

# Living and Dealing with Autistic Children: A Case Study of a Nigerian Family in Cincinnati, Ohio, United States

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## Abstract

Autism persists in isolated enclaves in many regions of the world. It is a vexing and tenacious problem, but one that has generally been overlooked. When brought to public attention, the disorder has usually been misdiagnosed, and the families with the autistic children have been held responsible for what is really society's illness. In seeking to understand the problem and its tenacity, we can derive important perspectives from the family and children who actually make up the category labeled "Autism Spectrum Disorder." The purpose of this study is to examine how a Nigerian family is coping with Autistic Children. Participant observation and semi-structured interviews were used to collect data. The findings show seven key parental concerns and feelings: social stigma, readjustment of family plans, financial burden, and feeling of helplessness, fear of the future for children, fight for a cure, and a vision to create of an Autism Family Center. Contrary to expectations, I did not find much shame in the family. Implications of the findings for policy and future research are presented.

**Keywords:** Autism, Autistic Child, Nigerian, Shame, Stigma, ASD

## Introduction

Autism persists in isolated enclaves in many regions of the world. It is a vexing and tenacious problem, but one that has generally been overlooked. When brought to public attention, the disorder has usually been misdiagnosed, and the families have been held responsible for what is really society's illness. In seeking to understand the problem and its tenacity, we can derive important perspectives from the family and children who actually make up the category labeled "Autism Spectrum Disorder." The families who grapple everyday with Autism can, in fact, contribute much insight into this longstanding disorder. If we were to observe them closely and elicit their perceptions, their hopes, their joys, and their despairs, we would finally see that the problem of autism is not as so often believed.

Autism Spectrum Disorder (ASD) is "an equal opportunity disorder" (Whelan, 2009), it occurs in all ethnic and socioeconomic groups, affects every age group no matter which country or culture and it is on the rise. Experts estimate that three to six children out of every 1,000 will have ASD. NIMH's recent studies show that an estimated 3.4 of every 1000 children 3-10 years of age have autism, and boys are four times more likely to have ASD than girls (NIHM, 2010).

To provide the contextual perspective on the problem of autism, an ethnographic study has been carried out in Cincinnati, Ohio to examine how a Nigerian family is coping with having two Autistic Children. An important assumption of this research has been that actors themselves are capable of providing significant insight into their own behavior.

Although there are studies on coping mechanism of families with ASD children, there has been none on the effects of stigma on the coping mechanism of blacks, immigrant Nigerians or other ethnic groups raising children with ASD in the United States. This study of a Nigerian family with two autistic boys, will examine the culture of fear, shame and social stigma as it affects their parents' attitude towards their children. Using the culture of social stigma and felt shame theory, I will explore the coping mechanism employed by this family living with two sons with autism. Ethnographic research method will provide insight and data that would hardly have been elicited through a more formal research method, capturing not only what people say they do, but what they actually do.

## Literature Review

According to the CDC (2009), "most scientists agree that genes are one of the risk factors that can make a person more likely to develop an ASD". This creates some anxiety, social stigma, shame and blame for parents who feel responsible for their child's predicament.

Stigma is defined as "a symbol of disgrace or infamy, a stain or reproach, on one's reputation" (dictionary.com, 2010). Jones, Farina, Hastoff, Makins, Miller, & Scott, (1984) makes it clear that, the stigma felt by the individual with a family member with disability is profound resulting in "emotions as diverse as anger, sadness, humiliation, shame and embarrassment". Gray (1993) also agrees that "stigma is the most difficult aspect of public encounters experienced by families with a disable member". It is therefore important to understand the tough emotions that accompany having a child with disability in Nigeria.

Of the many forms of this chronic illness, autism poses the most challenge not only to the afflicted individual but

to the entire family. Autism is a condition that is often associated with temper “tantrums, disruptive, self destructive acts and other forms of inappropriate public behavior” (Gray, 1993). Therefore, interacting with the outside world and extended family is with great difficulty because of the stigma experienced due to public display of these behaviors. Some families sever ties with families and friends and live in isolation to avoid the *embarrassments*.

Even though there has been no evidence that it affects more whites than blacks or any other race, there is still this believe that it is a white, rich people’s problem. It only seems that way because people from other races are reluctant to get diagnosed because of the stigma associated with it in their culture (Parashar, Chan & Leierer, 2008 p.235).

While there are some studies that explains that families of children with autism eventually adjust; stresses emerge and re-emerge in different forms over time due to the health and life expectations, social stress and perceived lack of community support.

A child with autism may never be able to express themselves, or perform simple tasks such as tying of shoes, get themselves a drink of water or know when they are full. Parents are therefore left playing guess games since they cannot determine what the child with autism wants at any particular time, this is challenging, frustrating, physically and emotionally exhausting. The gap between parents' expectation and ASD child's performance indicates a continued need for information and counseling (Wikler, 1981), but this is hampered by reactions from society and feelings of isolation. Parents become uncomfortable taking their child out in public or to community gatherings because the child’s behavior is unpredictable most of the times and they are afraid that people will talk or stare. Parents experience considerable stigmatization. Gray (2002) argues, that the socially inappropriate behavior of the child with ASD and their normal physical appearance, makes their behavior more stigmatizing (Farrugia, 2009; Gray, 2002a). For parents, these behaviors can lead to humiliation, social exclusion and isolation (Gray, 2002b) especially since the children are without any visible physical disability.

Autism diagnosis for a child affects every member of the family in different ways. Parents and caregivers must restructure their focus on helping their child with ASD, which may put strains on their marriage, other children, work, finances, personal relationships and responsibilities. Parents have to shift much of their resources of time and money toward providing treatment and interventions for their child, to the exclusion of other priorities. The needs of a child with ASD complicate familial relationships, especially with siblings. However, parents can help their family by informing their other children and community about autism and the complications it introduces, understanding the challenges siblings face and help them cope. Involving members of the extended family to create a network of help and understanding (Shore, Rastelli & Grandin, 2006) helps reduce the stress on parents. In a study by Nadeen, et al. (2007), they reported that stigma plays an important role in people refusing to seek mental health care thereby preventing early diagnosis of cases like depression or autism. Some parents might not want to discuss it with their doctor because “stigma concerns were associated with lower rates of wanting care” (Nadeen, et al., 2007).

Whiles there are several extensive studies in the United States (Shtayerrman, 2009; Gray, 1993; 2002b; Farrugia, 2009; Joachim & Acorn, 2000; Jones et al, 1984; Baskind & Birbeck, 2005; Nadeem et al, 2007) on the various effects of autism on the family and the different types of stigma (felt, enacted or courtesy) they are exposed to, there has been no such studies done Nigerian parents and their attitude towards disability and their reaction to social stigma, its effect on the child with autism or their coping mechanism, thus the importance of this study.

In Nigeria, there is a lot of mysticism around disabilities and people don’t often know what to attribute them to. Like their Asian counterparts who “believe a child’s impairment to be an act of punishment from the God” (Bywaters, Ali, Fazil, Wallace, and Singh, 2003, p. 503), Nigerian culture often blames diseases like ASD on witchcraft spirits, incest, hereditary causes or just simply bad parenting. Speculations and beliefs range from “cold and unfeeling mother” or “refrigerator mothers” (Bettelheim, 1967, 1974), being responsible for the child’s social and communication problems, to the belief that ASD tends to run in the families. In this case, a genetic defect is suspected (Bailey, Philips & Rutter, 1996. p. 6). Parents of autistic children often internalize these beliefs and blame themselves for doing or not doing something somewhere at a critical stage in their child’s development. This leads to the shame and stigma that parents of ASD children often feel.

Ignorance and lack of understanding of this disorder permeates through every community, ethnic group and economic class in Nigeria. To some, it is a shameful subject to discuss. Okey-Martins, (2007) stated that, “there is a serious and disheartening lack of awareness and misunderstanding about autism in Nigeria I have met many special educators, psychologists and even medical doctors who seem to be hearing the word autism for the first or poorly remembered second time”.

## Methods

The family who are living in Cincinnati, Ohio was contacted to schedule the interview and observation after research protocol was approved the Institutional Review Board of my University. I decided to use non-

standardize interview in order to gather sufficient data for a sensitive and complicated topic such as autism (Fielding, N. & Thomas, H. 2008).

### **Research Design and Strategies**

The data were collected by in-depth, open-ended interviews, and participatory observation. The instrument is a semi-structured interview with 15 questions prepared as a guide. The questionnaire gave some structure to the interview. "One way to provide more structure than in a completely unstructured, informal conversational interview, while maintaining a relatively high degree of flexibility, is to use the interview guide strategy" (Patton, as cited in Rubin & Babbie, 2001, p. 407). More structure, according to Rubin and Babbie eases the researcher's task of organizing and analyzing interview data. It will also help the reader of the researched report judge the quality of the interviewing methods and instruments used.

### **Procedure**

I visited the home to conduct a formal observation of the environment and collected data on coping mechanism and how autism affects social and daily life. Since both parents work, I did the interview and observation on weekends for about 4-6 hours.

Additional data collection method was a non-participant observation that I did by watching a video tape the family gave to me titled "*a day in AK's life*". Following the social science ethical guidelines, the family members were given an option of not participating. They were given a consent form explaining that there will be no financial compensation and that participation is voluntary.

The interviews were audio taped along with hand-written notes. The data were analyzed to examine the effect of stigma and shame on this Nigerian family and their coping mechanism. I listened to the audio while going over the transcript to identify themes from the parents' comments. Finally, the participant observation notes were compared to the video observation given to me by the family recording of "*a day in AK's life*".

### **Analysis and Results**

#### **Parents and siblings coping strategies**

In an interview with the father, he explained his experience when he first found out about his heir son's autism. He said that:

You see, our first daughter walked at 7 months and we were so excited about the birth of our son but I first noticed that he was not responding too much by the age of 10 months. So we started the trip back and forth to his doctor and we were told things like "all children are not the same, boys are slower than girls, and he is taking his time". But by 18 months, his doctor said "if it will make you feel better I will send you to a neurologist". That is when after a battery of test the doctor gave us the news. (Father)

He further said, the doctor just said he has autism; "he may never walk, talk or be able to take care of himself. What do you do with that kind of diagnoses, huh?"

Both parents mentioned their faith in God as one of the coping mechanisms. They have "become more prayerful and more focused on the positive instead of asking *why me?*" (Father). Their hope to live long enough to get the boys to self sustaining adults is their prayer and they see improvement, but they lament that there is so much they could have done with more resources.

One issue families with autistic children deal with that is rarely talked about, is the siblings of these children whose lives are also profoundly affected by the disorder. Most siblings might not understand why their brother or sister attracts negative comments or receives all the special attention. In the study family, Ama is too small to notice but GZ's case is not different from most kids with special needs sibling who experience 'courtesy stigma' which "is the stigma of affiliation" (Gray, 2002b). The parents try various ways to help her cope with the situation. Specifically, her mother said:

"She is quiet, not as outgoing as she used to be, she is very sensitive to comments about her brothers; she gets angry easily, now reads and writes a lot which is good. We try to teach her to educate people instead of getting angry and we give her enough information for her age, about her brothers' condition. It is easy to get carried away but we try to spend special time with her."

The parents in this study, despite their busy schedule have devised a way to make GZ feel cared for and loved as much as her brothers. This is an important finding. For example, Crystal Brown who has a brother with autism said:

Siblings will be in the lives of family members with special needs longer than *anyone*. Brothers and sisters will be there after parents are gone and special education services are a distant memory. If they are provided with support and information, they can help their sibs live dignified lives from childhood to their senior years (Brown, 2010).

Help from extended family support was mentioned as another coping mechanism. It was stressful trying to care for AK and his sister who was three years old at the time as other health complications like seizures started to

manifest. It became difficult to find daycare programs that will take AK as he grew older, so they got help from family. The grandmother came to live with them for a while to give them the needed support.

The parents spend a lot of time with their children thereby noticing their progress which is a relief to them and they celebrate each milestone as a family.

This family is actively involved in helping to educate and passing on the information, knowledge and experiences they have gained from this disorder. Giving back to others who are less fortunate as they have been is one way they cope with this disorder. They expressed their gratitude to God for being in a country where their children could be diagnosed early and have a chance at a relatively 'normal' adult life. The Father expressed his desire of going back to Nigeria with his boys for an extended period to help educate people about dealing with this illness when they said: "we did not ask for it, God chose us and we have to be good stewards of our knowledge and resources given to them" (Mother and Father).

#### *The family's social experiences and dealing with stigma*

The complication and stress from social interactions is expressed here by the Mother in response to the question, *do people treat you differently because of the children's condition?*

Nobody wants to talk about 'it', they do not even know how to ask about your children during phone conversations, and when you ask about their family it is "oh they are fine. You notice your friends do not want to talk about their children for fear of offending you (Mother).

This attitude cause some family to stop calling, talking or even show up in social settings to avoid making friends and families uncomfortable. The kind of stigma experienced by this parent is similar to that reported in Gray's *Perception of Stigma* studies where parents feel stigmatized by their autistic children's "public behavior like tantrums and destructive behaviors in public" (Gray, 1993). As the father commented:

Going to church is a challenging even with AK, things as simple as standing up to sing as it is customary with catholic churches, there are so many standing, sitting and kneeling down that sometimes once you get up as far as AK is concerned, it is time to go home. If you don't go and you try to sit down he begins to cause a scene (Father).

GZ has all kinds of emotional issues because of her brother's autism. She loves them but prefers to spend time away from home according to the mother. Some of the feelings of the parents socially concerning stigma can be seen in their responses to the following interview questions:

#### *a) What does his autism mean to you?*

To me it is an enigma of indescribable challenging proportion. It's a personal challenge. For OK, it was hard to accept, with the social stigma out there and the attention needed by one child having two with autism is challenging. You know how we are with male children, and here I am with my two boys who may never be able to call me Father. OK now has some communication and he spells a lot of things (*smiles*) out or write them by we are working with AK (Father). You go through all the emotions from a feeling of loss, sadness, guilt, shame, and confusion; then you wonder, *ok now that I know, what should I do?* It becomes especially hard when it is a condition without any real cause or cure. (Mother)

#### *b) How do you deal with the social stigma?*

There is really no real way of dealing with it. Many times you ignore, in our case, my wife and I chose to educate. And we are teaching GZ to do the same (Father). It is especially harder on GZ since they ride in the same school bus, she gets very defensive and sometimes angry when people call her brother (AK) retard, crazy or other names (Mother). We are worried for them (children), the social stigma out there is due to lack of education (Father).

#### *c) How has the stigma affected you?*

We choose where we go with them and make sure I have AK and my wife has OK. You really can have fun freely in public, you always want to know where they are every second (Father). You can't take both of them to the same occasion if you are going alone. Like grocery, you can't push the cart and hold onto a seven years old boy, OK is manageable but for AK, you never know what will trigger him to acting up.

#### *d) Do you feel any responsible, shame or inadequate in any way?*

Initially, you feel like "how will I explain this to anyone", especially since you don't have all the pieces together but then you take it one day at a time. Worse still they do not have any physical disabilities yet when they start acting out in public especially AK, you feel responsible.

The parents expressed that their ability to hire a live-in Nanny has helped them have a semblance of social life as a couple and with their older daughter-GZ. It has allowed them to integrate back into society by attending social functions by friends and family.

The extended family support is great but their immediate families are scattered all over the country. There is no one around Cincinnati but the Father admits that they understand the children's condition. One interesting finding was the extent to which stigma was mentioned as one of their worries not for themselves but for all their children. The Mother never used the word stigma and to questions related to stigma or shame the Father answered. She was more interested in the healing, new research findings, new stories of changes in the effect of

autism as a result of diet, medication or therapy. This was about the only time I noticed some disagreement between the parents. They were cohesive and engaged with their children, constantly trying different coping methods resulting in noticeable improvements. As stated by Altieri and Kluge (2008), “children in this type of family would be free to develop independence, when able.”

### Financial Issues

Another theme that came out from the interviews was the financial effect of the care and treatment of a child with autism and this family has two boys with it. The Mother said it cost them about \$35,000.00 a year per child to get all the therapy and medications you need. Same is found in the University of Missouri research which states that the

“costs include specialized child care, speech and language therapy, other types of one-on-one therapy, special interventions, and costly food or drug supplements. Applied Behavior Analysis (ABA), a widely respected and recommended behavioral intervention, can be expensive. .... some parents reported paying as much as \$30,000 a year for ABA therapy (University of Missouri-Columbia, 2008).

One of the great issues this family deals with is the financial stress associated with this illness which has caused quite some readjustment to major live plans as expressed here by both parents in response to the question *how has your life changed?*:

You can't just drop your child with a friend or regular baby sitter to make a run. We have to hire a live in nanny because of the cost of after school care for two of them is more than usual, we might as well have someone in here for all the kids (Father)

As the mother said smiling:

“I would have loved to have more children but can't afford to because the care for the two of them is just too much”, major decisions have changed in their lives. The father also echoed having to change jobs because of the unpredictability of AK's seizures as he explained having to “fly back from a company conference in New York when he got a frantic call that AK is dying from the nanny”.

Even though his company was gracious to put him on the next available flight back, he decided to live his job to be around.

### Conclusions

The purpose of this study is to examine how a Nigerian family is coping with Autistic Children. Participant observation methods and semi-structured interviews were used to collect the data. Based on the data gathered from the interview, this family is affected by felt social stigma. Their older daughter's withdrawal and eagerness to leave home for friend's house every chance she gets shows avoidance and courtesy stigma. The parent's reduction in social interaction shows evidence of stigma.

Contrary to my assumptions, there was not a strong perception and feeling of shame and stigma. This might be due to their changing abilities to deal with negative reactions from people and their understanding of the illness. The parent's academic and medical knowledge of autism may have also led to the reduction of evidence of shame as is common with African parents.

Even though there are several issues raised by this research, it was important to note the difference in the perception of stigma and shame between the mother and father. Unlike some research on autism and stigma which show more stressful effects on the mothers, my findings indicate the father has more stress and more concerned with the stigma resulting from the disruptive behavior associated with autism than the mother. This could be so because of the cultural background and importance placed on male child by an African father. Fathers want to see a resemblance of themselves in their offspring for reassurance. Thus, if disability is what they see it can lead to feeling of helplessness, hopelessness and shame (see Okey-Martins, 2007).

Enacted stigma manifests as discrimination against the stigmatized person imposed by others, whereas felt stigma is the fear of enacted stigma experienced by the stigmatized person. Felt stigma may result in the stigmatized person thought and beliefs, thereby limiting their life experiences and opportunities. Courtesy stigma is the “stigma by association” experienced by individuals in close social or physical proximity to someone who is stigmatized (Schneider & Conrad, 1981). Based on my research, courtesy stigma is the one this family feels from friends, family and the Nigerian community they associate with, some of whom wish discussions regarding children and their achievements would not be held in this family's presence.

In a study by Baskind and Birbirk (2005) titled *Epilepsy-associated stigma in sub-Saharan Africa: the social landscape of a disease*, they concluded that data from developed countries indicates that enacted stigma remains substantial even though felt stigma may be more limiting and apparent.

Coping with stigma involves a variety of strategies including the decision not to disclose the condition and suffer further stigma, or attempt to conceal the condition or aspects of the condition and pass for normal. But because parents rarely have the “option of passing in all circumstances, they have to confront the problem of limiting their exposure” (Gray, 2002b). This family freely talks about their children's condition mostly with the aim of

helping others.

The findings from my research indicated that parents with autistic children may vary in their attitude based on their knowledge of the illness, family support, religious beliefs and different stages of the child's development. For this family, there is a significant improvement for OK and AK' behavior and outburst are not as frequent.

Another finding is that of financial responsibility as a possible reason for way African parent's react and cope with their autistic child. The mother was more willing to talk about the financial burden of this illness than the father. This explains another African culture of the man's ability to cater for his family as admitting that there is financial burden might lead to loss or reduction of dignity.

In the context of this research, there was no apparent difference between felt stigma and courtesy stigma for this family and shame was minimal. Neither shame nor stigma has any effect on the way they treat their children. In other words, they treated their children with utmost respect and dignity and have almost the same aspirations for them as they do for their normal children and hoping for if not a cure but a breakthrough.

### Limitations

The study has a number of limitations. First, because this is a Nigerian family, these results cannot be generalized to other ethnic groups. Each family and each individual is in some sense different from all others. Second, in any social stratum, there are homes in which children receive open demonstration of affection and home where little human warmth is exhibited. It is difficult, then, to generalize about the people, or behaviors, or home life. Therefore, great caution must be exercised in seeking commonalities. There are many more questions raised by this research that cannot be answered by studying one family, thus a study with more Nigerian families both in the United States and Nigeria is encouraged. This is because autism is a spectrum and the behavioral display and illness associated with it are as varied as there are children.

### Consideration for future research

Future research should examine whether the parent's academic background and knowledge of the illness affect their perception of stigma and its influence on their motivation to seek treatment for their children. It will be better to expand the study to include more Nigerian families in America and in Nigeria with autistic children.

It is hoped that the observation presented here may help readers to understand a variety of Nigerian families with autistic children elsewhere in America. But until much research is accomplished, caution must be taken in applying conclusions based on one population to other populations with different parameters.

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