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The Right to Free Education of Autistic Nigerian Children

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INTRODUCTION

The plight of autistic children in developing countries like Nigeria is by no doubt limiting them from attaining their full potential in life. The absence of rehabilitation resources in schools is one out of the numerous limitations. Families of these children, knowing that the government has little or nothing to offer them, have resorted to keeping their children safely at home for the rest of their lives. Unfortunately, this lack of government intervention or educational resources is a reoccurring phenomenon for families of autistic children in most rural communities in Nigeria. Whereas in urban centers like Abuja, Lagos, and Port Harcourt, privately owned rehabilitation resources actively serve the needs of autistic children. However, in rural Nigeria which lacks modern intervention resources, there is poor autism awareness, and families of autistic children resort to traditional healing options to save their children. These traditional healing options, mostly administered by native doctors, are unproven healing techniques, but families of these children cling to them in their search to find healing for their children's ill health. They assume autism to be a curse from the gods or their enemies, and their only known way to address such a predicament is through native traditional interventions (Eaton and Agomoh 553). Unfortunately, autism, which is a developmental disorder, cannot be treated by native doctors' administration of local concoctions such as native herbs and roots (Ametepee and Chitiyo 11). But these native doctors seem to be the only intervention option in most rural communities in Nigeria because the Nigerian government has long ignored the need for even basic amenities in rural communities.

In Nigerian rural communities, healthcare centers are under resourced and have very few healthcare practitioners serving the masses; they have limited and largely outdated equipment. Other basic necessities such as electricity, pipe born water, and basic education are equally under

resourced, all of which prevents experienced professionals from residing in such communities. So in the absence of experienced education and health professionals, rural residents consult native doctors, and after years with no remedy for their children's ill health, finally give up on the hope of healing. I see these scenarios re-occur in rural communities in the eastern region of Nigeria, where my family is from. I have also watched family relatives and friends with adult autistic children give up on their children by constraining them in a room for the rest of their lives. I constantly wonder what would have become of these autistic individuals if the right intervention resources had been available for them earlier in their lives. Considering that they never had the opportunity to utilize their potentials in life, and that their community never had the chance to enjoy their gifts and talents. It is a shame that government negligence has left untapped undiscovered gifts from those who are doomed to perish for lack of governmental assistance in rural Nigerian communities.

Autism happens in cities, towns, and rural villages alike, and each autistic person and their family need help. As a mother of an autistic child, I advocate for their lives, for their futures, and for the realization of their potential. That takes resources and government assistance. I am not the first, and neither will I be the last to raise awareness about inadequate intervention resources in rural Nigerian communities, but my research work, which I believe is unique, stems first from the unquenchable pain I feel when I see my adult autistic cousin locked up in a room.

To help others understand this problem in rural Nigerian communities, and the need for an immediate intervention, I conducted semi-structured interviews in both rural and urban communities to critically analyze the impact of resource availability in these communities. This is because in the rural communities there are no forms of intervention resources, while in urban

cities, there are basic to moderate intervention resources mainly private owned. Data collected from these two population demographics, when analyzed, clearly reveals that autistic children in rural Nigerian communities have lesser chances of improving developmentally when compared to their counterparts in urban cities. In this qualitative research study, my interviewees were parents, guardians, and siblings of Nigerian autistic children, and as well as special education teachers in an American integrated classroom. Direct quotes of these interviewees played integral roles in all sections of my thesis because there are no better ways of connecting with my readers than through the voices of those who have lived and worked with those who experience autism. Also, due to the sensitive nature of this topic and in accordance to the wishes of my Nigerian interviewees, I have altered the names of these interviewees namely: Okafor, Ihuoma, Ekeoma, Ncheta, Josephine, Doris, Amaechi, Ukaefe and Charlie. Findings from my qualitative analysis clearly indicated that the Individualized Education Program (IEP) is most needed in the Nigerian public school system to recognize and address the early intervention needs of all autistic children, especially those in the rural communities.

My thesis proposes the introduction of IEP in all Nigerian public schools as a solution to increase intervention resources for all autistic children. With IEP in all public schools, all autistic children, regardless of their parents' income or geographic location, will have equal opportunity in using intervention resources provided via special education. In order to unpack the above in my thesis, I developed five topical areas, which sum up the main points in my research.

These five topics are as follows: 1) An overview of autism awareness in Nigeria, 2) education rights of children with autism cultural values, 3) its impact on autistic children, 4) government policies and services, and 5) individualized education program in public schools. My thesis will highlight the history of autism and the present day autism awareness in Nigeria,

analyze the right to free education of autistic Nigerian children, examine the Nigerian culture with reference to its impact on autistic children, consider the impact of unimplemented government policies on public school administration, and then recommend the integration of autistic Nigerian children in public schools.

With the increase in the number of children diagnosed with autism each year, it is crucial for the Nigerian government to realize it will have a future generation of developmentally challenged adults if it does not intervene to assure that new policies provide the needed resources to recognize and educate these children. This phenomenon asks two important questions. Why are autistic Nigerian children not integrated into public schools? How can the Nigerian government include and integrate autistic children in the education system? In spite of these limitations, disabled children under the UN Convention are not to be left behind, and autistic Nigerian children deserve the right to free education in the public school system.

LITERATURE REVIEW

Nigeria as a country is yet to embrace the increase in autism diagnosis worldwide in the last three decades, which Nigeria is also experiencing. But as other countries around the world arm themselves with intervening developmental resources to help autistic children reach their full potential in life, Nigeria falls short of even the most basic intervention resources for autistic children. As a crucial example, free education is a major need for autistic children whose parents cannot afford privately owned special schools that serve the needs most autistic children in urban Nigerian cities. However, the country's public school system has yet to include special education in existing public schools. These children, under Article 21 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), have full rights to education. Elizabeth Dickson in her work, considered the rights to inclusive education for students with disabilities

who, due to societal ignorance, are neglected. According to her, countries being signatories to the UNCRC is not a guaranty that disabled citizens are included in their respective education systems. This unfortunately is the scenario in Nigeria today.

Developed countries are more advanced and aware of the number of children diagnosed with autism each year, but Nigeria does not have adequate resources for autism diagnosis. If already diagnosed children are not attended to, how then can Nigeria meet the advances in autism research? Knowing an overview of the prevalence rate of autism in Nigeria is one step towards searching for answers in the treatment and management of autistic Nigerian children. MO Bakare et al. in their research sampled a group of Nigerian children with intellectual disabilities to ascertain the increase in the growing number of children diagnosed with autism. This study supports others that have proven an increased number of children diagnosed with autism in recent years. Another study conducted by Esiegbe et al. on the knowledge of autism in Nigeria among healthcare workers, concluded that pediatricians and psychiatrists are very aware of the prevalence of autism in Nigeria. This study highlighted the need to improve autism knowledge among other health care practitioners, which will facilitate autism awareness in the general public. As a further approach in the improvement of autism awareness for already diagnosed children, I argue that they, by right, should be provided with necessary intervention resources to enable them attain their full potential in life.

Not only autistic Nigerian children deserve the right to free education, but all disabled children deserve such rights under the United Nations Conventions on the Rights of a child, the Nigerian National Policy on Education, the United Nations Convention on the Rights of Persons with Disabilities, and the African Charter on the Rights and Welfare of the child. The fundamentals of my thesis are rooted in the application of a rights-based approach to the

education of autistic children. Sections in these policies, which include the human rights framework and rights-based approaches, are all relevant points in the affirmation of the education rights of autistic Nigerian children. Since by right, all autistic Nigerian children should be included in the education system, why are these children still excluded in the public school system? Existing socio-cultural and political factors in Nigeria influence the non-implementation of autistic children's right to free education.

Analyzing the cultural values in Nigeria, different authors discuss Nigeria's overall neglect of autistic children. This analysis is very important in my thesis because it unveils the Nigerian culture as a whole. In his book, *Socio Cultural Attitudes and Treatment of the Mentally Retarded in Developing Countries*, Mbubaegbu explores the underlying factors affecting families and individuals with mental illness in Nigeria. His detailed account on the belief, customs, and attitude of Nigerians towards mental health disabilities gives readers an insight into the everyday challenges of living with a disability, such as autism, in Nigeria. Also, Mandell and Novak explored the role of culture in families' diagnosis and treatment of autism. They explained that due to the diverse presentation of autism in every child, different cultures approach the cause and course of autism differently.

Political factors inherent in Nigeria's system of leadership include other limitations to autism awareness. The Nigerian government has unimplemented policies which from all indications do not protect the education rights of autistic children. With such a setback in the public school system, Saloojee et al. in a study expresses the similarities in most rural and sub-urban communities in developing countries, where government policies do not cater to the needs of disabled children. Findings from this study are similar to other studies conducted in other under resourced settings such as Nigeria. Regardless, if it hopes to improve this social picture,

the Nigerian government, as an avenue to improve autism awareness, must introduce special education programs in all existing public schools.

Individualized Education Program, popularly known as IEP, is a special education program adopted in the public school systems in countries such as America, Canada, and the United Kingdom, with the intent of helping disabled children reach their educational goals more easily. The National Research Council U.S. in the book *Educating Children with Autism*, formulated a guide particularly for the effective education of autistic children. Contents of this book, which is in line with the goals of IEP, sums up the key components of individualizing education goals for autistic children, with consideration to variations in the autism spectrum.

Moving forward, Nigeria has enough financial resources to address the basic education needs of autistic children, which obviously have not been met. In the pages ahead, I will unpack the underlying factors that lead to these unmet needs and add recommendations regarding how to provide these basic needs via special education programs.

AN OVERVIEW OF AUTISM IN NIGERIA

Autism is a disorder present from early childhood. It affects social interaction, communication of ideas and feelings, imagination, and relationships with others (as quoted by Lynn et al. 105). About twenty- five years ago, Africans considered Autism Spectrum Disorder to have been a western culture disorder. The universality of autism was questioned, and it was assumed to be peculiar to countries that are technologically advanced. It was believed that exposure to toxic matter such as intense air pollution causes autism, but with recent studies on autism, one can see that autism cuts across all countries and races. Tincani et al. writes, “Autism spectrum disorder is believed to affect children equally, regardless of culture, community, language, and socio-economic status” (as quoted by Fombonne 81). The prevalence of autism

spectrum disorder among sub-Saharan African children with intellectual disability is about 0.7% in the past thirty years (Bakare et al. 513). During this period, however, autism diagnosis has been on the increase worldwide. Nigeria, as in other countries, is experiencing an increase in the number of children diagnosed with autism every year, but the prevalent rate in Nigeria is unknown. In America for example, recent estimates suggest that 1 in 150 children have autism, with boys outnumbering girls by a ratio of 4 to 1 (as quoted by Ametepee and Chitoyo11). But with the unknown, undocumented prevalence rate of autism in Nigeria, it is hard for researchers, like me, to certify the number of Nigerians affected by autism today.

In my research, the few studies that sampled the number of Nigerian children with developmental delays were not comprehensive enough to categorize these children under different diagnoses. At the same time, sample sizes for other specific studies on autism were collected in big cities like Lagos, Abuja, Port Harcourt, and Enugu, where the majority of upper class Nigerians reside. Living conditions in other Nigerian cities are very poor, and researchers knowingly prefer to stay in cities where they have access to basic amenities. Bakare explained that the income disparity in Nigeria between the rich and the poor has influenced the living standards of these two demographic population: those living in cities have access to all the basic needs of life, whereas the majority of Nigerians in rural communities struggle to survive with less than an annual income of \$370 (1). Since the majority of Nigerians do not live in big cities, it is obvious that these few studies on autism did not accurately represent the Nigerian autism population, which according to Igwe et al. has affected the knowledge of autism prevalence among health care workers and the general populace in Nigeria (1).

From all indication, a greater percentage of Nigerians living outside the big cities are not documented in most studies of autism, and in these cases, undiagnosed children are basically

non-existent. The non-documentation of these children is equally common in other under resourced African countries, considering that very few studies on autistic African children were conducted. Ametepee and Chitiyo write, “However, the prevalence rate of autism in Africa is not known. It appears there are no studies that have been done to try and establish the prevalence rate of autism in this continent. The few studies that have examined the existence of autism were done on randomly assigned samples of children which could not be used to estimate a reliable prevalence rate” (11). With insufficient data as a major constraint on autism awareness, health care workers and educators can only attend to the needs of the few represented autistic Nigerians. To understand this scenario better, I conducted a structured interview among the few Nigerian mothers living in urban and rural communities, those who have children with developmental delays. Their responses to my questions instigated my analysis of a trend line in Nigeria’s autism awareness.

Trend line of Autism Awareness in Nigeria (Personal Perspective)

Most residents of eastern Nigeria have never heard of the term autism, and the few that have do not quite understand what it implies to be autistic. Judging from my research, it is very obvious that the absence of autism awareness in most rural Eastern Nigerian communities has prevented mothers of developmentally delayed children from seeking help in hospitals to understand their children’s delays. I met a few of these rural Eastern Nigerian children, and four out of the six children I met demonstrated traits of autism, which, from my own knowledge of autism, is very significant. From a sample size of fifteen families, where only two mothers know what autism is, I can clearly say that autism awareness in these communities is very poor compared to that of their counterparts in the cities. In Abuja, the capital of Nigeria, five out of the six mothers I sampled were very knowledgeable about autism. According to them, social

media had informed their awareness of childhood autism. They also gave credit to local television channels for broadcasting autism awareness campaigns and screening programs. One of the mothers, who has a four-year-old son with autism, reported that her primary care physician first told her about autism when her son was two years old. This mother has yet to receive a formal autism diagnosis for her son, but in the absence of a diagnosis, she has continued to research autism by buying autism publications and staying in touch with her physician, who is not a pediatrician. Another mother reported that as a result of her son's poor academic performance in a general education kindergarten class, she transferred him to a privately owned special education school in Abuja, where her son has significantly improved academically. Because her son also attended a special needs school, she met mothers of autistic children who introduced her to the world of autism. She has yet to receive a formal autism diagnosis for her son, as are the other mothers I met in my research. Although these mothers do not have a formal autism diagnosis, which is a function of the Nigeria health care system, they have continued to research available rehabilitation resources to help their children attain their full potentials in life. Still, even in cities like Abuja, existing services for autistic children are not sufficient to cater to the rise in existing cases of autism. Symon writes, "The existing services are generally insufficient to cope with the alarming increase in cases of autism, coupled with the intense and ongoing support needs of the children and their families" (159). In the absence of adequate intervention services in Abuja, mothers of autistic children have continued to spread awareness amongst their peers by supporting each other through information dissemination such as book exchanges and verbal discussions. Parents have adopted these informal communication avenues to increase their knowledge about intervention strategies for their children. In fact, several decades of research findings support the benefits of including parents as direct service providers

in their children's intervention process as a means of increasing the quantity and availability of intervention resources (as quoted by Symon 159). This system of spreading awareness is very common in other cities such as Lagos, Port Harcourt, Calabar, and Enugu.

But what happens to families of autistic children who live in rural Eastern and Northern Nigerian communities with low levels of literacy? Where there are also no awareness resources? In Nigeria, it is a given that the income disparity between the poor and the rich is almost equal to the literacy disparity between these two demographics. Using the Gini-co-efficient approach, Bakare discovered Nigeria's disturbing income inequality: the regression results show that one percent increase in literacy rate increased the Gini-coefficient by three percent, meaning that there is higher disparity in the income distribution in Nigeria with increase in literacy rate (1). Literate Nigerians, who live in cities, may depend on autism awareness publications and the media for information, but in the absence of adequate intervention resources, how do their illiterate counterparts, who live in rural communities, inform themselves? Bearing in mind that with the poverty level in these communities, the majority of the inhabitants cannot speak or read in English aside from their native languages. Also, residents in these communities cannot afford to buy televisions, mobile phones, or a computer, and even when they can afford any of them, the absence of a reliable electricity supply becomes a challenge. In very remote communities, a pipe-born water supply and electricity are themselves considered a luxury only to be enjoyed by the traditional rulers. Information about any subject, then, is hard to come by. Since only two mothers out of the fifteen mothers I interviewed in Eastern Nigeria know about autism, how did they increase their knowledge on this topic? Ekeoma for example, discovered her son might be autistic with the help of a distant cousin, who came to the village from the city for her Christmas vacation. Ekeoma's cousin, having met a family in Lagos with an autistic daughter, became

aware of autism through information shared by this family. So on close proximity with Ekeoma's son, Ekeoma's cousin saw similar traits of behavior patterns, which her friend's daughter has in common with Ekeoma's son. Ekeoma said, "Ogechi told me it looks like my son is autistic. She also told me that there is no cure for autism, but she will ask her friend in Lagos for a doctor's contact, who can help us understand what the problem is. Ogechi's doctor told us to come to Lagos, which is eight hours from here with public transportation and that will be very expensive for my family" (Personal interview). Because Ekeoma's family is not financially able to travel to Lagos to consult a child development pediatrician, she never made the trip, and at the time of this interview, her son is yet to be diagnosed. Ekeoma represents one of several mothers in rural communities, who as a result of poverty, refrain from searching for answers to their children's uncommon behaviors because they cannot afford it. Living in such impoverished communities where unemployment rates are high and household incomes low, caregivers are left with few options to prioritize the needs of their disabled children (Saloojee et. al. 234).

The second mother, whom I will call Josephine, declined traveling to Abuja because she feared the challenging behavior problems she will encounter from her son when traveling eight to nine hours in a public transportation bus. She said that autistic individuals have impaired communication skills, which can be translated as behavioral problems in real life settings. These impaired skills show significant deficits in verbal and nonverbal communication as well as in social interaction (as quoted by Ametepee and Chitiyo). If these two mothers, however, had consulted a developmental specialist respectively, they could have transferred their acquired knowledge back to their community by word of mouth to others there whose literacy level is also low. Other mothers who question their children's development can certainly go to the city for an evaluation and possible diagnosis of any developmental problem. With more mothers seeking

help in surrounding cities, an informal awareness network amongst mothers and caregivers of developmentally delayed children, as it is done in Abuja, can commence in these communities. But with low household incomes, which prevents many from outsourcing interventions in cities, families are left with no better choice than to continue hoping that their children will gradually improve as they get older. Charlie said, “I have seen children lose their behavior problems by age ten, and I have also seen some children speak at eight years. Sometimes these children are confused, but will later resolve the confusion as they get older and more mature” (Personal interview). Charlie, Josephine, and a couple of other parents are hopeful that their children, in the absence of rehabilitation services, will gradually grow out of their developmental delays as they get older. Not to say that being hopeful is wrong, but as a realist who believes in proven researches on autism, I know that without rehabilitation services, these children are most likely to developmentally regress rather than to improve with age. Findings from most early intervention researches on autism, such as from Symon’s research, have consistently demonstrated improved communication, general awareness and overall functioning of the sample size (169). There is an urgent need for such rehabilitation services in these communities, but if the Nigerian government does not address this need in the next couple of years, these affected children will likely grow into autistic adults who will need lifelong supervision and care. In the meantime, what are the realities of these children growing up autistic in the absence of rehabilitation services?

What is the Reality of an Autistic Nigerian Child?

I base my perspective on growing up autistic in Nigeria on the two demographics of Nigerians earlier mentioned: the rich and the poor, with the rich living in cities, and the poor in rural communities. Also, judging from the level of autism awareness portrayed by mothers on

both ends of the income margin, I can easily predict that their children's development will take opposite directions. Autistic urban children will continue to improve developmentally as a function of their parent's autism awareness while children in rural communities, whose parents lack autism awareness, will gradually regress as they get older. With awareness, parents in cities are more exposed to publications about home intervention strategies and local rehabilitation services like private schools. If possible, some parents may even relocate to other countries in search for advanced rehabilitation services. I, for example, fall into this category of "relocating" Nigerians who seek help for their autistic children. Reflecting on the early years of my son's life when I searched for answers to his awkward behavior, I, just like these mothers in Abuja, did not receive a formal diagnosis for my son's ill health. My knowledge on autism and developmental delays were not sufficient to say that my son is autistic. I knew that a specialist had to give me a formal diagnosis of autism. So, I consulted two pediatricians and a special educator, and I was basically told he was too young, at age two, to be evaluated for autism. But from my research, I knew that in developed countries like America, toddlers, younger than my son, can be evaluated on the basis of early signs of autism. I also knew that early intervention services could address his developmental delays. After twelve months of researching autism myself, I knew it was autism, but as a human being, I lived in denial by hoping that as he continued to grow, he would gradually overcome his developmental delays. But five months after his second birthday, I came to America to evaluate his development and learned that he is autistic. Hence, judging from my story and from the stories of other mothers in Abuja, who with their limited knowledge of autism will continue to struggle in the midst of insufficient Nigerian rehabilitation resources, one can see that awareness is key in autism recovery. Doris explained:

Since my son's autism diagnosis ten years ago, I have read numerous books on autism recovery, I have also followed American autism bloggers on social media, and every information I got from all these sources, I tried implementing them at home to see if my son will respond to them. Some of them worked while some didn't work, but I will continue trying out different strategies with hopes that things will get better for him and my family as a whole. (Personal interview)

Having moved to America, I can easily concentrate on my son's recovery and forget about my initial struggles with his autism diagnosis, but Nigerian mothers are still struggling with both the diagnosis and the recovery process.

What happens to autistic children who are not as fortunate as my son to move to a developed country? And also, what is the fate of autistic children whose parents cannot financially afford to move from rural Nigeria to cities to provide rehabilitation services for their children? These children of low income families are left in their rural communities where there are little or no chances of progressing. These parents, very unaware of autism, try to accommodate their children as much as possible by creating safe environments for them. Ekeoma said, "My son is very active, always running around the house, pushing furniture down and taking objects that may harm him. So we try to accommodate his behavior problems by constantly closing the exit gate and removing sharp objects from visible positions" (Personal interview).

Through my qualitative research, I concluded that the present trend line in the lack of autism awareness in Nigeria encourages negligence in autism research, in the sense that those who are aware and those who are not aware of autism live in two different regions totally opposite of each other. Those who are aware continue to find solutions to their children's needs,

whereas those unaware continue to lose faith in solutions to their children's needs. But if the people who are aware of autism, like me, can transfer their knowledge to those who are not aware through different awareness avenues, we can bridge the gap between the two awareness margins. In view of this potential, my thesis, which affirms the need to integrate autistic Nigerian children into public schools, if implemented, will streamline autism awareness by bridging the gap between the aware and the unaware. My target focus is on autistic children in rural communities, children whose parents, unlike the urban parents of autistic children, cannot afford tuitions in privately owned schools.

EDUCATION RIGHTS OF CHILDREN WITH AUTISM

Children in the autism spectrum, as with typically developing children, have equal rights to capture those qualities of life of which everyone is entitled to, regardless of disability, age, race, nationality, and gender (Child Rights Programming). The right to basic education is one more important human right that Nigerian children are also entitled to. In Nigeria, the Child's Rights Act has stressed the need to provide intervention resources for both mentally and physically challenged children so that they may achieve their fullest possible social integration and moral development in life (UNICEF Information Sheet 2). Since basic education is one of these essential intervention resources for challenged children, including autistic children, the Nigerian government should prepare the public school system so that it meets educational needs of its autistic children. To understand why autistic children are not integrated into public schools, one has to critically analyze the political and socio-cultural Nigerian factors that have over the years indirectly encouraged the exclusion of this group of children in public schools. Access to basic education in Nigeria is inhibited by gender issues and socio-cultural beliefs and practices, among other factors (Iman 194). These political and socio-cultural factors, which I will further discuss in-depth, are major determinants influencing the knowledge of education rights amongst

Nigerian citizens. As a result, most Nigerian citizens are not aware of the Nigerian “basic right to education” for all children, regardless of their physical or mental development status.

General Awareness on the Right to Free Education of Autistic Children in Nigeria

Because many Nigerians are unaware that their children with autism are by right entitled to basic education, they do not know what measures to take for the implementation of their rights. When I asked Ekeoma, an interviewee, if her son goes to school, she responded, “They are not allowed to go to school because no teacher will attend to them” (Personal interview). So most rural Nigerians with autistic children have learned that the public school system is strictly for typically developing children. Adding to this educational lack, no special education programs are available in most Nigerian public schools, especially in rural Nigerian communities. Again, I asked Ukaefe, a father, why his son is not in school, and he responded with a question, “Is my son allowed to be in school?” (Personal interview). His response clearly shows that Nigerians, undoubtedly, are not aware of their children’s rights to basic education. With the absence of special education, it has become common knowledge for most Nigerians to assume that their autistic children do not have the right to attend a formal public school setting. Scenarios like these are very common in rural Nigeria, where the literacy level is low. Because most rural Nigerian residents are not educated, they are basically aware of human rights since becoming informed entails reading and natural exposure to legislative facts.

Other Nigerians like me, who are aware of their children’s right to basic education in public schools, choose to access other resources available, outside the public school system,

because we have accepted this reoccurring phenomenon. Doris explained, “Since my son’s diagnosis, he has been in a private school, and I did not see the need to find a public school because I knew that finding a public school is as good as not finding one” (Personal interview). It is a reoccurring phenomenon in which those who can afford privately owned resources have chosen to take advantage of these private resources without questioning the Nigerian government or pressing legal charges on why their children cannot be in public school. As previously mentioned, there are no laws preventing autistic children from being in public schools; to the contrary, there are laws including them in basic education. But because there are no existing education programs for them, they are indirectly excluded from being in public schools because these children cannot function in typical mainstream classrooms. Ihuoma said:

My aunt told us to move to the city because her friend has a rehabilitation center in Port Harcourt where my son can receive therapy. But my husband and I cannot afford relocating our five children to the city, let alone pay tuition for his therapy. As a result of that, we are still here in the village, and I cannot leave my son with my aunt because she cannot manage his behavior problems, so I have accepted the situation. (Personal interview)

Families in rural Nigerian communities, like Ihuoma’s, are considering privately owned facilities, which are outside their communities, to provide their children with intervention resources necessary for their development. Hence, for genuine inclusion and integration in public schools, policies must demand cultural and symbolic changes to the ways schools are structured (as quoted by Dickson 1094).

The Nigerian government, in keeping to the Child’s Rights Act, must provide adequate education resources in public schools before autistic children can be integrated into public

schools. To better understand the binding laws to which the Nigerian government must adhere, I will analyze the United Nations Conventions on the Rights to Free Education of Disabled Children, as the basis for this contractual agreement.

The United Nations Conventions on the Rights to Free Education of Disabled Children

On January 20, 1990, Nigeria became a signatory or party to the United Nations Convention on the Rights of the Child (UNCRC), and a year after, in April 1991, it accepted the contents of the UNCRC (United Nations Treaty Collection). Since then Nigeria, as a member country, has continued to project the UNCRC as a platform for most child's rights based approaches in child welfare. But in reality, the socio-cultural and political factors in Nigeria are major determinants of child welfare. Not to say that Nigeria is not adhering to the UNCRC on purpose, but the fact remains that the Nigerian culture, which considers children as clueless citizens, over shadows the UNCRC in most child related matters. Hence, the Nigerian culture comes first before the UNCRC. In most child welfare cases, the contents of the UNCRC are considered when such child related issues appear in court, but in typical Nigerian settings, most cases are settled out of court. Take for example in marriage dissolution between an abusive husband and his wife, the husband is granted full custody of their children because the Nigerian culture considers the father as the ultimate head of the family regardless of the children's safety. However, article 9 (1) of the UNCRC which states differently:

Parties shall ensure that a child shall not be separated from his or her parents against will, except when competent authorities subject to judicial review determine, in accordance

with applicable law and procedures, that such separation is necessary for the best interest of the child. Such determination may be necessary in a particular case such as one involving abuse or neglect of the child by the parents or parent. (60)

This article does not stipulate that the culture determines a child's placement in the event of marriage dissolution. This case is one out of the numerous scenarios in Nigeria where culture comes first before a child's safety is considered.

Scenarios like these are not different from child protection issues for disabled Nigerian children, in which the Nigerian culture encourages the abuse of their human rights because of the stigma attached to disability. So with a domineering culture as a major determinant in child welfare, which includes health and education, what contents of the UNCRC should protect the education rights of disabled Nigeria children? Bearing in mind that autism is considered a disability, Article 23 (3) states as follows:

Recognizing the special needs of a disabled child, assistance extended in accordance with paragraph 2 of the present article shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development. (64)

This article proves that with Nigeria being a signatory to the UNCRC, all autistic Nigerian children must have effective access to education and intervention resources to enhance social integration and individual development. With social and communication impairments as the

down side of autism, neglecting the education rights of autistic children prevents them from integrating even into the communities where they live. As much as education is important in the intellectual growth of autistic children, the fundamental purpose of education is not to provide intellectual opportunities to students, but to provide information that students need to belong to and participate in their communities through established relationships in school (Dickson 1101). Furthermore, Article 28 recognizes the financial resources of parents caring for their autistic children, parents who, due to insufficient income, cannot afford privately owned intervention resources, a very common occurrence for rural parents in Nigeria. Again, still on the educational rights of autistic children, Article 28 (1) further states:

Parties recognize the right of the child to education, and with a view to achieving this right progressively and on the basis of equal opportunity, they shall in particular make primary education compulsory and available free to all; encourage the development of different forms of secondary education, including general and vocational education, make them available and accessible to every child, and take appropriate measures such as the introduction of free education and offering financial assistance in case of need. (65)

So, with the absence of special education in Nigeria public schools, how is Nigeria adhering to its membership contract with the UNCRC and its educational principles?

Undoubtedly, Nigeria has failed to disseminate the convention's principles and take all appropriate legislative, administrative measures for the implementation of the rights recognized in the UNCRC. Article 32 (2) recognizes that parties must take legislative, administrative, social, and educational measures to ensure the implementation of all the articles (66). To this day, both federal and state legislations in Nigeria are yet to implement free basic education in public schools for autistic Nigerian children. It has been twenty-six years since Nigeria became a

signatory to the UNCRC, yet many of the needs of autistic Nigerian children remain unmet and continue to be ignored. Neglecting the needs of disabled children is also very common in developing countries such as Jamaica, South Africa, and Thailand where the unavailability and inaccessibility of services combined with financial constraints and ignorance of available services were reasons put forward by similar studies on the unmet needs of disabled children (Saloojee 234). But in developed countries like America, families of disabled children have the right to demand for more resources if their children's needs are not met. In such cases, the UNCRC and UNCRPD (United Nations Convention on the Rights of Persons with Disabilities) are referred to as the guiding principles protecting the rights of the disabled. With a functioning legal system, neglected families in developed countries have the right to sue the government or the organization for depriving their children from accessing available resources. Not to say that Nigeria does not have a functioning legal system, but as aforementioned earlier, its culture dominates over the legal system, which in most cases presents the legal system as non-existent. In a functioning legal system, the UNCRC and UNCRPD stand to over-rule all other cultural ideologies involving persons with disabilities. So, to understand the functionality of UNCRPD, one has to first understand its underlying principles.

As with the UNCRC, the UNCRPD is another human rights convention under the United Nations that specifically protects the rights of disabled citizens. Nigeria became a signatory to UNCRPD on March 30, 2007, and similar to the UNCRC, the UNCRPD is meant to protect the rights of disabled Nigerian citizens. But in the true Nigerian culture, disabled Nigerians have yet to see the full implementation of all or some of the UNCRPD principles that protect and support their well-being. According to Shogren and Turnbull, "With the introduction of the UNCRPD into the international discourse about disability rights, there is now a clear international disability

policy agenda” (21). This disability policy, formulated specifically for disabled citizens, provides member countries like Nigeria, Italy, Indonesia, and Uganda with clear guiding rules in the protection of the rights of their disabled citizens. Judging from Nigeria’s negligence on issues affecting the disabled, one can see that being a member country is not a proof that these countries abide to the principles of UNCRPD. To mention but a few, there are other UNCRPD member countries like the United States of America, United Republic of Tanzania, and Canada, who over the years have continued to abide to the principles of UNCRPD by providing basic free education for disabled citizens. For example, Turnbull and Aldersy critically analyzed disability policy in Tanzania using the core concepts derived from America’s disability policy. They concluded that, with the exception of the core concept of accountability, Tanzania’s disability policy reflected the core concepts approach (as quoted by Shogren and Turnbull 21-22). From their study, it is obvious that there are other countries in Africa, regardless of their being a developing country, that implement UNCRPD principles in their national policies.

In reality, the educational right of inclusion for disable persons encompasses other rights of exclusion in any given society, which Article 24 of UNCRPD clearly explains. Article 24 (2a) states that “persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary and secondary education on the basis of disability” (United Nations Enable). Since children with disabilities must not be excluded from free primary and secondary education on the basis of disability, why is there no basic free education for autistic Nigerian children? Answers to this question result from unimplemented government policies, which the Nigerian culture supports. Subsections of Article 24 (2) clearly state that persons with disabilities should receive the general education to facilitate their effective education. Also, it requires that effective

individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of inclusion (United Nations Enable). Hence, since the UNCRPD stipulates that special education inclusion must be a part of the general education system, introducing the Individualized Educational Program is the solution to Nigeria's special education negligence, which this thesis proposes.

Aside from the UNCRC and UNCRPD conventions, Nigeria is a signatory to other human rights policies such as the African Charter on the Rights and Welfare of the Child, which was born out of the feeling by African members-states to include socio-cultural and economic realities of the African experience (Viljeon 20). African member-states felt that the United Nations Conventions missed important socio-cultural components that constitute the African culture. Both the African Charter and the Conventions provide the frame work through which children and their welfare are increasingly discussed. But the difference is that both Conventions generally make it clear that children are independent subjects and have rights, whereas the Charter stresses the need to include African cultural values and experience in considering issues pertaining to the rights of the African child (Olowu 128). For example, the UNCRC gives children the right to express their feelings since freedom of speech is acceptable, but in African culture, children are not allowed to express their feelings, let alone their concerns, on issues related to them or otherwise.

Because Nigeria is a signatory to both the Charter and the United Nations Conventions, one might assume that the right to free basic education of autistic children is by no doubt assured. But the truth remains that Nigeria, out of the need for international recognition, became signatories to these policies for political reasons. Because of this "other" priority, autistic children and their families are left with no option but to assume that their children are prohibited

from attending school. Hence, families, who are not aware of the right to free basic education, along with those who are aware, but have accepted the implementation of these rights, resort to privately owned special schools, which in most cases are meant for financially fortunate autistic Nigerian children. But whether or not families of autistic children are aware of their educational rights, and regardless of their respective incomes, every autistic Nigerian child deserves the right to free basic education in the public school system.

CULTURAL VALUES AND THEIR IMPACT ON AUTISTIC CHILDREN

The Nigerian Culture

The attitudes, customs and beliefs of Nigerians distinguish them from other culture groups. Nigerians are very spiritual, and this can be presented in different forms. Some Nigerians, for example the Ibos and the Yorubas, are overly aware of the manifestations of supernatural powers, and this knowledge impacts their everyday dealings in life. Anything out of the ordinary is usually considered an evil manifestation of supernatural powers. This definition, I believe, is the foundation of the stigmatization of disabled Nigerians because they are considered to be different. Culture, which is the unwritten book with rules of the social game, has nested this belief in Nigerian minds so that they consider disability of any form a taboo (Hofstede 26).

Although it is not a cultural value to segregate disabled individuals, the undeniable attitude of Nigerians on issues of disabilities clearly portrays the impact of the taboo cultural stigma. Eaton and Agomoh write, “High levels of stigmatization towards those with symptoms of mental illness have been recorded across many cultures. Nigeria is no exception, with low levels of knowledge and negative attitudes” (8). The low level of knowledge about mental health is primarily a function of poor awareness on issues of human disabilities. The society as a whole lacks adequate knowledge on physical and mental health disability, but their ignorance on mental health is most profound. In some cases, educated Nigerians who have either little or adequate

knowledge about mental health are not comfortable discussing or sharing their knowledge in public because they might receive negative responses from the audience. On rare occasions when a mental health topic arises, it has been treated with discretion by all those involved. In my family for example, my mother, in the past, has always whispered into my ear when we discussed the mental illness of a friend or relative. Her body language portrayed the discretion attached to that piece of information. Today, with her present level of direct exposure to human disability, she has become more comfortable discussing mental illnesses, although our Nigerian culture still informs her level of comfort with mental health topics. Such is true because culture is essentially a group of people's way of life, which consists of predictable patterns of values, beliefs, attitudes and behaviors; as a Nigerian, I can clearly say that the Nigerian culture is a strong determinant in addressing issues and stigmas of autism in Nigeria.

Autism and the Nigerian Culture

The superstitious belief system, which I attribute to the Nigerian culture, extremely affects families of children with autism regardless of their educational backgrounds. More globalized families, who by virtue of constant exposure to the western world are gradually coming to terms with the realities of autism, but some Nigerians, especially those residing in the rural communities, are yet to understand the neurological implications of autism. Even those aware families continue to seek help in churches for the sole aim of delivering their autistic children from evil spirits and ancestral curses. Mandell and Novak write, "Perhaps more than their interpretation of symptoms, families' beliefs about the etiology and prognosis of autism may affect their treatment decisions" (112). This Nigerian belief system in the manifestation of the supernatural powers limits families of autistic children from exploring early intervention resources earlier in their children's lives because they deny that their children have

developmental challenges, even autism. As stated earlier, in Nigeria, disability of any form is considered a taboo, and families with disabled children hide affected children in their homes. This system of belief is enabled by superstitious connotations attached to autism, and this stigma prevents parents from seeking help for their children outside their homes since it entails exposing the child to the rest of the world. Some cultures in other ethnic groups view a disability such as autism as a cause from the gods and ancestors, whereas others believe autism is inflicted on people by their enemies. Eaton and Agomoh write, “The traditional understanding of mental illness in this part of Nigeria is of a spiritual attack, often in the form of a curse placed by enemies through the traditional healer using incantations or poison” (553). For example, after my son’s autism diagnosis, my maternal aunt specifically asked me if I took my son to the village after his birth. Her real question was if by taking him to the village, I may have exposed him to evil people who inflict curses on their neighbors or relatives. Regardless of my knowledge on autism, I still pondered on her words and began searching my thoughts to remember if anyone untrusted in my family touched my son those years ago when we took him to the village. Growing up in a superstitious culture, members find it very hard to separate reality from myths. According to Okafor, “My son’s sickness was inflicted on him by my husband’s family, who took his destiny from him because they foresaw his bright future” (Personal interview). It is very typical for uneducated Nigerians like Okafor, living in the rural Nigerian communities, to believe that one’s destiny can be spiritually retrieved from them by cultic powers. Ekeoma explained, “My husband was a member of the Ogbonee fraternity, and he sacrificed our child’s future for wealth” (Personal interview). This belief system, aside from insufficient intervention facility, is a major constraint limiting families from seeking help for their autistic children since autism is believed to be a spiritual occurrence. Take for example the Hmong refugees in Anne Fadiman’s

text, who regardless of having assessable medical resources, still believe that illnesses were caused by the loss of their soul and can only be treated effectively by animal sacrifice (Fadiman 81). Because even with the presence of proven modern age intervention resources, parents who believe their child's predicament is a spiritual attack, which can only be addressed by spiritual interventions, will not consult pediatricians or educators for help. Okafor said, "We took Emeka to so many places in search of answers to his then behavior changes. Prayer houses like Eddie Naogu and Father Ede were our initial rescue solutions. We tried everything and everywhere people recommended, but to no avail" (Personal interview). Emeka, who is my first cousin, began losing his speech as a toddler, and his mother, Okafor, took him to the urban city Enugu, where Father Ede usually held his weekly prayers for distressed families. Initially, my aunt Okafor searched for healing answers from numerous prayer houses, whose leaders gave her insights to what must have instigated Emeka's behavioral changes. According to her, some prayer houses told her that her late husband was responsible for her son's illness, while others believed it to be an evil act of a family relative, whose aim was to make her life miserable. But as my aunt continued searching for answers in prayer houses, she gradually shifted to traditional healing doctors like Eddie Naogu, whom she mentioned in her interview. Mandell and Novak write, "Beliefs about the course of autism may also affect treatment decisions. For example, families that believe autism is a curable condition may follow a treatment regimen designed to cure the disorder. If symptoms are not ameliorated, they may become frustrated and switch or add treatments" (as quoted by Levy et al. 112). This frustration is very typical in most cases where families have exhausted all spiritual resources available to them, and after years of trying traditional healing doctors and orthodox prayer houses with no avail, some families either give up their search for healing or may decide to consult healthcare workers or educators, by which

time, in some cases, the child in question may have advanced in age. Not to say that at an older age autism recovery is not possible, but studies have shown that early detection of autism followed by immediate intervention is key in helping autistic children overcome initial developmental challenges, which may lead to insignificant impairments in their later years. Gladheart explained, “Some of my students who received early intervention programs like special education, proceeded general education in their later years because their impairments did not limit them from being in typical classrooms” (Personal interview). With my present knowledge on the need for early autism diagnosis and intervention, I know for a fact that affected individuals like Emeka, who represents one out of numerous Nigerians with undiagnosed neurological illnesses, would have had increased chances of recovery if the superstitious Nigerian culture did not play a role in early intervention resources adopted by their families. To date, my aunt still does not have definite diagnosis for Emeka’s illness, and I know that a part of her still believes her enemies are responsible for the then sudden change in Emeka’s behaviors. As she narrated her story and as I got to see Emeka, I undoubtedly knew Emeka is autistic because I could clearly see it. But how was I supposed to tell my aunt her son is autistic? She does not even know what autism is, but my job was to tell her that Emeka is different because he was born that way, which is still my Nigerian culture playing a key role in my conversations with her because we do not directly address issues of mental health.

As in every culture group, Nigerian’s cultural attitudes and beliefs about the origin of autism influence the intervention choices families of autistic children consider or adopt for their children.

The Negative Impact of Nigeria’s Cultural Values on autistic children and their families

Cultural factors are intertwined with thoughts and behaviors, and as a result culture assumes a major role in the way families of autistic children embrace their children's challenges. From experience, I can say that the most significant negative impact of the Nigerian culture on families of autistic children is shame. Abosi writes, "In Africa, the child is an extension of his or her parents' ego, and therefore, families will regard a disability in a child as a stain in their social status" (198). Because some Nigerians consider autism a taboo or curse from evil spirits, families of these children face the everyday shame of parenting an autistic child. As a mother of an autistic son, I was enveloped with that shame earlier in my son's diagnosis. But because my son was young, just over two years old, it was very convenient for me to make excuses for his improper behaviors by telling people he was overly active. But as he got older, the realities of autism gradually crept in, and as I continued seeking for intervention resources, it became more natural for me to tell people that my son is autistic. I will attribute my present acceptance of autism to the fact that I live in America, where autism or other disabilities are well accepted by the general public due to westernization and proper awareness on autism. But what about other mothers of autistic children who live in rural Nigeria and other developing communities where autism is still considered a taboo? How do they deal with the daily shame attached to parenting an autistic child? These belief systems are important components of health and illness behavior. They influence the choices that people make when they or their relations fall ill" (Eaton and Agomoh 556). The choices families of autistic children make are functions of societal perception of their children. In rural Nigerian communities, families hide autistic children in rooms, and they usually lock these rooms as these children grow up to become teenagers and adults. With impaired communication skills as significant traits in most autistic children, these children are considered to be intellectually disabled (ID).

Mbubaegbu, a renowned autism researcher, studied the socio-cultural attitudes of Nigerians towards the mentally disabled. He concluded that that the various cultural backgrounds resulted in different attitudes and treatment of people with what is now called ID, and that in general, children with ID were seen as worthless beings” (Ajuwon and Brown 62). In these communities, low functioning autistic children rarely go out in the public with their families, and by low functioning I refer to a child highly affected by autism with three or more developmental impairments. Not to say that highly impacted autistic children do not exist in Nigeria, but locking them in rooms for safety, and cultural blindness frees the society from the realities of their existence. Ekeoma said, “Since my son’s illness, my family has become the ridicule of our kindred. I hardly attend public meetings because I see people looking at me like someone who committed an atrocity. My son has become hard to manage at home, and because it is a challenge to be in the market with him, I resorted to keeping him in a room for safety purposes” (Personal interview). As I watched Ekeoma open up the locks to her son’s room during my visit, I couldn’t help but wonder how many more grown adults like Ekeoma’s son are permanently confined in a room for the rest of their lives. As a Nigerian, I understand the shame Ekeoma feels when she is out in the public with her grown son, who typically should not be dependent on her if the right resources were in place. As a grown man in his thirties, Ekeoma’s son is one of the numerous undocumented autistic or otherwise disabled Nigerians who never had the chance to discover his potential in life. Ajuwon and Brown write, “Although there is limited research available on life situations of Nigerians with disabilities or their families, within the growing population today there are millions of children, youths and adults with disabilities living in various types of communities” (62). With the pain and shame accrued from caring for an incapacitated child, parents of autistic children consciously erase their children’s existence in head counts. When I

asked him how many children he has, Amaechi replied, “I have five children but when you add Anaga that makes them six in total” (Personal interview). I will assume that Amaechi added Anaga in the head count because he knew I am aware of Anaga’s existence since I was in his home to interview him about Anaga. Regardless of his including Anaga as one of his six children, one can clearly see that his above statement has an exclusionary meaning to it. It was also reported in 2002 during the national identification card registration, that parents of disabled children, specifically not autism, consciously excluded their disabled children in the registration. Basically, disabled children were nonexistent in the minds of their families because of the shame attached to identifying them. National identification registration is the Nigerian equivalence of a Social Security Number used in identifying individuals in America, so not documenting these disabled children was a result of family shame. Again, when Ukaefe, another father, was asked if his son has a national identification card, he responded by saying, “The Nigerian government and my community do not know my son, and of what use is a national identity card to my son if he barely knows his name. National identity card is for functioning Nigerians, and since my son is permanently at home, I did not see the need to identify him when the rest of my family registered for national identity” (Personal interview). The exclusion of disabled children from such essential national programs enables the stigmatization of disability to thrive in our society. I also believe that excluding autistic children from the daily functions of any society, by keeping them permanently at home, encourages their stigmatization. Because with more autistic children in the public, it will become more natural for community members to interact with them and their families, and this mutual awareness will gradually limit the shame attached to autism. Again, with more autistic children in the public, members of the society will begin to ask questions about autism and this questioning, too, will instigate more autism awareness. With increased

awareness, the community will demand solutions and answers to autism intervention, which will lead to the provision of intervention resources in Nigeria. Eaton and Agomoh write, “A mental health awareness program, and particularly one that makes use of established resources such as village health workers is an essential component of any community psychiatric service that is going to have a significant impact on a population in the developing world context” (556). The future of autism awareness in Nigeria will become bleaker if its taboo stigma lingers and families continue to lock autistic children in their homes. Indeed, eliminating the shameful stigma of autism cannot be accomplished by merely writing about this topic because this cultural value has infiltrated Nigerian culture for decades. But exposing the underlying factors that encourage this phenomenon in Nigeria, which I believe is poor autism awareness, will lead to a new dispensation, where autistic children and their families have the freedom to be public. Today, they do not have that freedom. For example, Ncheta explained:

When my child and I go to the village square, people distance themselves from us because they are afraid he will hurt them, and I have lost several friends as a result of my son’s illness. Some of my old friends were ashamed to be identified with me in public when I am out with my son, while some of my friends denied me an invite to their events because of my son. (Personal interview)

It is tragic that Nigerian families of autistic children would in addition to the day to day challenges of raising a special needs child, also have to struggle with the shame and emotional instability of raising their children in an ignorant community.

Indeed, the extent of damages caused by Nigeria’s cultural values on the available resources to help those with autism is beyond the scope of my research, but as a contributing

factor to the negligence in the education rights of autistic children, one can clearly see that the foundation of this neglect is informed by the Nigerian culture.

GOVERNMENT POLICIES AND SERVICES

Government Policies

The intent behind government policies in Nigeria, which is to influence decisions and actions, is not different when compared to other countries; except that in Nigeria, the implementation of already stipulated government policies are influenced by the high level of corporate corruption. It is corporate corruption in the sense that workers in the corporate sector, both public and private, are involved in unethical actions because of their quest for more money. Although corruption is higher in the public sector, its base is grounded in corporate Nigeria, and as a result of unethical practices, corporate corruption is the single most damaging feature of Nigeria's economy (Adegbite 1). In Nigeria, those who practice corporate corruption, including those in authority such as political appointees, present reoccurring obstacles in all sectors of the economy. They seem to get away with it because most Nigerians perceive political appointments primarily as opportunities for wealth enrichment. This is because in Nigeria, the leadership trend is such that when a person is elected for a political appointment, supposedly to empower his or her community, he or she replaces already existing leaders with close friends and family relatives. According to Appleton et al:

The political tradition in African countries has been to some extent resigned to the use of political power for personal or family enrichment; the cynical use of the verb 'to eat' as a synonym for political power is an apparently ubiquitous reflection of this, as is the political survival of people who are perceived to have used their positions for personal gain. (332)

With personal gains as the drive for corporate corruption, how then does this drive for more money affect educational policies in Nigeria? Being that the continuous discussion on the high level of corporate corruption in Nigeria transcends the scope of this thesis.

An Outlook on Government Policies and Services Provided for Disabled Children

The Nigerian National Policy on Education stipulates rules for educating disabled children, autistic children included, but regardless of these rules, autistic children are yet to be included in the education system. The National Policy of Education states that “before integrating students with special needs in regular schools, all necessary facilities that would ensure easy access to education would be provided” (Oluremi and Olubukola 159). Since this education policy was adopted in 1977, one will think it might already have been implemented. Thirty-nine years is far too long for autistic Nigerian children to wait for access to education. But it is obvious that after all these years, conversations on the need to integrate special needs students into the education system are still research topics. As far back as 1955, Nigeria’s constitution stipulated that the government shall direct its policy towards ensuring that there are equal and adequate educational opportunities at all levels (Chuta 523). From 1955 to the late 1980’s, military administrators embarked on education programs in public schools, programs aimed at providing free education for all students, irrespective of disability, from elementary school to high school. But after years of fluctuations in the free education programs, it became obvious that military administrators, under the then current military regime, did not quite understand the financial cost of providing free education. Chuta explains:

Thus, none of the past administrations in the Nigerian civilian or military administrations endeavored to assemble hard empirical data concerning what the actual costs of free education would be at the various levels. Needless to mention, no systemic attempt was

made to comprehend in any detail the implications of adopting any educational policies within different time perspectives, given available resources. (524)

Nevertheless, the military regime managed to implement the free education policies which I, born in the early eighties, witnessed. Regardless of free education policies in those days, disabled children being in school depended on the nature of their disability, and this trend favored students with physical disabilities, who already had their special schools. But the poor awareness of autism as a developmental disability excluded autistic children from education, regardless of the National Policy on Education.

In 2008, The National Policy on Education adopted education policies for the education of disabled Nigerian children and youth. Section seven of this policy explicitly recognizes that children with special needs shall be provided with inclusive education services. This commitment to disabled Nigerian children is to equalize education opportunities for all children irrespective of their physical, sensory, mental, psychological, and emotional disability (Ajuwon 5). Since sensory, emotional, and psychological instabilities are all present in autism, why then were these children excluded from the public school system? The answer is that since autism is not a physical disability, and Nigerians not knowing what to make of autism, understand autism as a taboo. With the stigma attached to autism, public services like education programs were not available for these autistic children. As the years went by, educational policies in Nigeria underwent reforms, but even with these changes, the Nigerian government failed to implement these reformed policies. In reality, less attention had been focused on the burden of having low functioning autistic children when compared to the attention that had been given to the burden of Malaria and other communication disease” (Bakare et al. 8). Common to developing countries, basic amenities such as healthcare and education are considered luxury by those who cannot

afford them, and since government policies advocating for autistic children were not implemented, families in the cities began opting for privately owned services. This is understandable given that fewer than ten percent of these children currently have access to any type of formal or informal education (Ajuwon 6). A greater percentage of autistic children in rural Nigerian communities do not have access to any form of education intervention. Even with the existence of the National Policy on Education as well as other international policies like the United Nations Convention on the Rights of the Child, adopted to promote equal access to quality education, these children are excluded from educational opportunities.

The unsatisfactory state of education in Nigeria is the consequence of a lack of proper implementation of the national education policy, which is influenced by political and socio-cultural factors (Iman 194). The implementation of equal access to education will help eliminate distinct traits of these socio-cultural factors.

The Fall of the Nigerian Public School System

Since the onset of the first civilian democratic president in 1999, the public school system in Nigeria gradually lost its value, and this loss contributed greatly to the present rise in the number of privately owned schools. I also believe that the new democratic government is contributing to the fall of the public school system. With politically appointed democratic leaders there has been a significant increase in the circulation of Inland Revenue, which is a function of the high level of corporate corruption. Because with democracy, political appointees are being served by private individuals as opposed to the military regime, in which mostly military families financially benefited from. Also, during the military regime, military governors of all the states in Nigeria were subjects to the military president, who controlled most revenue allocations in the country. This system of government limited the In-land revenue circulation since only military alliances, a small percentage of the Nigerian population, benefited financially

from the government. But with the annulment of the military regime, cash flow improved because with civilian administrations came civilian managerial appointments, which of course lead to individual wealth enrichment by those in authority. Presently, the civilian system of government is marked by great inequalities in the distribution of wealth, leaving many citizens impoverished with great disparities in education, social opportunities, and healthcare (as quoted by Ajuwon and Brown 62). So, with wealth concentrating more on already wealthy Nigerian citizens, these wealthy Nigerians began opting for sophisticated system of education such as private schools. The demand for this new and improved system of education, modeled after foreign schools, led to the demand for even more private schools. These new private schools taught foreign languages such as Spanish, French, Dutch, plus other western educational programs, which the public school system did not teach. In the past, elective languages were Nigerian languages, in which we took pride because the curriculum promoted national diversity. But today, with foreign languages as electives in private schools, Nigerians are drawn to these foreign languages because, common to developing countries, they believe that learning these languages is considered as positive westernization or globalization, as some may call it. Presently, school age children hardly speak or understand their native languages because the private school system, with the foreign language vision, does not promote native Nigerian languages. With Nigerians yearning to be closer to the western world, the private school system has now become the ticket to western exposure, and undoubtedly this fact encouraged more Nigerian parents to enroll their children in private schools.

So with this shift in preference, the public school system began losing its value, which also led to a decrease in teaching staff because the private schools offered better incentives like higher salaries and conducive teaching environments. On the flip side, the public school system

has been known for late salary payments due to administrative negligence and greed, so teachers now have the option to switch to the private school system, which not only pays promptly, but also offers competitive salaries. This change is entirely different from the 80's and 90's when private schools were very few, and teachers even with late salary payments were stuck with the public school system. I, for example, experienced this financial uncertainty a lot in my family because my mother was a teacher, and I remember asking for a toy only to be told that she has not yet received her last month's salary or her salary for the month before. Today, there are countless private schools in every nook and cranny of major Nigerian cities. With the growth and expansion of more private schools came the death of countless public schools. Currently, public schools are more common in rural communities which private school investors do not consider profitable since the income margins of the residents are very low.

Looking back, attending a federal government college, which is a public school, was one of the heights of my teenage years because federal colleges, also known as unity schools, included students from all ethnic tribes in Nigeria. Unity schools promoted diversity, unity, and enculturation, of which my counterparts in private schools cannot brag. In privately owned schools, student enrollment is mainly based on family income and parental choice, which in turn is influenced by costs and benefits (Appleton et al. 316). But in public schools, tuition was free which allowed for open enrollment of students from all walks of life. Also, with no tuition came an over flow of interested applicants, which instigated competitive assessment tests for all interested candidates. These initial assessments tests promoted excellence and competitive learning in unity schools. But today, enrollment in private schools strictly depends on affordability of tuition because most private school owners in Nigeria are private investors reaping financial gains from the downward spiral of the public school system.

Another factor that contributed to the fall of the public school system is administrative negligence and greed. In the words of Groody, “Greed breaks communion and seduces people to the lowest form of human behavior” (76). Before the civilian regime or way before private schools took over Nigeria’s education sector, administrative negligence and greed have always existed. Because government schools are government properties, administrative leaders in the education sector neglect important details involved in managing public schools because of their government-owned mindsets. They undervalued these public schools as government properties and assumed they did not require complete dedication and management. This philosophy is similar to the conclusions drawn by Ntukidem from his study on public schools in Nigeria: “School equipment are sometimes misused by certain individuals with the mindset ‘after all they are owned by the government’” (122). Administrative negligence did not only affect school structures but teachers and students as well because they were left to teach and study in dilapidated buildings. Leaking roofs, blocked sewage systems, broken down classroom walls, limited classroom chairs and tables, and insufficient teaching resources are very common in these public schools. This situation does not encourage effective learning because teachers are not well paid, teaching resources are hardly available, and classroom conditions are very challenging (Abosi 198). On the other hand, Administrative leaders in the education sector, who rarely inspected these schools, were not aware of their poor learning conditions. Awareness is most often influenced by personal interest, but because they were not interested in the effective functioning of the so-called government properties, they neglected their administrative duties. In some cases, neglect and greed worked hand in hand, and some administrative leaders neglected the affairs of these public schools by diverting public funds originally allocated by the government for the improvement of public schools.

Ntukidem's study identified those public funds meant for special education resources diverted to non-relevant activities to be a major setback in public schools (122). This financial situation is very common in Nigeria, in the sense that a State's Commissioner of Education, for example, may simply decide to withhold federal allocation or release a portion of the allocation to the state without explaining or addressing his actions. As aforementioned, scenario like this became more rampant in this dispensation of civilian leadership, which instigated a higher level of corporate corruption practiced by these civilian leaders. Not to say that Nigeria was corruption free prior to 1999, but corporate corruption has been at its highest in the last seventeen years. Nigerians have created and are deepening a morally reprehensible gap between those who have too much and those who have not enough for life or for life without dignity (Moe-Lobeda 32). Hence, democracy which Nigerians perceived as liberation from military leaders has indeed turned out to favor some while the majority of Nigerians are left in abject poverty. Volf explains, "When people are kept in abject poverty and illiteracy while others grow rich and develop their personalities at the formers expense, we speak of oppression. When structures and persons that perpetuate powerlessness are replaced by structures that allow people to stand on their own feet and have their own voice, we speak of liberation" (102). So, with Nigerians losing their hopes of economic liberation in the democratic government, some Nigerians, as a result of the significant wealth disparity between the rich and the poor, are beginning to think that Nigeria as a nation was better off under the military regime. George explained, "Civilian leadership is a failure. Everything in Nigeria has fallen apart since 1999. The roads are damaged, healthcare centers are closing down, the Naira value is depreciating each day, and public schools are practically non-functional" (Personal interview). So, with already existing systems in Nigeria falling apart, where then lies the hope of establishing new systems like special education programs?

Personally, I am hopeful that the present Buhari administration will revisit unimplemented policies, which will positively impact the lives of millions of Nigerians that utilize government owned facilities.

Therefore, for the proper functioning of existing and prospective systems, the Nigerian government must implement all policies that affirm the provision of basic amenities to all Nigerians irrespective of income and geographic location. This affirmation extends to public schools prepared to teach disabled students, including autistic children.

INDIVIDUALIZED EDUCATION PLAN (IEP) IN PUBLIC SCHOOLS

The Individualized Education Plan, or IEP, was introduced into the public school systems around the world in 1975. Prior to the 1970's, children with disabilities were denied access to public education (Futureofchildren.org). But with the inception of IEP, children with different forms of disability were given equal opportunity to attend schools in designated public schools under special education. With special education, special needs students, who cannot be taught in a general education classroom, are either integrated in a special education classroom or included in a typical classroom. When special needs students integrate in general education classrooms, they need hands-on tutoring from the teacher with the help of a para-educator. IEP is structured to meet specific needs of children, teenagers, and young adults with special needs between the ages of three years to twenty-one years; this means that every student has his or her own IEP, and no two IEPs are the same (Gladheart). IEPs are also structured to highlight the strengths of a student, while targeting areas of improvement. Regardless of the student's level of disability, contents of an IEP must specifically explain the student's learning skills, his or her full potential, and the best possible way to support the student's educational goals (IDEA Parent Guide 39).

IEP as it is Done in Developed Countries

In America, special education is regulated by the Individuals with Disabilities Regulatory Act (IDEA), which was formerly the Education of all Handicapped Children Act of 1975. The structure of IEP differs from one school district to another, but regardless of the school district, all IEPs are targeted at meeting specific needs of an enrolled special education student. The bedrock of special education law in America is founded on five principles, which according to Cohen are as follows:

Children with disabilities have a right to an education, this education must meet a standard of quality that is sufficient to allow the child to benefit from the education that is individualized to meet the needs of the particular child, education must be provided to children with disabilities in the least restrictive environment appropriate to meet their needs, parents have a right to receive information about, and to participate in decisions concerning their child's education, and parents must be provided with procedural due process safeguards that ensure their access to information and their ability to participate in a meaningful way and that give them the ability to challenge the school district's decisions before a neutral decision maker. (15)

With these principles in place, parents, teachers, and the school district all work together to ensure that special education optimizes eligible students' learning potentials. Before a child is qualified or is said to be eligible for special education, the school district requires an initial evaluation of the child, and a special educator performs the evaluation, after which the school district decides if the child is a good candidate for IEP. The child must not only meet the criteria for one or more of the disability categories, but the disability must also cause an adverse effect on his or her educational performance (Cohen 34). Other factors to be considered while

developing an IEP also include the strengths of the child, parents' concerns for improving their child's education, results from the child's initial evaluation, and the academic, developmental, and functional needs of the child (IDEA Parent Guide 39). With these factors as a baseline for pre-qualification assessment, an IEP is drafted if the child qualifies, and the child is enrolled in special education.

At the beginning or ending of a school year, it is mandatory for parents or guardians of all students enrolled in special education programs to meet with a team of special education personnel, which usually includes the teacher, therapists, and administrators, to formulate a new IEP or modify an existing IEP for the next school year. Within the school year, IEPs are subject to modifications depending on the developing needs of the student as long as all parties involved in the initial IEP draft agree with the changes (IDEA Parent Guide). Every student's IEP contains highly confidential information, and schools are required to limit access to confidential student educational records. IDEA makes it clear that a student's IEP must be accessible to each person responsible for its implementation (IDEA Parent Guide). IEPs are self-explanatory because of variations in the education levels of parents and guardians of enrolled students. In America's diverse culture that comprises different races, IEP meetings may require the presence of a language interpreter, usually requested prior to the meeting. Special education teachers always consult each student's IEP on a weekly basis to stay in line with their student's education goals. Gladheart explained, "As a ritual to remind myself of each of my student's IEP, I use a cheat sheet, which has my daily notes on it, for data collection. But as the school year progresses, I may not often refer to their IEPs because I am more conversant with them" (Personal interview). Constant referral to IEPs is very important for teachers because special education is an integrated program that teaches children with delayed speech, down syndrome, sensory processing

problems, cerebral palsy, autism, attention deficit hyper activity disorder, and other delays that impact learning. Since IEP has been an effective educational program for special needs students in developed countries for over forty years, how can Nigeria and other developing countries effectively adopt IEP in their own educational systems?

Integrating IEP in Already Existing Nigerian Public Schools

The success of special education programs in public schools largely depends on the availability of appropriate intervention resources (Fareo and Ojo 160). Since most existing mainstreamed Nigeria public schools are under resourced, what needs to happen so that IEP resources for special needs students are available? All intervention resources such as specialized materials and equipment, special educators, and trained development personnel are expensive. Integrating IEP in existing public schools will be, indeed, a financial commitment for the Nigerian government; it will entail remodeling most of the dilapidated public schools, hiring new staff, and installing specialized equipment and materials in these schools. The National Policy of Education 1977; 2004 stated that “before the mainstreaming of students with special needs in public schools could take off, all necessary facilities that would ensure easy access to education would be provided” (Fareo and Ojo 159). But judging from the appalling conditions of most Nigerian public schools, one can see that integrating IEP in these schools is presently not feasible, unless the Nigerian government decides to abide by this policy, which obviously will come with financial commitments. The government of Botswana for example made a huge financial commitment and established a central resource center in Tlokweng which provides intervention resources and stimulation services for developmentally delayed children. As part of its commitment to special education, which sets the pace for other African countries, the Botswana government provided this center with fully qualified professionals and staff, along

with modern facilities for the effective tutoring of special needs students (Abosi 199). So, for the successful integration of IEP in existing public schools, the Nigerian government has to make a huge financial commitment to jump start and sustain special education programs. It will be a hurdle considering that Nigeria's annual expenditure on health – including physical and mental health – is only three percent of Gross Domestic Product (GDP), and mental health takes only a small part of this total health budget (Eaton and Agomoh 1). Because autism is a mental health condition, and considering that a small part of the GDP is allocated to issues of mental health, it is very obvious that for the Nigerian government to provide intervention resources both in school and health clinics, its annual expenditure on health and education has to increase. Hence, the foundation of special education integration in the public school system depends solely on whether or not the Nigerian government is willing to commit financially to the education and empowerment of all special needs students.

Recommendations on how IEP can be Implemented, Financed, Managed and Sustained in Nigeria with Consideration to Nigeria's Government Policies and Culture

My recommendations for implementing, financing, managing, and sustaining IEP in Nigerian public schools is purely based on my personal reflections from my field experience in an integrated classroom and also from data collected in my qualitative research. As I have stated earlier, if special education integrated in all Nigerian public schools can happen, the Nigerian government has to make a huge financial commitment in upgrading existing public schools, hiring developmental professionals, and providing specialized equipment. This commitment is only the first step in implementing IEP in special education, but it is essential because IEP cannot function in schools without special educators or in dilapidated school structures with

insufficient intervention facilities. Appleton et al. explains, “The commitment of African governments to development have certainly varied, but even those who are really committed to improving the lives of their people are not convinced of the need for public action in health and education” (332). This is to say that if the Nigerian government commits financially to all the funding that goes with IEP implementation, it has to see and believe in the need to educate autistic and other disabled students. Additionally, the government has to understand that adequate education will enable these disabled students contribute their own quota to the development of the nation (Ntukidem and Eyo 119). So, if the Nigerian government will consider the undiscovered potentials hidden in these autistic children, potentials brought to light with adequate resources, its annual expenditure on public education will become a major priority in budget allocations.

Consequently, with Nigerian autistic individuals often considered worthless, because of the stigma attached to autism, breaking this cultural barrier will be very challenging since the government may assume educating them as an unproductive expenditure. Abosi explained that poor vision, inadequate funding, selfish interests, and the lack of financial commitment are all negative governmental attitudes about special education, attitudes influenced by African values, tradition, and culture (as quoted by Ntukidem 120). To break this cycle of stigmatization that the lack of autism awareness causes, the Nigerian government will play a vital role in promoting autism awareness if it changes its mindsets and adequately funds autism related programs such as IEP. As a result of its mindset change, communities will begin to see more autistic children out in the public, these children will then be more recognizable and accepted because they are enrolled in public schools and no longer held bound in their homes. With more autistic children out in public, their very presence will instigate dialogues and open conversations about autism,

and the Nigerian society as a whole will embrace it. In *Exclusion and Embrace*, Volf identified opening the arms, waiting, closing the arms, and opening them again, as the four structural steps in embracing the other (141); and since autistic individuals are considered the “other,” seeing them in public places like schools will encourage the society to open its arms and accept them. Hence, integration of autistic students in public schools will go a long way towards breaking the cultural stigma, a heavy barrier against them. The Nigerian government can make it happen, and only the government can make it happen, with its increased financial commitment to special education to ensure basic education for all of its children.

The question remains as to how the government can/will finance, manage, and sustain IEP in public schools. It is well known that intervention resources such as auditory processing equipment, sensory integration toys and instruments, speech therapists, occupational therapists, special educators, applied behavior analysts are very expensive, and using them will also entail more running costs. But the government must first commit to the initial funding of IEPs, which hopefully will lead to subsequent funding of running cost. Second, it is likely that other organizations such as those in the non-profit sector will be encouraged to partner with the government to sustain IEP in these public schools. Foundations such as the Dangote and UBA each support child-based programs in main streamed privately owned schools, so inviting them to partner with the Nigerian government for an effective sustenance of IEP, another child-based program in public schools, will not be out of place. According to Ntukidem and Eyo, “The private schools being what it is seem to receive attention from the private organizations, non-profit organizations, churches, communities and individuals, hence the more facilities” (121). So, for IEP to become sustainable in established public schools, the Nigeria government must partner with other organizations that are interested in empowering autistic Nigerian children.

My third recommendation in this proposal requires a change in administrative leadership styles. Because private individuals often provide better services than do government personnel, I recommend that these public schools with special education programs employ private leaders. In fact, the administrative protocols in government owned facilities, those managed by private individuals, encourage that they closely monitor and supervise both human and material resources available in the school, so that anything provided is well cared for and properly maintained (Ntukidem and Eyo121). Not to say that school administrators hired directly by the government are incapable of maintaining and supervising resources, but from my experience living in Nigeria, I know that the administrative protocols employed by private individuals are often more effective than are those adopted by government employed head teachers and principals. Government employed leaders also do not submit to regular performance evaluations, and thus, they sometimes lack the necessary responsibility to effectively monitor their jobs or government resources. This situation is very common in most Nigerian public schools. Ntukidem and Eyo in their research also noted that government facilities and funds are misused by certain administrative leaders with the mind set of “after all they are owned by the government” or they are government properties (122). From my perspective, I strongly recommend a semi- public private placement (PPP), in which private consulting firms have the right to recruit and hire administrative leaders who will submit to the firm’s monitoring and regular performance evaluations. As a result, these public schools that integrate special education will partner with consulting firms to effectively manage and sustain special education programs.

Finally, I recommend that all Nigerian universities should consider including special education classes as required courses in the first two years of general education undergraduate

degrees. This addition may help general education teachers' substitute as special education tutors when needed since they would have at least a basic knowledge about special education protocols.

Since its onset in 1975, IEP has been quite instrumental in integrating autistic students into mainstreamed schools in developed countries. Studies by Abosi, Oluremi and Bakare et al. on special education in Nigeria have identified the negative impact of inadequate education programs for Nigerian special needs students, autistic students included. Findings from these studies, which were similar to mine, emphasized the need for an immediate intervention by the Nigerian government. Dickson explains, "By providing the opportunity for others to learn, students with disability are contributing to the good of the community and, as such, entitled to be accorded the respect of the community" (1106). Hence, introducing IEP as a special education program in all Nigerian public schools will help eliminate the social stigma of autism, but more important, it will help autistic children live out their full potentials in life.

CONCLUSION

The everyday challenges of raising an autistic child are being worsened with the absence of intervention resources, which unfortunately families of autistic children in rural Nigerian communities are compelled to live with each day. Autistic children living in these under-resourced communities may never have the opportunity to make friends and build relationships in their respective communities. Seemingly, families of these children have sought answers to address their children's impairments, and these answers have lain unnoticed in the hands of the Nigerian government, a government perhaps aware of the nonexistent resources in these communities, but one that has chosen to neglect these communities. The Nigerian government itself is to blame for the unquenchable pain felt by the families of these children. Families who in their bid to find peace as well as protect their children have resorted to restraining their children in a safe room away from the prying eyes of our Nigerian society that considers autism a shame.

The real shame is that the Nigerian government's negligence has continued to influence poor autism awareness in all parts of Nigeria. However, if the Nigerian government will financially commit to and introduce special education programs in all public schools, these programs will platform the new dispensation of autism awareness in Nigeria.

Autistic children have hidden potentials, strengths, and talents, all undermined by societal perception of autism. But with the right intervention approach, every autistic child, regardless of the degree of impairments, stands a chance to make significant development improvements. I say this as a mother who has watched her son steadily improve from not being able to understand any spoken word at two and half years of age, to a child with unlimited understanding of words and sentences. At age four, after two years of using early intervention resources within our reach, I stand firm in my belief that autism recovery is possible with the right intervention approach. Not to say that my son is recovered or is anywhere close to recovery, but judging from where he began his recovery journey, he has made significant improvements, which would never have been possible in the absence of intervention resources. Within two years of non-stop behavior therapy, speech therapy, and of course special education, these resources combined have been most instrumental in his recovery progress. I consider this a recovery because autism deprives children from attaining their individual development milestones, which they recover with intervention resources.

While reflecting on my son's recovery journey, I often wonder what would have become of Ukaefe, Ekeoma, Josephine and Okafor's sons, if they had been given the same intervention opportunities as my son. Not all families can afford behavior and speech therapies, but with free special education programs in public schools, I have seen children make significant progress. Since these other intervention resources are out of reach for rural Nigerian residents, the

Nigerian government must integrate special education programs in already existing schools to help all special needs children have the same opportunity as my son. Autistic children born into impoverished Nigerian communities did not have the right to choose their communities prior to their existence. But upon their existence in Nigeria, these autistic Nigerian children deserve the right to free education in public schools.

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