

EXAMINING THE LIVED EXPERIENCES OF AFRICAN AMERICAN AND SOUTH ASIAN PARENTS OF CHILDREN WITH DISABILITIES

by

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ABSTRACT

This study aimed to understand the lived experiences of African American and Asian Indian parents of children with disabilities in North Carolina. Using qualitative research, interviews were conducted online via Zoom to understand their experiences taking care of their children with disabilities. Parents had to be either African American or Asian Indian living in North Carolina with a child between the ages of 5-8 with a diagnosed disability to participate in the study. All participants were African American parents from eight North Carolina counties. Eight participants were female, and four were male. Their ages ranged between 25-33 years. The data were analyzed using content analysis, which revealed four major themes with subthemes. The four themes were (1) Lived Experiences as an African American Parent, (2) The Frustrations of Barriers, and (3) Much Needed Familial and Systematic Support. Implications and directions for future research are provided at the end.

Keywords: African American, Asian Indian, children, disabilities, ecological theory, minority stress theory

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CHAPTER 1: INTRODUCTION

Children are often overlooked when it comes to developmental disabilities worldwide (WHO, 2019). The acknowledgment of developmental disabilities has improved over the years; however, many individuals worldwide continue to experience a lack of recognition, services, and proper care. As with many adults, children should have access to resources, services, and assistance to accommodate their developmental disability. The Global Burden of Disease study of 2019 indicated the number of children and adolescents with a health condition associated with a developmental disability is 316.8 million (WHO, 2019). In terms of the statistics of children, "Overall, in the GBD study, the prevalence of these conditions ranged from 7.5% among children under 5 years to 13.9% for those aged 15–19 years" (WHO, 2019, p. 3). Globally, many kids have been recognized as having a disability. Unfortunately, children with disabilities are often bypassed and excluded. According to WHO,

"Children with disabilities, including those with developmental disabilities, are among the most excluded, discriminated against and unseen members of society, often experiencing a violation of their human rights, such as separation from their families, harsh punishment, abuse, harmful treatment and institutionalization" (WHO, 2019, p. 4).

Worldwide, parents of children with disabilities experience distinct challenges given their ethnic and cultural background (WHO, 2019). However, what is often overlooked is the rights children also have regarding their health and care. Globally, children with disabilities are common, but the rights of children are not recognized in all global communities.

The United Nations Convention on the Rights of the Child (UNCRC) maintains the rights of children with and without a disability. Article 23 of the (UNCRC), acknowledges disabled children should enjoy a full life, and every child should have access to special care, and

resources, also allowing parents to have access to financial resources. In other words, parents or guardians should be able to access resources and services for their child with a disability. Parents and caregivers are usually the ones caring for and have the most responsibilities for their children with a disability. According to Article 18 in the Convention on the Rights of Persons with Disabilities (CRPD), "Children with disabilities shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and, as far as possible, the right to know and be cared for by their parents" (United Nations). Such rights should be implemented. Though children are the ones with physical and intellectual developmental disabilities in this case, caregivers are the ones who too often experience obstacles in appropriately caring for their children in medical and educational settings. In the United States, the Individuals with Disabilities Education Act (IDEA) ensures children should be able to receive public education for children with special education and equivalent services (U.S. Department of Education, 1975). Under the IDEA Act Part C, birth to age two children with disabilities should receive early intervention services, while children 3- 21 years old receive special education services (U.S. Department of Education, 1975). Despite laws and policies ensuring children can receive services, and accommodations, and have rights; parents have had different experiences in accessing services and caring for their children.

Having understood children disability rates from a global perspective, it is essential to understand child disability rates in the United States. According to the U.S Census, "The percentage of children with a disability in the United States increased between 2008 and 2019, from 3.9 percent to 4.3 percent," which describes any disability of children between the ages 0-17 (Young, 2021, p. 2). It is also crucial to understand disability rates by ethnicity. The CDC has determined "Black children (2.82%) were more likely to be diagnosed with an intellectual

disability than Hispanic (1.77%), White (1.76%), and Asian (0.72%) children" (Zablotsky et al., 2023). Specifically, in North Carolina, the number of children under 18 with disabilities is 2,290 children, with children with any disability at 4.4 percent (Young, p. 13, 2021). Like other families, parents of children with disabilities often encounter barriers, discrimination, stigmatization, and challenges in caring for their child.

In terms of the current study, children with a disability should have a clear diagnosis of a developmental disability. Disabilities could fall under these categories; development delay, autism, ADHD, cerebral palsy, language and learning disorders, visually challenged or deaf. Further, children need to be between the ages of 5-8 years, which matches one of the diagnostic criteria stated above and are currently enrolled in the NC school system.

The main purpose of the study is to examine closely the lived experiences of Asian Indian and African American parents who have a child with a disability. Specifically, we are examining Asian Indian and African American families' experiences as parents of an ethnic minority group and having a child with a disability, as well as understanding the barriers and challenges experienced in their journey as a parent and the support as a parent for themselves and their own child. Research on this topic is sparse and much needed.

CHAPTER 2: LITERATURE REVIEW

Asian Indian Families

Several research studies have looked at the lived experiences of Asian Indian families who have a child with a disability across both countries (i.e., India and the U.S.) (Zechella & Raval., 2016; Sudarsan et al., 2022; Desai et al., 2012; John, 2012). These studies explored the importance of understanding the experiences and challenges of Asian Indian parents and their children with a disability. Though many families experience challenges caring for their children, Asian Indian families have unique issues with an emphasis on social support, culture, religion, and many other elements. In the following section, we will explore each of these unique factors in greater depth.

Social Support

Literature is scarce for Asian Indian families (John et al., 2016). Asian Indians have a unique perspective on their experiences and challenges in caring for their child, especially children with a disability. In Asian Indian families, culture, religion, and customs all influence the way these families take care of their children. The support of spouses, friends (John et al., 2016), and social support groups were sources of support for Asian Indian parents (John et al., 2016; Zechella & Raval, 2016). These groups helped fathers to connect with other families who are experiencing similar issues and learn from them. For Asian Indian parents living within the U.S., the supportive presence of other family members in the U.S. was mentioned (Zechella & Raval, 2016). In terms of coping strategies, many Asian Indian parents rely on social support (Zechella & Raval, 2016; John et al., 2016). However, support includes more than individuals, support from access to services, and awareness and acceptance from society. Access to resources and services is crucial to support, as parents work to negotiate, explain, and speak with teachers

and medical providers to ensure their children are well accommodated. The increased awareness and acceptance of autism in both India and the U.S. continue to make parents more comfortable with seeing families like theirs in public and influences their decision to live in the U.S. which can provide them with more support and services.

Culture and Religion

Asian Indian families also have a strong emphasis on the influence of culture. Zechella and Raval (2016) found cultural explanations and community response are all aspects of culture that influence Asian Indian families. Community responses from Hindu communities influenced the way parents viewed their children. Prevalent in the community was the lack of acceptance and understanding of the child's particular disability (Zechella & Raval, 2016). For older and extended family members, acceptance of the child's condition was an issue. In addition, there have been many traditional views of Long-Term Conditions (LTC) as life-threatening or contagious to other family members (Sudarsan et al., 2022). As a result, Asian Indian parents hide their children and choose not to disclose their child's condition out of fear of stigma and negative views.

The emphasis on religion also influences the situation (Zechella & Raval, 2016; Sudarsan et al., 2022). Many Asian Indian parents identify as Hindu and believe in many Hindu practices and traditions. Culturally, the understanding surrounding disabilities might be distinct within Hindu families. Many, believe it is the result of karma, God's will, an ancestral curse, or contracting negative energy from an eclipse if the mother was outside (John, 2012; Sudarsan et al., 2022; Zechella & Raval, 2016). Other families used religion as a source to cope. Families often visited holy places, offered prayer, fasted, made oaths, viewed horoscopes, wore special amulets or beads, and spoke to spiritual healers (Sudarsan et al., 2022). On the contrary, some

parents view their child's disability as a gift and seek to understand their experience in terms of spirituality. Understanding their child's medical condition and its spiritual meaning was also used as a coping mechanism for the parents.

Lack of Interventions for Children with Disabilities

Early interventions have been considered for infants at risk for developmental disabilities (Vipulaguna et al., 2022). Infants and children are often diagnosed too late, creating a gap in early intervention and diagnosis in research (Vipulaguna et al., 2022). Though the focus is on infants, many infants have been diagnosed too late, well into their school years, to be diagnosed or kept under surveillance. An initiative called the “Rashtriya Bal Swasthya Karyakram (RBSK)” seeks to prevent childhood disability in children between the ages of birth to 18 years old through early detection and more properly trained providers in India (Vipulaguna et al., 2022). Though this program is in India, it serves as an example of a program seeking to help parents with early detection of a disability in their children. Despite the continuous lack of intervention and diagnosis, several programs and services within India, Sri Lanka, and Bangladesh are being implemented (Vipulaguna et al., 2022). However, most parents have travelled to the United States to get treatment or better resources.

Parental Stress and Impact on Family

As with all other families, caring for their children with a disability can result in stress (John, 2012; Zechella & Raval, 2016; John et al., 2016). Stress has and continues to frustrate parents who are trying to help their children. Stress comes from social exclusion, challenges with access to services, and geographic distance away from family support in the U.S. Families also experienced social exclusion through negative reactions, comments, and perceptions from neighbors and family. Parents who newly immigrated to the U.S. had challenges with access to

services for their children who had Intellectual Developmental Disabilities (IDD). Every year once the child moved to a new grade the teachers changed, leaving parents to constantly explain and meet with new teachers to discuss who their child is, their condition, and the accommodations required for their child. Geographic distance also played a role in the amount of stress parents experience. Asian Indian parents grieved the lack of familial contact and support while living in the United States. The top stressors from one study highlighted were "(a) long-term planning for accommodations, (b) finding opportunities for the child to make friends, (c) child being diagnosed with a disability, and (d) planning for socioemotional support for the child" (John et al. 2016, p. 1600).

The entire family must be prepared to take care of the child or siblings with the disability. However, this process is different for each family. Families may have a more challenging time supporting their child with a disability than others. Balance is key (Zechella and Raval, 2016), though it may take time to learn the balancing skills. Most parents are taking on more responsibilities and roles due to their child's condition. The child's disability may also impact the family decision to have more children, after receiving negative reactions from extended family members (John, 2012). Alternatively, for some Asian Indian parents, their child with a disability had a positive impact on their purpose in life (Zechella and Raval, 2016). Caring for their child allowed parents to modify their own views of themselves and others. This finding hints at how some Asian Indian parents may see things in a positive light even though the situation looks seemingly very stressful.

Discrimination/ Unequal Treatment

Unfortunately, parents had to endure discrimination and unequal treatment while trying to care for their children. A mother was told she did not know how to take care of her child by a

doctor (Desai et al., 2012). Parents know their child's temperament, skills, abilities, and functions better than anyone else. Doctors assuming a parent does not know their kid only frustrates the parents who are trying to better understand their child's disability to take care of them. Doctors need to be more considerate and helpful when communicating with parents about what they need to do to help their child.

Parental Advocacy

Parents are working to advocate on their children's behalf (Sudarsan et al., 2022; John et al., 2016; Zechella & Raval, 2016; Desai et al., 2012). Parents have tried to modify academics for their children, improve their caregiving of the child, and have even worked to pass down Indian Heritage to their children. The care and support of the child was also important to the parents. Finding opportunities for the child to make friends, the child's social and emotional support, and search for solutions to help their child is a constant pursuit for the parents (John et al., 2016; Desai et al., 2012). Alternatively, Asian Indian families are not the only ones dealing with challenges and issues concerning the care for their child. African American families have similar and different challenges, which differ in terms of culture and treatment.

African American Families

Research is also scarce concerning the lived experiences of African American parents and their children with a disability (Ha et al., 2011). African American parents also have unique challenges when taking care of their children with a disability. Culture once again plays a role in the experiences families deal with concerning their children. Through the breakdown of literature concerning African American parents, identifying similarities and differences between the two families can highlight unique adversities both families have and continue to experience.

Social Support

Social support was important for African American parents (Evans et al. 2016; Aceves & Black, 2022). The African American family have a positive support system with extended family and kin networks (Evans et al., 2016; Pearson & Meadan, 2018; Aceves & Black, 2022). Kinship networks were mentioned as a source for emotional support. Another positive social support system was the church (Evans et al., 2016; Pearson & Meadan, 2018). Parents depend on faith communities to help them understand their child's disability and join church support groups. Professional support was also utilized by a mother in one study (Aceves & Black, 2022). Direct assistance from professionals also added a layer of support. A mother advocating for her son with a disability was able to communicate with her son's doctor, and he listened to her concerns and tried to understand her son.

Religion and Culture

Religion plays a critical role in African American families with a disability (Burkett et al. 2015, Evans et al., 2016). Christianity is the religion most Black families in America follow, depending on church, God, and faith to help with their children. Many turn to the church for coping mechanisms to weather through a situation. The church helps with coping with the challenges and demands of life and helps with healing from a disability diagnosis within the family (Evans et al., 2016). The church was a supplemental support for African American families who have children with disabilities. The church is instrumental in helping family members access materials such as food, clothing, shelter, financial support, as they care for their child. Faith in God was important to family members too (Evans et al., 2016; Pearson & Meadan, 2018). Faith allowed family members to trust that the situation would become better and more manageable. Alternatively, after examining the importance of religion in Asian Indian and African American parents, it is essential to decipher the difference between faith and religion.

Religion noticeably had more influence on Asian Indian parents, and faith was more apparent for African American parents. Religion and faith are two very different things for the sake of the two cultural groups within this study. Religion is more organizational and adhering to beliefs, practices, and customs whereas faith is the belief in something and someone, which is a little more personal to the individual (Hayden, 2020).

In addition, cultural influences may have played a role in the family's ability to receive an autism diagnosis and treatment for their child (Burkett et al., 2015). Most parents received or realized their child had a disability too late (Evans et al., 2016; Constantino et al., 2020), Burkett et al., 2020; Pearson & Meadan, 2018). The delay in diagnosis and lack of interventions continue to be a problem for the African American community. In addition, because of the lack of information, most parents may not have the knowledge or resources to know the signs of a possible developmental disability (Pearson & Meadan, 2018). These delays in diagnosis have challenging consequences for families who become aware of their child's diagnosis too late.

Lack of Early Intervention/ Delay in Diagnosis

Most African American children are diagnosed later and receive a lack of early interventions (Pearson & Meadan, 2018; Constantino et al., 2020; Burkett et al., 2020). Several studies have mentioned issues obtaining diagnosis and early intervention services for their children (Pearson & Meadan, 2018). Delays in diagnosis were made exceeding the period of early developmental therapies (Constantino et al., 2020). Cultural influences have been named as one of the reasons for delayed diagnosis and interventions (Burkett et al., 2015). However, the lack of intervention knowledge among African American parents with children with a disability has also been linked to early intervention and diagnosis (Evans et al., 2016; Pearson & Meadan, 2018). With the lack of knowledge, mothers tried to increase their knowledge of their child's

disability (Pearson & Meadan, 2018). Mothers have taken advantage of taking classes, developing partnerships with professionals, and sharing knowledge with family members and friends (Pearson & Meadan, 2018). On the other hand, news and media helped some mothers obtain services and detect the need for an early diagnosis for their child (Pearson & Meadan, 2018).

Parental Stress and Impact on Family

Like Asian Indian families, stress affects African American families in unique ways. Children with a disability are a huge stressor for parents. According to Ha et al. 2011, the effects of a child's disability on parental mental health and well-being is a massive stressor. The impact on parental mental health and well-being is because of the many responsibilities (e.g., work, housework, and other parental duties). The unfortunate heavy burden of caregiving affects the parents' ability to take care of themselves. Parents usually spend so much time caring and providing for their kids that they often forget to take care of themselves during the process. African American parents also experience high stress levels due to the limited number of resources for their children. The lack of access to resources is enough to stress out any parent struggling to properly care for their child. Also contributing to stress are the barriers to obtaining a diagnosis (Pearson & Meagan, 2018). Like the lack of access to resources, barriers prevent parents from acquiring a diagnosis for their children. As mentioned before, most African American kids receive a disability diagnosis too late, prompting more stress for the parents to understand how to care for their child.

The entire family is affected by the child with the disability. The pressure of caring for their children takes a toll on the mental and physical health of the parents (Ha et al., 2011). Other challenges of African American mothers are the challenges of being ignored and not listened to

(Aceves & Black, 2022). The unwillingness of doctors to listen to and consider the information African American parents give them regarding their child's disability is frustrating (Burkett et al., 2015). Both parents must learn to take care of their child and protect them, especially siblings. Siblings need to be prepared to learn about their sibling's disability to help their parents assist and take care of their sibling with the disability.

Discrimination and Unequal Treatment

Unfortunately, some families experience unequal treatment in community and health care (Burkett et al., 2015). Child safety and independence were essential for some parents because of the distrust of medical professionals and the healthcare community (Burkett et al., 2015). A father explained the three intersectionality elements of his daughter quoting " She's Black, she's a girl and she has a disability. Because my thing is I already know what the world is going to do to her." (Burkett et al., 2015, p. 3247). African American parents are all too familiar with the power of race. Race continues to be a driving factor of how individuals are treated in society, and Black children with a disability is no exception. In the quote above, the father is aware of how society will treat his daughter because of her unique intersections.

Parental Advocacy

In addition, African American families became advocates for their children in increasing their care (Burkett et al., 2015). Most parents took matters into their own hands and advocated for their children in terms of health, medical treatment, and education. African American families acted and made choices and decisions out of love for their autistic children. Families accessing treatment programs sought accurate diagnoses, and resources. Many mothers depended on their instincts, obtaining information, making direct requests and professional support, advocacy training, programs, and shaping advocate identity (Aceves & Black,

2022). Some parents often sought therapeutic practices or made their own treatment at home for their children's advancement. However, news of resources and treatment are disproportionately known between families. The differences in resources available and known between White and Black communities may be because "The White community may have access to more information than the Black community" (Burkett et al., 2015, p. 3249). This statement explains why it may be more difficult for Black families to find and access resources; therefore, making it more difficult to advocate for their child. The theoretical framework discussed in the next section highlights the stressful and unique intersections of Asian Indian and African American families caring for their child with a disability.

Theoretical Frameworks

African American families continue to experience stressful and unfavorable interactions with society at large as it relates to their children with disabilities. Usually, these unfavorable interactions and views form because of racial discrimination and prejudice (WHO, 2019). This phenomenon can best be explained by the minority stress model. Dr. Ian H. Meyer (2003), created the minority stress model to understand the stress experiences of LGBTQ individuals. The minority stress theory is "One elaboration of social stress theory may be referred to as minority stress to distinguish the excess stress to which individuals from stigmatized social categories are exposed as a result of their social, often a minority, position" (Meyer, 2003, p. 3). The lack of access and resources of African American and Asian Indian families to access care and advocate for their children with disabilities could be a result of their ethnic background. Parents have become overwhelmed attempting to advocate for their children through early diagnoses, accessing the right medical services, and community response (John et al., 2016; Aceves & Black, 2022; Pearson & Meadan, 2018; Burkett et al., 2015). Minority stress theory

assesses those of a stigmatized social identity to examine the specific stressors of the stigmatized individual (Meyer, 2003). Through the minority stress framework, African American and Asian Indian families experience stigmatization because of race and their child with a disability. These conflicting social identities make it difficult to access and receive assistance. Families have mentioned the lack of consideration, knowledge, and cultural competence as reasons for stress (John et al. 2016; Evans et al., 2016; Pearson & Meadan, 2018). The continual stress that comes with managing their children's condition becomes unbearable to endure.

In addition, the outside influences of the world create even more barriers and challenges for parents of children with disabilities. To gain a closer look at these levels, Bronfenbrenner's ecological systems theory will be used to understand each social level. Ecological systems theory was created by an American psychologist, Urie Bronfenbrenner in 1979 (White et al., 2019). The ecological framework has five systems to explain the entire framework. The five systems are the "microsystem, mesosystem, exosystem, macrosystem, and chronosystem" (Smith & Hamon, 2016). The microsystem is the first level, which contains the individual. It is also the level of direct contact with the individual (parents, co-workers, neighbors). The mesosystem is the second level containing the interactions between two systems (the individual's family and coworkers). The exosystem is the third-level environment in which the individual is not directly involved but affects them in some way (mass media). The fourth level is the macrosystem dealing with culture (SES, race, poverty). The fifth and final level is the chronosystem, which represents time (changes occurring over time) (Smith & Hamon, 2016). All the systems affect the individual in some form, either directly or indirectly. Ecological Systems theory is compatible with the research because it seeks to understand the outside environmental systems that influence the parent's ability to care for their children with disabilities.

Thus, the overarching goal of this research is to examine closely the lived experiences of Asian Indian and African American families who have a child with a disability and are living in the U.S. Specifically, we are examining their experiences as parent of an ethnic minority group and having a child with a disability, barriers and challenges experienced in their journey as parent and support acquired and want as a parent for themselves and their own child. Thus, the following research questions will be examined within the study:

- 1) What does it mean to be an Asian Indian or African American parent and have a child with a disability?
- 2) What barriers and challenges have they experienced as an Asian Indian or African American parent who has a child with a disability?
- 3) What supports do they need or have acquired for themselves and their child as an Asian Indian or African American parent who has a child with a disability?

CHAPTER 3: METHODOLOGY

Qualitative research seeks to understand how individuals live and interpret their experiences. Therefore, this research will implore a basic research design to understand the lived experiences of parents of children with disabilities. This qualitative study seeks to understand, 1. barriers such as lack of support for parents, 2. parental stress and the impact on the family, and 3. examining how culture and religion has a role in the parent's experiences. This aligns with the three aspects of qualitative research outlined by Merriam and Tisdell (2016), "(1) how people interpret their experiences, (2) how they constructed their worlds, and (3) what meaning they attribute to their experiences" (Merriam & Tisdell, 2016, p. 24). Thus, this explains the justification for using a basic qualitative research design for the study, which is to understand the experiences as parents having a child with a disability.

Recruitment and Sampling

Snowball and Purposive sampling were used to recruit parents through social media. The recruitment flyer was posted on Facebook, and Linked In, and sent to organizations that work with children with disabilities. Overall, close to 200 hundred participants indicated interest in participating in the study. After a review of interested participants, most of them were African American parents. Unfortunately, the researcher obtained one Asian Indian parent interested in participating in the study. Even after extending the recruitment period by another two weeks and emailing more Asian Indian organizations, no more Asian Indian participants expressed interest in the study. Therefore, in discussion with the research committee, interviews would be conducted to include only African American parents. Potential African American parents were contacted via email and the next part of the study was explained. Participants received a \$20 electronic gift card for participating in the study. The ECU Institutional Review Board (IRB) approved the study.

After recruiting almost 200 African American parents interested in the study, the researcher and thesis chair decided to make it more manageable by reducing the number of participants to a smaller sample size. The researcher and thesis chair selected distinctive participants to include in the survey and the interview process. The final pool of participants was reduced to 18 and chosen based on the eligibility requirements, NC county of residence, and their child's disability. Though 18 participants were invited to participate in the study, four participants never completed the surveys or scheduled an interview. The saturation point for the interviews was reached at ten interviews during this time. The researcher noticed a repetition of themes during the data analysis at 10 interviews. After a couple of days, four more participants responded and consented to take part in the survey and interview session, so they were included in the study and that brought the number to 14 participants. However, two participants who completed the interview had survey answers that did not meet the eligibility criteria after retaking the survey again and therefore, were omitted from the final data analysis and were not included in the final survey responses.

Thus, the final sample consisted of 12 African American parents. All participants identified as either Black, African American or used both terms interchangeably. The participant's ages ranged from 25-33 years and consisted of eight females and four males. All participants had a bachelor's degree, identified as Christian, and spanned across eight NC counties (Clay, Gaston, Granville, Lee, Martin, Orange, Pitt, and Union). Most worked full-time jobs. In terms of their children, all were between the ages of 5-8 years and ranged in disabilities, three children had autism spectrum disorder, three had a hearing impairment (deaf), one had cerebral palsy, one had a physical disability and the other an intellectual disability, but the family did not specify a specific name for the physical and intellectual disability.

Data Collection and Analysis

Data collection included a demographic survey and semi-structured interviews. The demographic survey was self-reported through Qualtrics before the participant's interview date. The demographic survey identified the participant's age, age of the child, religion, level of education, employment status, etc. A research assistant was provided to help conduct interviews. Interviews lasted between 25-40 minutes and were conducted via Zoom Pro. The reason for conducting interviews over Zoom is that many participants were spread out across various geographic distances within NC. Interviews were recorded and transcribed via Zoom Pro because of its transcribing feature. In total, 14 video calls were conducted. However, after a close inspection of the survey responses, two participants were removed from the study and data analysis because of inconsistencies with survey responses. Thus, 12 participant surveys and interviews were utilized and analyzed.

After each interview, the researcher began the data analysis. The researcher started by reading through each transcript to familiarize herself with the data. The researcher then conducted a content analysis by highlighting phrases, words, and quotes within the interview transcripts. The researcher took note of the words, phrases, and quotes during the data analysis and added the content in to a Microsoft Word document. This led to the creation of a codebook to organize data into content themes for better understanding and analysis of the participants' experiences. The content analysis and codebook were based on the three main research questions. Themes were created and developed by connecting and grouping similar codes and content that described the experiences of the parents from the interviews. To identify the most emergent themes, the content was ordered from greatest to least, and the themes that appeared the most were considered the most emergent. The themes were added to a chart, which included

the theme, definition, and a quote from the participants to support the themes found in the interviews.

Trustworthiness

In terms of trustworthiness, several methods were taken to ensure trustworthiness, including member checks, triangulation, audit trail, and positionality. Member checks were conducted during interviews. After each question, the researcher recited the participant's answers to ensure both parties understood and clarified any information. Critical friends is another trustworthiness method of having more than one individual discuss aspects of the study and look over the research data with researcher. The researcher had the help of the thesis chair and one committee member to review the data analysis process and ensure the researcher is thinking critically about the research findings and interactions. In addition, an audit trail was created during the study. The audit trail was used to keep a detailed account of each step of the study (Merriam & Tisdell, 2016). The audit trail is placed in a Microsoft Teams folder in case other researchers would like to replicate the study for use in future studies. As mentioned before my positionality is to understand the experiences, challenges, and disparities African American families have encountered in their lives. I am also an African American woman and part of one of the groups I am researching. I also have some family members with children with disabilities and have considered how their experiences and my own bias can obscure research findings. As a researcher, I wanted to understand their experiences and challenges as parents of children with disabilities. Therefore, I already have insight into some of the experiences of knowing African American parents of children with disabilities. With the help of guidance and review by one of my professors, biased and one-sided views were corrected and monitored.

CHAPTER 4: RESULTS

The results of the study are based on the main three research questions (1) What does it mean to be an Asian Indian or African American parent and have a child with a disability? (2) What barriers and challenges have they experienced as an Asian Indian or African American parent who has a child with a disability? (3) What support do they need or have acquired for themselves and their child as an Asian Indian or African American parent who has a child with a disability? Data analysis revealed three major themes based on the research questions of African American parents of children with disabilities, these included (1) Theme 1: Lived Experiences as an African American Parent, (2) Theme 2: The Frustrations of Barriers, and (3) Theme 3: Much Needed Familial and Systematic Support. All the themes and sub-themes have been explained in greater detail within this section. Additional quotes and information on each major theme and subthemes are presented in Table 1.

Theme 1: Lived Experiences of African American Parents

The lived experiences of African American parents were freely expressed within the interviews by African American parents as they emphasized and explained their everyday experiences with their children and what it means to be a parent who has a child with disabilities. Three subthemes emerged as the data was further analyzed within this section; (1) A Challenging and Unplanned Experience, (2) Cultural and Familial Expectations, and (3) Psychological Issues.

A Challenging and Unplanned Experience

Many parents described their experience as an African American parent as a challenge. One participant stated, *"I'll say, disabled child comes with unique challenges, yeah, like, lack of understanding and support."* Depending on the child's disability, parents described their experience as unique yet challenging. For example, the lack of understanding and support stems

from the parent's inability to understand their child's disability and lack of support from others. A mother explained, *"Personally, being a parent with a child with a disability is quite challenging. Cause it entails giving double care for the particular child. Or like other people that have normal children should I say, but you need to like double your care for your child..."* Unlike children without disabilities, this parent explained that the amount of care and responsibilities double with a child with a disability. Double care for this parent entails double attention, responsibilities, and care for the child with the disability. In addition, to the challenging experiences as an African American parent, several parents mentioned having a child with a disability is something you wouldn't think to plan for as a parent, *"We don't plan on being a parent to a disabled child."* For most of these parents, a diagnosed disability was unplanned for the child, ushering the parents to think of alternative ways to care for their child's unique disability.

Familial and Cultural Expectations

Parents mentioned cultural and familial expectations as a part of their lived experience. When it comes to their child, cultural and family expectations often make it difficult and frustrating for them to assimilate their child into their specific culture and family conventions. For example, A mother explained, *"Okay. I take family expectations. Some of the family members don't believe that [my child] has a disability because she kind of looks normal."* Some family members have a difficult time believing her child has a disability because she looks normal like the rest of the children in the family. However, this is not the case for other participants. Another mother stated, *"In my family, they usually have an expectation for academic and professional achievement, and they find it really difficult to believe that my child [has a] disability."* This participant's family had a difficult time accepting that the child has a

disability and therefore has high expectations and goals for the child to live up to, completely dismissing the child's disability that might interfere with those expectations. In terms of culture, A mother explained her *"faith"* in her daughter's ability to heal her disability. Faith for this mother has cultural significance because of her belief that her daughter will become better because of faith in Christ. Another mother mentioned the negative cultural views of the community has on her child. People in the community have linked the child's disability as a punishment. The mother explained, *"Most people in my community, they feel like "Oh, my child is view[ed] as a failure or, and most of them feel like my child being disabled is sort of a cost or punishment... they feel like my child is being cursed."* The researcher interpreted that beliefs like these causes more harm and damage to the mother and child, as in this case, the community prevents the mother and child from feeling a sense of belonging in their own community.

Psychological Issues

Due to these unpleasant encounters, parents described experiencing psychological distress as part of their experience caring for their children. The parents' psychological issues were expressed as challenges and difficulties because of their child's disability. Psychological symptoms included depression, anxiety, stress, and grief to name a few. One parent mentioned, *"...anxiety, depression, and stress related to caregiving and societal pressure."* Caring for a child with a disability involved more responsibility and social stigma for parents to manage. The increase in stress for some parents included medical bills, transportation, and lack of support. Several parents also discussed the psychological impact of isolation, *"I'm feeling disconnected from others. You know, we cannot think straight. At some point, you know, it's...withdrawal when it comes to friends...you know peer groups."* Because of their child's disability needs, some parents rarely have time to create relationships, which has led to the withdrawal of friends and

their community. Several parents have also mentioned the psychological impacts on their child with a disability as well. A mother mentioned isolating herself and her child from their own community. For example, *"my fellow community members. It's kind of discouraging and most times, it makes us like to live in isolation."* Parents have also discussed the similar psychological issues of depression, anxiety, social challenges, and shame that their child with a disability experiences.

Theme 2: The Frustration of Barriers

African American parents have and continue to experience barriers that prevent them from properly caring for and ensuring they and their children have access to help and assistance. Sadly, these barriers are frustrating for parents who are trying their best to care for their child and their unique needs and capabilities. The subthemes are (1) Financial Assistance, (2) Limited Access to Resources, and (3) Discrimination and Racism.

Financial Assistance

Nearly all parents mentioned financial troubles as a barrier. One parent explained, *"One of the major barriers I have experienced is the financial aspect. It's been so [many] demands to meet up with..."* Many parents have described financial troubles in different ways such as; *"financial strain"* and *"financial constraints"* to describe their difficulty meeting the financial needs of their children. Financial constraints and strains pertain to medication costs, parents' job demands and salary, costs of gas to appointments, and the cost of seeing specialists and therapists. Several parents mentioned the need for money or *"Financial assistance and government benefits"* to support their efforts in caring for their children. One mother explained, *"If I can have more financial support... it can make me feel [relieved from] financial stress..."* Another parent proposed, *"If they make health services pretty affordable at the hospital it would*

be easy for [us] parents so that you don't necessarily have to wait for the insurance people because sometimes the insurance services are delayed." The lack of support for financial assistance was reported as a barrier for all parents and their child's treatment.

Limited Access to Resources

Parents mentioned the lack of access or even difficulty finding resources, assistive tech, and much-needed facilities. One parent said, "The challenges with accessing some educational centers and medical facilities." In order to access the best educational and medical facilities and centers for their child, it requires more money to afford certain levels academically or mentally. Other parents mentioned *difficulty finding and accessing necessary resources*" such as *"access to technology and assistive devices."* Most importantly, there is a need for *"access to healthcare providers."* According to a father, because of the limited access to healthcare providers, there are, *"Delays in receiving appropriate therapies treatment or assistive technologies [and] limited access to educational resources."* These delays further hinder the parent's ability to adequately provide timely and effective resources and services for their child's disability.

Discrimination and Racism

Unfortunately, an experience all participants discussed during their interviews was their continuous encounters with discrimination and racism. As African American parents, many expressed experiences with racism and discrimination in hospitals, schools, and in public with their children. One mother stated, *"For me, as an African American, you know, as black people, we face a lot of intersectional discrimination, dealing with racism, which...mostly lead to marginalization and exclusion."* All parents were fully aware of their intersectional race and ethnicity, which influenced their encounters with unfortunate experiences. For example, one mother discussed her experience with discrimination in healthcare, she stated, *"Discrimination in*

healthcare, I think there was a time that I took my child to the hospital and... I was supposed to be next in line, but I was being dropped because they felt like my case wasn't really necessary."

Another mother mentioned, *"discrimination from people and people looking down on my child... [and] be like she's stupid because she has dyslexia."* During interviews, many parents shared their negative experiences within institutions and society with their children. Experiences with discrimination and racism were the most discussed topics in all interviews. All parents explained their specific experiences with racism and discrimination.

Theme 3: Much-needed Familial and Systematic Support

More Support

The need for support was another emergent theme from the data analysis. Parents need more support from several people, organizations, and institutions to support them and their children through challenges. For example, *"Finding and maintaining a supportive community or family. Friends and professionals"* were mentioned multiple times by several participants. Most parents were searching for a *"support group that's connecting with other parents to understand,"* because most parents feel more comfortable joining support groups with other parents with similar disabilities as their child to share ideas, methods, and activities to better care for their child. A mother even suggested *"autism support groups, and online social media groups"* for parents in different geographical locations. However, other parents preferred support from higher institutions, such as the government. One father mentioned support from the *"government making laws to support we blacks from discrimination."* As mentioned in Theme 1, several parents have described their encounters with racism and discrimination while trying to obtain help from hospitals, schools, and even society. Other parents suggested more *legal representation, government benefits, and an "easy insurance policy without discrimination."* The

suggestions and support needs are described directly by the parents who need more support and assistance as parents of children with disabilities.

Medical Assistance

Parents mentioned the need for medical support such as healthcare services, management, or healthcare coordination to help their child seek appropriate medical attention. Parents also discussed the need to consult specialists or services for their child's specific disability or needs. One parent mentioned more access to specific healthcare providers like *"consulting with dyslexia specialists and experts."* Other parents desired a "healthcare personnel" or "healthcare coordination" to help them keep up with their child's medical needs. Other medical support mentioned were *"affordable healthcare services, checkups, and medical management."* In addition, parents mentioned the need for more mental health services for themselves and their children because of the stressful and negative challenges. Similarly, related to Theme 2, parents discussed their experience with psychological issues as parents of children with disabilities. Many parents described self-care or personal activities they do to prioritize their health, most mentioned listening to music, physical activity, meditation, and utilizing online resources. One father stated, *"[If] you do not take care of yourself. You are going to pretty much take that frustration out on your children. So, it is important that you take care of yourself as a person and then you'd be able to take care of yourself and also take care of your child or your children."* Unfortunately, the children of the parents were not exempt from psychological and negative issues from society. A father desired the need for, *"Mental health services for my child to be mentally stable."* With the previous themes and subthemes prior, it's easy to see why both the parents and children need increased medical support.

Accommodations and Assistive Devices

Parents mentioned the need for accommodation and assistance in caring for their children. The need for affordable gadgets, home modifications, transportation, and materials was described as a huge asset for not only themselves but their children. A parent mentioned the need for transportation services, *"[to] help with transfer transportation to medical appointments."* A mother described the need for an *"individualized education program tailored to your child's need."* This accommodation will specifically focus on the child's specific disability needs. In addition to individualized needs, a parent stated, *"...home-based service and support [that] direct our culture and practices."* The need for accommodations and services that correspond with the family's culture like traditions, values, and practices. One father has a daughter who is deaf and explained the difficulty acquiring hearing aids. The father stated, *"...devices like those hearing aids, I wish they were cheaper to be honest because the government the only thing they can provide is you know low budget..."* The father went on to express the need for the government to offer affordable gadgets for children. The father also mentioned how receiving the ear implant would impact his daughter, *"You know, her life would be a little bit close to normal because she will be happy to be at school and be able to be at home... I think she would be happy that way."* All these parents had similar goals of making sure their children had the appropriate accommodations, assistive devices, and services needed to assist with their child's disability.

Table 1

Three major themes of qualitative interviews with African American parents on their experience as parents of children with disabilities.

THEMES	SUBTHEMES	QUOTES
Theme 1: Lived Experiences as an African American Parent	Challenging/ Unplanned	"Unique and challenging" "Something you don't plan for"
	Cultural and Familial Expectations\	"Hard for the family to accept my child has a disability and have high expectations"
	Psychological Issues	"Physical and mental stress"
Theme 2: The Frustration of Barriers	Financial Assistance	"Not enough money"
	Limited Access/ Difficulty	"This is a very big challenge because at this point the child is unable to have access to education and resources being given it's difficulty assessing inclusive educational resources and support. "
	Discrimination and Racism	"This is a very big challenge because at this point the child is unable to have access to education and resources being given it's difficulty assessing inclusive educational resources and support. "
Theme 3: Much Needed Familial and Systematic Support	More Support	"Family is everything. So, when you create this small circle of friends, where you could share your problems with not just me, but my kid can talk to them talk to their kids and feel free It really helps a lot."
	Medical Assistance	"There are some medical facilities that you cannot access as a black woman or black parents and also Couple with the fact that you have a child with a disability you have to go the extra mile to find supports..."

	Accommodations/ Tools (Devices)	“So that implant is expensive, and I think for a child it should be free... to adjust to the environment. I of course had to get hearing aids to try and see if she would improve.”
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CHAPTER 5: DISCUSSION

The purpose of this study was to examine the lived experiences of African American and Asian Indian parents of children with disabilities. As noted, in the data analysis section, the researcher was unable to recruit enough Asian Indian parents, and therefore, focused mainly on the lived experiences of African American parents. Though the original research purpose was about Asian Indian and African American parents, the study was modified to only African American parents. However, the researcher was still able to learn more about the lived experiences of African American parents and their struggles in caring for their child's disability. The results not only revealed three significant themes of their experiences but also highlighted the much-needed support and acknowledgment of parents of children with disabilities to institutions, communities, and society.

The first theme delves into the lived experiences of African American parents, with the subthemes of (1) A Challenging and Unplanned Experience, (2) Familial and Cultural Expectations, and (3) Discrimination and Racism. These three subthemes appeared the most during data analysis and highlighted the challenging experiences African American parents encounter every day. The experiences of African American parents of children with disabilities are scarce in literature and research (Ha et al., 2011), however; the interviews have provided a closer look into the difficult experiences of the parents. Caring for a child with a disability was labeled as "challenging," especially given the specific developmental disability of the child. An example of this is that a child with a physical disability is different to take care of than a child with a hearing disability. Both children have different needs and challenges. Parents need to know how to care for their child properly based on their child's individual needs. One child

requires more physical labor than the other in terms of feeding, baths, transportation, and movement.

Familial and cultural expectations have also caused distress among parents because of the familial and cultural pressures of high expectations and superstitious cultural reasons as to why their child has a disability. The familial expectations the parents mentioned in their interviews make it difficult for parents who realize their child will have difficulty living up to those high expectations. Parents define cultural expectations as the traditions and values that families expect children to learn and embody. On the contrary, it also meant cultural explanations of why the child may have a disability, which according to community members may be some form of punishment or curse. The cultural expectations in interviews were different than the cultural influences within the literature review because culture in the interviews had more to do with faith and cultural explanations of how the child ended up with the disability (Burkett et al., 2015; Evans et al., 2016; Pearson & Meadan, 2018; Constantino et al., 2020). In addition, all parents discussed their experience with discrimination and racism in hospitals, schools, society, and within their own community. Discrimination and racism prevent parents from accessing support groups, services, and medical assistance for their child. African American parents mentioned their experience with constant run-ins with prejudiced individuals making it difficult for their kids to receive care. Discrimination and unequal treatment were mentioned in the literature as a barrier for African American parents (Burkett et al., 2015). These themes uncovered the distinctive experiences of African American parents of children with disabilities in North Carolina.

The second theme explains the frustration of barriers among African American parents, with the subthemes of (1) Financial Assistance, (2) Limited Access to Resources, and (3)

Psychological Issues. Financial constraints were a barrier discussed by many parents because of the high expenses of seeking medical treatment, assistive devices, and paying medical bills. Many parents are working one or more jobs to afford to take care of their children. Some parents mentioned having other children besides their child with a disability to care for, which means more financial help. Limited access to resources was another barrier mentioned by parents seeking resources from higher institutions such as healthcare providers, medical facilities, and educational centers. Limited access to resources was mentioned among African American parents in the literature (Burkett et al., 2015; Pearson & Meagan, 2018; Aceves & Black, 2022). Most of the limited access is due to racism, discrimination, expensive costs, and geographic location. Some families live far away or do not have adequate transportation to access resources leaving them feeling anxious. Unfortunately, psychological issues continue to overwhelm parents because of the negative barriers of finances, limited resources, and even discrimination. Parents have mentioned depression, anxiety, grief, stress, and even shame. These findings were similar to (Ha et al., 2011), which emphasized the mental and physical toll on parents. These experiences have caused stress and frustration among parents doing their best to provide for their child. In addition, the parents experiencing these barriers ultimately affect their children's ability to receive better education, treatments, and healthcare regarding their disability.

The third theme explains the much-needed support, with the subthemes of (1) More Support, (2) Medical Assistance, and (3) Accommodations and Assistive Devices. Parents desired more support from organizations and people such as family, friends, professionals, and medical providers. Most parents wanted individuals to talk to regarding their experiences with their children. Parents wanted a support group to connect with other parents and learn about advice, activities, and care ideas for their child's specific disability. Social support from friends,

family, and professionals was also mentioned as essential in the literature (Evans et al. 2016; Aceves & Black, 2022). Medical assistance is also needed by parents and their children. Mental health services were desired for both parents and their children, which is similar to the psychological issues parents experience in society. Medical assistance also pertains to acquiring more medical checkups, medicine, and surgery that will improve their child's wellbeing. Lastly, the need for accommodation and assistive devices was mentioned as a need for support for their children. The inability of parents to acquire assistive devices and accommodations also had a place in the literature among parents (Burkett et al., 2015; Aceves & Black, 2022). Parents described their inability to obtain ear implants, transportation, assistive devices, and home modifications corresponding to their child's specific disability needs. The parents' inability to secure additional help highlights the limited support and assistance available to them in North Carolina and their communities. It is also indicative of the amount of support and assistance parents in North Carolina currently have in supporting their children.

After a close examination of the themes and subthemes presented in the results, African American parents experience unfortunate challenges and situations. In addition, many participants perceive these difficulties as being directly related to their racial identity. To reiterate, the purpose was to understand more about African American parents and their exact experiences as parents of children with disabilities. Many of the parents believed the increase in racism and discrimination was due to their African American or Black status, which in turn affected their ability to afford financial assistance, access resources and accommodations, and seek support for themselves and their children. Most importantly, these findings can be associated with other African American parents in both North Carolina and the United States.

Theory Connection:

The minority stress theory is “One elaboration of social stress theory may be referred to as minority stress to distinguish the excess stress to which individuals from stigmatized social categories are exposed as a result of their social, often a minority, position” (Meyer, 2003, p. 3). Minority stress theory primarily focuses on the minority stress of an individual. For example, an African American father explained, *"being an African American parent to some extent on its own is like, yeah, one step back from others...."* An African American mom, stated *"As an African American, you know, as black people... we face a lot of intersectional discrimination and dealing with racism, which can lead to, marginalization and exclusion."* Many African American parents explained the added stress of caring for their child with disabilities, simply because of their minority status. A few other examples related to minority stress are *"discrimination in healthcare," "racial discrimination"*, even *"racial profiling"* because they are African American. These negative experiences have caused great stress among African American parents seeking assistance or simply spending time with their child in public.

Bronfenbrenner's Ecological Systems theory explains the impact of stress on the other environments of a person's life (Smith & Hamon, 2016). In the case of African American parents, all the environmental systems (levels) are affected. The first level is the microsystem, which includes friends, family, or coworkers. Parents have mentioned contact with usually family, but most of their direct contact goes to their child. A participant noted it's about, *"creating a bond between you and the child."* One mother explained, *"[she] tried to make [herself] a best friend [to her child], you know, so... she could always relate and feel more comfortable around me."* Most parents were concerned with their relationship and making time with their children. The mesosystem is the second level regarding the interactions between two systems (the individual's family and coworkers). Several parents mentioned *"community*

isolation" and *"isolation,"* which prevented them from creating relationships with others because of their caretaking responsibilities for their child with a disability. Some of the children's disabilities required more care and attention than others, making it difficult for even the parents to interact with people in their environment. The exosystem is the third level in which the individual is not directly involved but affects them in some way (mass media). Unfortunately, parents discussed the negative experiences their children face in school and society. One parent explained, *"People in your community see the child's disability as a failure or a punishment."* A mother explained her daughter's challenge with mental health because of society, *"And she has a lot of anxiety...., facing negative attitudes outside stereotype and discrimination can also mess with a mental health so it's many affecting her."* Even though the parents are not directly going to school or walking in their child's shoes in society, the parents have still observed the impacts of *"shame," "anxiety"* and their child *"developing negative self-image or low self-esteem"* from the environments the children directly experience. The fourth level is the macrosystem dealing with culture (SES, race, poverty). Several parents mentioned the expectation of culture and family. A parent mentioned it, is *"Hard for the family to accept the child has a disability and have high expectations."* Another parent mentioned the *"financial constraints"* and *"work-life balance"* of caring for their child with disabilities. The fifth and final level is the chronosystem, which represents time (changes occurring over time). There was no specific mention regarding time and how it impacted their life.

Strengths

Although the research study did not include any Asian Indian parents, the study did provide insight into the experiences of African American parents of children with disabilities. In addition to receiving much interest from African American parents, all of the parents were African

immigrants. During the interview portion of the study, all participants had African accents, which provided even more insight into their experiences and challenges as African American parents in the state of North Carolina. These experiences truly emphasized the amount of support even African immigrants receive as new residents in North Carolina.

Additionally, all participants had a higher level of education. Each African American participant had a bachelor's degree, which can be both a strength and a limitation. All participants had high level of education and jobs, thus, parents were better able to describe their experiences and issues with society. Unfortunately, that also limits the generalizability of the results to other parents who may not have the same education level or employment status.

Like the valuable insight from African American parents, the participants' children had a wide range of disabilities to gain knowledge and understanding about the parent's specific challenges and struggles. The children's disabilities ranged between autism, deafness, blindness, muscular dystrophy, ADHD, and several different intellectual and physical disabilities. A blind child is different to care for than a child with cerebral palsy or who is deaf. Therefore, the parents shared unique insights into their inability to receive professional help or assistive technology to help aid their child's specific disability.

Limitations

As with all other studies, this study is not exempt from limitations. The first limitation is the insufficiency of Asian Indian parents willing to participate in the study. After much recruitment on social media, such as Facebook and NC organizations for Asian Indian parents of children with disabilities, only one Asian Indian parent was willing to participate in the study. Unfortunately, one Asian Indian participant would not be enough to fully examine the lived experiences of most Asian Indians of a child with a disability living in North Carolina.

Therefore, for time purposes, the difficult decision was made to interview only African American parents with a child with a disability because of the high volume of interested African American participants. In the future, more intentional and focused recruitment efforts need to be directed to recruit Asian Indian parents.

Another limitation is the small sample size. The small sample size limits the generalizability of the results. This is due to some participants never emailing back, limiting the other types of disabilities and challenges the researcher could have examined based on their unique experiences. We included parents who have children with various kinds of disabilities. It would be interesting in the future to limit the study to a particular disability, such as “children with autism”, “children with deafness” etc., and explore the lived experiences of the parents from one angle.

Lastly, virtual interviews were extremely helpful and helped participants to participate from a distance. Although convenient in many ways, at times the uncertainty with internet connectivity posed a challenge. Thus, face to face interviews or telephone interviews as a tool for data collection could be further explored.

Implications and Future Research

The research study has revealed much about the lived experiences of African American parents of children with disabilities. Several parents had final remarks related to the topic at the end of the interview that have benefited in identifying implications to help parents in North Carolina. Final remarks include governmental, medical, and financial support and awareness. There is a need for more governmental assistance and support, as many parents mentioned financial assistance, legal support, and policy rings. It also comes as one father would like the government to make a law to forbid discrimination among Black parents and children. Medical

support has also been discussed as a great need for parents' ability to receive screening services, mental health services, and better access to medical providers. North Carolina lawmakers and policymakers can acknowledge the challenges and struggles of African American parents of children with disabilities and provide much-needed relief for parents. As mentioned above, relief includes governmental, medical, and financial support. This support will allow parents to have better control and a sense of accomplishment in helping their kids.

Despite the study focusing on parents in North Carolina, these findings can also have similar significance in other global countries and communities. As mentioned in the introduction, children are often overlooked when it comes to developmental disabilities worldwide (WHO, 2019), meaning the issue is not just local or concerns one specific race or ethnicity of people. Global institutions such as United Nations International Children Emergency Fund (UNICEF), the World Health Organization (WHO), and the United Nations can utilize these findings to create new policies to support children with developmental disabilities and their guardians to access more assistance from their respective countries. Research can also be extended to other parents of color to help them understand their lived experiences and the specific support they need to care for their children properly. As noted in the study, the researcher was unable to recruit Asian Indian parents to understand their experiences, which has left the opportunity for future researchers to bridge the gap in the literature regarding Asian Indian parents.

Conclusion

As mentioned in the beginning, children with disabilities are the most overlooked individuals when it comes to disability knowledge worldwide (WHO, 2019). However, the parents and guardians are the ones responsible for taking care of the child, ensuring they receive the assistance, support, and recognition needed. African American parents have boldly shared their

experiences and challenges in obtaining proper support and acknowledgment from higher institutions. If the parents are experiencing this much difficulty obtaining services, access, and support for their children, imagine the impacts on the children themselves. The children are ultimately the ones suffering because they are not receiving the appropriate assistance and support from various institutions. As a result, this creates psychological stress and frustration among parents fighting the barriers to giving their children the life they deserve. The recognition of parents of children with disabilities needs to be acknowledged by government officials and lawmakers with the power to make services easily accessible and affordable for all families.

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APPENDIX A: INSTITUTIONAL REVIEW BOARD APPROVAL

EAST CAROLINA UNIVERSITY



University & Medical Center Institutional Review Board

Willis Building · Mail Stop 682

600 Moye Boulevard · Greenville, NC 27834

Office  252-744-2914 · Fax 252-744-2284 ·

rede.ecu.edu/umcirb/

Notification of Initial Approval: Expedited

From: Social/Behavioral IRB

To: [Chrishay Pearce](#)

CC: [Archana Hegde](#)

Date: 5/15/2024

Re: [UMCIRB 24-000657](#)

Examining the Lived Experiences of Asian Indian and African American Parents

I am pleased to inform you that your Expedited Application was approved. Approval of the study and any consent form(s) occurred on 5/15/2024. The research study is eligible for review under expedited category # 6, 7. The Chairperson (or designee) deemed this study no more than minimal risk.

As the Principal Investigator you are explicitly responsible for the conduct of all aspects of this study and must adhere to all reporting requirements for the study. Your responsibilities include but are not limited to:

1. Ensuring changes to the approved research (including the UMCIRB approved consent document) are initiated only after UMCIRB review and approval except when necessary to eliminate an apparent immediate hazard to the participant. All changes (e.g. a

2. change in procedure, number of participants, personnel, study locations, new recruitment materials, study instruments, etc.) must be prospectively reviewed and approved by the UMCIRB before they are implemented;
3. Where informed consent has not been waived by the UMCIRB, ensuring that only valid versions of the UMCIRB approved, date-stamped informed consent document(s) are used for obtaining informed consent (consent documents with the IRB approval date stamp are found under the Documents tab in the ePIRATE study workspace);
4. Promptly reporting to the UMCIRB all unanticipated problems involving risks to participants and others;
5. Submission of a final report application to the UMCIRB prior to the expected end date provided in the IRB application in order to document human research activity has ended and to provide a timepoint in which to base document retention; and
6. Submission of an amendment to extend the expected end date if the study is not expected to be completed by that date. The amendment should be submitted 30 days prior to the UMCIRB approved expected end date or as soon as the Investigator is aware that the study will not be completed by that date.

<https://epirate.ecu.edu/App/sd/Doc/0/DR5KBC8IQ88UV3LAHQVP0LIG00/fromString.html> 1/2 5/15/24, 1:00 PM
epirate.ecu.edu/App/sd/Doc/0/DR5KBC8IQ88UV3LAHQVP0LIG00/fromString.h
tml The approval includes the

following items:

Name	Description
Consent Form	Consent Forms
Demographic Questionnaire	Surveys and Questionnaires
Interview Guide	Questions Interview/Focus Group
Scripts/Questions	Research Recruitment Flyer
Recruitment Documents/Scripts	

For research studies where a waiver or alteration of HIPAA Authorization has been approved, the IRB states that each of the waiver criteria in 45 CFR 164.512(i)(1)(i)(A) and (2)(i) through (v) have been met. Additionally, the elements of PHI to be collected as

described in items 1 and 2 of the Application for Waiver of Authorization have been determined to be the minimal necessary for the specified research.

The Chairperson (or designee) does not have a potential for conflict of interest on this study.

IRB00000705 East Carolina U IRB #1 (Biomedical) IORG0000418

IRB00003781 East Carolina U IRB #2 (Behavioral/SS) IORG0000418

<https://epirate.ecu.edu/App/sd/Doc/0/DR5KBC8IQ88UV3LAHQVP0LIG00/fromString.html> 2/2

APPENDIX B: RECRUITMENT FLYER

Are you an Asian Indian or African American parent with a child with a disability?

Tell us about your experience as a African American or Asian Indian parent of child with a disability in American society.

Participant Criteria

- 1) Are you Asian Indian or African American parent?
- 2) Do you have a child between the ages of 5-8?
- 3) Do you have a child with a disability?
- 4) Are you from NC?
- 5) Have you lived in NC for one year and in the U.S. for at least five years?

If you answered yes to all the above questions, you are eligible to participate in this research study. Contact the email address below for more information!

Research Location: Online
Survey Length: Less than 10 min
Interview Length: An hour

 **You will be compensated with a \$20 gift card**

Principal Investigator: Chishay Pearce
Contact Email: pearcec18@students.ecu.edu

APPENDIX C: DEMOGRAPHIC QUESTIONNAIRE

Demographic Questions:

Please type in the name you told the interviewer to refer to you by during the interview. This is to ensure confidentiality and who is who.

Allow space for them to manually add their interview name

What is your age? Type in your age

How do you self-identify as a race??

- African American
- White
- Native American
- Hispanic
- Asian Indian
- Other

Which gender do you identify most with?

- Male
- Female
- Prefer not to say

What is your relationship status?

- Married

-
- Cohabiting
- Divorced
- Separated
- Widowed
- Unmarried (Single)
- Prefer not to say

What is your religious affiliation?

- Christianity (Catholic, Protestant, Orthodox, etc.)
- Islam
- Hinduism
- Buddhism
- Judaism
- Sikhism
- Other (please specify)
- None/No religion
- Prefer not to say

What is your primary language? (Select all that apply)

- English
- Hindi
- Other (please specify)

-
- What is your educational level?
 - No degree
 - Less than a high school diploma
 - High school diploma or equivalent degree
 - Bachelor's degree
 - Master's degree

What is your current employment status?

- Full-time employment
- Part-time employment
- Unemployed
- Self-employed
- Stay-at-home parent
- Student
- Retired

If you are from North Carolina, which region of North Carolina do you live?

- Piedmont (Central North Carolina)
- Coastal Plain (Eastern North Carolina)
- Mountains (Western North Carolina)

If you are from North Carolina, which county do you come from? Please type in the NC county you are from

- Insert County

Do you consider yourself to have a disability?

- Yes, I have a disability.
- No, I do not have a disability.
- Prefer not to say.

Do you have a child(ren) between the ages of 5 and 8 with a disability?

- Yes
- No

What is your child's disability?

Autism Spectral Disorder (ASD)

ADHD

Hearing Impairment (Deaf)

Blind

Cerebral Palsy

Intellectual Disability

Speech and Language Disability

Chronic Neurological Conditions (Epilepsy)

Other (Please Specify)

APPENDIX D: INTERVIEW GUIDE

OPENING

Hello, [participant's name], My name is Chrishay Pearce. I am a graduate student at East Carolina University in the Human Development and Family Science Department. We've been in contact via email recently about this study, so it is nice to speak to you over Zoom.

I wanted to take a minute to remind you about this study and why I am interviewing you. I hope to learn about your lived experiences and challenges as a parent to a child with a disability.

You have previously consented to participate in this study on the online platform. As a reminder, your participation in this study is completely voluntary. You can stop participating at any time without penalty and you do not have to answer any questions you do not feel comfortable answering.

The interview will last about one hour and will be audio-recorded via Zoom so the interview can be transcribed verbatim for the research analysis.

1. (NO, I DO NOT MIND.) Thank you.

2. (YES, I MIND.) Okay. However, for research purposes, we need to video record this interview. Because of that, you will be unable to participate in this interview today.

Thank you for your time!

Before we begin the interview, I would like you to make a new name for yourself. The new name is to protect your identity. What name would you like me to call you?

GENERAL INFORMATION AND DIRECTIONS

Thank you again for meeting with me today to discuss your experiences. I am interested in your experiences as a parent to a child with a disability. This includes any challenges, barriers, problems, and experiences you have encountered as a parent.

If you are comfortable, you may provide examples and stories when possible. However, when you are telling a story, please do not refer to the individuals by their real names. You can make up a pseudonym or refer to them by their relationship to you. This is to ensure confidentiality.

Keep in mind that this is all about what you think and your experiences. It is okay if you are unsure or do not know how to answer some questions. After each question, I will recap our conversation and give you a chance to add to or correct anything that is said during our talk today. Throughout our conversation, I will take notes, so I may pause to finish writing. As we are on Zoom, please be sure to stop me and ask me to repeat anything. Also, please let me know if the internet connection suddenly stops or you are having trouble hearing me.

Do you have any questions before we begin? (*Answer any questions.*) Wonderful! Let's get started!

I will now begin recording.

(Start Recording on Zoom)

The recording is on, and you are now being recorded.

INTERVIEW QUESTIONS – For an Asian Indian Parent/African American Parent who has a child with identified disability.

QUESTION 1:

To begin our conversation, What does it mean to be a parent of a child with disability?

REQUIRED PROBES	GENERAL PROBES
Can you share a <u>story</u> or an <u>experience</u> as a parent who has a child with disability.	Can you explain this point more?

REVIEW PROBES
Did I get that right?
Do you have anything else to add?

--

QUESTION 2:

Tell me about your experiences being an Asian India parent/African American parent and having a child with disability.

REQUIRED PROBES	GENERAL PROBES
What positive experiences have you had?	How have these experiences changed or altered due to your ethnic identity?
What negative experiences have you had?	Can you give an example or tell a story related to a particular experience?
	Can you think of anything else?

REVIEW PROBES
Did I get that right?
Do you have anything else to add?

QUESTION 3:

Please explain things you do that help you manage life as a parent whose child has a disability.

REQUIRED PROBES	GENERAL PROBES
Think about people or things (e.g. family (including extended family), friends, religion (faith), attitude and coping mechanisms (positive thinking, therapy)) How has that resource/s (identify it based on participant response) impacted your life as a person and parent? How has that resource helped your child?	Any resources, support groups, family/friends/social groups or organizations that you are part of and how they help.

REVIEW PROBES
Did I get that right?

Do you have anything else to add?

QUESTION 4:

Discuss any barriers you have experienced as an Asian Indian/African American parent of a child with a disability.

REQUIRED PROBES	GENERAL PROBES
Think about people or things (e.g. time, resources, interactions). State one of your biggest barriers among the list of things you just mentioned. How do these barriers impact your life as a parent? How do these barriers impact your child's life?	Can you explain this more? Can you give me an example? Can you think of anything else?

REVIEW PROBES

Did I get that right?

Do you have anything else to add?

QUESTION 5:

What supports do you need in the U.S. as a parent who has a child with a disability?

REQUIRED PROBES	GENERAL PROBES
Think about people or things (e.g. support groups, communication with professionals, therapy for your child, support or accommodations in the classroom, counseling services)	Can you explain this more?
State one of your biggest need for support among the list of things you just mentioned.	Can you give me an example?
How gaining those supports will impact your life as a parent?	Can you think of anything else?

How will those supports impact your child's life?	
---	--

REVIEW PROBES
Did I get that right?
Do you have anything else to add?

QUESTION 6:

What support does your child need/have in the U.S?

REQUIRED PROBES	GENERAL PROBES
Think about people or things (e.g. support groups, communication with professionals, therapy for your child, support or	Can you explain this more? Can you give me an example?

accommodations in the classroom, counseling services) State one the biggest need for support for your child among the list of things you just mentioned. How gaining those supports will impact your child?	Can you think of anything else?
--	--

REVIEW PROBES
Did I get that right? Do you have anything else to add?

QUESTION 7

Do you have any final remarks on the topic before we review and close the interview?

REVIEW PROBES
Did I get that right?
Do you have anything else to add?

SECTION III: CLOSING & THANK YOU

This concludes our interview. I want to thank you for taking the time to talk with me today. I have learned a lot from you and enjoyed our conversation. I also want to thank you for trusting me and sharing your experiences with me today. This research would not be possible without you. Thank you so much for your time and have a good rest of the day.

