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*University of Mississippi*

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Explanatory Models of Autism in Nigeria:

Exploring Sociocultural Beliefs to Inform Systems of Care

By Gabrielle Udoka Robertson

A thesis submitted to the faculty of The University of Mississippi in partial fulfillment of the requirements of the Sally McDonnell Barksdale Honors College.

Oxford  
April 2021

Approved by

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Advisor: Laura Johnson

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Reader: Carey Dowling

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Reader: Grace Rivera

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## ABSTRACT

### Explanatory Models of Autism in Nigeria: An Exploration of Cultural Beliefs (Under the direction of Dr. Laura Johnson)

Advancements in the diagnosis, understanding, and treatment of individuals with autism spectrum disorder (ASD) have yet to benefit children and families struggling with ASD in Nigeria and other African countries. Not only is there a scarcity of research on ASD in sub-Saharan Africa, but also a lack of mental health and special education services and a lack of understanding of the sociocultural considerations that must inform culturally responsive care. As such, this study explored the sociocultural conceptualizations of autism spectrum disorder (ASD) in Nigeria and how these conceptualizations affect the experiences and care of people with autism. The unique culturally patterned pathway with which Nigerians seek care can be examined utilizing Arthur Kleinman's theory of the explanatory mode. Key components of explanatory models include etiology, social and cultural meaning, seriousness and course, fears, help seeking, and treatment. To explore Nigerian beliefs about ASD, a comprehensive literature review was conducted which included criteria for searching studies from Nigeria, Sub-Saharan Africa, and the U.S. Next, material was organized into Kleinman's explanatory model framework in order to illuminate the sociocultural and lived experience through the help-seeking pathway, from recognition of the problem of ASD to treatment outcomes. Finally, case material gleaned from two key informant interviews was included to provide details and support for literature. The literature review was conducted by loose applications of the SPIDER tool, while the results were analyzed using explanatory models. Overall, this analysis suggests that there are major gaps in the research of ASD across Africa. In the case of Nigeria, there is evidence that negative beliefs

about autism have contributed to failing help seeking patterns. Despite these inadequacies, there have been significant efforts to create inclusive educational options that can create a more direct pathway to care. Providing educators and other stakeholders with the tools to educate their communities about autism will be a significant step towards the progress needed to transform the lived experiences of Nigerians with autism.

*Keywords:* autism spectrum disorder, explanatory models, Nigeria, Sub-Saharan Africa, help seeking, cultural beliefs

## DEDICATION

This thesis is dedicated to my cousin Zami who continues to inspire me every day.

## ACKNOWLEDGMENT

I would like to thank my advisor, Dr. Laura Johnson, for her support and guidance throughout my capstone project. I would also like to show my appreciation to the entirety of the NICE lab for their patience and advice. Additionally, I would like to thank my committee members, Dr. Carey Dowling and Dr. Grace Rivera, for providing me with their time and knowledge.

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## LIST OF ABBREVIATIONS

|      |  |
|------|--|
| ABA  | Applied behavior analysis                |
| ADHD | Attention-deficit/hyperactivity disorder |
| ASD  | Autism spectrum disorder                 |
| DALY | Disability-adjusted life years           |
| EM   | Explanatory model                        |
| IEP  | Individualized education plan            |
| OSS  | One stop shop                            |



## INTRODUCTION

Autism spectrum disorder (ASD) is a developmental disability that manifests in the form of atypical social behavior, language development, and interests (World Health Organization, 2019). Despite its mischaracterization in the past, ASD has become increasingly visible in Western society, such as in public discourse and in media (i.e. television shows and movies feature characters and actors with ASD). According to the Centers for Disease Control and Prevention (CDC) (2016), in 2000, 1 in 150 children were reported to have ASD, but now about 1 in 54 children in the United States are reported to have ASD, which suggests that the number of children being diagnosed with autism is on the rise in the United States. However, mischaracterization and significant under diagnosis are still prevalent in other parts of the world. Therefore, globally, many experience symptoms of autism without being understood, diagnosed, or properly treated by their communities. This increasingly common disability has a significant impact on diagnosees' lives, which researchers assess using DALYs (disability-adjusted life years). According to the World Health Organization (2020), DALYs are calculated by adding the number of potential years of life lost to premature mortality and the years of productive life lost due to disability. Baxter et al (2014) reported 7.7 million DALYs associated with ASD worldwide in 2010, suggesting ASD has a significant impact on lifespan and life experience. Therefore, the effects of ASD are not only significant but ubiquitous.

Victor Lotter was one of the first to characterize ASD by its key behaviors (Evans, 2013). With this experience, Lotter began to expand his questioning of abnormal behavior in children associated with ASD to wider populations. At the time, ASD was believed to be a Western

disease. Consequently, Lotter (1978) began to question whether autism extended to indigenous populations, particularly Africans, before finally concluding that ASD is prevalent in non Western populations as well. Since Lotter's initial research, it has become even more clear that ASD is prevalent in African populations, but inadequate research has limited academic understanding of how ASD presents in Africans, and its impact within the continent's varying communities. Jeffery Arnett (2008) found that in an analysis of psychology related developmental journals, publications from the United States accounted for over 90% of published findings, with the least number from the African region. Franz's (2017) findings on ASD research coincide with Arnett's report that North America and Europe lead in the number of publications about ASD with 11,569 and 7,577 respectively, numbers that far exceed Sub-Saharan Africa's 120 publications. Among these scarce publications, researchers have begun to investigate the lived experiences of the African autism community. Even with these small advancements in African ASD research, it would be impossible to ignore how overwhelming white and Western ASD research is, while the world is filled with an array of races, ethnicities, and cultural backgrounds. The narrow and exclusive research conducted in the United States has neglected the remaining 95% of the world (Arnett, 2008). As a result, Western literature dominates current discourses about ASD, and understanding about how ASD affects non-Western populations is limited. As pointed out by Arnett, the large majority of the world's children and youth come from Africa, Asia, and South and Central America. Children and families from such backgrounds are likely to have views and behaviors related to mental health informed by collectivist values, religious and/or spiritual beliefs, and informal or traditional care

seeking.

In non-Western nations, understanding autism is complicated by varying perspectives that do not always align with a Westernized notion of ASD as a biopsychosocial phenomenon. Most African nations, due to hybridization resulting from colonization, must mold Western knowledge, culture, religion, etc. with traditionally African ways of living. This hybridization also applies to how many African people define, relate with, and understand ASD. For example, in Sub Saharan countries like Nigeria, there is a specific cultural distinction between illness of the body and mind that implicates how people define illnesses and seek help (Patel, 1995). Therefore, in order to understand the sociocultural conceptualizations of ASD as it currently exists in Africa, specifically Nigeria, this paper will employ Arthur Kleinman's explanatory model framework, which asserts a connection between a person's beliefs and how their disability/sickness may be treated.

## CHAPTER I: THE PRESENT STUDY

Arthur Kleinman (1980) reconceptualized physical and mental disorders by drawing attention to the experiences of those with proximity to the disorder. In doing so, Kleinman coined the term “explanatory models” (EM) which has expanded our understanding of the relationship between the conceptualization of illness, help seeking, and health outcomes. Understanding the link between a person’s beliefs and their treatment is a key component of EMs. A person’s beliefs are born out of their culture, environment, and experiences. This is what makes the healthcare system a “cultural system” (Kleinman, 1980). In other words, the healthcare system has been shaped by the intersections of science and culture. Maybe the most significant addition of this model is its capability of incorporating local and traditional beliefs. Kleinman (1978) hoped to create new ways of talking about illness that were not exclusive and that did not require subscribing to biomedical interpretations of illness.

EMs are an important lense with which to examine the cultural context that informs the experiences of those with disorders like ASD. However, popularized Western EMs about autism do not seamlessly translate to African contexts. Therefore, this paper aims to understand 1.) How are the lives of families of those with ASD in Nigeria impacted? 2.) What are the social implications of having ASD in Nigeria? 3.) Once detected, how do parents of children with ASD address their child’s problems? 4.) What are some of the ways that Nigerians conceptualize and experience ASD that may be different from ‘standard’ Western notions and experiences? This study does not aim to be a comprehensive review of the literature on ASD in Nigeria but rather to (a) describe the conceptualizations and experiences related to ASD among Nigerians, (b) to explore how these factors impact help seeking and treatment, and (c) to identify common themes

in order to understand how to better support the Nigerian autism community and inform treatment policy.

*Methods and Analytic Strategy*

The research questions will be addressed via (1) a literature review; (2) organization of the material into Kleinman’s explanatory model; and (3) inclusion of case material gleaned from two key informant interviews.

**Literature Review.** This study used a variety of databases, including PsychInfo, Pubmed, and Scopus. A search strategy was developed by creating a concept chart (Figure 1). Article collection began after a preliminary search of each concept was conducted. The SPIDER tool (Sample, Phenomenon of Interest, Design, Evaluation, and Research Type)(Figure 2) was adapted and used as the primary search strategy. After completing this search, articles that did not include autism or similar pervasive disorders, African populations, and repeating articles were excluded. While examining these articles, a substantial number of additional articles from cited reference searching were selected. From the 40 articles collected 12 were retained.

| Concept 1                      | Concept 2   | Concept 3   | Concept 4          |
|--------------------------------|-------------|-------------|--------------------|
| autis*                         | Nigeria     | Qualitative | Explanatory models |
| Pervasive development disorder | Africa      | pheno*      | Arthur Kleinman    |
|                                | Sub Saharan | Interview   | Help seeking       |
|                                |             | Narrative   |                    |

Figure 1. Concept Chart



|                                       |  |
|---------------------------------------|--|
| <b>S - Sample</b>                     | “Nigeria*” OR “Africa*” OR “Sub Sahara*”<br>AND “autis*” OR “ASD” OR “pervasive<br>developmentaldisorder” OR “mental”                      |
| <b>PI- Phenomenon<br/>of interest</b> | “help seeking” OR “lived experience*” OR<br>“social meaning*” OR “illness experience*” OR<br>“treatmentseeking” OR “parent” OR “caregiver” |
| <b>D - Design</b>                     | “Questionnaire” OR “survey” OR “interview” OR<br>OR“focus group” OR “pheno*” OR “review”   |
| <b>E - Evaluation</b>                 | “belie*” OR “view*” OR “attitude*” OR “perce*”<br>OR“opinion*” OR “narrative” OR “feel*”   |
| <b>R- Research type</b>               | “Qualitative” OR “mixed method”  |

Figure 2. SPIDER

**Conceptual and Theoretical Framework.** After collecting the research articles that met the criteria, Kleinman’s explanatory model theory was used to create six categories: etiology and label, social and cultural meaning, seriousness and course, fears most, help seeking, and treatment (Figure 3). The literature will be analyzed using these categories.

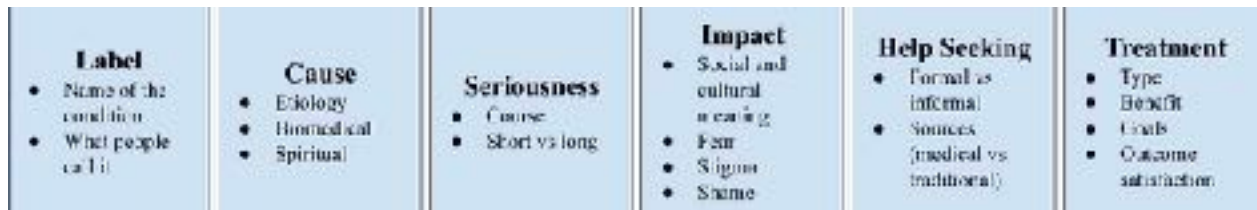


Figure 3. Kleinman’s Framework

**Case Study.** In the case study, 2 in-depth interviews were conducted - one with a Nigerian parent and one with a school director. The participants will be referred to as Parent 1 and Professional 1 respectively. Parent 1’s child is eleven years old and has been receiving the

current intervention since the age of eight. Professional 1 is a college graduate with varying experiences working with children with learning, reading, and intellectual disabilities. The identity of the participants will remain anonymous. After receiving their consent, the participants were asked a series of questions over Zoom. The questions (Figure 4) directly addressed the concepts explored by Kleinman and in this analysis. This process was approved by the University of Mississippi Institutional Review Board.

| <b>EM Factor</b>                   | <b>Parent/Caregiver Questions</b>  | <b>Provider Questions</b>  |
|------------------------------------|--|--|
| <b>Etiology</b>                    | What do you call your child's condition, what name does it have?<br>What do you think caused it? What is the most important cause?<br>Why do you think your child's problems started when it did?  | What do most parents/ caregivers call the condition of their child (autism)?<br>What do most parents/ caregivers believe are the causes of the condition?<br>What are the main precipitating events that lead to the recognition of a problem? |
| <b>Social and Cultural Meaning</b> | To what extent does the condition affect you? To what extent does the condition affect your child?<br>To what extent does the condition affect your family?<br>What is the main problem?<br>How has your child's condition affected your life? | What are the main ways the condition impacts the life of caregiver and family?   |
| <b>Seriousness and Course</b>      | How serious do you believe the condition is? How long do you think it will last?   | How serious is this condition perceived by families? Is it perceived to have a long or short course?   |

|                     |   |  |
|---------------------|---|--|
| <b>Fears Most</b>   | What do you fear most about your child's condition?   | What is the most worrying, concern, or fear that parents express about their child's condition?  |
| <b>Help Seeking</b> | <p>What kind of treatment do you think your child needs?</p> <p>How long did you experience problems before you sought help?</p> <p>Did you seek other help before coming to Ephphatha Academy Owerri?</p> <p>If yes, where did you go?</p> <p>What type of help/treatment did you receive? Do you still seek/ benefit from other sources of care?</p> <p>- Did that treatment lead to any improvements?</p> <p>- How satisfied were you with other treatments/sources of help?</p> | <p>Do most parents seek alternative help before coming here? What kinds of help? From where?</p> <p>What brings parents here? How do people find out about the school?</p> |
| <b>Treatment</b>    | <p>What type of treatment have you received here?</p> <p>- Has it led to improvement? Explain.</p> <p>What are the most important changes or benefits you hope to get from intervention?</p> <p>- How satisfied were you with that treatment?</p>   | <p>What type of services do you offer? What are the main interventions that the school uses? What benefits do families perceive to be most helpful?</p>                    |

Figure 4. Interview Questions

## CHAPTER II: Autism Spectrum Disorder

### *Autism Spectrum Disorder*

Academic understandings of autism have evolved as researchers learn more about ASD and its effects. The criteria for ASD diagnosis has expanded to include various pervasive developmental disorders and Aspergers Syndrome (level one ASD) (Center of Disease Control and Prevention, 2020). The American Psychiatric Association’s (2013) fifth edition of its Diagnostic and Statistical Manual of Mental Disorders (DSM-5) outlines distinct diagnostic criteria for ASD (Figure 5). While the DSM-5 is recognized in the United States, the International Classification of Diseases 10 (ICD-10), which is sponsored by the World Health Organization, is used to provide diagnoses in the rest of the world. The ICD-10 is recognized throughout the world while the DSM-5 remains popular primarily in the United States.

| <b>DSM-5 Diagnosis Criteria</b>   | <b>ICD-10 Diagnosis Criteria</b>   |
|---|--|
| A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history | <p>A. Abnormal or impaired development is evident before the age of 3 years in at least one of the following areas:</p> <ol style="list-style-type: none"> <li>1. receptive or expressive language as used in social communication;</li> <li>2. the development of selective social attachments or of reciprocal social interaction;</li> <li>3. functional or symbolic play.</li> </ol> |

|  |   |
|--|---|
| <p>B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history</p> | <p>B. A total of at least six symptoms from (1), (2) and (3) must be present, with at least two from (1) and at least one from each of (2) and (3)</p> <p>1. Qualitative impairment in social interaction are manifest in at least two of the following areas:</p> <ul style="list-style-type: none"> <li>a. failure adequately to use eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction;</li> <li>b. failure to develop (in a manner appropriate to mental age, and despite ample opportunities) peer relationships that involve a mutual sharing of interests, activities and emotions;</li> <li>c. lack of socio-emotional reciprocity as shown by an impaired or deviant response to other people's emotions; or lack of modulation of behavior according to social context; or a weak integration of social, emotional, and communicative behaviors;</li> <li>d. lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g. a lack of showing, bringing, or pointing out to other people objects of interest to the individual).</li> </ul> |
|--|---|

|   |   |
|---|---|
| <p>C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities or may be masked by learned strategies in later life).</p> | <p>B. Continued</p> <p>2. Qualitative abnormalities in communication as manifest in at least one of the following areas:</p> <ul style="list-style-type: none"> <li>a. delay in or total lack of, development of spoken language that is not accompanied by an attempt to compensate through the use of gestures or mime as an alternative mode of communication (often preceded by a lack of communicative babbling);</li> <li>b. relative failure to initiate or sustain conversational interchange (at whatever level of language skill is present), in which there is reciprocal responsiveness to the communications of the other person;</li> <li>c. stereotyped and repetitive use of language or idiosyncratic use of words or phrases;</li> <li>d. lack of varied spontaneous make-believe play or (when young) social imitative play</li> </ul> |
|---|---|

|  |  |
|--|--|
| <p>D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.</p> | <p>B. Continued</p> <p>3. Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities are manifested in at least one of the following:</p> <ul style="list-style-type: none"> <li>a. An encompassing preoccupation with one or more stereotyped and restricted patterns of interest that are abnormal in content or focus; or one or more interests that are abnormal in their intensity and circumscribed nature though not in their content or focus;</li> <li>b. Apparently compulsive adherence to specific, nonfunctional routines or rituals;</li> <li>c. Stereotyped and repetitive motor mannerisms that involve either hand or finger flapping or twisting or complex whole body movements;</li> <li>d. Preoccupations with part-objects of non-functional elements of play materials (such as their order, the feel of their surface, or the noise or vibration they generate).</li> </ul> |
|--|--|

|   |  |
|---|--|
| <p>E. 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 that expected for general developmental level.</p> | <p>C. The clinical picture is not attributable to the other varieties of pervasive developmental disorders; specific developmental disorder of receptive language (F80.2) with secondary socio-emotional problems, reactive attachment disorder (F94.1) or disinhibited attachment disorder (F94.2); mental retardation (F70-F72) with some associated emotional or behavioral disorders; schizophrenia (F20.-) of unusually early onset; and Rett's Syndrome (F84.12)</p> |
|---|--|

Figure 5. ASD Diagnosis Criteria

ASD's impact is exhibited through its effects on an individual's ability to communicate and thrive in social settings. In order to navigate social interactions, it is essential that people with ASD develop a toolbox of adaptive skills (Ben-Sasson et al., 2019). Creating this type of repertoire is often difficult and requires the assistance of professionals to ensure that these skills are not maladaptive. Additionally, this toolbox must include skills to confront sensory issues and natural responses to differences in sensory processing.

Effective intervention involves the cooperation of the family unit. Children with autism rely on consistency and routine, but even typically developing children cannot accomplish this alone. The family is an integral part of establishing routine. Therefore, both the child with autism and the family suffer when the routine is non-existent or disrupted (Factor et al., 2019). Although these routines allow families to create a comfortable environment, children with autism may find difficulty navigating new and challenging social situations. While creating routines can be an example of resilience, avoiding social outings and hiding behind those routines can be a sign of avoidance and poor coping skills. Expanding from previous research, Gunty (2020) has found



that family resilience is not only an important factor in how interventionists should address treating families and their children, but also family resilience has a direct relationship with the family's environment. The struggles of a child with autism are a joint venture experienced by the child and their family.

There are multiple treatment options to address the symptoms of autism and teach those with ASD daily living skills. The CDC (2019) recommends a combination of behavior and communication approaches and provides resources about dietary approaches and medication. Applied behavioral analysis (ABA) is a notably efficient and popular behavioral approach in the field. ABA is known to improve language acquisition, social skills, and overall quality of life (Axelrod et al., 2012). Although autism does not have a cure, this type of intervention, early in life, is essential to addressing its symptoms.

#### *Autism in Nigerian and Sub-Saharan Africa*

Since Lotter et al.'s original explorations of autism in Africa, ASD literature across the continent has slowly expanded; however, the number of services available is increasing at an evenslower pace. Although the advancement of Western autism literature has improved intervention approaches in the United States, research serving the rest of the world is underdeveloped (Elsabbagh et al., 2012). Firstly, many Western forms of intervention and diagnostic tools are not only impractical but also costly (Ruparelia et al., 2016). Secondly, according to Oshodi (2019), although Africa is a diverse continent, many countries face the common issue of scarce resources. Finally, in most African nations, there is no or limited policy to support families in need of medical intervention (Oshodi, 2019).

In Nigeria and similar countries, the responsibility of paying for health care is most commonly left to families (Adeniyi & Adeniyi, 2020). Less than 5% of Nigerians have access to health insurance with the majority of that population relying on the National Health Insurance Scheme and others relying on local solutions (Pharmacces, 2016). In addition to funds, the Nigerian health care system is lacking another very important resource: health care workers. Nigeria's most glaring problems are poor coordination between the public and private sectors and the inconsistency of healthcare workers (Global Health Workforce Alliance, 2010). These issues are amplified in rural settings. For those who choose to seek health care outside of Westernized medical settings, they must agree to take on considerable risk. A Nigerian study reported that about 75% of those selling traditional herbal medicines are not licensed to do so (Awodele et al., 2014). Without proper regulations from the Nigerian government, there is no way to guarantee the safety and legitimacy of these traditional medicines.

The Nigerian government's inadequacies in supporting children with ASD manifest in various ways. Nigerian government officials report that mental health policy is not a priority, which is evident in the country's lack of state-level mental health desk officers and outdated, nonfunctional existing policies (Abdulmalik et al., 2016). With this level of dysfunction, the existing mental health policies are not an asset to people with ASD. Additionally, the Nigerian special education sector has not been exempt from the mismanagement of funds and corruption that is common in Nigerian government and nongovernmental programs alike. Section 8 of the National Policy on Education suggests for schools to make accommodations for special education, but the government has not set standards to uphold this policy or authorized the

enforcement of this policy (Obiakor et al., 2012). Without the backing of the government, many special education programs that should be supporting the ASD community are not inappreciable but are not meeting the current need.

A major consequence of the neglect of the ASD community in Africa is that researchers have been unsuccessful in establishing a consensus on the prevalence (Elsabbagh et al., 2012). The inconsistencies between reports can most likely be explained by the infrastructure problems in most African healthcare systems. Research examining African immigrants outside of the continent suggests that the prevalence of autism in African populations is significant (Bakare & Munir, 2011). A study conducted in the Democratic Republic of the Congo concluded that, similar to the United States, diagnosing boys with autism is more prevalent than diagnosing girls (Mpaka et al., 2016). This research suggests that autism persists in the same way in African populations that it does in the well-researched American populations. Although the prevalence of ASDs in Africa is controversial, it is clear that the potential impact of ASD on African populations is larger than assumed. The estimated DALYs for ASD in west Sub Saharan Africa was reported to be 58.2 per 100,000 in 2010 (Baxter et al., 2014). While this rate is consistent with global rates, it does not account for the undiagnosed ASD cases in the region.

## CHAPTER III: KLEINMAN'S EXPLANATORY MODELS

### *Kleinman's Explanatory Models*

The strength of Kleinman's model comes from its ability to reconcile cultural misunderstandings between the clinician and the patient and to build trust and empathy through a patient-clinician "therapeutic alliance" (Weiss & Somma, 2007). This alliance is cultivated by illuminating the identification, conceptualization, and help-seeking pathways of an illness/problem as experienced by the patient. Understanding the impact of these factors is the key to understanding the lived experiences associated with any disorder. Particularly, this line of questioning can be used to grasp the cultural and social meaning of a disorder. Kleinman's (1978) goal was to create a model that could directly translate to a clinical line of questioning. For example, questions like, "How severe is your condition?", can directly address a key component such as severity.

| Questions  |
|--|
| <ol style="list-style-type: none"><li>1. What do you think caused this problem?</li><li>2. Why do you think it started when it did?</li><li>3. What do you think the problem/sickness does to her?</li><li>4. How severe is the problem? Do you think it will last a long time, or will it be better soon in your opinion?</li><li>5. What do you think are the chief problems this issue has caused her?</li><li>6. What would you fear most about this problem?</li><li>7. What kind of treatment do you think she should receive?</li><li>8. What are the most important results she should hope to get from treatment?</li></ol> |

Figure 6. Kleinman's Questions

Since the development of EMs, Kleinman's model has been able to ameliorate professional and academic interpretations of illness while making strong implications for care.

The Explanatory Model of Illness Catalogue and the Short Explanatory Model Interview, from Kleinman's original research, created assessment tools which assessed patients' conceptualizations in research settings (Dinos et al., 2017). In addition, The Barts Explanatory Inventory Checklist was created to assess explanatory models in the clinical setting, using varying direct and indirect techniques to examine perception and help seeking behaviors (Rüdel et al., 2009). The success of these tools suggest not only that Kleinman's theory has practical applications, but it has had a notable impact on how academics evaluate relevant cultural components of care. Kleinman's research has also inspired the adoption of multiple culturally competent training practices in the psychiatric field. Specific additions to the DSM-V, including the cultural formulation tool, have given practitioners protocols to document and organize important patient cultural information, improving previous guidelines with no standardized cultural assessments (Dinos et al., 2017).

Kleinman's research has been able to remain relevant due to its pragmatic and versatile nature. Although Kleinman initially hoped to apply EMs to facilitate his work on depression in China, Kleinman's theory has been used to explain the cultural context of multiple conditions including schizophrenia. However, since its conception, researchers have applied its principles to research that has broad implications for coordination of care. For example, Bussing et al (1998) made a significant contribution to the literature on attention-deficit/hyperactivity disorder (ADHD) by using EMs to describe differences in how African Americans and people with other minority statuses experience ADHD. This research found that African American parents were more likely to view ADHD as a behavior problem rather than a medical problem, which made them less likely to pursue medical solutions. Informing the trajectory of this paper, Patel (1995)

has made similar conclusions while conducting research in Sub-Saharan Africa, asserting that conceptualizations of mental illness based in spirituality has led Africans to put an emphasis on atypical behaviors associated with mental health issues. This interpretation of mental illness often does not quantify mental health symptoms as such but rather an expression of differing internal issues. Considering that many Africans do not identify mental health issues as mental health issues has important implications for mental health research and epidemiology work in the continent. Using EMs to draw these types of conclusions makes way for practitioners to become more culturally competent and leaders to make more informed recommendations.

### *Important Components of Explanatory Models*

The research necessary to produce explanatory models of autism in the Western world is already robust. The pathway to care begins with beliefs about the cause of ASD. Although the cause of ASD is controversial and unclear, researchers have pointed to a few significant factors. In a recent review, Waye & Cheng (2018) emphasize that even though research has pointed to environmental, biological, and genetic factors, it would be misleading to suggest that any of these factors act in isolation. Although academia has not been able to decipher a cause of autism, through peer review and empirically based research, researchers have adequately challenged niche beliefs including claims that autism is caused by vaccinations (DeStefano, 2007). Beliefs that autism is caused by vaccines is an example of how a belief can direct the path of care of an individual, especially if the belief is rooted in distrust.

Research suggests that a combination of stigma and challenging behaviors are the most significant players in causing life difficulties among parents of children with autism (Kinnear et

al., 2016). Notably, Kinnear et al found that a major component of autism-related stigma is the perception that the parents of children with autism are simply incompetent, or the child's atypical behavior can be explained by poor parenting (Kinnear et al., 2016). Fear of these types of judgments can be damaging to the parents' confidence and social life. Parents who experience intense internalized stigma often also experience symptoms of anxiety and depression (Öz et al., 2019). But with support from their community, families may be able to avoid some of the negative emotions associated with being a stigmatized community. The unique social context created by a family's relationship with the public, school, friends and peripheral family members dictates how said families experience feelings of stigmatization (Broad et al., 2017).

Multiple studies have found correlations between beliefs about autism and treatment sought. Dardennes et al (2011) found that women who believed that their child's autism was caused by trauma sought behavioral therapy, and those who believed that autism was caused by their actions sought to address it through medicine or supplements. This research adds to the literature suggesting that beliefs are a predictor of treatment.

## CHAPTER IV: EXPLANATORY MODEL OF ASD IN NIGERIA AND SUB-SAHARAN AFRICA

### *Etiology and Label*

**What do Nigerians call ASD and what do they believe causes it?** Firstly, autism and similar conditions have negative perceptions starting from how people describe and define them. In the Yoruba culture and language, people with autism are often referred to as “didirin” or “akuri” which can be translated to idiotic and insane (Obiakor et al., 2012). “Olukun” is another word that is commonly used to describe people with intellectual disabilities which roughly translates to “slow”. These names, similar to the use of “retard” in the United States, are not only damaging but are a constant reminder of how people with disabilities are seen as less than in society. These negative associations with pervasive developmental disorders guide how people interpret the disorders.

The meaning of autism varies depending on people’s understanding of its etiology. The prevailing belief in most African countries is that autism has roots in biology or supernatural persuasions. Belief in the supernatural is a significant component of most traditional African cultures. The common theme among these cultures is that everything has a cause and everything happens intentionally (Patel, 1995). This has led many to believe that illness is never or rarely a coincidence, and it is more likely to be an act of divine intervention or evil entities. Notably, evil is interpreted as being deliberate and often an active attack in Nigerian culture. While navigating care for people with autism, Nigerians may not consider it a disorder, but rather an actor in spiritual warfare that the whole family must confront. Although these beliefs do not seem to fit in a Western framework, many Nigerians have been able to maintain these beliefs while also adopting a scientific perspective. Belief in generational curses are not reserved for people who



believe solely in traditional African religions. Religious syncretism is a significant aftereffect of colonialism. Ideas about generational sin have been molded to fit a Christian context and have been preserved in Nigerian society.

A major theme within West African cultures is that there is something or someone to blame for an unwanted condition. As discussed, this manifests in deeming evil forces responsible but also implicates family members. For instance, many people, particularly in Ghana, believe that intellectual disabilities are caused by the behavior of the woman during pregnancy (Kpobi & Swartz, 2019). This blame can vary from biological explanations, such as something the woman ate, to implications that the woman committed some spiritual wrong doing. The responsibility placed on women for their child's condition has a significant impact on how the woman and her child are viewed within her community.

These beliefs are not isolated within lay people or even in rural communities. In a study conducted by Bakare et al (2009), he found that, in a sample of Nigerian healthcare workers, more than one fourth of participants believed that autism stems from supernatural causes. These perceptions of autism profoundly impact how people with autism and their families navigate their community.

### *Social and Cultural Meanings*

**For those impacted by ASD, how does it affect their lives? How does stigma and shame impact their experiences?** The way that Nigerians label and explain autism has direct effects on the daily lives of people affected by ASD. The specific social and cultural implications of raising a child with autism in Nigeria consequently leave parents grappling with damaging stigmas and shame. Children experience stigma in a way that is unique from their parents,

because their experience is shaped by how their parents navigate the challenges presented by raising a child with ASD and obtaining resources for that child (Oshodi et al., 2019). One of the most significant stigmas that follow families with children with autism is that the disorder is proof of damage in a family's bloodline. Ulofoshio (2018) reported the testimonies of Nigerian mothers who are parenting children with ASD, and those mothers echoed this anxiety of being unable to maintain the reputation of their "family line". Cultural beliefs about the significance of family lines make this stigma even more damaging. For example, in the Igbo tradition, before a man is to marry a woman, he is to seek out the lineage of her family that must be approved by the family and God (Chukwuma et al., 2017). Evidence that there are family members with mental illness or disabilities would be a red flag in this process, which has led many families to attempt to protect their children with ASD and their family from scrutiny. This fear of autism damaging the whole family's reputation can be explained by the concept of courtesy stigma. Courtesy stigma can be described as the discrimination that extends to other family members and proximal loved ones (Oshodi et al., 2019).

Fear of this stigma has been the root of deep feelings of shame and embarrassment within African families within the autism community. In a study of Ethiopian parents, 45.1% of parents reported feeling ashamed or embarrassed of their child's disorder, and 24.6% felt the need to hide their child (Tilahun et al., 2016). Hiding children with disabilities is common within most African communities, which some believe to be a relic of colonialism and the anti-disability rhetoric that was enforced during the development of Nigeria as an independent nation (Obiajoret al., 2012).

**Do Nigerians interpret ASD to be serious? How do they experience the course of the disorder?** Sometimes cultural stigmas prevent parents from accepting the seriousness of their child's condition. Nigerian parents often mischaracterize the severity of their child's behavioral and emotional problems, often claiming that their children should not be isolated with other children with developmental disabilities (Adeniyi & Adeniyi, 2020). This reaction usually stems from a belief that other children with disabilities will be a bad influence on their children. This belief is not completely unfounded because research suggests that people with disabilities benefit from being integrated into classrooms with typically developing children (Buysse & Bailey, 1993). American leaders in this space are still navigating what that will look like (Rodriguez & Garro-Gil, 2015). Perception of severity can also be guided by animated physical symptoms. The seriousness of ASD symptoms can often be overshadowed by attention grabbing comorbidities like epilepsy (Oshodi, 2019). Despite the tendency of many parents to prioritize only a few symptoms of ASD, there is a general understanding among African parents that ASD is austere, and its course is lifelong. A Ghanaian examination of explanatory models concluded that parents measure the severity of their child's intellectual disabilities based on their ability to assimilate into social settings (Kpobi & Swartz, 2019). This finding suggests that parents' interpretation of severity is grounded in how the disorder affects their family and how they must alter their behaviors and social life to accommodate their child.

The course of ASD begins with a diagnosis, but this step is daunting in the Nigerian healthcare system. Unfortunately, many Nigerian healthcare workers are not equipped to diagnose ASD. Failure to diagnose autism has been linked to stigma and ignorance of healthcare

professionals (Oshodi et al., 2017). A study exposed that in a sample of final year medical students over 70% had not been exposed to autism (Bakare et al., 2015). Additionally, the majority of students were not familiar with signs of autism like abnormal eating, absence of social smile, regimented behaviors, and non-specific gaze focus (Bakare et al., 2015). Failure of medical personnel to diagnose ASD early can be damaging and delay the child's success. Beyond diagnosis, African parents must adapt to accommodate their child. Consistent with research done on Western populations, African populations have been found to have a better quality of life when their family unit prescribes to a routine (Schlebusch et al., 2016).

### *Fears and Worries*

**What do Nigerians fear most for their children with ASD?** The most common fear of families with children with ASD is social ostracization. Many families hide their children at home in fear of the discrimination their child could face in public (Chukewueloka, 2016). This discrimination could vary from mocking to physical exclusion. Fear is not reserved for only how their child is perceived but also how their child is treated. Children with autism are often at risk of abuse. Multiple Nigerian mothers fear physical and sexual abuse of which their children could easily become a victim (Ulofoshio, 2018). In the United States and globally, there is insufficient research on the prevalence of sexual abuse among children with ASD, but evidence does suggest that people with ASD's poor understanding of social interactions puts the ASD population at risk of abuse (Sevlever et al., 2013). This risk is elevated in non-verbal populations who can not voice their abuse. In addition to these fears related to well-being, a study reported that the primary concern of Nigerian parents is that their child will not acquire communication skills

(Oshodi et al., 2017).

### *Help Seeking*

**Do Nigerians believe treatment is necessary for ASD? Where do they go?** Due to the rural landscape and underdeveloped social services of Nigeria and similar African nations, seeking help is a complicated venture for Nigerian parents. Most commonly, care for children with ASD is received from “faith-based organizations and mainstream schools” (Adeniyi & Adeniyi, 2020). These resources can look very different depending on the region and the financial capacity of their occupants.

The persistence of traditional African religions has led many parents to spiritual healers. Help seeking behavior and etiology are linked, therefore spiritual problems tend to have spiritual answers (Bakare et al., 2009). In an Ethiopian study, the majority of parents admitted that they sought “traditional” resources first when they were confronted with their child’s symptoms of ASD (Tilahun et al., 2016). Similar healers are popular in Nigeria and can provide hope to families seeking intervention. In Nigeria, there are specific traditional healers that identify and treat mental disease (Patel, 1995). When diagnosis is left to traditional healers, it is less likely that that diagnosis is scientific and even less likely that the parents will find empirically backed solutions. Although not all of these solutions will necessarily have negative outcomes, the extremes taken by spiritual leaders to cure children with autism have been known to result in death (Chukewueloka, 2016).

### *Treatment*

**Do Nigerians affected by ASD seek varied sources of care? What do these treatments look like?** Some caregivers resort to attempting to control their child rather than

truly treat them. Chaining is not the most popular practice among parents, but about 9% of parents in an Ethiopian study reported using the technique (Tilahun et al., 2016). Reports of this practice are echoed by the testimony of a Nigerian mother in interviews conducted by Ulofoshio (2018). Restricting children's movement is not unique to African cultures. In the United States, autism activists have fought to extinguish the use of dangerous methods to control behavior, such as prone restraint that requires the patient to lay face down and risk affixation.

There are a limited number of autism specialists living in Nigeria. The CDC (2019) recommends that children with ASD should receive a combination of behavioral therapies, speech therapy, occupational therapy, social skills training, and even assistive technology (such as communication tablets). These fields are underdeveloped in Nigeria. For example, there have been multiple failed attempts to develop occupational therapy programs in Nigeria that have been explained away by lack of training resources and the professional brain drain in Nigeria (Eleyinde et al., 2012). This reasoning is sound but does not excuse the gap in care. Without thriving occupational therapy programs, there are not enough therapists to meet the needs of the Nigerian population, and those seeking training must travel abroad.

While medical and traditional treatment can be useful, teachers are responsible for the daily task of teaching and maintaining appropriate behaviors. The special education sector in Nigeria has been expanding in recent years. Some schools have been able to provide assistive technology to children with intellectual disabilities, but many of these programs have been only partially successful due to poor teacher training and failing electricity reliability throughout the country (Ajuwon & Chitiyo, 2016). Despite these shortcomings, this sector with daily access to

children with ASD have the ability to create promising improvements in the lives of their students.

## CHAPTER V: CASE STUDY

### A Parent and Professional from Ephphatha Academy

Ephphatha Academy in Owerri, Nigeria is one of the only schools in the area that celebrates neurodiversity. The school welcomes elementary age students into a program that incorporates special education principles in order to support children with autism and related intellectual disabilities. Specifically, the staff designs Individualized Education Programs (IEP) for each child to ensure that each child is receiving the individualized care necessary for them to succeed academically and in their personal lives. Uniquely, the school does not segregate the children based on their disabilities or lack thereof.



Figure 7. Class presentation at Ephphatha Academy





Figure 8. Teachers and students sing call and response gam

### ***Etiology and Label***

Parent 1 was not completely convinced that her child has ASD. She felt that even though his speech was delayed and he has shown other signs of ASD, because he can now speak and is gaining academic skills, he has overcome much of the “problem.” She reported reading books and watching videos online that have led her to a new diagnosis, dyslexia. She seemed to come to a conclusion because she now interprets his main problem to not reading at his age level. Notably, she originally said she did not know the cause of ASD, but then she later admitted that she sometimes wonders if a medication she took in the first 3 months of pregnancy caused the disease. Professional 1 further elaborates that within her school’s community parents have come to understand what autism is and label it as autism. Within the community, beliefs about what causes autism varies.

| Informants             | Quotes   | Themes   |
|------------------------|--|--|
| <p><b>Parent 1</b></p> | <p>“I would not say that he is pure autism. Do you understand. Because he can communicate... Dyslexia, he finds it difficult to read and understand.”</p> <p>“It was because I started consulting books about certain behavior I witnessed or experienced... that pushed me into hyper activity, dyslexia, and all the rest of them.”</p> <p>“When I gave birth to him and started noticing all of these things, my mind normally go back to that drug, who knows during that time of formation because most doctors don’t give that sort on injection, because if the baby wants to go out let it go be aborted, the fetus so to say. But my mind kept telling me, maybe because of that drug something must have gone wrong, hence his formation stage... It might be the cause of all this because we don’t have such history around us.”</p> | <p>Uncertainty about diagnosis</p> <p>Evolution of beliefs</p> <p>Caused by action</p> |

|                       |   |  |
|-----------------------|---|--|
| <b>Professional 1</b> | <p>“They would all call it autism... but you know we are in Africa, and nothing happens ordinarily. So for some of them it’s something from the village. It's somebody that said something, somebody has done something”</p> <p>“Quite a number of them blame themselves... I didn’t eat right. Some things they blame themselves. I gave inoculation at birth... So because of that after the autism is noticed and diagnosed the parents don’t like to give them inoculations... So we are still trying to break that myth that vaccines cause autism.”</p> | Social or SelfBlame (including vaccination ) |
|-----------------------|---|--|

***Social and Cultural Meaning***

Parent 1 explains that she felt unable to seek support in her community in fear of judgement. Professional 1 echoes this by describing how the autistic parents in her community often avoid social settings that put their child in a vulnerable position. People who are not familiar with autism might interpret the children as being crazy or disobedient.

|                 |  |   |
|-----------------|--|---|
| <b>Parent 1</b> | <p>“I’ve never gone out to discuss this issue with anybody, even my friends.”</p> <p>“The reason why I decided not to tell people is because that stigma... for them not to use it... for them not to make jest of me or the boy... most times I don’t really allow people to come to my house... so that they will not say, ‘Hey! This woman’s child’.”</p> | Shame, stigma<br><br>Failing to meet social norms |
|-----------------|--|---|

|                                  |   |  |
|----------------------------------|---|--|
| <p><b>Profession<br/>all</b></p> | <p>“We’ve had some parents of neurotypical children come in, see children with autism, especially them who have autism and attention deficit disorders you know combined, and they wonder why we have mad people in the school.”</p> <p>“She has taught her child to sit still in church... but she says apart from church she usually doesn't go anywhere else because she doesn't want anyone to talk down to the boy or bully the child.”</p> <p>“Well you know here it takes a village to raise a child, and you know whoever [in public] is going to reprimand that child doesn't know he is working through issues... The person will reprimand that child based on their size or their age and not understand that there is something else the child is going through... It's everybody's right to correct, to reprimand... so instead of putting your child in that situation or instead of you having to explain to everybody he is not a neurotypical child, no no he is just having a meltdown, it will get better, it's better to keep the child home.”</p> | <p>Seen as crazy/”mad”</p> <p>Social isolation</p> <p>Fear of social reprimand/ bullying</p> |
|----------------------------------|---|--|

*Seriousness and Course*

Parent 1 compared her child to the other children at the school when asked to consider the seriousness of her child’s disorder. She insisted that because her child can now speak, his

condition is not as serious. Although Parent 1 one expressed a lot of optimism about her child’s condition, Professional 1 explains that many of the parents coming to her school don’t expect her staff to make significant efforts to reform their child’s behavior and expect the child to remain the same throughout their lives.

| <b>Informants</b>     | <b>Quotes</b>  | <b>Themes</b>   |
|-----------------------|--|---|
| <b>Parent 1</b>       | “When I look at kids in that school.. I knowthat maybe he may have what is called dyslexia... because he can communicate.”   | Perceived seriousness fluctuates based off symptom presentation |
| <b>Profession all</b> | “For most people they don't believe that thechild will overcome. It actually shocks them... For many, they just think that they are dashing you school fees... When they begin to see improvements, they are gingered to start working at home..... Most of the parents see it as a lifelong thing.” | Long term condition   |

***Fears Most***

Parent 1 explains that before her child’s improvements, she feared that he would become a “public boy.” She despised the idea of her child doing odd jobs at a low rank in society. She later expresses that she genuinely believes that he can become a physician or an engineer.

| <b>Informants</b> | <b>Quotes</b>  | <b>Themes</b>                            |
|-------------------|--|--|
| <b>Parent 1</b>   | “When he was young... I was afraid. I had that fear: how I could give birth to a public boy. All in the sense, those kinds of people. Come wash my | Social ostracization andlimited economic |

|  |   |   |
|--|---|---|
|  | car for me. Come do this, you know? Those types of people who normally go on the freerange that people use anyhow.” | opportunity<br>Poor treatment bythe community |
|--|---|---|

***Help Seeking***

Parent 1 first noticed differences in her child when he did not learn to walk at the typical rate. Once he also did not gain linguistics, she sought the help of her child’s pediatrician who assured her that her child is fine. He notably did not mention the potential of a developmental disorder like ASD. After sending her child to the school that she sent her other children, she realized that the school was not equipped to address his behavior problems and speech delays. She does seek religious comfort at home, but ultimately finds refuge in the school her child currently attends. As experienced by Parent 1, Professional 1 explains that her school is normally not a family’s first stop on the pathway to care. People often come after having negative or unproductive experiences at religious institutions and schools lacking special education programs. Notably, there is not a resource in the town to give an official diagnosis.

| Informants | Quotes | Themes |
|------------|--------|--------|
|------------|--------|--------|

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|------------------------|--|--|
| <p><b>Parent 1</b></p> | <p>“We tried going to the hospital to ensure that whatever they said is supposed to cut off beneath the tongue. They said that he will talk and all the rest of them”</p> <p>“He said all children are not the same, he doesn't have any problem.”</p> <p>“When I dispelled my fear was when I went to the hospital to ask them if there was any problem.”</p> <p>“Before this time the former teacher was not taking care of him they didn't even take cognizance of his problem that he has a kind of personality problem or what it may be called. I don't know... At times, they would flog him. Whenever he comes back, we would see some strokes of cane on his body. We would ask him, but he could not talk. What I would normally do is go to the school to whip up sentiment... Is it his fault that he cannot do this, do that?”</p> <p>“That didn't make me start to go to one prayer house or another. We were just there praying to God that God will restore him... I've never for one day taken him to any of these.”</p> <p>“[Around 8 years old] a teacher from that [former] school visited our house, and there was no light... the teacher now realized that he had problems that we can't even understand. She called my attention and said there is this school.”</p> | <p>Local physicians have limited knowledge of ASD and symptoms</p> <p>Isolation in regular school system</p> <p>Physical abuse</p> <p>Prayer houses are frequented</p> |
|------------------------|--|--|

|                            |  |  |
|----------------------------|--|--|
| <p><b>Professional</b></p> | <p>“I have one who kept going from prayer house to prayer house from prayer house to prayer house and didn't know what it was until she came here... [I told her] Set your mind. No one did anything to anybody. Have you heard of this word before? She had never heard of it ... A few days later, she came back, and she said it was just like the article I gave her was talking about her child. I said, okay, early intervention is the key. You've spent the last 7 years of this child running from pillar to post looking for the enemy that is non-existent. Don't you think it's time to start helping your child... We are on a pathway to help”</p> <p>“I noticed that in this town, this particular town, we really don't have anyone that can give diagnosis for autism, so we are doing the best we can with the limited knowledge we have... We still need help, doctor wise, this part of the world.”</p> <p>“Many of them don't start school on time... Some of them are in school but are only in school because their siblings are going to school... The child doesn't do any learning. They just leave the child in a classroom until it's time to come back.</p> | <p>Nowhere to get an official diagnosis</p> <p>Initial help seeking largely tradition and or religious (based on witchcraft)</p> <p>Delayed and inconsistent schooling</p> |
|----------------------------|--|--|

**Treatment**

Parent 1 attributes her child's success to the specialized attention he gets at school and the suggestions of the school staff. Professional 1 details popular resources that people in her



community use to find advice and treatment options. She goes on to reveal how a local psychiatrist is treating ASD and what practices she is implementing to intervene within her school.

| Informants             | Quotes   | Themes   |
|------------------------|--|--|
| <p><b>Parent 1</b></p> | <p>“If we started working with this school before this time, maybe he would have improved more than this, but thank God we were able to detect this school.”</p> <p>“Some were suggesting supplements... to help with brain development... the school mama advised us not to give him sugar.”</p> <p>“Rosemary leaf... We normally use that for him... They said it works on cognitive abilities... When you don't eat well, I don't think that the brain will function effectively”</p> <p>“Wherever I am, if I witness any abnormal behavior, abnormal disposition, by any of the children around me, I will tap the mother and say what are you doing about these kids. I thank God many of them have started attending the school... I am an advocate of people with certain problems because of what I have witnessed because of what I have seen.”</p> | <p>Use of supplements</p> <p>Satisfied with care at Ephphatha Academy and refers others in the community</p> |

|   |  |   |
|---|--|---|
| <p><b>Professional</b><br/><b>1</b></p> | <p>“Most of them have doctors they see at the medical center.. One or two of them don't use doctors but spend a lot of time with these supplements... Youknow we are praying people here. All of them are praying one way or another... Social media [is suggesting the supplements]... There are lots of groups on social media on WhatsApp, on Facebook and most of the parents especially the mothers are in one autism group or another and they are always banding supplements.”</p> <p>“I had one doctor come in here to talk with me... askme what I knew about autism... She said she's beginning to see more cases of autism in her clinic. She's a psychiatrist. She just wanted to have a first hand view of what typical characteristics we see here... and see what she can add to it because what she had been doing is giving them drugs for ADHD most of the time.”</p> <p>“So we start them off with just basic things, learning to write, learning to play, learning to work with other people, learning to take turns, learning to sit down when they are supposed to sit... potty training..... We found that with children with autism... you are</p> | <p>Lay use of social media and supplements</p> <p>Psychiatric use of ADHD medication</p> <p>Life skill training at Ephphatha</p> <p>Use of IEPs atEphphatha</p> |
|---|--|---|

teaching practical life skills. You are teaching social skills and regular school work.”

“We are teaching them fine motor skills... so we give them work like put garri in a bowl, dry garri, you don't put any water in it and give him a wooden spoon and let

him turn, so he can build muscle. Allow him to play with modeling clay, practicing and squishing it. Make modeling clay at home or just make soft eba to allow them to use their hand and squish it... getting them ready

for writing.”

“We have an IEP for each of them.”

## CHAPTER VI: DISCUSSION

### *Discussion*

ASD is a poorly researched disorder across the African continent, but in the face of this neglect, local autism communities have shown resilience. They have been the recipients of flagrant attacks from community members with little understanding of the disorder. This has evoked a fear response that is maintained by stigma and shame, but with the help of passionate autism activists, families have been able to find places to seek help for their children and their families. This paper highlights this pathway to care that many Nigerian parents must walk, by adopting Arthur Kleinman's theory of explanatory models.

The present explanatory model of ASD in Nigeria offers insights to the Nigerian pathway to care. Strikingly, the literature and accounts of the informants suggest that traditional beliefs in witchcraft and wrongdoing perpetuated by community members, often lead help seekers to prayer houses. There is almost no research on the means taken in these prayer houses, and how these efforts have positively or negatively impacted the ASD community. In the experience of Professional 1, parents are often able to put aside these beliefs when presented with information about autism. This has demonstrated a deep need to expose Nigerians to the word "autism" and the symptoms associated with it. Currently, people with ASD are clumped together with groups of varying disabilities by cultural terms that equate to stupid or crazy. These negative connotations lead to extreme stigma and shame. The literature and informant accounts detail hiding and isolation in fear of social repercussions. Labeling and social meaning are intertwined concepts that inform each other. Their relationship has consequently led people with ASD to religious/traditional solutions or attempts to hide the problem completely, neither of which have

evidence of helping people with autism. This labeling issue has serious implications for where and how people seek care.

Parent 1 expressed multiple ideas about what her child's condition may be called or what caused it. This phenomenon of evolving beliefs is cited in the EM literature. It is common for people to hold multiple beliefs about a condition at the same time, especially while in the process of getting a diagnosis (William & Healy, 2001). The lack of diagnostic resources in Owerri and similar Nigerian communities can leave parents in a continuous state of changing beliefs about ASD or their child's condition. Although this fluidity is not inherently negative, this instability can lead to the need to repeatedly seek out new forms of help and answers. This can be demonstrated in what the informants describe as reliance on supplements often promoted by questionable sources prophesying pseudoscience. Without regulation of these supplements (Awodele et al., 2014), there cannot be clear evidence of their validity.

When people with ASD decide to turn to health care professionals for answers, their knowledge of the disorder is likely to be limited. The literature suggests that medical schools in Nigeria have failed to expose their students to autism and its symptoms. This aligns with the experience of Parent 1 who brought her child to a pediatrician when she began to notice delays, but the doctor did not mention the possibility of any pervasive disorder. Other professionals, such as speech and occupational therapists, are unavailable in most parts of the country limiting the support provided to the ASD community (Adeniyi & Adeniyi, 2020). Considering that most parents send their children to school, teachers are often the first one's to confront a child's ASD symptoms. According to the informants, lack of understanding of ASD in schools has led to abuse of corporal punishment and almost no advancements in behavior or coping skills of

children with autism. Since there is limited research on the ASD experience in the school setting and special education sector, expanding this research may point to a way to eliminate abuse and direct children with ASD from school to further care.

This path often begins with the identification of an irregularity or evidence of atypical behaviors. Throughout the literature and in the experience of the informants, speech delays were the most alarming and clear indicator that a child may have some type of health issue. Creating a link between speech delays, other key symptoms of ASD and autism may be the key to equipping medical professionals, teachers, and lay people with the knowledge to identify and understand autism. Kleinman's line of questioning revealed that ignorance and fear are not just preventing people with ASD from seeking help, but are preventing the professionals around people with autism from providing it. This is not to say cultural beliefs cannot coexist with empirically backed beliefs, but rather to suggest that Nigerian professionals have not been given the knowledge to incorporate both understandings. Kleinman's theory emphasizes the importance of the relationship between clinicians and patients, and these findings echo the need for the two groups to work together. Despite Kleinman's analytic strategy's sufficient academic support and relevance in this paper, there are a few limitations.

**Limitations.** Although it is common and sometimes appropriate to make generalizations across the African continent, these generalizations can sometimes hide the true extent of research gaps. Most of the research conducted about autism in Africa comes from South Africa, Nigeria, and Kenya (Franz et al., 2017). Not only are there significant cultural, political, and historical differences between African nations, Nigeria can be characterized by significant regional and

religious differences. We've discussed specific cultural aspects of the Yoruba and Igbo traditions, but there are countless additional cultures in Nigeria, and there are even regional dialects and sub cultures of the previously mentioned tribes.

Much of the research conducted on Nigerian parents and their children with ASD is limited. Notably, research samples have often excluded poor and non-english speaking families (Chukewueloka, 2016). The perspectives provided in the present case study also come from educated english speakers. Although this bias is mostly due to convenience, its impact may have a significant effect on the literature. Considering that as of 2009 only about 53% of Nigeria's population spoke english and the salary gap between english and non-english speakers was about 30%, it is fair to assume that we have failed to adequately represent non-english speaking and poor populations (Euromonitor International, 2010). This population often encompasses rural populations. Apart from testimonies, there is little knowledge of what happens to Nigerian children with autism in extremely rural and traditional settings.

Although Kleinman has made significant efforts to contextualize help seeking, Kleinman's model does not properly address access, availability, affordability, and quality of care issues. Initial critics of Kleinman argued that excluding social determinants of health like these, limited the validity of the model and discounted practical "social priorities" (Weiss & Somma, 2007). The popular therapies in the United States are often expensive and sometimes not covered by insurance companies. With a low functioning insurance and healthcare system, these therapies are even more inaccessible in Nigeria. Impoverished families are less likely to seek care for ASD in a professional setting. In a South African examination of the Family Impact of Childhood

Disability Scale on families of children with autism, about 70 percent of participants reported that the financial cost of treating their child placed a “substantial impact” on their family (Schlebusch & Dada, 2018). A combination of ideology about illness and financial blockades may be the active culprits in slowing access to care.

Additionally, Kleiman asks what we call an illness, but does not fully address diagnostic barriers. It is not simple for lay people to notice and characterize all of the symptoms of ASDs. In an autism center in Ibadan, Nigeria, parents brought their children with down syndrome, ADHD, and hearing and visual impairments, with the common complaint that their child had speech delays (Adeniyi & Adeniyi, 2020). Another researcher reported that while seeking out ASD populations in Nigeria, about 70% of responses came from people with down syndrome, ADHD, speech and language disorder and cerebral palsy (Oshodi et al., 2017). Although speech delays can be a clear sign to parents that there is an underlying issue, it does not always lead parents to the correct conclusion. If Nigerian medical professionals do not have the tools to differentiate between common disorders like autism and hearing impairments, families will not be able to find the appropriate interventions.

**Recommendations.** The first step to treating ASDs is identifying that they exist. Without characterizing a child’s atypical behaviors, parents will continue to struggle to find solutions. Research suggests that parents in African settings most commonly recognize speech delays and communication issues as the first and often most significant problem (Chinawa et al., 2016). This behavior is easy to spot but often after years of missed opportunity to apply intervention. After a 2014 summit, Ruparellia et al (2016) developed a three level pathway to diagnosis in Africa that



begins with the combined efforts of parents and school teachers, regional hospitals and pediatricians, and then central research hospitals and child psychiatrists. Creating awareness and providing autism diagnostic tools to actors in the first level such as community health workers and school teachers can be the first step in providing Nigerian children with early autism diagnoses. As long as they are equipped with accurate information, it is suggested that respected "aunties" in the community should act as community health workers in a familiar and culturally competent manner. Similar systems, like Community Based First Aid, have been successful in the United States. Because early intervention is so critical for children with ASD to develop speech and important life skills, implementing a system that empowers community health workers to be the guiding forces toward intervention could help to avoid the social isolation many families experience when their child's symptoms become unmanageable.

The One Stop Shop (OSS) model could revolutionize the healthcare system in Nigeria. After a cross-sectional study of HIV treatment and prevention OSSs across eight Nigerian states, researchers concluded that adaption of the OSS model increased prevention and treatment within at-risk populations (Onovo et al., 2016). Although their growth has been stunted by lack of access to trained professionals, the University College Hospital has shown how the OSS model can be adapted for children with developmental delays and their families. Significantly, the OSS has been able to provide assessments to patients within 48 hours of contact with the clinic and provide various therapies along with a diagnosis (Adeniyi & Adeniyi, 2020). The quick growth of this program over the short time since its creation is not only testimony to its viability but the persistence of the few psychiatrists with adequate knowledge of ASD living in Nigeria.

As of 2017, there has only been one study conducted in Nigeria that explores the applicability of an autism intervention. The study explored the use of operant conditioning to teach speech skills to children with severe ASD (Franz et al., 2017). Without additional research, it is unclear how popular behavioral interventions in the United States will translate to an African setting. Although Latin and African cultures are not agnate, the extensive literature detailing the relevance of ABA in Latin America and the Caribbean suggest that the principles of behaviorism are not limited to Western cultures which is consistent with existing literature regarding behaviorism . Bertilde Kamana, BCBA-D, has already begun to shape a model of how to provide ABA services in Africa via telehealth. Although her work is new, it certainly is promising to look forward to what she will uncover through her work.

In addition to the need to examine the validity of Western behavioral interventions in Africa, there are still adequate gaps in various areas of ASD research. Primarily, there is still a limited understanding of how prevalent ASD is across Africa and Nigeria. The Nigerian government should fund a task force to screen all schools for a better understanding of the prevalence rate. Although this may omit children in rural areas unable to attend school, this effort could still dramatically increase our understanding of how ASD is affecting Nigerian children. The country would also benefit from creating a health campaign that summarizes the symptoms of ASD to allow lay people to correctly label autism and seek more information about the disorder. In addition, a similar campaign in Nigerian universities can tackle informing the multiple professional communities that may confront a person with ASD.

**Global Context.** As Americans attempt to insert themselves into ASD care in Africa, it is

important to approach African cultures with grace and with an understanding of their EMs. Asking Africans to abandon their religious and traditional beliefs is not only impractical, but it is reminiscent of colonial attempts to Westernize and “civilize” the continent. American doctors do not ask Christians to stop seeking healing at churches, so it would be hypocritical for Western academics to do the same to African people. Although traditional healing and allopathic services are often incompatible, competency in both is the key to remaining non-alienating to Africans with intersecting beliefs. Rather than question and undermine traditional and faith-based beliefs, researchers and medical professionals should be working to create a system where all systems coincide.

Any conversation that includes the Nigerian healthcare and education systems can not exclude colonialism. The British government invested little-to-no money in these systems. When Nigeria became an independent nation, the country was forced to quickly pivot and create the social systems that the British ignored in order to focus on economic gain. To suggest that the infrastructural issues in Nigeria and akin postcolonial nations are solely the result of corrupt governments and political transitions is irresponsible. This type of thinking has spawned neo-colonial efforts to “save” Africa that are often racist and unhelpful. Advocates and researchers alike should work towards supporting the Nigerian ASD community while allowing Nigerian leaders to guide necessary change.

### *Conclusion*

The present analysis explored the help seeking pathways of Nigerians with ASD and

their families using Arthur Kleinman's explanatory model. These pathways are constructed by their beliefs, interpretations of social and cultural meaning, and concerns about the impact of autism on their families. Ultimately, these concepts translate to how people with autism seek care which is reflected in the testimonies of the Ephphatha community. In order to create long lasting change in the way Nigerians talk about autism and the way Nigerians with autism are treated, there will need to be significant changes to the way people identify and name autism. This can begin with educating professionals and lay people about the earliest signs of autism and separating it from ideas of stupidity and spiritual shortcomings. Future research should explore effective and culturally sensitive techniques to create understanding about autism in Nigeria and across Africa.

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