Y. M., Lopez, M., Gonzalez, N., & Jimenez, M. E. (2020). Parental Concerns of Underserved Young Children at Risk for Autism. *Journal of health care for the poor and underserved*, *31*(2), 742-755. https://doi.org/10.1353/hpu.2020.0058

Cohen, P. N. (2019). Racial formation theory. *Salem Press Encyclopedia*. https://search.ebscohost.com/login.aspx?direct=true&AuthType=shib&db=ers&AN=96397614&site=eds-live&scope=site&custid=s6527200

Cohrs, A., & Leslie, D. (2017). Depression in Parents of Children Diagnosed with Autism Spectrum Disorder: A Claims-Based Analysis. *Journal of Autism &*

Developmental Disorders, *47*(5), 1416-1422. https://doi-org.ezp.waldenulibrary.org/10.1007/s10803-017-3063-y

Crawford, C. L., & Levine-Rasky, C. (2007). Breaking Down 'Race': A Radical Retheorization of Racial Formation Theory. https://www.collectionscanada.gc.ca/obj/s4/f2/dsk3/OKQ/TC-OKQ-686.pdf

Creswell, J. W. (2013). Qualitative inquiry and research design: Choosing among five approaches (3rd Ed.). Thousand Oaks, CA: Sage. https://us.sagepub.com/en-us/nam/qualitative-inquiry-and-research-design/book246896

Darcy-Mahoney, A., Minter, B., Higgins, M., Guo, Y., Zauche, L. H., & Hirst, J. (2016). Maternal and Neonatal Birth Factors Affecting the Age of ASD Diagnosis. Newborn and infant nursing reviews : NAINR, 16(4), 340-347. https://doi.org/10.1053/j.nainr.2016.09.033

DeFilippis, M., & Wagner, K. D. (2016). Treatment of Autism Spectrum Disorder in Children and Adolescents. *Psychopharmacology Bulletin*, *46*(2), 18-41. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5044466/

Denzin, N. K., & Lincoln, Y.S. (2013). Chapter 1: Introduction: The discipline and practice of qualitative research. *In The landscape of qualitative research* (4th ed., pp. 1-44). Thousand Oaks, CA: Sage Publications. http://www.sagepub.com/sites/default/files/upm-binaries/17670_Chapter1.pdf.

Donohue, M. R., Childs, A. W., Richards, M., & Robins, D. L. (2019). Race influences parent reports of concerns about symptoms of autism spectrum disorder. *Autism: the international journal of research and practice*, *23*(1), 100-111.

https://doi.org/10.1177/1362361317722030

Doody, K. R., & Patti, A. L. (2017). Impact of rural communities-Based Event for Families of Children with Autism Spectrum Disorders. *Rural Special Education Quarterly*, *36*(3), 128-135. https://doi.org/10.1177/8756870517721899

Duan, N., Bhaumik, D. K., Palinkas, L. A., & Hoagwood, K. (2015). Optimal Design and Purposeful Sampling: Complementary Methodologies for Implementation Research. *Administration and policy in mental health*, *42*(5), 524-532. https://doi.org/10.1007/s10488-014-0596-7

Duffy, F. H., & Als, H. (2019). Autism, spectrum, or clusters? An EEG coherence study. *BMC Neurology*, *19*(1), 27. https://doi-org.ezp.waldenulibrary.org/10.1186/s12883-019-1254-1

Eissa, N., Al-Houqani, M., Sadeq, A., Ojha, S. K., Sasse, A., & Sadek, B. (2018). Current Enlightenment About Etiology and Pharmacological Treatment of Autism Spectrum Disorder. *Frontiers in neuroscience*, *12,* 304. https://doi.org/10.3389/fnins.2018.00304

Ennis, J. (2018). Rural matters: While our country relies on rural communities for everything from food to manufacturing, many rural Catholics feel like second-class citizens. *U.S. Catholic*, *83*(8), 18-22. https://search-ebscohost-com.ezp.waldenulibrary.org/login.aspx?direct=true&db=a9h&AN=130307622&site=eds-live&scope=site

Estes, A., Swain, D. M., & MacDuffie, K. E. (2019). The effects of early autism intervention on parents and family adaptive functioning. Pediatric medicine

(Hong Kong, China), 2, 21. https://doi.org/10.21037/pm.2019.05.05

Galvin, R. (2015). How Many Interviews Are Enough? Do Qualitative Interviews in Building Energy Consumption Research Produce Reliable Knowledge? Journal of Building Engineering, 1, 2-12. https://doi.org/10.1016/j.jobe.2014.12.001

Gemegah, E., Hartas, D., & Totsika, V. (2020). Public attitudes to people with ASD: contact, knowledge and ethnicity. *Advances in Autism*, *7*(3), 225-240. https://doi.org/10.1108/AIA-01-2020-0009

Ghrayeb, O., Damodaran, P., & Vohra, P. (2011). Art of triangulation: an effective assessment validation strategy. *Global Journal of Engineering Education*, *13*(3), 96-101. http://wwwwietecomau/journals/gjee/publish/vol13/07

Golash-Boza, T. (2013). Does racial formation theory lack the conceptual tools to understand racism? *Ethnic & Racial Studies*, *36*(6), 994-999. https://doi.org/10.1080/01419870.2013.767919

Goldman, S. E., Glover, C. A., Lloyd, B. P., Barton, E. E., & Mello, M. P. (2018). Effects of Parent Implemented Visual Schedule Routines for African American Children with ASD in Low-Income Home Settings. *Exceptionality*, *26*(3), 162-175. https://doi.org/10.1080/09362835.2017.1294984

Graves, L. (2017). Filters of influence: The help-seeking process of African American single mothers living in poverty seeking mental health services for their children. *Child & Youth Services*, *38*(1), 69-90. https://doi.org/10.1080/0145935X.2016.1251836

Griffith, D. M., Bergner, E. M., Fair, A. S., & Wilkins, C. H. (2021). Using Mistrust, Distrust, and Low Trust Precisely in Medical Care and Medical Research Advances Health Equity. *American journal of preventive medicine*, *60*(3), 442-445. https://doi.org/10.1016/j.amepre.2020.08.019

Hayes, S., & Watson, S. (2013). The Impact of Parenting Stress: A Meta-analysis of Studies Comparing the Experience of Parenting Stress in Parents of Children With and Without Autism Spectrum Disorder. *Journal of Autism & Developmental Disorders*, *43*(3), 629-642. https://doi.org/10.1007/s10803-012-1604-y

Hazen, E. P., & McDougle, C. J. (Eds.). (2018). *The Massachusetts General Hospital Guide to Medical Care in Patients with Autism Spectrum Disorder*. Springer. https://content.e-bookshelf.de/media/reading/L-12055688-540b927e4a.pdf

Heitzman-Powell, L. S., Buzhardt, J., Rusinko, L. C., & Miller, T. M. (2014). Formative evaluation of an ABA outreach training program for parents of children with autism in remote areas. *Focus on Autism and Other Developmental Disabilities*, *29*(1), 23-38. http://dx.doi.org/10.1177/1088357613504992

Hochman, A. (2019). Racialization: a defense of the concept. *Ethnic & Racial Studies*, *42*(8), 1245-1262. https://doi-org.ezp.waldenulibrary.org/10.1080/01419870.2018.1527937

Hong, M., Lee, S. Y., Han, J., Park, J. C., Lee, Y. J., Hwangbo, R., Chang, H., Cho, S. W., Bhang, S. Y., Kim, B., Hwang, J. W., & Bahn, G. H. (2017). Prescription Trends of Psychotropics in Children and Adolescents with Autism Based on Nationwide Health Insurance Data. *Journal of Korean medical science*, *32*(10), 1687-1693. https://doi.org/10.3346/jkms.2017.32.10.1687

Hua, C. L., Bardo, A. R., & Brown, J. S. (2018). Mistrust in physicians does not explain black-white disparities in primary care and emergency department utilization: The importance of socialization during the Jim Crow era. *Journal of the National Medical Association*, *110*(6), 540-546. https://doi.org/10.1016/j.jnma.2018.01.006 http://dx.doi.org.ezp.waldenulibrary.org/10.1016/j.jnma.2018.01.006

Jacobson, G. (2015). Racial Formation Theory and Systemic Racism in Hip-Hop Fans' Perceptions. *Sociological Forum*, *30*(3), 832-851. https://doi.org/10.1111/socf.12186

Jaiswal, J., & Halkitis, P. N. (2019). Towards a more inclusive and dynamic understanding of medical mistrust informed by science. *Behavioral Medicine*, *45*(2), 79-85. https://doi.org/10.1080/08964289.2019.1619511

Jenabi, E., Ataei, S., & Bashirian, S. (2019). Evaluation of drug interventions for the treatment of sleep disorders in children with autism spectrum disorders: a systematic review. *Korean Journal of pediatrics*, *62*(11), 405. https://doi.org/10.3345/kjp.2019.00668

Kahlke, R. M. (2014). Generic Qualitative Approaches: Pitfalls and Benefits of Methodological Mixology. *International Journal of Qualitative Methods*, *13*(1), 37-52. https://doi.org/10.1177/160940691401300119

Kennedy, B. R., Mathis, C. C., & Woods, A. K. (2007). African Americans and their distrust of the health care system: healthcare for diverse populations. *Journal of cultural diversity*, *14*(2). https://pubmed.ncbi.nlm.nih.gov/19175244/

King, N. & Brooks, J. (2018). Thematic analysis in organisational research. In *The sage handbook of qualitative business and management research methods* (pp. 219-236). SAGE Publications Ltd. https://www-doi-org.ezp.waldenulibrary.org/10.4135/9781526430236

Korstjens, I., & Moser, A. (2018). Series: Practical guidance to qualitative research. Part 4: Trustworthiness and publishing. *European Journal of General Practice, 24*(1), 120-124.

Kruger, L. G. (2017). Definition of "Rural Community." *Congressional Research Service: Report*, 17-18. https://doi.org/10.1080/13814788.2017.1375092

La Roche, M. J., Bush, H. H., & D'Angelo, E. (2018). The assessment and treatment of autism spectrum disorder: A cultural examination. *Practice Innovations, 3*(2), 107. https://psycnet.apa.org/doi/10.1037/pri0000067

Lee, M. J., Reddy, K., Chowdhury, J., Kumar, N., Clark, P. A., Ndao, P., ... & Song, S. (2018). Overcoming the legacy of mistrust: African Americans' mistrust of medical profession. https://doi.org/10.22461/jhea.1.71616

Longtin, S. E., & Principe, G. (2016). The relationship between poverty level and urban African American parents' awareness of evidence-based interventions for children with autism spectrum disorders: Preliminary data. *Focus on Autism and Other Developmental Disabilities, 31*(2), 83-91. https://doi.org/10.1177/1088357614522293

Lovelace, T. S., Robertson, R. E., & Tamayo, S. (2018). Experiences of African American Mothers of Sons with Autism Spectrum Disorder: Lessons for

Improving Service Delivery. *Education & Training in Autism & Developmental Disabilities*, *53*(1), 3. https://doi.org/10.1177/1088357614522293

Maenner, M. J., Shaw, K. A., & Baio, J. (2020). Prevalence of autism spectrum disorder among children aged 8 years—autism and developmental disabilities monitoring network, 11 sites, United States, 2016. *MMWR Surveillance Summaries*, *69*(4), 1. https://www.cdc.gov/mmwr/volumes/69/ss/ss6904a1.htm

Magaña, S., Parish, S. L., & Son, E. (2015). Have Racial and Ethnic Disparities in the Quality of Health Care Relationships Changed for Children with Developmental Disabilities and ASD? *American Journal on Intellectual and Developmental Disabilities*, *120*(6), 504-513. https://doi.org/10.1352/1944-7558-120.6.504

Malik-Soni, N., Shaker, A., Luck, H., Mullin, A. E., Wiley, R. E., Lewis, M., Fuentes, J., & Frazier, T. W. (2021). Tackling healthcare access barriers for individuals with autism from diagnosis to adulthood. Pediatric Research, 1-8. Advance online publication. https://doi.org/10.1038/s41390-021-01465-y

Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample Size in Qualitative Interview Studies: Guided by Information Power. *Qualitative health research*, *26*(13), 1753-1760. https://doi.org/10.1177/1049732315617444

Mello, M. P., Urbano, R. C., Goldman, S. E., & Hodapp, R. M. (2016). Services for children with autism spectrum disorder: Comparing rural and non-rural communities. Education and Training in Autism and Developmental Disabilities, 51(4), 355. https://www.researchgate.net/publication/312058917

Mills, A. J., Durepos, G., & Wiebe, E. (2010). Encyclopedia of case study research (Vols.

1-0). Thousand Oaks, CA: SAGE Publications, Inc. https://dx.doi.org/10.4135/9781412957397

Monz, B. U., Houghton, R., Law, K., & Loss, G. (2019). Treatment patterns in children with autism in the United States. *Autism research: official journal of the International Society for Autism Research*, *12*(3), 517-526. https://doi.org/10.1002/aur.2070

Morales-Hidalgo, P., Roigé-Castellví, J., Hernández-Martínez, C., Voltas, N., & Canals, J. (2018). Prevalence and Characteristics of Autism Spectrum Disorder Among Spanish School-Age Children. *Journal of autism and developmental disorders*, *48*(9), 3176-3190. https://doi.org/10.1007/s10803-018-3581-2

Nguyen, C. T., Krakowiak, P., Hansen, R., Hertz-Picciotto, I., & Angkustsiri, K. (2016). Sociodemographic Disparities in Intervention Service Utilization in Families of Children with Autism Spectrum Disorder. *Journal of autism and developmental disorders*, *46*(12), 3729-3738. https://doi.org/10.1007/s10803-016-2913-3

Omi, M., & Winant, H. (2014). *Racial formation in the United States*. Routledge. https://canvas.ucsd.edu/courses/19288/files/2156917/download?wrap=1

Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research. *Administration and policy in mental health*, *42*(5), 533-544. https://doi.org/10.1007/s10488-013-0528-y

Papoudi, D., Jørgensen, C. R., Guldberg, K., & Meadan, H. (2020). Perceptions, Experiences, and Needs of Parents of Culturally and Linguistically Diverse

Children with Autism: A Scoping Review. *Review Journal of Autism and Developmental Disorders*, 1-18. https://doi.org/10.1007/s40489-020-00210-1

Patton M. Q. (2002). Qualitative research and evaluation methods (3rd ed.). Sage Publications. https://aulasvirtuales.files.wordpress.com/2014/02/qualitative-research-evaluation-methods-by-michael-patton.pdf

Pearson, J. N., & Meadan, H. (2018). African American parents' perceptions of diagnosis and services for children with autism. Education and Training in Autism and Developmental Disabilities, 53(1), 17-32. https://doi.org/10.1352/1934-9556-59.2.155

Pearson, J. N., & Meadan, H. (2021). FACES: An Advocacy Intervention for African American Parents of Children with Autism. *Intellectual & Developmental Disabilities*, *59*(2), 155–171. https://doi-org.ezp.waldenulibrary.org/10.1352/1934-9556-59.2.155

Pearson, J. N., Meadan, H., Malone, K. M., & Martin, B. M. (2020). Parent and Professional Experiences Supporting African-American Children with Autism. *Journal of racial and ethnic health disparities*, *7*(2), 305-315. https://doi.org/10.1007/s40615-019-00659-9

Percy, W. H., Kostere, K., & Kostere, S. (2015). Generic qualitative research in psychology. *The Qualitative Report*, *20*(2), 76-85. https://doi.org/10.46743/2160-3715/2015.2097

Perzichilli, T. (2020). The historical roots of racial disparities in the mental health system. Counseling Today. Retrieved December 13, 2020.

https://ct.counseling.org/2020/05/thehistorical-roots-of-racial-disparities-in-the-mental-health-system/.

Picardi, A., Gigantesco, A., Tarolla, E., Stoppioni, V., Cerbo, R., Cremonte, M., Alessandri, G., Lega, I., & Nardocci, F. (2018). Parental Burden and its Correlates in Families of Children with Autism Spectrum Disorder: A Multicentre Study with Two Comparison Groups. *Clinical practice and epidemiology in mental health: CP & EMH*, *14*, 143-176. https://doi.org/10.2174/1745017901814010143

Predictive Analysis Today. (2016). Top 21 free qualitative data analysis software. http://www.predictiveanalyticstoday.com/top-freequalitative-data-analysis-software/

Ramdinmawii, & Kaur, R. (2017). A Descriptive Study to Assess the Level of Stress, Social Support and Life Satisfaction among Parents of Children with Autism Spectrum Disorder at Selected Centres in Delhi. *International Journal of Nursing Education*, *9*(2), 172-177. https://doi.org/10.5958/0974-9357.2017.00058.7

Ravitch, S. M., & Carl, N. M. (2016). *Qualitative research: Bridging the conceptual, theoretical, and methodological*. Thousand Oaks, CA: Sage Publications. https://us.sagepub.com/en-us/nam/qualitative-research/book259238

Reed, P., Howse, J., Ho, B., & Osborne, L. A. (2017). Relationship between perceived limit-setting abilities, autism spectrum disorder severity, behaviour problems, and parenting stress in mothers of children with autism spectrum disorder. *Autism*, *21*(8), 952-959. https://doi.org/10.1177/1362361316658775

Ritchie, J., Lewis, J., Nicholls, C. M., & Ormston, R. (Eds.). (2013). *Qualitative research* *practice: A guide for social science students and researchers*. Sage. http://www.sxf.uevora.pt/wp-content/uploads/2013/03/Ritchie_2003.pdf.

Robertson, R. E. (2016). Effectiveness and acceptability of parent-implemented behavior interventions for children with autism in three African American families. *Education And Training In Autism And Developmental Disabilities*, *51*(2), 107-121. https://eric.ed.gov/?id=EJ1102806

Rubin, H. J., & Rubin, I. S. (2012). Qualitative interviewing: The art of hearing data (3rd ed.). Thousand Oaks, CA: Sage. https://us.sagepub.com/en-us/nam/qualitative-interviewing/book234196

Saldana, J. (2016). The coding manual for qualitative researchers (3rd ed.). Thousand Oaks, CA: Sage. https://us.sagepub.com/en-us/nam/the-coding-manual-for-qualitative-researchers/book243616

Sanjari, M., Bahramnezhad, F., Fomani, F. K., Shoghi, M., & Cheraghi, M. A. (2014). Ethical challenges of researchers in qualitative studies: the necessity to develop a specific guideline. *Journal of medical ethics and history of medicine*, *7*. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4263394/

Schlinger, H. D., Jr. (2017). The importance of analysis in applied behavior analysis.*Behavior Analysis: Research and Practice, 17*(4), 334-346. https://doi.org/10.1037/bar0000080

Schreier, M. (2014). Qualitative content analysis. In *The SAGE handbook of qualitative data analysis* (pp. 170-183). SAGE Publications Ltd, https://www-doi-org.ezp.waldenulibrary.org/10.4135/9781446282243

Schreier, M. (2018). Sampling and generalization. In Flick, U. *The sage handbook of qualitative data collection* (pp. 84-97). 55 City Road, London: SAGE Publications Ltd https://doi.org/10.4135/9781526416070.n6

Shaia, W. E., Nichols, H. M., Dababnah, S., Campion, K., & Garbarino, N. (2020). Brief Report: Participation of Black and African-American Families in Autism Research. *Journal of Autism & Developmental Disorders*, *50*(5), 1841-1846. https://doi-org.ezp.waldenulibrary.org/10.1007/s10803-019-03926-0

Sheldrick, R. C., & Carter, A. S. (2018). State-level trends in the prevalence of Autism Spectrum Disorder (ASD) from 2000 to 2012: A reanalysis of findings from the autism and developmental disabilities network. *Journal of autism and developmental disorders*, *48*(9), 3086-3092. https://doi.org/10.1007/s10803-018-3568-z

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for information*, *22*(2), 63-75. https://doi.org/10.3233/efi-2004-22201

Shi, Y., Hunter Guevara, L. R., Dykhoff, H. J., Sangaralingham, L. R., Phelan, S., Zaccariello, M. J., & Warner, D. O. (2021). Racial Disparities in Diagnosis of Attention-Deficit/Hyperactivity Disorder in a US National Birth Cohort. *JAMA network open*, *4*(3), e210321. https://doi.org/10.1001/jamanetworkopen.2021.0321

Singh, J. S., & Bunyak, G. (2019). Autism disparities: a systematic review and meta-ethnography of qualitative research. *Qualitative health research*, *29*(6), 796-808.

https://doi.org/10.1177/1049732318808245

Speed, C. L. (2013). *Exploring the lived experiences of rural African Americans accessing mental health services* (Order No. 3602849). Available from ProQuest One Academic. (1468723270). https://www.proquest.com/dissertations-theses/exploring-lived-experiences-rural-african/docview/1468723270/se-2

Stahmer, A. C., Vejnoska, S., Iadarola, S., Straiton, D., Segovia, F. R., Luelmo, P., Morgan, E. H., Lee, H. S., Javed, A., Bronstein, B., Hochheimer, S., Cho, E., Aranbarri, A., Mandell, D., Hassrick, E. M., Smith, T., & Kasari, C. (2019). Caregiver Voices: Cross-Cultural Input on Improving Access to Autism Services. *Journal of racial and ethnic health disparities*, *6*(4), 752-773. https://doi.org/10.1007/s40615-019-00575-y

Stewart, R. (2016). *Intercultural and Career Experiences of African American Women Midlevel Leaders at Predominately White Institutions*. ScholarWorks. https://scholarworks.waldenu.edu/dissertations/2177

Strunk, J. A., Pickler, R., McCain, N. L., Ameringer, S., & Myers, B. J. (2014). Managing the health care needs of adolescents with autism spectrum disorder: The parents' experience. *Families, Systems, & Health*, *32*(3), 328. https://doi.org/10.1037/a0037180

Stubbe, D. E. (2020). Practicing cultural competence and cultural humility in the care of diverse patients. *Focus*, *18*(1), 49-51. https://doi.org/10.1176/appi.focus.20190041

Taylor, A. R. (2020). Racial Disparities in Health Care and a Move Toward Abundant

Life. *Health Progress*, *101*(3), 9-13. https://www.chausa.org/cha-we-are-called/stories/detail/racial-disparities-in-health-care-and-a-move-toward-abundant-life

Tewolde, A. I. (2019). Embracing colouredness in Cape Town: Racial formation of first-generation Eritrean refugees and asylum seekers in South Africa. *Current Sociology*, *67*(3), 419-437. https://doi-org.ezp.waldenulibrary.org/10.1177/0011392118807524

Tromans, S., Chester, V., Gemegah, E., Roberts, K., Morgan, Z., Yao, G. L., & Brugha, T. (2020). Autism identification across ethnic groups: a narrative review. *Advances in Autism*. https://doi.org/10.1108/aia-03-2020-0017

Voliovitch, Y., Leventhal, J. M., Fenick, A. M., Gupta, A. R., Feinberg, E., Hickey, E. J., Shabanova, V., & Weitzman, C. (2021). Parenting Stress and its Associated Components Prior to an Autism Spectrum Disorder (ASD) Diagnostic Evaluation. *Journal of autism and developmental disorders*, 10.1007/s10803-020-04804-w. Advance online publication. https://doi.org/10.1007/s10803-020-04804-w

Williams, T. V., Hartmann, K., Paulson, J. F., Raffaele, C. T., & Urbano, M. R. (2019). Life after an autism spectrum disorder diagnosis: A comparison of stress and coping profiles of African American and Euro-American caregivers. *Journal of autism and developmental disorders*, *49*(3), 1024-1034. https://doi.org/10.1007/s10803-018-3802-8

Williamson, L. D., & Bigman, C. A. (2018). A systematic review of medical mistrust measures. *Patient education and counseling*, *101*(10), 1786-1794. https://doi.org/10.1016/j.pec.2018.05.007

Wink, L. K., Pedapati, E. V., Horn, P. S., McDougle, C. J., & Erickson, C. A. (2017). Multiple Antipsychotic Medication Use in Autism Spectrum Disorder. *Journal of child and adolescent psychopharmacology*, *27*(1), 91–94. https://doi.org/10.1089/cap.2015.0123

Xu, G., Strathearn, L., Liu, B., O'Brien, M., Kopelman, T. G., Zhu, J., Snetselaar, L. G., & Bao, W. (2019). Prevalence and Treatment Patterns of Autism Spectrum Disorder in the United States, 2016. *JAMA pediatrics*, *173*(2), 153-159. https://doi.org/10.1001/jamapediatrics.2018.4208

Yakut Çayir, C., & Saritaş, M. T. (2017). Computer Assisted Qualitative Data Analysis: A Descriptive Content Analysis (2011-2016). *Necatibey Faculty of Education Electronic Journal of Science & Mathematics Education*, *11*(2). https://dergipark.org.tr/en/pub/balikesirnef/issue/32151/373444

Yob, I., & Brewer, P. (2015). Understanding and practicing social change in higher education. Paper under review for publication, pp. 1–35.

Appendix A: Participant Recruitment Flyer

DOCTORAL RESEARCH STUDY

AUTISM RESEARCH PARTICIPANTS NEEDED

The purpose of the study is to bring awareness of African American mothers' perceptions of the effectiveness of services available to their children diagnosed with autism spectrum disorder living in rural communities.

The study will focus on your personal journey, including the struggles and successes you have and currently experience with the services provided for your child diagnosed with Autism Spectrum Disorder. Sharing your story will provide awareness and insight into the experiences of African American mothers with children diagnosed with autism living in rural communities.

Requirements to participate in this study:

- **African American mothers with biological children diagnosed with autism.**
- **The mothers & children must live in rural U.S cities or towns.**
- **The child has to live in the same home as their mother.**
- **The mothers must identify as African American or Black (i.e., not biracial, multiracial, white).**
- **The child is identified as African American or Black (i.e., not biracial, multiracial, white).**
- **The mothers must be at least 18 years of age, and their child with autism must be under 18 years old.**

What You Will Be Asked to Do:

You will be asked to participate in a virtual interview that will last no more than 60 minutes. The interview will be recorded by a voice recorder (there will be no video recordings). The interview will be conducted at a time that is convenient to you. All information will be kept confidential and used only for the purpose of the study. This research project is part of a dissertation study conducted by Brandi Treadway a Walden University doctoral student.

Brandi Treadway, MMFT, MPhil

If you are interested, please contact Brandi by e-mail at brandi.treadway@waldenu.edu.

Appendix B: Demographic Information Form

First Name (For researcher only):	
Code Name (For Study):	
Phone:	E-mail:
Age of Participant:	Marital Status:
County you reside:	City and State you Reside:
Are you employed? Yes _______ No _______	Employment status: Full time ______ Part Time _______
Occupation	Highest level of education completed:
Are you the primary caregiver at least 50% of the time?	

Please provide some brief information about your child (ren) with autism

Child 1	Child 2
Current Age	Current Age
Age Diagnosed with ASD:	Age Diagnosed with ASD:
Sex:	Sex:
Grade/School level:	Grade/School level:

Appendix C: Consent Form

CONSENT FORM

You are invited to participate in a research study about African American mothers' perception of the effectiveness of services provided to their children diagnosed with autism. This form is part of an "informed consent" process to allow you to understand this study before deciding whether to participate.

This study seeks 15-20 volunteers who are:

- African American mothers with biological children diagnosed with autism.
- The mothers & children must live in rural U.S cities or towns.
- The child has to live in the same home as their mother.
- The mothers must identify as African American or Black (i.e., not biracial, multiracial, or white).
- The child is identified as African American or Black (i.e., not biracial, multiracial, or white).
- The mothers must be at least 18 years of age, and their children with autism must be under 18 years old.

This study is being conducted by a researcher named Brandi Treadway, a doctoral student at Walden University.

Study Purpose:
This study aims to understand African American mothers living in rural communities in the United States perceive services provided to their children diagnosed with autism.

Procedures:
This study will involve you completing the following steps:

- Fill out a demographic form (it will take about 10 minutes to complete).
- Participate in a 60-minute interview that is audio recorded, where I will ask you several questions about your experience raising a child with autism and your experiences with their services.
- Review the researcher's interpretation of your response to the interview questions and inform the researcher if her interpretations were adequate or not by email (it will take about five to 10 minutes to review).
- Possibly participate in a 30-minute follow-up interview if the researcher's interpretation of your interview answers does not reflect your answers.

Here are some sample questions:

- How old was your child when they were diagnosed with ASD?
- Who diagnosed your child with autism spectrum disorder?
- What caused you to have your child evaluated initially for autism?
- What were your initial feelings when told your child had a diagnosis of autism?

Voluntary Nature of the Study:

Research should only be done with those who freely volunteer. So, everyone involved will respect your decision to join or not.

If you decide to join the study now, you can change your mind later. You may stop at any time.

Risks and Benefits of Being in the Study:

This study could involve minor discomfort in daily life, such as sharing sensitive information. This study would pose minimal risk to your well-being with the protections in place. If you feel that you need psychological support, here are some free resources for you:

- Crisis Text Line
  Text "HELLO" to 741741
- National Suicide Prevention Lifeline
  Call 1-800-273-TALK (8255)
- **The NAMI Helpline can be reached Monday through Friday, 10 a.m. – 10 p.m., ET.**
- **1-800-950-NAMI (6264) or info@nami.org**

This study offers no direct benefits to individual volunteers. This study benefits society by sharing your unique experience as an African American mother of a child with autism living in the rural U.S. I hope that your voices educate professionals, providers, and clinicians who serve African American children and families who live with autism. Once the analysis is complete, the researcher will share the overall results by emailing you a summary.

Payment:

The researcher will email a $10 Walmart gift card to volunteers once they complete the interview.

Privacy:

The researcher is required to protect your privacy. Your identity will be kept confidential, within the limits of the law. The researcher will not use your personal information for any purposes outside of this research project. Also, the researcher will not include your name or anything else that could identify you in the study reports. If the researcher were to share this dataset with another researcher in the future, the dataset would contain no identifiers, so this would not involve another round of obtaining informed consent. Data will be kept secure by encrypted software. Data will be kept for at least five years, as the university requires.

Contacts and Questions:
You can ask questions of the researcher by email at [redacted]. If you want to talk privately about your rights as a participant or any negative parts of the study, you can call Walden University's Research Participant Advocate at 612-312-1210. Walden University's approval number for this study is **# is 02-14-22-0337846**. It expires on **February 13, 2023.**

You might wish to retain this consent form for your records. You may ask the researcher or Walden University for a copy at any time using the contact info above.

Obtaining Your Consent

If you feel you understand the study and wish to volunteer, please indicate your consent by replying to this email with the words, "I consent."

Appendix D: Interview Protocol

Introduction:

First, I want to welcome you to this study. Thank you so much for your willingness to participate in this research study. This study aims to learn about African American mothers' perceptions of services provided to their children diagnosed with an autism spectrum disorder. I am interested in hearing the voices of African American mothers living in rural U.S. The interview will last approximately 60 minutes. However, we may be done for then. After the interview, I will be examining your answers and other mothers' answers to complete data analysis. As part of my doctoral study, I will not identify your legal name in my research documents, and no one will identify you with your answers.

In order to protect your identity, I allowed each participant to give a code name to identify your responses in my study. To confirm, you gave the code name ________________________ to identify you as. Also, I need to let you know that this interview will be recorded using Zoom and a backup voice recorder so that I can convert it to a transcript. Your face does not have to be shown during the interview as I will be recording the interview for the audio. Before we begin, do you have any final questions about any items on the informed consent or regarding any other aspect of the research study or process? Finally, before we begin, I would like to share my goals and expectations for today.

First, my goal is for you to feel comfortable sharing you and your child's experiences with me today. My goal and expectation are that you answer each question honestly to your best knowledge. My goal is that your honesty and openness will provide data of this study to shed light on the thoughts and experiences of African American mothers living in rural communities and caring for their children diagnosed with autism. Also, during the interview, I will be asking you several questions. Please feel free to stop and ask me to repeat or clarify any questions I ask. I will also be doing my best to make sure I understand your answers correctly. If you do not think I have something right, please let me know.

Finally, I hope you will remember that there are no right or wrong answers to the questions. I hope for your honest answers and responses and not what you think the correct answer might be. Please know that you can choose to stop this interview at any time. Are you ready to begin?

Interview Questions

- How old was your child when they were diagnosed with ASD?
- Who diagnosed your child with autism spectrum disorder?
- What caused you to have your child evaluated initially for autism?
- What were your initial feelings when told your child had a diagnosis of autism?
- What were your initial thoughts about hearing that your child was diagnosed with autism?
- What services did the clinician recommend when your child was diagnosed with autism?
- What were follow-up referrals scheduled for your child after they were diagnosed with autism?
- What services is your child currently receiving to help with ASD symptoms?
- What services do you feel are currently most helpful in helping your child manage autism symptoms?
    a. Why do you feel that these services were most helpful?
- What services do you feel are currently the least helpful in helping your child manage autism symptoms?
    a. Why do you feel that these services were least helpful?
- How has living in rural communities impacted your child from receiving effective services?

- What effective services have you used in the past that have to help your child manage their ASD symptoms?

    a. Why were those services effective?
    b. Why were the services discontinued?

- What services were ineffective in the past in helping your child manage their ASD symptoms?
    a. Why were they not effective?
    b. Why were the services discontinued?
- How does being African American impact your child getting the help they need to manage their autism symptoms?
- Are there other resources that you have found helpful with supporting your child? If so, what are they?
- What do you feel would help improve services for African American children living in rural communities?
- Is there anything else you feel may be helpful in sharing for this study?

Wrap Up

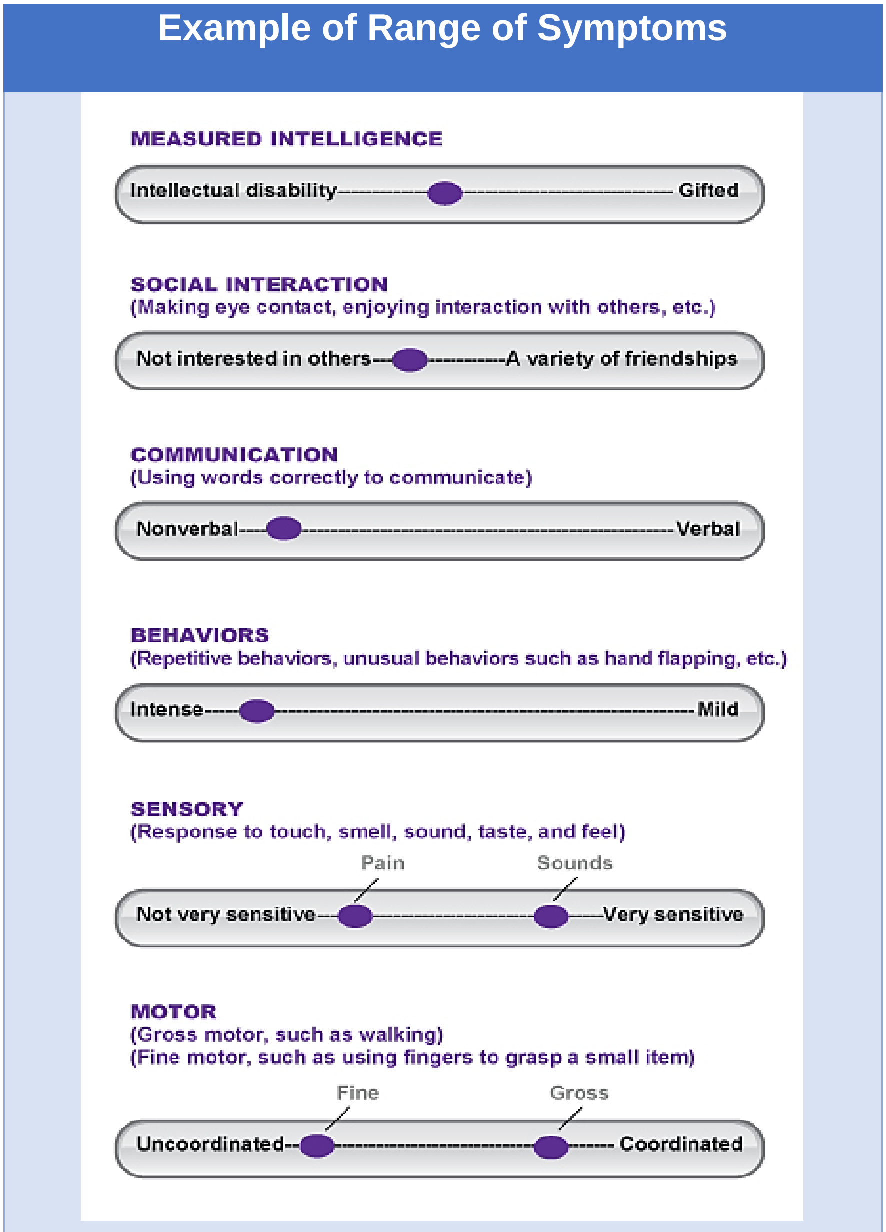
1. Thank you for your answers and for taking the time to meet with me today.
2. Do you have anything else you would like to add or that you feel you should clarify before we finish today?
3. Do you have any final questions for me?

4. Thank you so much for your time. I will be in touch to provide you with a summary of my interpretations of your answers by email.
5. Once you receive my emailed summary of my interpretations, you can respond to me by email, letting me know if my summary was accurate or not. If you do not respond to my email in a week, I will assume that my summary was accurate.
6. If you let me know that my interpretations do not reflect your answers, I will contact you by email to schedule a follow-up time to speak by phone or Zoom for a brief follow-up interview that will take no longer than 30 minutes.
7. Please remember that my contact information is on the consent form if you wish to contact me.
8. I will email you your gift card today by the email you provided me. Will that work for you?
9. Again thank you, and I appreciate your help. Goodbye!

Appendix E: DSM-5 Autism Diagnostic Five Criteria

DSM-5 Autism Diagnostic Five Criteria
Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history.
Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history
Symptoms must be present in the early developmental period (but may not fully manifest until social demands exceed limited capacities or may be masked by learned strategies later in life).
Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.
These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below expected for the general developmental level.

Appendix F: Example of Range of Symptoms



(CDC, 2019)

Appendix G: Severity levels for autism spectrum disorder

Severity level	Social communication	Restricted, repetitive behaviors
Level 3 **"Requiring very substantial support."**	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited social interaction initiation, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only straightforward social approaches	The inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres—great distress/difficulty changing focus or action.
Level 2 **"Requiring substantial support."**	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, has markedly odd nonverbal communication.	The inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be evident to the casual observer and interfere with functioning in various contexts. Distress and/or difficulty changing focus or action.
Level 1 **"Requiring support."**	Without supports in place, deficits in social communication cause noticeable impairments. Exhibits difficulty initiating social interactions and clear examples of atypical or unsuccessful responses to social overtures of others. They may appear to have decreased interest in social interactions. For example, a person who can speak in complete sentences and engages in communication but whose to-and-fro conversation with others fails and whose attempts to make friends are odd and typically unsuccessful.	The inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning.

Appendix H: Interview Questions and Participant Answers

1. How old was your child when they were diagnosed with ASD?	
Participants	Answers
Pat	2
Young	3
Erica	3
Cycy	2
Lisha	2
Nina	4
Sag Girl	3
Swayy	2
V9	6
Lizabeth	3
2. Who diagnosed your child with autism spectrum disorder?	
Participants	Answers
Pat	A doctor
Young	pediatrician
Erica	general doctor
Cycy	pediatrician
Lisha	A developmental pediatrician
Nina	nurse practitioner
Sag Girl	pediatrician
Swayy	a testing center for exceptional children
V9	doctor
Lizabeth	pediatrician
3. What caused you to have your child evaluated initially for autism?	
Participants	Answers
Pat	• she was not able to talk properly like other two-year-old kids.
	• she was not playing with other kids
Young	• I felt like my child wasn't hitting the milestones.
	• poor eye contact
	• meltdowns
Erica	• random checkup
	• unresponsive to name
	• Didn't act like "normal" child her age
Cycy	• developmental delays
	• not talking, not meeting some of her developmental milestones.

Lisha	• She experienced developmental delays
	• not talking
	• not meeting some of her developmental milestones.
Nina	• He wasn't talking or socially engaging
	• He wasn't meeting developmental milestones
Sag Girl	• my child was not speaking (nonverbal)
Swayy	• issues with hearing and not responsive to social cues
V9	• developmental delays
	• not talking
Lizabeth	• child was having unusual behaviors
	• loved ones mentioned that child should be check
4. What were your initial feelings when told your child had a diagnosis of autism?	
Participants	Answers
Pat	I was shocked
Young	fear
Erica	stressed
Cycy	worried, I didn't know what to do, shocked. For a moment I just panicked
Lisha	I had kind of suspected it, so I wasn't surprised
Nina	Judgment of self
Sag Girl	I've felt like a failure. I felt defeated and still I have days where I feel defeated.
Swayy	overwhelmed and confused
V9	heartbroken, I don't understand myself, seriously
Lizabeth	• feeling sadness.
	• I was also feeling guilty blaming myself I felt like I had not done my best.
5. What were your initial thoughts about hearing that your child was diagnosed with autism?	
Participants	Answers
Pat	• I had never experienced this before
	• I didn't know how to take care of my child.
	• I couldn't pinpoint anything I did wrong.
	• I questioned maybe the pregnancy or taking care of the baby caused it.
Young	• concerned about his future
	• stigmatization that comes with parents who actually have children with autism
	• he might not be able to live like his full life and a happy
	• I haven't been around any other child who has autism
Erica	• I wasn't familiar with word autism
	• Is it deadly?
Cycy	• How I'm going to handle everything about it?
	• I was actually thinking about his life

	• how he's going to cope with everything because he's different
	• I was thinking about the future of my kid
Lisha	what's the next step?
Nina	Where did I go wrong?
Sag Girl	• What could I have done to prevent this?
	• Ignorance about autism
Swayy	Never heard of a child diagnosed with autism around here in our area
V9	• will my child ever be normal
	• just thinking I was not even thinking straight then.
Lizabeth	I was scared for my child's growth.
6. What services did the clinician recommend when your child was diagnosed with autism?	
Participants	Answers
Pat	speech therapy
Young	speech therapy
	special education program at school age
Erica	therapy sessions
Cycy	• Speech & language therapy
	• she told me to monitor my child
Lisha	• Speech therapy occupational therapy.
	• Immediately early intervention services.
Nina	• screening through a program provided by a school system
	• networking pod for extraordinary kids through school.
	• recommendation was, I think he needs to repeat preschool and change his school environment
Sag Girl	referred to neurologist
Swayy	Never got a recommendation.
V9	supervising him, monitor, just keep an eye to the child
Lizabeth	speech therapy
7. What were follow-up referrals scheduled for your child after they were diagnosed with autism?	
Participants	Answers
Pat	I had to do that by myself
Young	No follow up scheduled just recommendations
Erica	no
Cycy	No, I took him to the clinic with us a speech therapist
Lisha	• No, no, the pediatrician did not do that.
	• I would say they have recommendations, but it wasn't feasible for me to access those services because of how far they were.
Nina	none
Sag Girl	• referred to neurologist

	• mom did research while waiting for appointment
Swayy	• they never scheduled him an appointment
	• never recommended one.
	• do it yourself after you leave your doctor's office type of thing
	• they don't give you no resources
	• they don't give you much information about it once they diagnosed basically
	• look it up yourself type
V9	No
Lizabeth	No. Mom was responsible for seeking speech therapy
8. What services is your child currently receiving to help with ASD symptoms?	
Participants	Answers
Pat	behavioral therapy and also some medication.
Young	currently my child is undergoing this speech language therapy and also the occupational therapy
Erica	behavioral therapy anti-anxiety medication and stimulant
Cycy	• has an education plan in that school whereby it was specialized for kids who are special
	• school therapy
	• occupational therapy
Lisha	• A school geared towards special needs kids and in addition to speech therapy, they kind of did everything else
	• Speech therapy still at school.
	• Occupational therapy
	• physical therapy.
Nina	Behavioral interventions with rewards
Sag Girl	School special education program
Swayy	• school • speech therapy
	• educational therapy
V9	Mom led interventions, I just have to be predictable, like, when talking to him and. I directly teach him social skills.
Lizabeth	• physical therapist
	• speech therapist
	• psychiatrist
9. What services do you feel are currently most helpful in helping your child manage autism symptoms?	
Participants	Answers
Pat	behavioral because she's also able to put into action some social skills so that she can go to interact with others.

Young	speech therapy has really helped my son
Erica	behavioral therapy anti-anxiety medication and stimulant
Cycy	school therapy and occupational therapy
Lisha	speech therapy at school and special education program
Nina	Current school atmosphere
Sag Girl	speech therapy at school and special education program
Swayy	educational therapy
V9	supervision, social skills, eye contact
Lizabeth	none
9a. Why do you feel that these services were most helpful?	
Participants	Answers
Pat	he's able to construct even a sentence
Young	School therapy helped in coping up and understanding everything about themselves.
Erica	They have helped my child improve
Cycy	speech therapy helped build his confidence
Lisha	• I think helping her with tone.
	• Just because she was nonverbal. That's a big issue with her. You know, for seven years.
Nina	• SPED coach's help with reading skills
	• School environment predominantly African American women. just having them in those atmospheres of people who truly care about
Sag Girl	Special ed program:
	• Speech therapy
	• sensory interventions
	• behavioral therapy
	• special curricular activities
Swayy	• educational therapy teacher is resourceful due to having an autistic child
	• He's more verbal and can communicate
V9	supervision, social skills, eye contact
Lizabeth	speech is the most important because express himself clearly
10. What services do you feel are currently the least helpful in helping your child manage autism symptoms?	
Participants	Answers
Pat	none
Young	school support
Erica	No, not at the moment
Cycy	none
Lisha	none
Nina	none

Sag Girl	none
Swayy	none
V9	none
Lizabeth	none
10a. Why do you feel that these services were least helpful?	
Participants	Answers
Pat	n/a
Young	due to bullying issues
Erica	n/a
Cycy	n/a
Lisha	n/a
Nina	n/a
Sag Girl	n/a
Swayy	n/a
V9	n/a
Lizabeth	n/a
11. How has living in a rural community impacted your child from receiving effective services?	
Participants	Answers
Pat	• delayed services because of the geographical distance
	• when you get diagnosis you have to like do they follow up on your own
Young	• More accessible interventional services
	• More accessible resources
Erica	• time consuming and stressful
	• balancing work and sessions due to distance
	• keep up with the session we have and the medications
Cycy	• time receiving those services.
	• I think he was quite discriminated a bit by kids and adult due to being different
	• Struggling because sometime there's a time I used to go get services outside the town outside the place because the services here before parents weren't good at time.
Lisha	• Because I didn't live in the area, I had to pay out of pocket and so I could only afford two days a week. Half a day.
	• I paid on my own and traveled out so
	• I would have to travel to that area, stay there, you know, kind of in the area, and tell, you know, while she did preschool for a couple of hours, and you know didn't make financial sense to come back and forth.
	• Accessing the services, it's just not available in my community.
Nina	It made me research more and know my rights because there wasn't much for my child.

Sag Girl	-From getting on the list for him to get extra therapy like I'm still waiting on, I'm on the waiting list now like I lost a whole year because I didn't know if people are too afraid of being judged and speaking on it.
	-It seemed like they would have a safe place for them to play your, you know, for artistic children I know they're having in Nashville, but we live in Covington and there's so many children people because even when I speak on my experience, like.
	-I like when he was diagnosed that's all like I lost a year. they have you on the waiting list and I'm still on the waiting list and I don't even know what this service. Y'all give me this paper and say do this and I'm left alone during.
Swayy	-Never heard nobody child diagnosed with autism around here in our area
	-doctors don't really know a lot
	-It's not many really good resources, school limited resources,
	-They haven't really dealt with a lot of kids with autism , it's hard getting the resources that you really need
V9	-lack of support and advice
	-the distance is very long, few qualified specialists
	- we have to work with their schedules, lack of close resource
Lizabeth	-the distance is very long
	-few qualified specialists
	-we have to work with their schedules
	-lack of close resource
12. What effective services have you used in the past that have to help your child manage their ASD symptoms?	
Participants	Answers
Pat	speech and behavioral therapy
Young	a psychologist
Erica	• Child has been using services since being diagnosed.
	• behavioral therapy anti-anxiety medication and stimulant
Cycy	• Child has been using services since being diagnosed.
	• speech therapy and occupational therapy through school
Lisha	• I feel like occupational therapy was helpful.
	• Speech therapy was helpful.
	• Aquatic therapy is something we did.
Nina	n/a
Sag Girl	Special education school program which is one of the best schools for autistic children
Swayy	special education program at a local school
V9	therapy and counseling Together.
Lizabeth	therapy (talk therapy)
12a. Why were those services effective?	
Participants	Answers

Pat	They helped child speak and become more socially engaged
Young	So, like the psychologist did a good job in trying to explain things to my child and trying to like access in terms of his mental health and that has really helped us as a family.
Erica	They have helped my child improve
Cycy	School therapy helped in coping up and understanding everything about themselves. occupational therapy, which is quite helping so much. speech therapy helped build his confidence
Lisha	• I felt like those were super helpful
	• I could, you know incorporate that at home and I found that to be most helpful.
	• You know she was you using different interventions and tools.
Nina	n/a
Sag Girl	• Preschool was great…he could verbalize feelings and identify people
	• environment was structured
Swayy	• environment was structured
	• Provided mom with tools to implement at home
	• great with communicating with mom
V9	Therapy and counseling (talk therapy) help mom with communicating with child and help child understand more about himself
Lizabeth	therapy (talk therapy) to help mom with communicating with child-discontinued due to feeling tired due to frequency and distance
12b. Why were the services discontinued?	
Participants	Answers
Pat	due to distance for treatment
Young	a little bit expensive and things actually got so hard, especially with the pandemic.
Erica	n/a
Cycy	n/a
Lisha	discontinued because she aged out of the preschool
Nina	n/a
Sag Girl	He aged out of the school system
Swayy	He aged out of the school system
V9	discontinued due to feeling tired due to frequency and distance
Lizabeth	discontinued due to feeling tired due to frequency and distance
13. What services were ineffective in the past in helping your child manage their ASD symptoms?	
Participants	Answers
Pat	none
Young	support groups
Erica	n/a
Cycy	Chelation therapy
Lisha	casework coordination services
Nina	Screening program

Sag Girl	Speech therapy was not helpful because they are only the service that I was getting.
Swayy	school support- IEP meetings and he with the TEIS program like every two weeks.
V9	none
Lizabeth	none
13a. Why were they not effective?	
Participants	Answers
Pat	n/a
Young	the resources provided were not helpful or didn't respond when she reached out for help they simply told me that I should just go back home and they're going to call me and that was it, and I've never had from them again.
Erica	n/a
Cycy	I didn't feel like it was so much necessary because it's quite OK. It's quite expensive and it's. There wasn't so much change in him.
Lisha	I feel like it's basic parenting.
	Didn't need support for basic parenting skills.
Nina	The resources weren't useful, and they took forever to follow up with mom. It took 3 years for the child to be diagnosed with autism
Sag Girl	They were only dealing with children with speech impediment, I believe because they did not know my son was autistic, so they were only trying, and they were trying to tell me teaching sign language.
Swayy	these were not effective as the child did not respond well to services
V9	n/a
Lizabeth	n/a
13b. Why were the services discontinued?	
Participants	Answers
Pat	n/a
Young	No response from resources
Erica	n/a
Cycy	I didn't feel like it was so much necessary because it's quite OK. It's quite expensive and it's. There wasn't so much change in him.
Lisha	Didn't need support for basic parenting skills.
Nina	n/a
Sag Girl	n/a
Swayy	these were not effective as the child did not respond well to services
V9	n/a
Lizabeth	n/a
14. How does being African American impact your child getting the help they need to manage their autism symptoms?	
Participants	Answers
Pat	• it took a while before he got the diagnosis

	- delayed services because being a person of color does not make you quite a priority when you like such a series conditions.
	- sidelined when it comes to services
Young	- discrimination
	- another Caucasian friend of mine connected to the resources that they wanted. But for us, yeah, it was so hard for the interaction linked to these
Erica	we really don't have a problem being an African American.
Cycy	- Racism is not as impactful
	- It's quite low because we have like neighbors, also African American and also the services where I get the services.
	- Also, some of them, some of them, they're specialists are also African Americans.
Lisha	- Everything is a fight that's have become a master at advocating, and so I definitely feel like, you know, as an African American child, she kind of just.
	- You know would get left to the wayside if it wasn't for my advocacy skills even to this day, even as high functioning as she is.
	- For the most part, my daughter is not, you know, displaying those type of behavior, but I have seen the people who've gotten pigeonholed because of that.
Nina	- when it comes to our children is so stagnant and slow but so is our little chocolate of kids over here, our little black boys especially.
	- late placement in new school
	- have kids from out of the country getting more benefits than our kids
Sag Girl	- In our in our community, we don't know about it, and sometimes children are misdiagnosed because they you know they have seen it.
	- You know, black kids are being misdiagnosed or they just kind of push it away.
	- Undisclosed town population as in blacks and white is more white dominant. African Americans--we are here and its nothing here for our child. Not even to take to the playground not to even have a place play.
	- I feel like we get the short end of the stick
	- And, we're left out because our children even though they are autistic, they put this label on them. And it's because he's an African American male.
Swayy	- They give you a piece of the information, They don't actually just help you.
	- They're not going to give you the straight answers
V9	lack of support and advice
Lizabeth	Feel judged, blamed for not "doing better", blame for autism, feels discrimination or racism
15. Are there other resources that you have found helpful with supporting your child? If so, what are they?	
Participants	Answers
Pat	- I can say I've been doing a lot of reading on autism and how to manage it and how to take your off.

	- I also joined a support group on Facebook where we share experiences and help each other with um, ways to be of more help to people who are artistic in our families.
Young	It's the specialist (speech therapist). He's not just a specialist to us. I can say he has become family because he's a friend, and he has been able to help us to provide free services in the home.
Erica	mother to child moment we spend together
Cycy	Community support group
Lisha	- Did the research on the front and read every book through my rights but for and.
	- YouTube channels and groups on Facebook where adults with autism. I found this one with this African American lady that I wowed me and so they can, you know, verbalize and she's talking about like how she felt when she was younger, how she was married. What I found
	- my friends who have special needs kids is.
Nina	- Behavioral interventions with rewards
	- Music therapy. He loves art
	- Put him in atmospheres that allows him to be himself has been the biggest help more
Sag Girl	I connect without my kid's teacher she's. She's great.
Swayy	educational therapy teacher is resourceful due to having an autistic child
V9	there's no resources
Lizabeth	Like I usually try to engage him in activities, narrative activities and also in educational activities for him to learn
16. What do you feel would help improve services for African American children living in rural communities?	
Participants	Answers
Pat	- I think we should probably create awareness what of autism is
	- remote services
Young	- More accessible interventional services
	- More accessible resources
Erica	- openness of medical services.
	- open-minded rule
	- help us so we would not feel kind of intimidated.
Cycy	I really feel like they should build more hospitals specific for children with special needs because.
Lisha	You know, diagnosing earlier you know getting that you know getting those markers early, getting intervene, early intervention.
Nina	- always educate
	- yourself advocacy
Sag Girl	- I just feel like that we need more resources.

	• school needs more support to support autistic children
Swayy	It's best to do to do your research and continue doing your own research.
V9	• more support
	• build like hospitals in the rural areas with adequate personnel , easier for people to access these services, early interventions and proper people will take proper interventions to it, employ the qualified people,
Lizabeth	• Education of people on diseases like conditions like autism; people take lightly and it's something that it's critical and serious.
	• education because it's so important
17. Is there anything else you feel may be helpful in sharing for this study?	
Participants	Answers
Pat	n/a
Young	• my experience has been physically and emotionally exhausting
	• parents need to be educated on autism
	• Stigma with autistic black children
Erica	Autism is not a death sentence for your child
Cycy	• There have been challenges as child ages
	• my kid is already 12. He's in his puberty stage.
	• It's a really hectic, recently because sometimes he may get an emotional outburst
	• So, it's kind of challenging because I think this is the time where he's like developing… knowing his body and stuff, you know.
	• He's got anxiety issues. So, he's got some medication for anxiety.
Lisha	• Teach these kids with autism social skills you know so that as they start to get older, you know they're able to make friends and make connections and things like that.
	• They tend to be loners, and by the time we realize they're, you know.
Nina	• parents need to be more educated on what an IEP is before going into a meeting
	• then, of course, always educate yourself. Take time out, read some things outside of what the school gives you, including your rights. I think that's more important so you know what you're getting into when you go to those (IEP) meetings.
	• I'd say, it (parenting) made me do more digging on my own. It made me be more vocal when it came to his choices. It really prompted me for the advocacy because I'm realizing that a lot of young black women like myself are having the same issues of finding help.
Sag Girl	• Sometimes it feels like it's just too much, but once I go breathe and come back, I'm straight.
	• When it comes to family like and not because they want to be the least helpful, you we're so ignorant to the fact we just don't know.
	• I feel defeated and still I have days where I feel defeated.

	• I have to check the atmosphere. Like you know, a lot of kids, because even when he's trying to play in his way, they feel like he's being aggressive for because he's not speaking the words and they trying to speak to him because they see his big boy.
Swayy	• You have to do your own research.
	• help yourself. educate yourself so that you can try to help educate others
	• It's a tough journey. I have to fight for him. I have to be his voice. Guidance for him. very hard learning process.
V9	I just want them to have faith and know that their child is not and is never an isolated one. You keep on loving the child and give them the support they need and never feel. Make them feel as if they are not a human and understand.
Lizabeth	Education of people on diseases like conditions like autism; people take lightly and it's something that it's critical and serious. education because it's so important

Appendix I: Categories and Codes

Categories	Codes
Age Diagnosed	2 3
Clinician who Diagnosed Child	Doctor Nurse practitioner Pediatrician
Symptoms	Meltdowns Not reaching developmental milestones Not socially engaging with peers and adults Not speaking/nonverbal Poor eye contact
Initial Feelings	Fear Heartbroken Self-judgment Shame Shock Worried
Initial Thoughts	Concerned about child's future Did I do something wrong? I don't know about autism Will my child have a normal life?
Clinicians' Most Recommended Services	Speech therapy
Did Clinicians schedule follow-ups	No Moms had to schedule follow-up appointment
Impact of Race on Receiving Effective Services	Delay in diagnosis Discrimination Late school placement Later diagnosis Misdiagnosis Mother advocates Sidelined
Current Effective Services	Behavioral therapy Speech therapy School interventions and support Occupational therapy
Impact of Current Effective Services	Children are verbal Improved social skills School provides multiple services School supports helps mothers
Least Current Effective Services	Overall, none Two said some school program

Past Effective Services	Behavioral therapy Occupational therapy Pre-school programs Psychologist/psychotherapy Speech therapy
Past Effective Services Impact	Easy to use interventions at home Effective because improvements in child's symptoms Helped child be more engaged Helped child express themselves Helped child speak
Past Effective Services Discontinued	Child aged out of preschool program Cost Distance
Past Ineffective Services	Chelation therapy Some community resources Some school resources None
Impact Past Ineffective Services	No benefit Lack of follow through Doesn't meet needs due to child being misdiagnosed
Impact of Living in Rural Communities	Delay in services Delay in treatment Distance issues Expensive Inaccessible services Lack of community resources Long travel times Poor work-life balance Stressful Struggle Time consuming Travel Wait lists
Helpful Resources	Facebook support groups Having African American providers Having African American teachers and school support Research Self-study Teachers
Ways to improve services	Do your own research Educate others Educate yourself I have to fight for my child I have to be their voice

	Mothers have to gauge environments due to safety concerns for their physical and emotional well-being Social skills are necessary Stigma with autistic children There are specific concerns raising children at puberty age