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PARENTAL EXPERIENCES OF RAISING A CHILD WITH AUTISM SPECTRUM DISORDER IN GHANA

A case study research analysis

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Abstract

Aim: This study explores parental experiences of raising a child with Autism Spectrum Disorder (ASD) in Ghana. It investigates parental stress, stigma, access to education for children with ASD and coping strategies employed by parents to manage the situation. This was necessitated by the prevalence rate of ASD globally and the limited number of research available on this phenomenon in Ghana.

Theory: The religious or magical model of disability proposed by Avoke (2002) and the social model of disability proposed by Oliver (1996) were adapted to explore this phenomenon in the Ghanaian society.

Method: Informed by the interpretive paradigm of research, qualitative case study research was used to closely investigate, explore and describe the identified research problem. In all five parents were interviewed as major sources of data for the research. In addition, three heads of institutions were also interviewed to complement the data gathered from parents about access to education. Further, field notes were taken, a research diary was kept and the legal policy regarding education for children and education for children with disabilities in Ghana were outlined to give a fair idea of what the legal framework proposed. The data was analyzed using thematic analysis.

Results: It emerged that parents of children with ASD in Ghana are stressed, stigmatized, and find it difficult when accessing basic education for their children. Also, spirituality and the belief in the supernatural was identified as dominant cultural opinion regarding the cause of this condition. Hence, most parents cope by seeking spiritual help, seeking family and friend support, educating themselves about the condition, changing their lifestyles, and disregarding negative societal attitudes.

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Further, I would like to express my gratitude to the head of institution who declined to participate in the study yet, offered a reduction in school fees for a participant's child who was not schooling when the study began to enable him start schooling by the time the study was brought to an end.

Finally, I would like to thank all the parents, caregivers and heads of institutions in the Greater Accra region of Ghana who availed themselves for me to interview them for the purpose of conducting the research. I am very grateful because this study would not have seen the light of day without their permission and cooperation.

Foreword

The present study is a little under the 30,000 words limit when the words preceding the introduction and the words in the appendix are excluded from the word count. This is because having thoroughly discussed the relevant themes in the study, and considering the fact that the text is not substantively smaller than required, it was deemed right to submit it as it was rather than to include extra wording that may be irrelevant just to augment it.

Also, it is worth knowing that this research was primarily motivated by my aunt's cry for help from me to assist her in finding out what was wrong with her child and to help her in seeking the needed help and education for him. It is also motivated by the limited research available in Ghana on parents' experiences of raising a child with autism. Therefore, with the desire to contribute to scholarly literature in this part of the continent and the compassion to help not just my aunt, but people in Ghana who are faced with a challenge like hers, I decided to conduct this research.

Eugenia Allotey.

Table of contents

List of tables

Table 3.1
Table 3.2
Table 3.3
Table 3.4

List of figures

Diagram 2.1
Diagram 3.1

Abbreviations

ASD	Autism Spectrum Disorder
CWID	Children with intellectual disability
IMER	International master's in educational research
FCUBE	Free Compulsory Universal Basic Education
PWID	People with intellectual disability
WHO	World Health Organization

Definition of terms

Children with intellectual disability (CWID)	CWID in this paper represents both children with autism and intellectual disability (see chapter one).
Parents	For the purpose of this study, both care givers of children with autism and parents of children with autism are all referred to as parents.
Scopus and Eric	Online databases found in SuperSearch.
SuperSearch	Gothenburg University Library's online search engine containing databases and majority of the collections acquired by the library since 1976.

List of Appendices

CHAPTER ONE

1. Introduction

1.1 Background

Little is known about Autism Spectrum Disorder (ASD) in Africa. Research in Africa shows that parents of children with ASD adapt coping strategies to enable them to manage the condition and care for their children. These include acceptance of the situation, seeking spiritual healing, seeking emotional support, seeking medical intervention and collaborating with teachers (Gona, Newton, Rimba, et al. 2016; Thwala, Ntinda, & Hlanze, 2015). Autism spectrum disorder is a pervasive neurodevelopmental disorder that is characterized by impairments in social communication and restricted repetitive patterns of behavior, interests or activities (American Psychiatric Association, 2013). This includes disorders ranging from one severe end where we have non-communicative children to the other end where we have individuals who are highly functioning in intellectual and language skills (Ametepee, & Chitiyo 2009). Children with ASD may be unable to express what they want, may be upset when routines are changed or can be diagnosed with epilepsy or intellectual disability (Depape & Lindsay, 2014). Thus, the characteristics displayed by an individual on the spectrum depends on the severity of the disorder.

According to Dominic, Davis, Lainhart, Tager-Flusberg & Folstein, (2007), children with autism exhibit behavioral traits that cause serious distress for both the child and the family. These include unusual eating habits, abnormal sleep patterns, temper tantrums, and aggression to self and to others. Studies show that bringing up a child with autism is immensely stressful (Baker-Erickzen, Brookman-Frazee, & Stahmer, 2005; Falk, Norris, & Quinn, 2014). Children in the autism spectrum also exhibit behaviors that are disruptive and hard to manage, and this can create chaos throughout the household and extended family. It can leave parents feeling locked at home, as they fear taking the child out in public lest he creates a scene or runs into danger (Myers, Mackintosh, & Goin-Kochel, 2009 p. 671). Thus, parents are faced with a range of extra pressure as they attempt to learn about ASD and what this means for their child (Webster, Cumming, & Rowland, 2016). The World Health Organization (2013) epidemiological data estimate the global prevalence of ASDs to be one person in 160, accounting for more than 7.6 million disability-adjusted life years and 0.3% of the global burden of disease.

Unfortunately, few studies conducted on the existence of autism in Africa were not clear or comprehensive enough. They were done on randomly assigned samples of children which could not be used to estimate a reliable prevalence rate (Ametepee, & Chitiyo 2009; Inglese & Elder, 2009). Admittedly, Wireko-Gyebi & Ashiagbor (2018) mention that the little information about ASD in Africa have centered on clinical characteristics indicating similarities of children with ASD in Africa and the Western world. Also, data available in Ghana suggest that most children diagnosed with ASD have intellectual disability (Botts & Owusu 2013; Thomas, Badoe, & Owusu, 2015), therefore the term CWID is sometimes identified in academic literature in this part of the continent as representing children with autism and intellectual disability.

1.2 Problem statement

Recent global discourse suggests an increase in the prevalence rate of ASD in people (WHO, 2013). There is therefore an urgency for nations across the globe to look out for the well-being of persons with ASD. Unfortunately, due to outmoded traditional beliefs and superstitions, the general attitude in many communities in Ghana towards children with intellectual disabilities is that they are children of the rivers and forest and, in the past, they were returned to the forest or the rivers under the guise of helping them to go back to where they came from. In those days it was considered a taboo to have children with disabilities, hence many children were either killed or left in the forest to die. (Avoke, 2002; Gadagbui, 2010). Fortunately thanks to modernization, these practices are archaic and punishable by law. However, the stigma and discrimination against people with intellectual disability (PWID) and their families still remain. According to Botts & Owusu (2013), 82% of their interviewed respondents agreed that PWID are discriminated against. This is a disturbing situation in the Ghanaian society which needs to be addressed.

Furthermore, the United Nations Universal Declaration of Human Rights; article 26 states that everyone shall have the right to education, and the Convention of the Rights of Persons with Disabilities reaffirms that all persons with all types of disabilities must enjoy all Human Rights and fundamental rights. In accordance with these, the 1992 constitution of the Republic of Ghana Article 25 (1) stipulates that all persons shall have the right to equal educational opportunities and facilities and with the view of achieving the full realization of that right, basic education shall be free, compulsory and available to all. Similarly, the Government of Ghana's Ministry of Education 2015 Inclusive Education policy enacts that, the regular school shall provide education for all children regardless of their physical, intellectual, social, emotional, or linguistic conditions. These laws are integrative and make room for all children in Ghana, thus it includes persons with ASD.

Despite the existence of these laws, Ghanaian parents, who have children diagnosed with autism struggle to get their wards enrolled in both regular and special education schools. Botts & Owusu (2013) report that thirty-five percent (35%) of their sample size answered that it was very difficult to get good quality education for Children with Intellectual Disabilities (CWIDs) and forty-six percent (46%) of this same group answered that it was difficult. Indicating that an enormous sum of eighty-one percent of the respondents viewed getting a good quality education in Ghana for CWIDs as difficult.

Besides, Silva & Schalock (2011) report a mean parenting stress level in parents of children with autism to be four times higher than parents who do not have a child with disability and twice as high than parents who have children with other disabilities. This huge difference between parents in these categories reveal intense stress in parents of children with ASD. Also, research shows that parents of children with ASD encounter negative social perceptions and are stigmatized because their children have autism (Amponteng, et al 2018; Avoke, 2002; Hsu, et al., 2015; Kinnear, et al, 2015). Therefore, they devise various coping strategies to help them cope with the situation (Gona, et al., 2016; Owen, & McCann, 2018). Hence the need to undertake this research to investigate this phenomenon.

1.3 Purpose, relevance and aim of the study

The intent of this study is to investigate and describe Ghanaian parents' experiences of raising a child with ASD. This is necessitated by the increase in the prevalence rate of ASD in people across the globe and the limited research available on Ghanaian parents' experiences of bringing up a child with ASD. Also, most of the research done on this topic in Ghana is often quantitative based, therefore my use of case study as a qualitative research method would provide an in-depth and more detailed description of the parents' experiences with regards to stress, stigma, access to basic education, and

how they cope with the situation. This I anticipate would add new perspectives to the discourse surrounding parental experiences of raising a child with autism in my country. In addition, recent global discourse surrounding education for children with disabilities, suggests that parents have to negotiate access and struggle to ensure their children's admission and continuity in school (Johansson, 2015). Hence, the need to undertake this research to explore these themes and draw the attention of relevant stakeholders to their experiences as a whole. This is expected to bring help to the participants, and to motivate policymakers to enact laws that outline support and intervention centers for these parents and to also, review the policy and supervision of Inclusive Education and Special Education in educational institutions in Ghana.

1.4 Research question

This research is guided by the principal question: **what are parents' experiences of raising a child with autism in Ghana**? This principal question is subdivided into the questions below in other to get a better understanding of this phenomenon and address the themes the study intends to explore.

    a)   How do parents perceive raising their children with ASD?
    b)   How do parents view the social perceptions about their children with ASD?
    c)   What are parents' experiences when seeking education for their child with autism?
    d)   How do parents cope with their children's condition?

The focus of this paper is on parental experiences of raising a child with ASD in Ghana, however, to enrich the data and analyze findings about access to education for children with ASD not just from one point of view but also from the perspective of relevant stakeholders regarding the subject of education for children with ASD, a complementary question would be employed and institutional heads would be interviewed to complement parental experiences about access to education for their children with ASD. Thus, the complementary question below was added to support parents' perception about access to basic education.

    •   What are institutional heads' perceptions about access to education for children with autism?

1.5 Theory and Methodology

Granted that the importance of religion in the Ghanaian society precedes Christianity and Islam (Addai, 2000 p. 330), and religion has been the central force of social organizations in traditional African societies for ages so that, it has not been possible to distinguish between religious and non-religious aspects of life (Busia, 1967 cited in Addai, 2000 p. 330). This research adapts the religious magical model of disability proposed by Avoke (2002) and the social model of disability proposed by Oliver (1996) to explore parents' experiences of raising a child with Autism Spectrum Disorder in Ghana.

Guided by the constructivist tradition and the interpretive paradigm of research (see chapter 3), case study research method would be used to closely investigate, explore and describe this phenomenon. Given that, qualitative case study research facilitates the exploration of a phenomenon within its context using a variety of data sources thereby ensuring that the issue is not explored through one lens, but rather through a variety of lenses which allows for multiple facets of the phenomenon to be revealed and understood (Baxter & Jack, 2008), five parents and three heads of institutions were interviewed. The boundary of my case is parents and their experiences, and it constitutes the perspective of institutional heads to complement parents' experiences with regards to access to education for their children with ASD. Also, the study was bounded by the geographical location of the parent or care giver, age of the child with ASD, languages spoken by the parent and willingness of the parent to participate in the research. Here parents who were geographically located in the south

eastern part of the Greater Accra region of Ghana and could fluently speak either Akan[1], Ga[2] or English were taken into consideration because it was imperative that both the participants and the researcher should be able to communicate and understand each other vividly. Parents in the Greater Accra region were chosen because Accra[3] was the closest city to the researchers dwelling.

Also, it was necessary that these parents were raising a child with autism between the ages of six to ten. This was because one of the key themes mentioned in the literature review is access to basic education, and Ghana has a Free Compulsory Universal Basic Education policy enacted for all children of school going, targeting children below the age of eighteen (Republic of Ghana, 1992). Meanwhile, although the Education Act of 2007 mandated inclusive education for all children in Ghana and added two years of kindergarten as part of the basic education system (Botts & Owusu, 2013), Ghanaian parents on the average first attempt to access the right to education for their children in government assisted schools between the ages of six and ten. In addition, the study will include institutional heads who have come into contact with parents and children with ASD in their institutions to enable the researcher to understand parents experiences regarding access to basic education not just from their perspectives but also, from the points of view of relevant stake holders to enrich the data and contextualize the findings. Further, legal policy documents regarding the FCUBE policy and the education of children with disability were outlined to give a fair idea of what the law said and what was in practice. Moreover, field notes would be taken, a research diary would be kept, and the data would be analyzed using thematic analysis (see chapter three for details).

1.6 Limitations and delimitations

The study was limited to the Greater Accra region of Ghana due to financial restraints. This is because the research was self-funded and having a wider scope of study would have been expensive for a young researcher like me. In addition, proximity from my home to participants who had accepted to take part in the research limited the study to Accra. These factors did not have any effect on the findings of this paper. Also, granted that I can speak both of the languages widely spoken within the Greater Accra region that is Akan and Ga, there was no challenge with language, and participants were able to express themselves freely. Besides, since I am a native of the country some participants sometimes assumed that I automatically understood what they meant and usually used the phrase "abi you know" meaning I am already familiar with a situation they are describing. This was delimited by constantly reminding them to say exactly what they meant, and they did.

In addition, access to some participants was a challenge. Most of the heads of institutions in the government operated schools refused to take part in the research. Out of five government assisted schools that I contacted only one agreed to participate in the study, and it was on condition that, the interview was not recorded. This limitation was delimited by the fact that the researcher was given ample time to take notes. Also, the refusal of some heads of institutions in the government assisted schools to join the discussion rather enriched the study by highlighting parents struggle to gain access to education for their children with ASD in the government schools. Also, some parents, although joining the study based on recommendations, were initially skeptical about giving out information for the study but became comfortable and opened up when they were informed that the researcher had a

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[1] Akan is a group of dialects or closely related languages, spoken mainly in Ghana: separately named Asante, Fante, and Akuapem or Twi (Mathews, 2014).

[2] Ga is a language spoken mainly in the coastal area of Ghana, including Accra (Mathews, 2014).

[3] Accra is the capital and major economic city in Ghana and also the largest city in the country (Grant &Yankson, 2003).

cousin who had autism and that their identities and what they say would remain anonymous and confidential.

This thesis is divided into six chapters. First is the introduction which presents a brief background knowledge of ASD globally and in Africa, the research problem this paper seeks to address, the relevance and aim of the study, and the research questions employed to guide my findings. Also, it briefly discusses the theory, and methodology underpinning this study and outlines the limitations of the research. Second is the literature review and the theoretical framework. Here, previous literature relevant for the study would be systematically reviewed and the gap in research identified. In addition, key themes that emerged during the review will be briefly discussed. Also, the religious and magical model of disability which suits the Ghanaian context and was proposed by Avoke (2002), and the social model of disability proposed by Oliver (1996) will be adapted as the main theoretical perspective for this paper. These are intended to help explain the stigma, name calling and inability of parents to access basic social facilities like education.

Third is the methodological framework. This chapter, guided by the constructivist tradition and the interpretive paradigm, will discuss case study as the preferred method in conducting the research. Here, semi structured interviews, field notes, research diary, and legal policy notes on education for children were relied on as the sources for data collection followed by how the data was analyzed. Also, measures put in place to address the subject of ethics in conducting the research will be discussed in this chapter. The fourth chapter will present the findings from the research. Followed by the fifth chapter which discusses the results from my study. The last chapter will summarize salient points in the study and suggest recommendations for future research.

2. Literature review

This chapter critically reviews existing research on parental experiences of raising a child with autism spectrum disorder in Ghana, Africa and the rest of the world. It highlights and briefly discusses parental stress, stigma, access to basic education and coping strategies as keys themes encountered by parents while caring for their children with ASD. Furthermore, the chapter discusses the theoretical framework that aided in understanding the data collected for the study.

Guided by the question what are parents' experiences of raising a child with ASD in Ghana? This review was systematically done in conformity to features that make a review systematic as suggested by Jesson, & Lacey (2011) and Booth, Sutton, & Papaioannou (2016). First of all, the review began by seeking relevant literature through SuperSearch with the key words Autism Spectrum Disorder Ghana. This provided over sixteen thousand scholarly literature to be analyzed. This number of literatures was too large; therefore, the search was limited to scholarly literature in Scopus and Eric with the key words: autism and Ghana, resulting in eight documents and two articles respectively. The sum, being ten literatures, was too small to form the corpus of this review, hence additional searches were made in the journal *Research in Autism Spectrum Disorders* on three separate occasions with the key words Ghana, autism Ghana, parental experiences Ghana, and surprisingly, it yielded zero results.

The keys words were then modified and searches where done on Scopus, Eric, and the Sage Journal to get a broader scope for my corpus resulting in about one thousand one hundred literatures. These were further limited to one hundred and two after which duplicate copies and literatures irrelevant to the topic were screened and eliminated by skimming through the titles and abstracts. In addition, book chapters and articles were added after consultations with some IMER professors, bringing the total number of scholarly literatures for this review to twenty. The criteria for inclusion and exclusion were as follows**:**

Criteria for inclusion

- Studies within the social sciences.
- Studies on experiences of parents and care givers of people with ASD.
- Studies focused on education of people with ASD.
- Studies focused on Ghana, Africa and the rest of the world.

Criteria for exclusion

- Studies focused on clinical analysis.
- Studies focused on neurological and psychiatric analysis.
- Studies with the full text unavailable

However, after several readings, a decision was made to include scholarly literature that although outside the social sciences, were relevant for this study, thereby further augmenting the academic literature reviewed.

2.1 The Reviews

Studies show that parents and care givers who have children with ASD experience stress, stigma, and difficulty in accessing education for their children. Therefore, they employ diverse strategies to manage the situation (Avoke, 2002; Baker-Erickzen, Brookman-Frazee, & Stahmer, 2005; Botts, & Owusu, 2013; Denkyirah, & Agbeke, 2010; Depape, & Lindsay, 2014; Falk, Norris, & Quinn, 2014; Glazzard, & Overall, 2012; Gona, et al, 2016; Hsu, Tsai, Hsieh, Jenks, Tsai, & Hsu, 2015; Ludlow, Skelly, & Rohleder, 2011; Owen & McCann, 2018; Paynter, Davies, & Beamish, 2018; Stewart, Knight, McGillivray, Forbes, & Austin, 2017). These to a large extent highlight important themes that provide answers to questions asked on similar research conducted within this field, thereby answering this study's key research question: what are parents experiences of raising a child with ASD in Ghana? Below briefly interprets and analyzes these themes:

2.1.1 Parental Stress

According to Deater-Deckard, Chan, & El Mallah, (2013), parenting stress arises when parenting demands exceed the expected and actual resources available to the parents that permit them to succeed in the parent role. Unfortunately, majority of the scholarly literature reviewed pointed out that parents who have children with ASD are constantly faced with this situation while performing their roles as parents (An, Chan, & Kaukenova, 2018; Baker-Erickzen, Brookman-Frazee, & Stahmer, 2005; Oti-Boadi, Asante, & Malm, 2019). Admittedly, being a parent is associated with stress because of the changes in one's daily routine but being a parent of a child with ASD can be extremely difficult (Depape, & Lindsay, 2014).

According to Marks, Lurie, & Schutt (2016) and Webster, Cumming, & Rowland (2016), parents experience stress following their child's diagnoses and their attempt to learn about the condition and what it means for their child. Also, fighting for services and coping with negative social attitudes, financial strains, and constantly having to communicate and build relationship with education and health professionals contribute immensely to this feeling of stress. Similarly, An, Chan, & Kaukenova (2018) report that parental or caregiver stress was associated with insufficient and fragmentary social supports, stigma, social isolation and lack of support for caregivers.

Meanwhile, Baker-Erickzen, Brookman-Frazee, & Stahmer, (2005) argue that parents of children with autism exhibit stress in relation to the child's uneven intellectual profiles, pervasive disruptive behaviors and long-term care. And, Owen, & McCann, (2018) portray the parents' task of making home adjustments to meet the needs of their children and to protect the children themselves, as well as others from harm contribute to stress. These differences in opinions prove the fact that Marks, et al., (2016) where right to say that if you meet one person with ASD, you have simply met one person, for indeed each individual is unique and might require specific needs.

2.1.2 Stigma

Throughout the analysis, stigma was one of the most emphasized social challenges faced by parents who have children with ASD and disability in general. Stigma, according to Goffman (1963) is a deeply discrediting attribute that makes an individual different from others by reducing him from a whole and usual person to a tainted discounted one. This attitude described as discrediting in the sixties is surprisingly still evident in our societies today.

Unfortunately, Kinnear, Link, Ballan, & Fischbach (2015) report that studies done in the United States (U.S.) and Canada reported that parents who had children with ASD were often excluded from events and activities by others because of their child's disability. Similarly, Gona, et al., (2016) emphasize

that parents of children with ASD in Kenya often experienced stereotyping and negative public reactions. Likewise, in Ghana parents and children with ASD are shunned from society and labelled with names such as 'fools', and 'idiots' (Amponteng, Opoku, Agyei-Okyere, Afriyie, & Tawiah, 2018; Avoke, 2002). And sadly, in Taiwan the challenge of stigma from the society is evident specifically from the husband's family where the mother is expected to bear the blame of not being able to provide a healthy child to carry on the family name, especially where the child is a boy (Hsu, et al., 2015). These emphasize the fact that being a parent of a child with ASD can be extremely difficult irrespective of the part of the continent you find yourself.

2.1.3. Coping Strategies

Majority of the corpus of this review revealed that parents had to develop coping strategies like seeking medical care to manage their children's conditions irrespective of the help available to them through the social systems in their respective countries. According to Owen, & McCann, (2018), some parents had to cope with the situation by ensuring the safety of their children with ASD and other family members as well as property by taking extra measures to keep all doors locked. Meanwhile, others had to put their needs on hold and enter into survival mode to take care of their family while others participated in recreational activities, talked to others about the situation or stayed in denial (Paynter, et al., 2018; Stewart, et al., 2017). Elsewhere, parents had no social support, hence they are forced to be self-reliant and resort to beliefs and superstitions like seeking spiritual healing and changing their children's diet (Gona, et al., 2016). Therefore, it can be observed that while some parents simply had to rely on the social systems available in their countries to help them deal with the situation, others had to make drastic adjustments in their life to help them deal with their children's condition.

2.1.4. Access to Basic Education

Access to basic education is one of the United Nations fundamental Human Rights. However, Ilias, Liaw, Cornish, Park, & Golden (2016) and Johansson, (2015) argue that parents who have children with ASD struggle to ensure their child's admission and continuity in school. While this may be the situation in Malaysia and India, the situation in Australia and the United States is slightly different. Here, Webster, et al., (2016) report that parents are able to get access to education for their children but that is not enough. They want to play key roles in the planning and discussion of appropriate intervention strategies for these children.

Unlike Australia, the U.S. and to some extent similar to Asia, the situation in Africa, specifically Ghana is extremely difficult. In fact, Botts and Owusu (2013) report that thirty-five percent (35%) of their sample size answered that it was very difficult to get good quality education for children with autism and Children with Intellectual Disabilities (CWIDs) and forty-six percent (46%) of this same group answered that it was difficult. Indicating that an enormous sum of eighty-one percent of the respondents viewed getting a good quality education in Ghana for children with ASD and CWIDs as difficult. These high figures indicate the degree of difficulty parents encounter when seeking education for people with autism and disability in general.

2.2. Gap

Compared to the rest of the world, it was observed that there exists limited research in the Ghanaian society with regards to parents' experiences when raising a child with ASD (Thomas, Badoe, Owusu, 2015; Oti-Boadi, Asante, & Malm, 2019). Also, little is known about the education of children with the Autism Spectrum Disorder in this country, and the few studies done are mostly quantitative based. Here, the quantitative based studies reported findings based on large data sets, thus they could not highlight deep contextual experiences of Ghanaian parents' real perceptions of raising their children who had autism. However, it was observed that the only academic document that used qualitative research to investigate parental experiences of raising a child with ASD in Ghana was recently published[4] and it targeted aged parents who were caring for young adults with autism. Therefore, this study intends to fill this void by using case study as a qualitative research method to add new perspectives to the discourse surrounding parental experiences of raising a child with autism in Ghana. Also, adapting qualitative research to explore this phenomenon, would provide an in depth and more detailed description of the Ghanaian parents' experiences as opposed to the quantitative data available.

Further, it was observed that the Ghanaian society despite believing in the practice of western medicine, was also highly religious and superstitious. Hence, there will be a need for a theoretical perspective that can rationally explain this phenomenon within the Ghanaian context. Therefore, the models of disability theory; that is the religious / magical model of disability, proposed by Avoke (2002) and the social model of disability, proposed by Oliver (1996) would be adapted as the main theory underpinning my studies because they provide a suitable theoretical perspective for the Ghanaian context. These would be further discussed in the theoretical framework section below.

2.3. Theoretical framework

According to Llewellyn, & Hogan (2000) just as theorists, throughout history have made use of the technology of the day to provide explanatory models of the behavior they observe in order to provide an improved understanding of human behavior, so can models aid understanding of disability in both research and clinical settings. To them a model represents a particular type of theory, namely structural, which seeks to explain phenomena by reference to an abstract system and mechanism (p. 157). Therefore, the religious model of disability presented by Avoke (2002) to suit the Ghanaian context and the social model of disability as presented by Oliver (1996), would be adapted as the main theoretical perspectives underpinning this research. These include:

- The religious/ magical model of disability
- The social model of disability

2.3.1. The Religious/ magical model of disability

According to Avoke, (2002), the religious model of disability envisions disability as evil placed on an individual from the gods as punishment for an offence committed and it is evident in societies where superstitions and eugenics are prevalent hence in Ghana, attitudes of the community of those with disabilities were shaped largely by the beliefs in and fear of the deities and gods, who were considered morally equipped to guide law and order, and were capable of inflicting punishment on those who had offended or strayed away from the norms of society (p. 771). Accordingly, Mitchell (2013) suggest that religious constructs that culturally and socially perpetuated and reiterated the Religious model of disability were more prevalent within African American communities. And Ghana being an African

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[4] that is Oti Boadi, Asante, & Malm's (2019) article: *The experiences of ageing parents of young adults with ASD.*

country is intertwined with cultural belief systems, where spirituality is interwoven in all aspects of life (Anthony, 2011).

Thus, granted Ghana is a highly religious nation it is therefore not astonishing, that persons with disability in this nation are sometimes considered to be a curse, hence they are shunned and stigmatized. This is evident when Avoke (2002), asserts that in many communities in Ghana, the use of pejorative labels and the manner in which people with disabilities are treated tends to be considered justified, because disability in the past was so strongly attributed to religious or magical models where evil was placed on an individual from the gods. For instance, in Ghana people with disability together with their families are labeled and referred to with negative expressions like 'buulu'[5] and 'asovi'[6] (p. 774). This name calling emerges from socio-cultural beliefs that see people with disabilities as some sort of curse or punishment. Hence the use of the religious or magical model of disability will enrich the study by providing an in-depth explanation about the cultural and religious point of view of the Ghanaian society to explain the name calling and people's behavior towards parents of children with autism.

2.3.2. The Social model of disability

The social model of disability according to Oliver (1996) is all the things that impose restrictions on disabled people ranging from individual prejudice to institutional discrimination; from inaccessible public buildings to unusable transport systems, from segregated education to excluding work arrangements (p.33). He (Oliver, 2013) emphasis in his article *The social model of disability: thirty years on* that, the social model of disability originates from the Fundamental Principles of Disability document, which was first published in the mid-1970s, and he argues that people with disabilities were not disabled by their impairments but by the disabling barriers they face in society. Similarly, Llewellyn, & Hogan, (2000 p. 160) assert that the social model of disability emphasizes that disability emanates from society, hence individuals different by virtue of an impairment observe that they are oppressed by a society obsessed with concepts of normality. Likewise, Sinclair (1998) in his review of Oliver's book *Understanding disability: from theory to practice,* emphasized that, the social model of disability highlights restrictions imposed on people with disabilities by externally imposed physical, social, and psychological barriers.

Critiques of this model argue that, it does not account for differences between individuals with disabilities and does not acknowledge disability as an observable characteristic of the individual. However, disability through the microscopic view of the social model can be considered as the disadvantage or restriction of activity caused by a social organization that does not take into account people who have impairments and excludes them from community life (Haegele & Hodge 2016). In other words, I side with Oliver and say that disability is only visible in a society where people are discriminated following their inability to perform a task rather than being accepted and presented with equal opportunities. Hence the social model of disability, would provide a basis for explaining and understanding the discrimination and exclusion of parents and their children with ASD from enjoying social facilities like education.

Therefore, the use of these models in this study will each highlight and explain salient aspects of meaning and behavior within the Ghanaian society that informs people's behavior and perceptions towards parents of children with autism. Thus, the religious or magical model will help to explain the origin and rationale behind people's attitude, the name calling and the stigma in the Ghanaian society, while the social model will help to explain society's exclusion of parents and their children with

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[5] Which means fool.
[6] Which means idiot.

autism from enjoying basic social facilities like education. The figure below gives a pictorial representation of the intent of these models in the study.

Diagram 2.1:   Theories used in the study
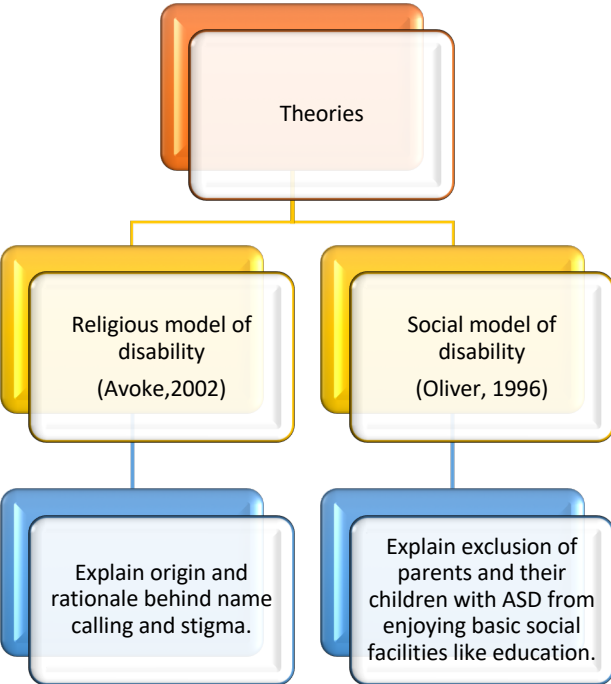
Source: Diagram based on Avoke (2002) and Oliver (1996).

CHAPTER THREE

3. Methodological framework

This chapter discusses the epistemology of the research and the paradigm informing my decision to choose qualitative case study as the ideal research method for the study. Here case study as a research method is briefly discussed, and the type of case study I employed to conduct the research is outlined. Further, the procedure for data collection, the methods for data collection and analysis are discussed. Finally, ethical issues like voluntary participation, informed consent, anonymity and confidentiality and harm to participants, that were considered during the research are also presented.

The present study is informed by the constructivist worldview of research originating from Lincoln and Guba's (1985) naturalistic inquiry which suggests that there are multiple constructed realities that can be studied only holistically as opposed to the positivist version that suggests that there is a single tangible reality out there fragmented into independent variables and processes, any of which can be studied independently of the other. Likewise, Creswell & Creswell's (2018) assertion that individuals seek understanding of the world they live and work in and develop subjective meanings of their experiences. Thus, a researcher's quest for reality, and understanding in a study is guided by the paradigm informing the research. According to Guba & Lincoln (1994), 'a paradigm is viewed as a set of basic beliefs (or metaphysics) that deals with ultimates or first principles which represents a worldview that defines, for its holder, the nature of the "world," the individual's place in it, and the range of possible relationships to that world and its parts'. Admittedly, Kivunja & Kuyini (2017 p. 26) asserts that a paradigm has significant implications for every decision made in the research process, including choice of methodology and methods. Hence, the paradigm underpinning this study is the interpretive paradigm.

The interpretive paradigm endeavors to understand the individual and the interpretation of the world around them thereby, making an effort to understand the viewpoint of the subject being observed rather than the observer (Kivunja & Kuyini, 2017 p. 33), hence, its use in this study enabled me to investigate and understand parents lived experiences in the discourse: bringing up a child with autism in Ghana, and tell their story meticulously. Although this paradigm is criticized for being time consuming and sometimes biased, it endeavors to understand the subjective world of human experience and retains the integrity of the phenomenon under investigation by making efforts to understand the person or participants under discussion from within (Cohen, Manion, & Morrison 2007 p. 21). Thus, enabling a researcher to understand and envision participants' experiences holistically and report the findings from the subject's point of view.

3.1 Method

Based on the desire to collect empirical data to closely investigate, describe and understand parents' experiences of raising a child with autism in the Ghanaian society, case study as a qualitative research[7] method was the appropriate method relied on for this research. In defining case study, Stake (1994 cited in Mertens 1998) uses the criterion that case study research is not defined by a specific methodology but by the object of study. Hence, he distinguishes three types, the intrinsic, the instrumental and the collective. In an intrinsic case study, a researcher, having an interest in a case, examines it so as to get a better understanding of that particular case. In an instrumental, the researcher

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[7] Qualitative research is an approach to research that provides a unique grounding position from which to conduct research that fosters particular ways of asking questions and provides a point of view onto the social world whose goal is to obtain understanding of a social issue or problem that privileges subjective and multiple understandings (Hesse-Biber, 2016).

selects a small group of subjects in order to examine a certain pattern of behavior. And in a collective case study the researcher coordinates data from several different sources such as schools or individuals to learn more about a phenomenon and extend it to cover several other cases (Punch, 2009).

Meanwhile, Yin, (2014) defines case study as an empirical inquiry that examines a contemporary phenomenon in its real-life context, especially when the boundaries between phenomenon and context are not clearly evident. He (Yin, 1981 p. 100/101) suggests two types; single case design and multiple case designs; where a single case design can be used to test a theory, especially in a disconfirming role and multiple case designs are used in cases where conclusions can be drawn from a group of cases where the same phenomenon is believed to exist in a variety of situations. Indeed, a case study is a method of studying social phenomena through the thorough analysis of an individual case - which may be a person, a group, an episode, a process, a community, a society, or any other unit of social life. Also, it provides an opportunity for the intensive analysis of many specific details that are often overlooked with other methods (Theordorson and Theordorson, 1969 cited in Punch, 2009: 120). To sum up, it is rich, robust, and involves in-depth analysis of a phenomena.

In spite of this robust nature, case study is criticized for being time consuming, biased and providing little scientific generalization (Cohen, et al, 2007 p. 256; Yin 1981). Nonetheless, acknowledging Yin's criteria for the selection of the type of case study design, multiple case study design was used as my choice of methodology for this study. In that, although I am related to one of the participants and so had a genuine interest in the case under investigation, I chose to include data from other participants to aide in the understanding of the research problem so as to report the findings in its reality. Thereby, confirming Yin's (1994) proposition that case study research allows researchers to retain holistic and meaningful characteristics of real-life events. To recapitulate, I chose multiple case study research design for this study because siding with Yin (2014), it enabled me as a researcher, to compare alternative descriptions or explanations of the same case via different perspectives.

The decision to conduct the research in Ghana despite living and studying in Sweden was informed by my desire as a young researcher to contribute to scholarly literature pertaining to parental experiences of raising a child with ASD in that part of the world, where little academic literature concerning this phenomenon exist. Also, this decision was taken due to barriers to language. In that, granted most Swedes speak English apart from their mother tongue, it was important for the participants and me to communicate freely in a language that is well understood by both parties and doing so in our mother tongues[8] and English[9] was the ideal choice. In addition, it was perceived that gaining access to participants in Ghana would be less stressful than in Sweden, because I was born and raised in Ghana and having worked in some educational institutions in that country for more than five years was a great advantage. In that, I was familiar with the culture of the people and had already been in contact with one of the participants.

3.2. Procedure for data collection

3.2.1. Sampling

According to Creswell (2003), a researcher's choice of a sample is dependent on how adequate it is in answering the research questions. Considering the fact that most parents who have children with ASD in Ghana keep that information hidden thereby making it difficult to identify them, snowball and purposeful sampling were adequate in identifying participants for the study. Here, having already come into contact with a participant who had a child with ASD, that participant recommended a parent and an educational institution. The head of that institution also recommended some parents who were

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[8] Akan or Ga
[9] The official language in Ghana.

raising children with ASD, thus the potential participants increased in number. Requiring the researcher to use purposeful sampling to select parents whose experiences could contribute essential information for the progress of the study and also fell within the boundaries (see chapter one) set for this research. One of these parents also recommended another institution where the head also purposefully recommended one participant who contributed vital information for the study.

3.2.2. Participants

The key participants interviewed for the study summed up to eight. Including four parents, one care giver and three heads of institutions. As already mentioned in definition of terms, in this study, both the care giver and the parents are all referred to as parents. All the parents who participated were females with their children aged between six to ten years. Out of these, four of the parents had male children with ASD and one had a female child with the condition. At the time of the study four of the children were schooling and one was not schooling. Out of the three heads of institutions interviewed, two were heads of private owned institutions and one was the head of a government assisted institution. Two of the institutions were special needs institutions and one was a regular school. The total number of students in each school were twenty, about one hundred and fifty and one hundred and sixty-five. The number of children with autism encountered by the heads of the institutions were twelve, two and about fifty respectively. The tables below give a summary of this information.

Table 3.1: Parents as research participants

Name of parent[10]	Gender of parent	Gender of child with ASD	Age of child with ASD
Abena	Female	Male	9
Attaah	Female	Male	10
Cynthia	Female	Male	7
Gifty	Female	Male	6
Yaa	Female	Female	10

Table 3.2: Heads of institutions as research participants

Name of institution	Name of head of institution	Gender	Type of institution	Category of institution	Total number of children	Number of children with ASD encountered
A	Akwele	Female	Private	Regular	150	2
B	Bernice	Female	Private	Special needs	20	12
C	Dzidzor	Male	Government assisted	Special needs	165	50

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[10] Parents' names have been replaced with pseudonyms.

3.2.3. Negotiating access

Granted that gaining access to participants is a constant process of negotiation and renegotiation of what is and is not permissible (Bryman, 2012), negotiation of access to most participants took place via telephone. Nonetheless, permission letters were also sent in person to all participants to make it official. This provided a brief background knowledge of the researcher, the institution I am affiliated to, my research topic, how the research would be conducted, potential benefits to participants and assurance of my adherence to ethical issues in conducting a social research. Some parents agreed to participate in the study right away and fixed dates for the interview to take place. Others were reluctant because they felt their names and voices would appear on social media but gave in once they were assured that, the study was strictly for the purpose of research whereby their identities would remain anonymous and confidential. However, there were two parents whose children were not schooling yet they were in denial of their children's condition, so declined to participate in the study.

Meanwhile, most of the challenges faced at this juncture had to do with gaining access to heads of institutions. The heads, with the exception of one, in the private owned schools were eager to take part in the study and more concerned about what the information gained would be used for and the help their institutions may get out of this research. The only head of institution from a private special education school who refused to take part in the study had compassion by my motivation to conduct this research and offered a reduction in school fees for any of the children with ASD I find who was not schooling. However, majority of the government assisted institutions who were randomly chosen and contacted, either refused outrightly to participate in the study or backed out on the day scheduled for the interview. Out of five government assisted schools that was contacted, only one agreed to participate in the study with the condition that, the interview is not recorded. After gaining access to participants, consent forms were given to them and the research vividly explained in English, Akan or Ga where necessary, to ensure that they completely understood what the research was about and their role as participants. They were then asked to read through the consent form, sign it and return it on the day scheduled for the interview.

3.3. Methods of data collection

According to Delamont & Jones (2012 p. 346), the researcher's job is to find out what the participants think is going on, what they do, why they do it, how they do it and what is normal and odd for them. Therefore, in an attempt to explore what participants, think is going on regarding parental experiences of raising a child with ASD, what they do about it and how they do it, interviews, field notes, research diary and legal policy contexts in Ghana on education for children, specifically children with disabilities were used as sources of data collection for this research.

3.3.1. Interviews

The principal aim of this research was to investigate and describe what Ghanaian parents' experiences are when they are raising a child with ASD. Therefore, the use of interviews was to enable participants to discuss their interpretations of the world they lived in and to express how they regard situations from their own point of view (Cohen, Manion, & Morrison, 2011 p.409). Also, granted interviews are done in order to find out what we do not and cannot know. And we record what we hear to systematically process the data and better understand and analyze findings in a dialogue (Delamont & Jones, 2012 p. 364), semi-structured interviews were employed to gather data for this study. Thus, the topics and issues to be discussed were specified in advance and the questions were sequenced to generate free-ranging conversations about research topics that were directed by what participants had to say (Cohen, Manion, & Morrison, 2011 p. 413; Flick, 2018 p. 233). Semi-structured interviews were employed because they are flexible and enable a researcher to cover areas that point to the

research questions in a study (Poole & Mauthner, 2014). Thus, parents were interviewed to specifically gather information about their real-life experiences of raising their children with ASD. And institutional heads were included in the interview to enrich the data and verify parents' assertion of difficulty in accessing basic education for their children.

The interviews with parents were held at their homes and at designated offices in the institutions their children attended behind closed doors, and those with institutional heads were done in their offices. Some of the follow up interviews were conducted over the phone due to unavailability of some participants to have a face to face meeting. Since telephone conversations had already been had with most participants and the informed consents already submitted, the interview began by reminding participants about the study, its aim, what they are supposed to do and their right to withdraw. The interview with parents were held in English, Akan and Ga, and they lasted between twenty-five (25) to thirty-five (35) minutes. During the interviews, a recording device was used to record findings and field notes were occasionally taken to highlight important themes. Since trust had already been built via telephone with parents, the general atmosphere between the researcher and the parents was cordial and the interview began with general informal conversations about the country and their children. However, it was realized that some parents were initially skeptical about what to say when the recording started but became relaxed once they were assured no other person would have access to their names or the recordings. The interviews were paused and parents who became emotional while narrating their experiences were given ample time and the opportunity to calm down or end the proceedings.

Adapting Arksey & Knight's (1999), proposal of interviewing elites, access to institutional heads was gained through formal letters and follow up telephone conversations. The interviews, conducted in their offices, with the exception of one which was conducted via telephone, began with questions about a general background knowledge about them and their institutions, their views about the phenomenon under discussion and specific policy areas relating to the study. The general atmosphere was relaxed and cordial, perhaps because they knew the researcher was a teacher in the country some time ago. All institutional heads, except one who refused to be recorded, were eager to participate in the study and willingly offered to let their names and those of their institutions be published. However, their desire for such information to be revealed was declined due to ethical reasons and for the sake of parents who participated in the study and had their children in their schools. All participants were given the opportunity to verify findings via telephone so that they could confirm if the findings corresponded with the information they provided. To sum up, the interviews went well and there were no major setbacks, except the fact that I had to constantly remind participants to explain in detail and say what they specifically meant instead of assuming that I knew exactly what they were referring to because I am a native.

3.3.2. Field notes

Historically referred to as scratch notes and originating from ethnography, field notes are a detailed chronicle of events, conversations, behavior, and the researcher's initial reflections on them (Phillippi & Lauderdale, 2018; Bryman, 2012). This source of data collection was chosen because they prompt researchers to closely observe their physical environment and interactions, encourage their reflection and identification of bias, increase rigor, and facilitate preliminary coding (Phillippi & Lauderdale, 2018). Thus, while undertaking this study, they enabled the researcher to take notes of the interviews, highlight salient points and serve as a record for later reference, especially during the interview with the head of institution who chose not to be recorded. The information recorded here included the day and time of the interview, short description of participants general mood and behavior during the interview and key themes that participants talked about with passion. This was very helpful in documenting a chronological account of the interviews and writing down reflections of daily procedures in the research diary.

3.3.3. Research diary

Given that research diaries are written personal documents, keeping a log of a researcher's activities and reflections (Bryman, 2012 p. 711), they were employed while undertaking this study to compliment the field note by giving a detailed report about the interviews and documenting personal reflections about each interview. Also, it enabled the researcher to document discussions which were had outside the interviews but had a connection with the research. These helped to better understand and reflect on the experiences shared by participants. This was also very helpful during the coding and analysis of the findings. For instance, it was through such written reports that the theme of stigma by association was identified and understood. Below are extracts from my research diary:

14-02-2019.   *Reflection on interview with Bernice; head of institution*

Bernice's experience with some of her friends raises strong concerns about stigma by association as reported by parents. By virtue of her position I assume most of her friends would be elite, and I thought education had eliminated or drastically reduced discrimination against people who associate with children popularly referred to as "nsuba" and "sika dru ba". But her report reveals that this is still in practice.

17-02-2019   *Conversation with a friend concerning my study*

I had a conversation with another friend concerning my research interest and she asked: "why are you interested in these children? Can't you focus on any other group of children? You know how society regard this people and their families, are you ready for the stigma?"

I told her they are part of the society yet very few people are interested in them, therefore it's time we all got involved with them and do away with the stigma. Moreover, I already have one in my family and that relative who has a child with autism constantly talks to me about her challenges.

"She said okay and moved on to another topic".

Reflection
This is the third time a friend has tried to persuade me to change my research interest because of the beliefs and notions regarding person's with autism and their families. This time the conversation with this friend drew my attention to the fact that stigma by association still remain in Ghana and either my friend was trying to draw my attention to that fact, or she genuinely wanted to understand the reason why I was so passionate about my research. Also, the head of institution, Bernice, shared her experience just few days ago about losing friends because of her decision to work with children with autism. This has helped me to understand how parents feel when they reported that some people; who do not even know if they are the biological parents or not, just shun their company the moment their children have a tantrum. This proves that parents are not exaggerating, they are indeed stigmatized by association with their children with autism.

3.3.4. Policy contexts on education

Policy contexts on the education of children and the education of persons with disabilities in Ghana were outlined to enrich the discourse concerning accessing basic education for children with ASD by highlighting the legal framework in Ghana about access to basic education, thus exploring and understanding the phenomenon through multiple lenses. Also, it was to determine what the policy said and what was in practice. It was observed that the 1992 constitution of the Republic of Ghana Article 25 (1) stipulates that all persons shall have the right to equal educational opportunities and facilities and with the view of achieving the full realization of that right, basic education shall be free, compulsory and available to all. It continues to add in article 28 (4) that, no child shall be deprived by any other person of medical treatment, education or any other social or economic benefit by reason only of religious or other beliefs.

Similarly, Ghana's Education Act 778 section 5 enacts that a parent or guardian shall take advantage of the inclusive education facilities to send the child with special needs to the appropriate education facility or subject to the availability of resources make a request for the provision of the appropriate education facility, where inclusive education means the value system which holds that all persons who attend an educational institution are entitled to equal access to learning, achievement and the pursuit of excellence in all aspects of their education. Likewise, the Government of Ghana's Ministry of Education 2015 Inclusive Education policy enacts that, the regular school shall provide education for all children regardless of their physical, intellectual, social, emotional, or linguistic conditions. These laws emphasize that education shall be a right for all children in Ghana, thus, it includes children with autism hence irrespective of the level of the spectrum they are diagnosed with they shall have the right to education.

3.4. Thematic analysis of the data acquired

The analysis of the data gathered was done by extracting key themes that emerged from the study (Bryman, 2012); thus, findings were analyzed using thematic analysis. Here, adapting Braun & Clark's (2006) phases of thematic analysis[11], the findings were analyzed by firstly familiarizing myself with the data. Thus, I did the transcription of the recorded interviews myself and read over my field notes, and research diary to remind myself of my initial reflections when I first conducted the interviews. While reading and re-reading the data gathered, I highlighted salient points to facilitate coding and the identification of themes. Secondly, the areas of interest identified were generated into initial codes for the study in order to aid in my identification of themes. That is during the familiarization stage, potential themes which were identified were highlighted as salient points and general themes which shared some similarities throughout the data gathered were collated.

Thirdly, the collated codes were searched to identify relevant themes for the study. These were used to group and identify major themes the findings revealed, thus gradually beginning the analysis of the data gathered. Next, was the review of the themes identified. Here, the themes were reviewed to check if they correspond with the coded data. This is where themes with insufficient examples to substantiate their inclusion in the report are eliminated and those with enough evidence and have multiple facets are divided into sub themes. This was followed by the stage where the findings were named and explained. Thus, as part of the analysis, the themes were clearly defined and divided. For instance, it was at this stage that the themes stigma by association and spirituality as causal agent of stigma were identified, named and explained. Lastly, while taking into consideration the research questions and theories employed for the study, the findings were systematically reported (see chapter four). The diagram below gives a pictorial representation of the phases of thematic analysis used to analyze the

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[11] See diagram 3.1

data. And this entire process is summarized by briefly elaborating on the transcription process and the coding process.

Diagram 3.1: Thematic analysis of data.

Transcribe the data.
Read over the data gathered.

Familiarization

Generation of codes

Identify and highlight saleint points.

Collate codes to identify themes.

Search for themes

Review of themes

Eliminate and/or justify inclusion of themes.

Name and explain the meaning of the themes .

Definition of themes

Producing the report

Report the findings .
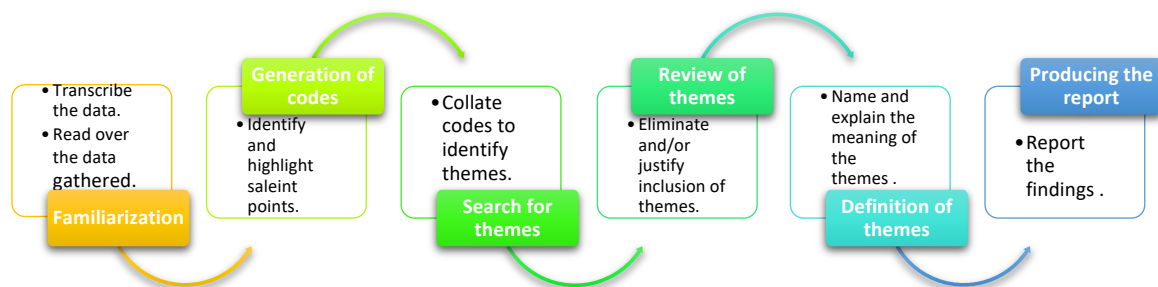
Source: Diagram based on Braun & Clark's (2006) phases of thematic analysis.

3.4.1. Transcribing the data

The interview with participants were held in three languages; English, Akan and Ga. Participants either spoke English with occasional addition of phrases from the Ghanaian language or they spoke one of the Ghanaian languages mentioned above and occasionally introduced the English language. Therefore, there was the need to translate most of the information gathered from Akan and Ga into English and granted the researcher could speak all three languages fluently, transcription and translation were done simultaneously. This was a great advantage since it enabled the researcher to familiarize herself with the data and be in a better position to understand and explain what participants said. However, some of the words from Akan and Ga were not translated word for word because that would inhibit the meaning and essence of what participants were describing. Rather, the emphasis was

to convey the message and describe the phenomenon based on the contextual meaning of what participants were saying. Hence phrases like "sika dru" which literally means money medicine but in context means blood money was translated to convey the actual meaning participants wanted to convey.

Admittedly, transcribing interviews can be time consuming, therefore, adapting Kvale & Brinkmann's (2009, cited in Johansson, 2015), advice, only data relevant for the study were transcribed thus the transcription excluded sections of the interview that were clearly irrelevant like background information of the heads of institution, informal discussions held about the state of the nation, and current affairs in the news (Johansson, 2015; Poole & Mauthner, 2014). However, pauses, laughter and emotional situations were noted to enable the researcher to make a fair judgment on participants mood and the general atmosphere of the interviews. These were done throughout the transcription stage and they aided the researcher in easily identifying themes, associating the themes to respondents and determining the demeanor of participants during the coding process. Later, the transcribed document was compared to the audio recorded to justify its accuracy, and the fieldnotes, and research diary were read several times to facilitate coding.

3.4.2. Coding and identification of themes

Coding is the process of managing data into smaller manageable parts. This was done by conducting a preliminary review of the data gathered into themes, merging and summarizing the derived themes into descriptive codes and reviewing and collapsing the descriptive codes into analytical categories revolving around the phenomenon under discussion (Poole & Mauthner, 2014). Therefore, guided by the research questions, the data was analyzed by generating preliminary codes to identify potential areas for a further analysis. For instance, during the initial coding process, instances that depicted stress were all grouped together. Later, areas where similarities were identified were merged together and themes were specified, categorized and explained to facilitate the production of a report for the study. The tables below give a vivid description of an example of the coding process and the process used in identifying specific themes in the study.

Table 3.3: Example of coding process.

Findings	Theme
I become embarrassed and weep when people start calling us names like "buulu" …. My son's parents are divorced because the mother was not taking care of the boy properly and this disturbed the father (**Gifty**). My marital problems began when my ex-husband accused my mother of making my son spiritually sick …… I find things difficult taking care of my child… I use 50% of my salary to pay his school fees (**Attaah**). …. I am overwhelmed by my son's condition. …. I nearly bought rat poison to drink (**Cynthia**).	Stress

The money I pay to keep my daughter in school is twice the money I pay for my other children to be in school (**Yaa**). ….. it is hard to see my son banging his head against a wall for no obvious reason, …… I weep when I think of it (**Abena**).	Stress

Table 3.4: Example of categorization of broad themes into specific analytical themes.

Findings	Specific theme	Explanation
…. I am overwhelmed by my son's condition. …. I nearly bought rat poison to drink (**Cynthia**). I become embarrassed and weep when people start calling us names like "buulu"(**Gifty**) ….. it is hard to see my son banging his head against a wall for no obvious reason, …… I weep when I think of it (**Abena).**	Emotional stress Emotional stress	Instances which show that parents were emotionally stressed.
I find things difficult taking care of my child… I use 50% of my salary to pay his school fees (**Attaah**). The money I pay to keep my daughter in school is twice the money I pay for my other children to be in school (**Yaa**).	Financial stress	Reports that indicate their children's condition resulted in financial difficulties for the family.
My marital problems began when my ex-husband accused my mother of making my son spiritually sick (**Attaah**) My son's parents are divorced because the mother was not taking care of the boy properly and this disturbed the father (**Gifty**).	Marital stress Marital stress	Reports that depicted stress on marriages because spouses had a child with autism.

3.5. Ethical considerations

According to Trimmer (2016), ethics and politics are integral and indispensable elements of any examination of the social issues and problems confronting education. Hence, researchers must take into account many ethical and political considerations alongside scientific ones in designing and conducting their research (Babbie, 2014). Considering the fact that ethics needs to be a critical part of the substructure of the research process from the inception of the research problem to the interpretation and publishing of the research findings (Hesse-Biber, 2016), ethical principles in conducting a social research were taken into account throughout the study. In that, the topic itself is sensitive and my ability to get access to participants by creating a welcoming environment and being able to relate to them in such a manner where they were able to freely open up about certain aspects of their lives without fear of judgement from me in its self has some elements of ethics. Thus, the feeling of intimacy and power equality was fueled by the unstructured, informal, anti-authoritative and non-hierarchical atmosphere in which I established relations with the participants (Karnieli-Miller, Strier, & Pessach, 2008). Again, the pauses during the interviews and exhibition of compassion towards parents who were overwhelmed by their emotions during the interview to enable them to regain their composure all related to ethics. Perhaps talking about their difficulties and venting out their emotions might have been therapeutic for some of them because they had the opportunity to express themselves to someone on neutral grounds.

Further, it was challenging for me, knowing that the people had absolute faith in their belief systems and in the spiritual help they sought for their children, yet knowing how things worked I addressed such beliefs from a researcher's perspective as superstitions. In that as an educational researcher who cared about the children, I envisioned conflicting positions of how modern medicine would approach the condition and what the spiritualists may propose, yet I felt it would be rude and cruel to point it out bluntly to them to stop spending money on spiritual help because, as a native I understood how important it was for parents to have some sort of hope, and as a researcher I needed to respect the values of the people who had given me permission to undertake the study. Also, in my reflections I sometimes had conflicts with myself by thinking: "was I being too hard on them when I thought some of the beliefs and practices should be extinct, especially in the 21st century?" Again, the subject under investigation itself was ethical. In that, the study explored sensitive issues like stigma, superstition and unequal resources that were available to people. Therefore, having in mind Patton's (2002, cited in Hesse-Biber, 2016) checklist of ethics, this section, acknowledges that ethical dilemmas were considered during the entire study and the following simply gives a summary of some salient ethical issues that were addressed.

3.5.1. Informed consent

Acknowledging that participants have the right to be informed about the nature and consequences of experiments in which they are involved (Denzin, & Lincoln, 2011), I gained access to the participants based on trust and not deception. My intentions were explicitly described to participants and they were given the opportunity to either accept or decline my proposition to join the study. Here after having sought their permission to carry out the study, I gave participants an informed consent letter where information about the study was clearly described. Also, their role as participants were defined and possible risks associated with joining the study were outlined. Here participants were informed that the interviews may last between twenty-five to thirty-five minutes and the themes that would be discussed may be sensitive; hence, they had the right to withdraw at any point during the interview if they felt they were uncomfortable.

Also, participants were informed that the interviews may be audio recorded and they had the right to decide if they wanted the proceeding to be recorded or not. In view of this they were given prior information each time the audio device was turned on. Potential benefit from the study was to draw the attention of relevant stake holders to their experiences and to motivate policy makers to enact laws that outline support and intervention centers for them, and to review the policy and implementation of inclusive education in Ghana. However, one of the interviews with a head of institution was coincidentally scheduled for the 14th of February: chocolate day in Ghana, therefore out of my own free will I presented a box of chocolates to the head of institution, she appreciated the gesture a lot because she mentioned she used to buy chocolates to commemorate the day every year but she forgot to do so on that day, hence she placed it in clear view of her staff and visitors and asked anyone who was interested to have one.

Besides, participants were specifically informed that the findings of this research would be presented to the University of Gothenburg as a master thesis and it may be electronically published by the University's library. Also, I may publish these findings as an article in a scholarly journal or present them at a scientific conference and electronic copies would be given to participants on request. During this process I wondered how I could explain my objective and the purpose of my study to participants in a better way for them to completely understand, therefore, apart from giving participants this consent letter, the contents were verbally explained to them in the Ghanaian language and they were given the opportunity to review the document for some few days before signing it.

3.5.2. Voluntary participation

Granted that human research participants have the right to exercise their free will in deciding whether to participate in a research activity or not (Lavrakas, 2008), participants in this study voluntarily decided to participate in the research without any form of coercion from me. In fact, most of the parents I interviewed were satisfied with the notion that someone was willing to listen to them, document their experiences, and draw the attention of relevant stake holders to it. As proof of their willingness to take part in the study, participants signed the consent forms thereby attesting that they knew what the research was about and gave their support for what the findings would be used for.

3.5.3. Confidentiality and Anonymity

According to Babbie (2014 p.71), a research project guarantees confidentiality when the researcher can identify a given person's responses but essentially promises not to reveal that information publicly. Thus, the findings of the study were strictly confidential because I alone know the true identity of participants and can relate the information they reported during the interview to their personalities. During the research, participants were clearly informed about my intent to keep the information gathered from them strictly confidential and this assurance encouraged participants to open up and express themselves freely. For instance, during the interview with one of the participants I got to know through the institution her son attends, when I asked her in a leading question about how she perceives the cost of education for her son, she was hesitant in the beginning so I reminded her that every information she gives me is strictly confidential. Once I cleared this with her, she opened up and told me how hard it was for her to raise funds to keep her child in the school.

Taking into consideration the sensitive nature of the study, and the cultural demands of exchanging pleasantries on first meetings, it would have been perceived as rude on my part to ask participants not to tell me their names. Therefore, I knew the names of the participants in my study, however I kept that information confidential. Thus, I used pseudonyms to hide the identities of participants and replaced the names of institutions where the heads of institutions worked, with letters. This was to

achieve confidentiality and protect their identities by ensuring that the people who read about the research cannot identify participants by their response to questions asked or their experiences (Babbie, 2014 p.71). Further, during the description of my participants, I intentionally withheld information about the educational status of participants children to make sure that they are not easily identified.

3.5.5. Harm to participants

Acknowledging that in conducting research, harm to participants may include emotional or psychological distress, physical harm, legal harm or political harm (Babbie, 2014 p.75; Patton, 2002 cited in Hesse-Biber, 2016 p. 83), I envisioned that participants may experience some form of emotional distress during the interviews because of the sensitive nature of the subject and the potential themes that would be discussed. Therefore, siding with Patton (2002 cited in Hesse-Biber, 2016 p. 83), I asked myself how hard would I push for the data? Here, acknowledging that these potential displays of emotions would enrich the data and benefit society at large by revealing experiences encountered by parents while raising their children with autism, I decided to allow such moments to arise.

However, questions that had the potential to stimulate distress were addressed judiciously and I gave parents the opportunity to end the discussion at any point when they felt they were uncomfortable. Thus, during the interviews, I deemed it ethically right to pause the discussions when such instances of emotional distress were displayed. Also, I comforted parents and gave them enough time to regain their emotions and signal to me when they were ready to continue. Further, prior to the interviews, I contacted some non-profit organizations who sometimes offered support group discussions for parents who have children with autism and with their permissions, I gave parents their contact details so they may contact these organizations and join their support group discussions if interested. Thus, measures were put in place to minimize the harm that this study had on parents.

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CHAPTER FOUR

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4. Presentation of results

Adapting the comparative structure of reporting case studies where the same case study material is repeated two or more times by comparing alternative descriptions of the same case (Yin, 2014 p. 188), the findings that emerged during the analysis of the data collected are presented in this chapter. Guided by the sub research questions, it emerged that, parents perceived raising their children with ASD to be stressful in diverse ways (see below). They are stigmatized by association with their children and stigmatized by belief systems that portray them as spiritual causal agents for their children's condition. Also, it was deduced that accessing basic education for their children with ASD was difficult. And Institutional heads confirmed this by admitting that despite the existence of the FCUBE policy and the policy of inclusive education for children with disabilities in Ghana, lack of personnel, and inadequate facilities and infrastructure, limit the number of children admitted into their institutions. Parents therefore cope by generating different strategies like seeking spiritual help, seeking family and friend support, educating themselves about the condition, changing their lifestyle and disregarding negative social attitudes.

4.1. Stress

The findings from the data gathered report that, Ghanaian parents, while caring for their children with Autism spectrum disorder experience stress emotionally, financially, and on their marriage.

4.1.1. Emotional stress

It emerged that parents experienced high levels of emotional stress. They reported that dealing and managing with their children's condition is demanding. In a leading question, where participants were asked to explain why they say taking care of their children with ASD is difficult, most participants with a change in their tone of voice, reported being emotionally stressed because they felt they were on their own and since there was no social support system they felt they were stuck and left to deal with the situation alone. These were evident when parents reported that: "prior to his diagnosis, I was troubled by not knowing exactly what was wrong with my child and moved from one hospital to the other trying to find answers. Now I am overwhelmed by my son's condition and the way my life has turned out because of it, sometime ago, I nearly bought rat poison to drink" (Cynthia). At this point she was very emotional and weeping so the interview had to be paused and the researcher consoled her until she indicated that she was ready to continue with the interview. Likewise, Abena expressed the stress she goes through emotionally by reporting that "most of the time I feel I am not myself but there is no help from anywhere, so I have to be with my child all the time. I am always sad and crying in the night, just wondering what I did wrong to deserve this". Also, Gifty reported that "when I take him to the market to do some shopping and he begins his tantrums I become so embarrassed and weep especially when people start calling us names like "buulu"[12] and "bodamfo"[13]. I have had to quarrel in the market because of such names people label him with".

Meanwhile, others were emotionally disturbed by their children's inability to communicate especially when something is wrong with them, stating that it makes it difficult to understand their children and care for them adequately. Also, they were emotionally stressed by their children's unusual behavior at home and in public. Some mentioned that their children spit on others without any provocation, bang their heads against a wall with no reason, harm themselves or their sibling during play and ran towards

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[12] Meaning fool.
[13] Meaning mad person.

moving vehicles when they get the least opportunity. In their own words, parents had this to say "Everyone abandons you when you give birth to a child with autism. In fact, your life becomes standstill. It is very difficult not knowing when he is in pain, …. I pray he can just talk so I will know how he feels and what is exactly wrong with him to enable me to help him; it is hard to see my son banging his head against a wall for no obvious reason, …… I weep when I think of it" (Abena). "I wish he could communicate; I was going to the market with him one day and he kept stopping briefly in the middle of the road. Initially I thought he was about to have tantrums but after a while I realized he was not walking properly. I stopped for a moment and checked his shoes only to find thorns in them, when I saw these I wept" (Cynthia). "people refer to my child as the 'abnormal one' and it makes me sad. …… I wish he would be calm and not hyperactive, when my other kids come running to me because she pushed them during play, I feel I have failed in providing a safe environment for my children" (Yaa). These experiences narrated by parents reveal some of the emotional turmoil they go through while raising their children with autism.

4.1.2. Financial stress

The data showed that parents are burdened with high financial obligations while raising a child with autism. These arise from the high cost of education, cost of professional care for their children, cost of spiritual help for their children and parents' inability to keep a job due to the demands of their children's condition. In that, parents who were fortunate to get admission for their child with autism in a private special education school had to pay high school fees and additional fees to employ the services of a speech therapist to help their child with communication. This strain on their finances is evident when Yaa stated that: "The money I pay to keep my daughter in school is twice the money I pay for my other child to be in school and because of that, my husband and I could not buy new clothes for them during Christmas and we could not take them to visit their grandparents". It is also evident that participants are stressed financially because while responding to the question, how do you perceive raising your child with autism? Attaah narrated that: "Hmmm I find things difficult taking care of my child with ASD. I am a single parent and I use fifty percent (50%) of my salary to pay his fees, and twenty percent (20%) to seek for spiritual help so I am always borrowing money from family and friends to support myself". And Cynthia reported that "when the symptoms first started, I spent all my savings travelling to seek for spiritual cure for him".

On the other hand, a parent who could not afford to pay the high demanding fees in the private institutions and was unable to gain admission for her child in the government assisted schools where she is required to pay little or no fees was forced to stop working and stay at home to be able to take care of her child with ASD. She mentioned that, staying at home meant she was unable to contribute financially to the wellbeing of the family, making her husband the sole provider thereby, having significant strains on their finances. In her words Cynthia narrated that: "When my child was schooling in a private normal stream school, I was constantly called from work to go and get him because he had either hit another child or had sneaked out of the school compound while a parent was dropping off a child. This became unbearable for me and my employers, so I had to look for another school for him. I informed the head of another institution about his condition and he admitted him. When I went to pick him from the new school on his first day, the head gave me back the fees I paid and said he was sorry he cannot admit my child because he does not stay at one place. Eventually, I had to stop work and stay at home to take care of him and my husband's job doesn't pay much, so I go round the streets of Accra hawking and doing petty trading, yet that is not enough so we sometimes solicit help from our extended family". These revealed clear instances of the financial stress parents in Ghana encounter while they raise their children with autism.

4.1.3. Marital stress

Some participants expressed intensive stress on their marriage as a result of their children's condition. Out of five parents who were interviewed, two were divorced due to their child's condition and one was married but was encountering challenges with her husband for the same reasons. In all three marriages, participants reported that challenges on the marriage were partially because their spouses believed that either they, or their relatives did not care for the child when needed or they were spiritually responsible for their children's condition: Gifty reported that: "my child's parents are divorced because the mother was not caring for the boy and this disturbed the father". Cynthia contributed to the discourse by narrating that: "initially my husband accused me of pampering our child with autism and not training him properly that is why unlike his siblings, he is unable to do simple things expected of him like using the toilet on his own therefore he played and took care of my other kids but wanted nothing to do with our child with autism. Now he says I have bewitched the boy". Attaah also reported that the genesis of her marital problems occurred when her ex-husband accused her mother of making their son spiritually sick simply because her mother moved in with them for two months to help take care of the baby when she gave birth.

Meanwhile, another participant reported that apart from inadequate time for she and her husband, having a child with autism has not affected her marriage in anyway. And the fifth participant narrated that she was enjoying peaceful marriage with her spouse only because she educated herself about what autism is and then educated her husband about the condition. Thus, only two participants were technically peacefully married to their spouses. In their own words they narrated that: "Frankly speaking my husband has been very supportive, he has not allowed my daughter's condition to affect our relationship. He helps me take care of all the children and constantly assures me of his love. My only problem is we do not have time for ourselves" (Yaa). "It has not been easy oooo, it took time for my husband to accept my son's condition. I had to read about what autism is and then educate him so he will not believe what people were saying about someone cursing us" (Abena).

4.2. Stigma

4.2.1. Spirituality as causal agent for stigma

It emerged that parents, while raising their children with ASD are stigmatized because of superstitious religious beliefs that they are the cause of their children's predicament. Parents reported that in ancient days, children with disabilities like their children, were believed to have been born to parents who had committed some sort of sin or parents who had used their children for money rituals, hence to discourage others in the society from doing same, parents of such children were shunned and viewed as wicked people. Participants, therefore believed that it was because of these ancient beliefs that people in their society shun them, point accusing fingers at them and call them names like "nsuba maame"[14], "sika duro papa"[15], "juju papa"[16]. In addition, they reported that other people see them as the cause of their children's condition because they may have taken a forbidden drug during their pregnancy. For instance, Gifty reported hearing someone say, "look at how nice this boy is, his father has used him for "sika duro" (blood money) and "juju" (voodoo). She explained that because the child's father is wealthy, people in their neighborhood assume he has used his last child for money rituals, so they whisper and call them names like "nsuba papa" and "sika duro papa" each time they see them. She added that it was a big relief when the hospital gave them the diagnosis for the child's condition because now, she knows what the condition is, and she is able to boldly tell people who call the boy and his father names the medical condition the child has.

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[14] Mother of a river child.
[15] Father of blood money.
[16] Father of voodooism.

While Gifty experienced stigma as a causal agent from non-relatives, Cynthia reported to have experienced stigma as the spiritual causal agent from her relations. She (Cynthia) reported that, her husband accused her of bewitching their son, and has stopped eating the food she cooks. Some of his extended family also see her as the cause of the child's condition for similar reasons. She therefore defends herself by reminding her husband each time he brings that issue up that their other children do not have autism. Ironically, Cynthia reported that some of her extended relations also accuse her husband and his family of making her son spiritually sick for monetary purposes. She defends her in-laws by asking her relatives this question: "if they have used him for money rituals then why are we not wealthy?". However, she believes another person somewhere who possessed spiritual powers, and disliked her had possessed her handsome son just to make her suffer. Away from that, Yaa reported that in an argument with a neighbor some time ago over the neighbor prohibiting her children from playing with her daughter, the neighbor mentioned that: "I did not ask you to either invite a curse for yourself or take strange medications when you were pregnant". That was when she realized that other than the assumption that she had been cursed, people also assumed that, she caused her daughter's condition by taking some sort of medication. This assumption was confirmed when Akwele, the head of institution in the normal stream school while talking about how she dealt with the parent who asked her to send the children with autism away from her school, said: "I told the parent the condition is not contagious and that it may be because their mothers mistakenly took some sort of medication".

4.2.2. Stigma by association

Parents reported that people simply stopped interacting with them once they realized they had or were in contact with children popularly referred to as "nsuba"[17]. Some have lost lovers and friends because of their association with these children. Gifty; narrates that her boyfriend who had proposed marriage to her broke off the relationship when he realized that the child, she was caring for had autism. In her words she narrated that: "when my boyfriend got to know that the child, I cared for had autism, he asked me to stop taking care of him, I refused, and he broke up with me". In addition, stigma by association was evident when Attaah reported that people who know about her child's condition refuse to sit with her when they meet at public places and some of her neighbors do not allow their children to play with her daughter because they claim when their children play with her daughter, other children refuse to play with them.

Furthermore, parents reported that they felt they and their relatives were being stigmatized because they had relations or were in contact with their children with autism. In that, some of their friends and acquaintances started behaving strangely towards them once they realized they had children with autism. For instance, Cynthia tearfully narrated that when she goes around the streets of Accra with her son to sell goods, people shun her goods, so she leaves her seven year old child with autism alone at home for about six hours to enable her raise money for the family's upkeep. On days when she is heartbroken and unable to leave him behind, she goes with him and comes home with very little or no money and both of them exhausted. She added that when she moved to her current home, she was in good terms with a particular neighbor who lived about four blocks from her house. But she has realized that since that neighbor saw her son and realized he had autism; she has stopped communicating with her. When she (Cynthia) is passing by and greets her, the neighbor pretends she does not hear or hurriedly goes back into her home immediately she sees her (Cynthia) approaching. Yaa also reports that her other children complain that their neighbors who attend the same school with them refuse to play with them at school and tell their friends in school that their sister has a strange sickness.

Also, some of the heads of institutions who participated in the study confirmed parents report of stigma by association by reporting that: "when I started working with children with autism, I lost some

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[17] That is children from the rivers.

friends because they did not want to associate with the people I worked with. Some people were also bold enough to approach me and ask me to stop working with these children and wait at least until I have given birth to all my children else, I may give birth to children with similar conditions. I educated them about autism and assured them that it was neither a contagious disease nor a spiritual disease. Currently I have given birth to three children and none of them has ASD, some of the friends who ended our relationship have come back to make amends" (Bernice). Another head of institution in a normal stream school, Akwele, reported that, when she had children with autism in her school other parents approached her and asked her to send those children away because they did not want their children to mingle with them. Whilst these participants recounted their experiences of stigma, Abena reported that she did not have to experience stigma because she never gave anyone the opportunity to behave negatively towards her or share their negative opinion about her son. She made sure she educated the people she encountered at social gatherings about her son's condition each time she takes him out. However, she acknowledged that she knew people talk behind her, but she is content with the fact that they cannot do so in her face.

4.2.3. Difficulty accessing basic education

Most parents reported that accessing basic education for their children with ASD was a great challenge. It was deduced that parents could easily access education for their children with autism both in the private operated and government assisted schools before the symptoms of the spectrum began. However, once their children began to show signs of the disorder it became difficult to keep them in school, especially in the government assisted schools. In that, parents observed that private operated schools simply allowed their children with ASD to remain in the school because of the school fees parents paid while government assisted schools; where they pay little or no school fees, recommended that they withdraw their children and take them to special needs school. When they do not comply, they are informed after some few weeks or months that there is no place for their children with special needs in the school. Further, parents reported that, there exist limited government assisted special education schools for children with autism in Accra. Apart from that proximity from their home to the few that were in existence was great and gaining admission for their children in these schools was extremely difficult. Also, there were very few private special education schools for children with autism; where gaining admission for their children was not so difficult however, the school fees they had to pay were extremely expensive.

This was evident when Gifty reported that: "my son's mainstream preschool was not giving him the needed help, they just kept him in the school so we can pay the huge school fees, therefore we started looking for a special needs school for him. It was very difficult to find one, we had to search and wait for almost two years before we found the private special needs institution where he is now, it is far from our house and the fees is very expensive because of that most parents who cannot afford have withdrawn their children". Similarly, Abena narrated that when her son was first diagnosed, she struggled to gain admission for him in a special needs school and when she did, she had to drive for about two hours to take him to school and drive same hours when picking him from school. Therefore, he travelled to and from the school four times a day because she needed to get back home after dropping him off, hence, she spent almost eight hours a day commuting because of her son's education. This became unbearable and eventually she made him stay at home for a while until she gained admission for him in a private operated special school which was forty-five minutes away from her home. The story was no different from Yaa, who reported to have struggled in gaining admission for her child in a special school and to be paying fees twice the amount she pays for her other children.

Likewise, Attaah reported that her daughter was expelled from the government operated regular school she was attending due to her disability and she the mother, struggled but never had admission for her in other mainstream government schools. In her response to a leading question where she was asked if she tried gaining admission in a private mainstream school or a government operated special

needs school for her daughter with ASD she answered that: "some private regular schools refused to admit my daughter, the one that accepted her only made me pay the fees and called several times in a day to pick her up for one reason or the other. As for the government special needs school I tried gaining admission at, they told me I should go and teach her how to use the bathroom before coming. Moreover, the place was too far, and they said they could only admit her as a day student even though they had a boarding facility. I really struggled until I got admission for her at this private special school, which is about one hour from my house, my only problem is the school fees is very expensive".

In the same way, Cynthia also reported that, her son was denied admission both in the private and government mainstream schools because they said his behavior was different from the other kids in the school so she should seek for admission in a special needs school for him. She added that the school fees demanded in two special needs school she contacted were too expensive for her. And when she tried to gain admission in a both day and boarding government assisted special school; located about two and a half hours away from her home, she was given the option to either go and potty train him so he can be admitted as a boarder or to bring him to day school. She said she had no option but to stay home with her son because she despite efforts to potty train him she has been unsuccessful although she had successfully potty trained her younger children. Moreover, she could not afford the time and cost of commuting to and from her home to the school premises on daily bases. In her words she said: "if I take him to day school over there it means I cannot even go round to do my petty trading because I would have to leave home at 6:am, get to his school by 8:30am, drop him off and return home by 12noon. Meaning immediately I return I would have to go back so I can pick him up at 14:30, what work can I do then? Do I stay in the school and wait for him to close? If I do so how do I go and sell to provide for my family?".

Meanwhile, the institutional heads who participated in the study reported that, the number of institutions equipped with handling children with intellectual disability specifically autism in Ghana, are just a few and are very limited in the Greater region. They added that the few special needs school in this category; both private and government assisted, admit children from not only Accra but from all parts of the country. This is because parents from other parts of the country who are unable to find special education schools for children with autism go to Accra; the capital city to seek for admission for their children. Hence the need for insisting that parents within the region would take the day option and those from outside the region would choose the boarding facility. Moreover, some parents use the provision of boarding facilities provided by some of the institutions as ways of abandoning their children. Some also expect the school administrators to simply admit their children when they seek admission because their children have been diagnosed by a doctor, but they have to also send their children to the National Assessment and Resource Center so that an assessment can be done to find out the level of the child's spectrum before they can admit the child. Further, institutional heads made reference to the fact that, the FCUBE policy and the policy of inclusive education for children with disabilities mandated the regular or mainstream schools to admit these children so that their institutions would not be put under pressure but would be assessed by children on the extreme end of the spectrum. However, this is hardly practiced because the institutions do not have adequate personnel and facilities to admit children with special needs like autism. Moreover, Ghana's educational system expects children to sit in a class over a, period of time and be able to read and write, and these are skills that most children with autism find difficult to perform, especially in the early stages of their diagnosis.

Apart from that, they narrated that, most parents of children with ASD attribute the condition to spiritism so they continually take the children away from school for several days to prayer camps to be exorcised, and by the time the children come back they may have picked up new habits, making it difficult for them to manage the children. They added that parents of the "normal" children also complain and ask that the children with autism should either be expelled or not allowed to mingle with their children. When asked why they deny children with autism the right to basic education they

reported that they are willing to admit as many children as their institutions can accommodate but most of their institutions are understaffed and lack adequate facilities that would enable them to operate moreover parents inhibit the continual training process of their children by frequently taking the children away from school to seek for spiritual help . These were evident when Dzidzor reported that: "my institution has the infrastructural capacity to admit up to three hundred students but we lack the personnel to do so, and the regular schools who are supposed to support and admit some of these children because the law says every child of school going age must not be denied the right to education irrespective of their disability, are unable to admit these children because they also lack trained personnel and adequate facilities to handle the condition. moreover, we see that parents just want to abandon their children in the boarding school. During vacations we sometimes have to call parents several times before they come for their children.

Likewise, when Akwele reported that: "we wanted to help one boy with autism, but the parents kept taking him to prayer camps and when he came back he wanted to mimic what he saw there by pretending to be praying for his classmates and pushing them to fall". Besides Bernice reported that: every child in Ghana has the right to education, it has been said and it has been written, but when you go to the field that is not what is happening. Our educational system is such that the child should be able to read and write, sit in a class for a lesson to be taught, however a child with autism may not have language and may be hyperactive so it would be unrealistic to achieve these expectations within the timeframe given to children attending the regular school. Therefore, they would need extra time and effort to be able to learn and adapt to the systems expectations, making it difficult for the regular schools to admit them. That is why we the private special education schools are in existence to make up for the limited number of the government assisted special need schools. Moreover, some parents of children with autism do not understand that each child with autism learn at a different pace. They expect to see drastic changes in their children once they start attending the special school, if they don't see that they tend to believe it is a spiritual illness and take the child away to seek spiritual help. When they go and see no results they try to come back and by then the child's place may have been occupied".

Further, institutional heads from the private schools reported that the cost of living in Accra is expensive, and they receive no funds from the government to operate, therefore they bill parents with the utility bills they pay for their operations, that is why their schools are presumed to be expensive. In addition, they also reported that, since access to education for children with ASD in the government operated schools was not so easy, it is often those who have the money and can afford who send their children to the private schools, that could be one of the reasons why people assume these parents have used their children for money rituals. Also, they narrated that parents who are unable to afford usually keep their children at home, hidden from the public eye and are often unwilling to admit that they have children with ASD, perhaps out of fear of being stigmatized. These reports revealed parents' challenges in accessing basic education for their children and the varying reasons why the institutions are most often incapable of admitting them. Here it can be observed that stigma from the society defined by a child with autism's inability to behave like other children in the society force some parents to hide their children.

4.3. Coping strategies

Parents report that there exist little social support and government intervention agencies in Ghana for parents who are raising children with autism. Therefore, they continually generate and employ different strategies to cope with and manage their children's condition. These included seeking for spiritual help, seeking for help from family and friends, educating themselves about ASD, changing their lifestyle, and disregarding negative social attitudes.

4.3.1. Spiritual help

It was evident that although parents sought for medical assistance to help them identify and understand their children's condition, they lived in a society that had a lot of religious beliefs and superstitions, therefore motivated by these belief systems they sought for spiritual assistance to cure their children from autism. They admitted that they believed what the doctors have said concerning their children's condition, but they also believed there was a higher power out there so to cope with the situation they try to have faith and hope that with some sort of spiritual assistance it shall be well. Out of five parents who participated in the study four of them reported to continually seek spiritual assistance for their children with the hope that their children will be cured in future. For example, Attaah reported that she uses twenty percent (20%) of her salary to seek for spiritual healing for her child because she believes that is the only way her child's condition can improve.

Also, Cynthia narrated that: "A friend of mine has a child with a similar condition, she visited one pastor and by God's grace the child can now speak, so I believe it shall be well. Although I have visited a lot of pastors and have not yet seen any improvement, I will keep on praying and hoping that it shall be well one day". Gifty confirmed seeking spiritual help is a way of coping with the situation by saying that: "We have been going for prayers and inviting pastors to come to our house to pray and drive away any bad omen so I think it shall be well, …… if we do not go people may think we don't care, and they would believe the gossip that the father has truly used the child for money rituals, so we go so they may know that we are not afraid to go there. Moreover, the way the child behaves sometimes if you don't take care you will believe that the child is truly possessed by evil powers so seeking for spiritual assistance helps to assure us that he is not possessed or whatever possessed him has been driven away". Similarly, Yaa reported seeking for spiritual help as a means of coping because the doctor she visited informed her that her child's condition cannot be cured but it can be managed, therefore spiritual assistance gives her hope that in future, she would get out of the stressful situation she finds herself in.

4.3.2. Family and friend support

Findings from the research highlighted that there exist little social support systems for parents who are raising children with ASD in Ghana. Therefore, parents rely on their family members to support and help them in caring for their children. They obtain financial support and care giving support from their family members because that is the only resort they have. Abena reports that: "nobody is ready to help, after all the taxes and stuff we pay. I employed the services of a babysitter whom I told my child had special needs some time ago to look after my son for two hours while I go and supply goods to clients. She called me after forty-five minutes that she had to leave for an emergency. The next time I tried to book her she declined; therefore, I can only rely on my aged mother or my younger sister to care for him in my absence".

While Abena relies on her family for physical support, Cynthia reported to have relied on her family for financial support. She narrated that when her son started showing signs of the disability, she spent all her savings trying to find solution, therefore when she stopped working and stayed at home, she had no money. She went to her municipal social welfare department and was informed they were currently handling cases of physical disability. She was financially handicapped to an extent that proving a three-square meal for her children and herself became a challenge. Therefore, she talked to her siblings who joined resources together and gave her an amount of money to start petty trading. The story is no different with Attaah; a single mother, she reported that she continually borrowed money from family and friends to support her family because her income was not enough.

4.3.3. Self-education

The data revealed that most parents in Ghana who are raising children with autism educate themselves about their children's condition. Parents reported that after their children's diagnosis, they struggled to get adequate information about how to handle the condition. In that it was expensive and difficult to book appointments to see a doctor post diagnosis to simply talk about autism spectrum disorder. Therefore, they relied on teachers who the society they live in believe to be custodians of knowledge. Only to be disappointed by realizing that the regular or mainstream schools have little knowledge about the condition and how to care for such children. The teachers in these schools often directed parents to special education schools which they believe are very few in the country and difficult to access. Therefore, parents had no choice but to educate themselves on the condition and how best to help their children. Those who can, get professional training about the condition and how to manage it, others read articles and newsletters online and some also listen to radio stations and watch television programmes that broadcast issues concerning the spectrum.

It was through such media, they report, that they got to know that limiting their children's consumption of artificial sugars and encouraging gluten free and corn free diets help to reduce their autistic children's hyper activeness. This is evident when Gifty in saying how she copes with the situation reported that: "availing myself to be educated about the spectrum has really facilitated my child's learning process. He is now sometimes able to use the bathroom when he needs to, and I am able to identify the different ways of communication he uses to signal his needs.". Abena added that: I also read a lot from the internet to get some knowledge about what to do and what not to do. That is how I came across the knowledge on nutrition and have changed my diet. Likewise, Cynthia reported that she seeks education by listening to radio programmes and surfing the internet.

4.3.4. Change in lifestyle

The findings also revealed that parents had to change their lifestyle so that they could cope with their children's condition. In that, most parents had to sacrifice and stop working to be stay at home mothers to enable them to adequately care for their children. Also, some parents had to change their lifestyle by making adjustments to their diet. This was to accommodate the nutritional preferences they claimed helped with their children's hyperactivity. This was evident when Abena reported that she had to resign from her office job to get ample time and take care of her son. In her words she narrated that: "I had to stop working for my employers so that I would have time for my son and adequately manage his condition, now I am self-employed and work from home". She added that when she gives him something apart from what she eats he does not eat the food, so she has changed her diet to gluten free and corn free foods. Cynthia also reported that she changed her lifestyle by resigning from her work, changing the food she eats at home, and reducing her attendance to social festivities. These she mentioned was because she could neither afford the expensive fees in the special needs school for her child nor find a normal stream school that was willing to admit her son so she had to stay home to take care of her child so currently, she sells small goods and merchandise on the streets of Accra and in the open market. Also, she changed her diet to reduce his hyperactivity, and reduced her attendance of social events like weddings to reduce the stigma.

Similarly, Yaa reported that she and her husband had to change their lifestyle by reducing the yearly shopping they do for their family and cancelling family vacations. In that, it was custom for them to buy new clothes for their children during Christmas and take the children to their hometowns to visit their (children) grandparents. However, they were unable to do so this past Christmas because they needed to save money for their children's school fees. Gifty on the other hand testified that she noticed the regular schools could not give her child the professional help he needed, hence she had to stop her usual work to be trained as her child's personal facilitator and care giver to enable her care for him. Therefore, she currently works as a co facilitator in his school and as his care giver at home.

4.3.5. Disregard for negative social attitudes

The research revealed that, parents intentionally disregard negative social attitudes towards them and their children as a way of dealing with the situation. They report that society stigmatize them and judge their children by their inability to perform certain simple activities like going to the washroom when they need to, communicating, sitting still for a couple of minutes, eating gently and keeping quite during social gatherings like church activities, birthday parties and weddings. Therefore, they call them names like "gyimi gyimi"[18], "bodamfo"[19], "buulu"[20]. But they ignore the stigma and the name calling because they know their children are neither fools nor mad, but have a medical condition, so instead of waging war with society they rather direct their energy and time to ensuring that their children feel loved and cared for. This was evident in Attaah's response to her view about social perceptions regarding her child with ASD: "….. if I listen to what people say then I would be miserable and probably kill myself. He is my child, and there is nothing I can do to change that. I will not hide him like people do or abandon him in the village or give him slow poison like the rumors I hear. The best I can do is to have a lot of patience with him and love him with all my heart".

In addition, Yaa reported her disregard for negative social attitudes when she narrated that, ever since she had the argument with her neighbor and got to know that some people are ignorant of the condition, she tries to create awareness in her own way by taking her daughter to social gatherings and ignoring it when people stare at her daughter's way of eating or the sounds she makes when she tries to speak, instead she educates people who are curious enough to ask her about the condition. Cynthia also confirmed disregarding negative social attitudes as a way of dealing with her son's condition. she reported that it is because of those attitudes that gave her suicidal thoughts. Upon reflections, she has realized that life is about survival so she would fight back and not allow such attitudes to determine her existence or destroy the gift of life she has. She would rather ignore them, work hard, love her children and enjoy the rest of her life.

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[18] Meaning fool.
[19] Mad person.
[20] Meaning fool

CHAPTER FIVE

5. Discussion

With respect to the research questions outlined in chapter one, the present chapter discusses the findings that emerged from the study as reported in the chapter that precedes this one.

5.1. Stress

When asked how they perceive raising their children with ASD, all the parents mentioned that it was difficult and stressful. They explained why it is stressful by citing instances that informed their perception:

5.1.1. Emotional stress

Granted that parents of children with disabilities in general feel sorrow, frustration, guilt, anger and pain, especially when comparing their children with special needs with others (Heiman, 2002 p. 167) and parents of children with autism suffer physical and mental health issues like depression, anxiety, weight gain because of their children's condition (Fletcher, Markoulakis & Bryden, 2012 p. 57), the findings from the research clearly indicate Ghanaian parents' experiences of emotional stress while caring for their children with ASD. Indeed, parents in Ghana are emotionally stressed just like parents elsewhere as a result of their children's condition but they are also exceptionally stressed by the stigma they receive from others. This is evident when most of the parents interviewed revealed clear occasions when they were emotionally stressed by their children's condition.

For instance, Cynthia's report amid tears, of nearly committing suicide because of the stigma she encountered in her community due to her son's inability to behave like others in the society and how her life had changed reveals how stressful and depressing it is for parents to raise a child with the spectrum in Ghana. Likewise, Abena's report that she often weeps at night because of the pain and sadness she feels by her son's condition. Not forgetting Gifty's anger at the name calling: "bodamfo" "nsuba" she receives when she takes him to public places resulting in her quarrels with people who label her child as such. These reveal immense understanding of the emotional duress parents in Ghana go through and some disheartening consequences of society's unacceptance of people with disability specifically ASD.

5.1.2. Financial stress

The personal experiences parents shared about the nature of the financial stress they encounter, compliments and contributes to existing research concerning financial pressures faced by parents around the world when caring for their child with ASD. In that just as parents elsewhere are financially drained by the medical and educational obligations they have to fulfil to care for their children (Depape & Lindsay, 2014; Heiman, 2002, p. 160; Myers, Mackintosh, & Goin-Kochel, p. 673), so are Ghanaian parents financially stressed to also take care of their children. This is obvious when parents reported experiences highlight the need for middle class families like Yaa's family with both parents working, had to massively cut down on their expenses and sacrifice to be able to provide for the needs of their child with ASD.

Again, it can be observed that apart from the stress in providing expensive health and educational help for the well-being of their children, parents are also stressed financially by the need to provide spiritual healing for their children. This is because they are motivated by cultural spiritual beliefs that attribute their children's condition, although medically explainable to some sort of supernatural

powers. In their quest to seek for answers and help for their children parents therefore rely on the spiritual beliefs they grew up with and have faith in, to manage their stressful situation. This explains why although parents who participated in the study admit to taking their children to the hospital to get medical opinion and diagnosis about their condition, they still spend huge sums of money chasing after spiritual healing. Hence, the use of the religious or magical model of disability explains the rationale behind why participants, although economically underprivileged resort to spiritual assistance.

5.1.3. Marital stress

Research shows that parents report difficulty in family and marital quality like family adaptability, affection expression and marital satisfaction when caring for a child with ASD (Harper, Dyches, Harper, Roper &South, 2013). The story is not different in Ghana, where the present study revealed that, parents who have children with ASD experience immense stress on their marriages. It was observed that parents attributed this stress to their partners their partners blaming them for being spiritually responsible for their children's condition, to their spouses' lack of care for their child with autism, and to their partners comparison of their children who have the spectrum with others who did not. These are evident when Cynthia and Attaah report that their husbands accused them or their relatives of bewitching their children. It is also evident when Cynthia's husband compares his son with autism to his other children by pointing out his inability to use the toilet on his own, thereby giving him reason to refuse caring for his son. Likewise, when Gifty's son's biological mother is accused of not taking adequate care of the child resulting in their divorce.

These exhibit intense duress parents endure in their marriage by virtue of their children being born with autism. And also raises concerns of misconceptions about the cause of ASD in the Ghanaian society due superstitious religious and cultural beliefs thereby highlighting the importance of the religious or magical model of disability in this study. Besides, Cynthia's husband's attitude depicts judgment and rejection for their child based on his inability to behave like his sibling or every other child in the society as a whole. This shows how the social model of disability compliments the religious model in this study by highlighting society's judgement of an individual by his or her ability or inability to perform a task.

5.2. Stigma

When parents were asked about their views on the social perceptions regarding their children with ASD, majority reported to have been stigmatized in one way or the other.

5.2.1. Spirituality as causal agent for stigma

According to Opoku (1969 cited in Addai, Opoku-Agyeman, & Ghartey, 2011) in Africa religion is life and life is religion. Africans are in engaged with religion in whatever they do therefore religion gives meaning and significance to their lives. Admittedly, Ghana is a very religious pluralist country with the most notable religion being the three dominant faiths of Christianity, Islam and the indigenous African religion; otherwise known as the African traditional religion (Golo & Yaro, 2013). Therefore, it is not surprising that the findings of this study revealed that spirituality and the belief in the supernatural was the dominant cultural opinion regarding the cause of autism in Ghana. The Ghanaian society, influenced by spirituality and the belief in supernatural powers, accuse parents of being the casual agents of their children's autistic condition. That is why they call these children "nsuba", "bodamfo", "buulu" "sika dru ba" "juju ba" and call the parents "nsuba papa", "nsuba maame" and "sika duro papa". It is evident that these beliefs, presumed to be fading (Avoke, 2002 p.

771) are in fact strongly existent in Ghana. Thus, parents are shunned and discriminated in society for a condition they have nothing to do with.

Ironically, it can be observed that some parents although saddened by people's accusation of them being spiritually responsible for their children's condition, also have the belief that their children's autistic condition is as a result of a supernatural power somewhere. Hence, they also play the spiritual blame game by accusing others of being spiritual responsible for their children's condition. This is evident when Cynthia narrated that, she believes neither she nor her husband are responsible for their child's condition because they do not have the money which is expected to come with using someone for blood money. But she believes that someone out there, who either dislikes her or was jealous of her child's beauty when he was born, bewitched him to make her suffer.

These allude to the fact that the Ghanaian society's accusation of parents as spiritually being responsible to their children's autistic condition emerges from their belief in spirituality, superstition and supernatural powers. Hence the religious or magical model of disability explains the origin and justification of society's attitude towards parents of children with ASD in Ghana. However, with reference to Yaa's report of being accused of taking medications that caused her child's condition, it can be deduced that both the religious model of disability and the social model of disability as theory, failed in this regard to address parents' report of stigma as a result of taking medications. Therefore, another model; perhaps the medical model of disability would be able to compliment these models in this regard by explaining why parents are stigmatized due to the fact that they are perceived to have taken some medications during their pregnancy which resulted in their children's autistic condition.

5.2.2. Stigma by association

The study confirmed research that states that parents of children with ASD are shunned in the society and excluded from events ((Amponteng, et al 2018; Avoke, 2002; Kinnear, et al, 2015; Gona, et al., 2016). Indeed, parents in Ghana are discriminated and stigmatized by virtue of their association with children with autism, however, compared to the rest of the world, the Ghanaian society's display of discrimination and stigma for parents who have children with ASD is intense as a result of a strong belief in the supernatural. For instance, Gifty's revelation of her fiancé threatening to break up with her and eventually breaking up with her when he got to know she cared for a child with ASD and did not want to stop performing that role, clearly raised concerns of stigma by association. In that although Gifty was not the biological mother of her child, she was stigmatized, shunned and called names because she associated herself with a child with that condition. Likewise, stigma by association was portrayed by people's refusal to buy from Cynthia when she goes to do petty trading with her son who sometimes behaves out of the ordinary. She stated that some of these people were often people who did not even know she was the boy's mother yet simply refused to buy from her once he had a tantrum.

Further, Bernice's report about her personal encounter of stigma by association from her friends who advised her against working with children with autism signifies how serious the stigma of association is in Ghana. In that, if people who are not biological parents of children with ASD are stigmatized because of their association with them, then the stigma and discrimination faced by parents of children with autism is great. These experiences exhibit the Ghanaian society's intolerance and unacceptance of children with ASD and also, reflects a society that has supernatural belief systems strongly embedded in individuals who despite modernization and education still rely on their religion and beliefs in peculiar aspects of their lives.

5.3. Access to education

While parents elsewhere are able to get access to education for their children but want to play key roles in the planning and discussion of appropriate intervention strategies for their children (Webster, et al., 2016), this study revealed that parents in Ghana struggle to gain access to basic education for their children with ASD. The FCUBE policy and the 2008 Education Act shows that although policy makers and law makers in Ghana have enacted laws and policies that are expected to ease access to education for persons with disability, parents who have children with autism report otherwise and institutional heads managing mainstream institutions and special needs institutions for children in this category confirm parents report of struggling to gain access.

When parents were asked about their experiences when accessing basic education for their child with autism spectrum disorder, majority reported that it was difficult. Most of them could neither get admission in the government assisted special schools nor the government assisted regular schools. They perceived the government assisted special school's set unrealistic criteria for admission for their children which made it impossible to gain admission for their children with ASD. Few parents that had the opportunity to gain admission for their children in these schools which operated both boarding and day facilities were admitted to the day school; an option which parents report to be too demanding. In that, by virtue of their geographical location from the school, they had to spend a total of about eight hours a day commuting to, and from their children's school and this is too stressful for them.

However, the report from the institutional heads revealed that they were understaffed and lacked the necessary facilities to enable them to operate. For instance, one head of institution in a government assisted school reported that, his institution had the capacity to accommodate about three hundred students but lacked personnel to take care of that huge number, so they only had on admission one hundred and sixty-five students. In addition, they argued that most parents prefer the boarding facility simply because they use it as avenues to abandon their children and hide them from the public. This confirms critiques assertion that residential schools for children with disabilities in Ghana, can potentially perpetuate negative cultural beliefs and attitudes toward disability as they can serve as avenues for the exclusion of persons with disabilities from mainstream society (Lamptey, Villeneuve, Minnes, & Mccoll, 2015). Also, parents reported that the government assisted regular schools simply refused to admit their children or demand that parents take their children elsewhere once these children begin showing signs of having the disorder. When contacted, none of the government assisted regular schools were willing to participate in the discussion. This may have been due to socio-political issues in the country hence the heads might have felt the need to remain loyal to their employers who are appointed by the government in power.

It may also show that either the heads of the government assisted regular schools felt guilty about refusing to admit children with autism or they were just not interested. In that these heads probably knew what the law and policies said about inclusive education for children with disabilities which includes children with ASD in the mainstream schools but chose to ignore them. Notwithstanding, the institutional heads who participated in the study voluntarily came to the defense of the government assisted regular schools by reporting that the regular schools are also understaffed and lack adequate infrastructure and facilities. They added that the regular or mainstream schools may be unable to admit children with autism because it was difficult for these children to adapt to the expectations of the curriculum mandated by the Ghana Education Service for implementation in schools across the country. The fact that children with ASD are not admitted because they do not fit into the "expectations" of Ghana's educational curriculum reveals children with ASD are judged and denied access due to their inability to behave and perform tasks like others in the society, hence the social model of disability which envisions disability as emerging from society's discrimination of an individual's inability to perform a task, best explains why parents are unable to access basic education for their children with autism.

Apart from these, parents also reported that access to education in both private mainstream schools and special needs schools was not so difficult but was quite expensive therefore this either deterred them from sending their children to school or gave them huge financial responsibilities which were stressful for them. Admittedly, institutional heads narrated that it was expensive to engage in individual teaching approach and to employ or train enough personnel to handle these children. And granted that they do not receive any support from the government they are forced to include the bills they pay for operating the school to the school fees. These include water bill, electricity bill and cost of rent.

5.4. Coping strategies

During the study, it was observed that just like parents in the rest of the world who have children with autism, Ghanaian parents who have children with ASD also have to devise strategies to manage their children's condition. Meanwhile, whiles parents elsewhere coped by ensuring the safety of their children, their family and property and others coped by participating in recreational activities (Owen, & McCann, 2018; Paynter, et al., 2018; Stewart, et al., 2017), Ghanaian parents coped through other diverse means.

5.4.1. Spiritual help

According to (Gona, et al., 2016), parents of children with autism in Kenya sought spiritual healing as means of coping with their children's condition, and Ghana is no different. Granted that spiritual and religious belief systems influence the perceptions of and treatments towards individuals with disability in the Ghanaian society (Anthony, 2011), parents in Ghana seek spiritual help to enable them cope with their children's condition. Here, it was deduced that parents resort to this strategy because with the belief in Ghana that a disease can have both physical and spiritual origins (Okyerefo, & Fiaveh, 2017), seeking spiritual help tells them the cause of their children's condition and offers them hope that their children can be better in future. In that, being surrounded with superstitious beliefs that informed their decisions and perceptions all their lives, it would be prudent to resort to what they believed in to enable them to understand the cause of their children's disability and put them in a better place to help them.

Also, it can be observed that, seeking spiritual assistance gave parents an opportunity to use the same media society uses to accuse them of causing their children's disability to prove to society that they are not the perpetrators of evil upon their children. In that by virtue of culturally constructed belief systems that assume that such people would be unable to go to deities out of fear of being exposed or punished because of the evil they have committed; parents dare to go to these places in search of help.

5.4.2. Family and friend support

The findings of this study revealed that due to limited support systems, parents in Ghana who have children with ASD also relied on their family and friends to help them cope with their children's condition. This confirms existing research that asserts that, parents of children with autism rely on family to compensate for the lack of support (Glazzard & Overall, 2012; Thomas, Badoe, Owusu, 2015; Paynter, et al., 2018; Stewart, et al., 2017). Most parents in Ghana relied on their friends and relations for financial assistance because most of them could not afford the high financial demands for education, speech therapy and spiritual intervention that came with caring for their children with ASD. This was evident when Attaah reported that she used 70% of her salary to pay her child's school fees and seek for spiritual help. Similarly, it was evident when Cynthia reported that she spent all her savings seeking for spiritual help to identify and cure her son's condition.

Apart from these, parents also relied on their family and friends for care giver assistance. This was as a result of the difficulties they encountered when seeking babysitters and care givers for their children with ASD on occasions when they were unavailable. We see this when Abena narrated that the babysitter she employed to take care of her son while she was away, called within forty-five minutes to terminate the contract with the excuse that she had an emergency. Here, her call of an emergency was perceived by the parent as an excuse and a sign of stigma because she refused to care for the child the next time Abena tried to book her to care for him. Therefore, Abena had no alternative than to rely on her aged mother or little sister for assistance on occasions when she is unavailable. These reveal that social perceptions and religious beliefs within the Ghanaian community sometimes determine people's choice of work.

5.4.3. Self-education

The research revealed that in Ghana, parents of children with ASD educate themselves to enable them to manage their children's condition. This emphasizes that, just like parents in other parts of the world, parents in Ghana had to avail themselves to be educated in order to empower themselves and be part of facilitators who intervene and help to manage their children's condition (Hutton, & Caron, 2005; Depape, & Lindsay, 2014; Webster, Cumming, & Rowland, 2016). Thus, most parents in Ghana take it upon themselves to read about autism spectrum disorder or to listen and watch educative programmes about the condition so that they may be well informed, and they would be in a better position to help their children.

In that, in the study, parents are reported to have educated themselves professionally and via the internet as means of coping with their children's disability. Thereby enabling them to take appropriate decisions for the wellbeing of their children with autism. Here, Abena and Cynthia reported to have changed their children's diet due to information they read online and heard from radio and television stations. And Gifty, narrated to have been trained professionally to be her child's facilitator and care giver as her own way of dealing with the child's condition.

5.4.4. Change in lifestyle

The findings confirmed research conducted by researchers like Depape & Lindsay (2014), Glazzard & Overall (2012), and Gona, et al. (2016), which revealed that parents had to make changes in their lifestyle to enable them cope with their children's condition. This was a means employed by parents in Ghana to compensate for the limited resources available to them to manage the condition. Most of the parents in the study, reported to have changed their daily routine and way of life by resigning from their work or changing jobs to enable them care for their children. This they reported was necessitated by the frequent request from their children's school to pick them up from school in the middle of the day due to reasons like hyperactivity. Also, their struggle in accessing basic education for their children contributed to parent's decision to stop working and stay at home to take care of their children because employing babysitters was also a challenge as a result of the stigma and beliefs associated with children with autism in the country.

In addition, parents changed their lifestyle in order to cope with the situation by isolating themselves from some social events like weddings as means of reducing the stigma. Here most parents reported to have sacrificed their social lives in order to reduce the number of discrimination and stigma they face when they went to such events with their children who have ASD. In that when they attend social events, some people who know about their children's condition refuse to associate with them and those who do not know about it but happen to witness a meltdown from the children who autism on

such occasions give them a stare and immediately disassociate with them. This becomes overwhelming for parents therefore they choose to stay at home with their children rather than to go to social events where they may hardly enjoy themselves.

In addition, parents also changed their lifestyle by cutting down on their expenses in order to be able to afford the needed professional assistance and the nutrition necessary for the well-being of their children who had ASD. This was evident when Yaa reported that her family had to sacrifice their yearly Christmas shopping and vacation to the village to save money and be able to pay for their child's educational needs. Also, parents changed the nutrition of their children and their entire family to aid in managing their children with autism's condition. Thus, they changed their regular diets in order to exclude and include diets suggested to be beneficial to their children's health like excluding corn and gluten from their regular food as reported by Abena. These reveal that influenced by society's beliefs and unacceptance of children with ASD in Ghana, parents had to make significant changes to their lifestyle to enable them cope with their children's condition.

5.4.5. Disregard for negative social attitudes

It is evident that parents who have children with autism in Ghana retreat from or disregard negative social attitudes as a way of coping with their children's condition. Here, parents reported that influenced by socio-cultural ideologies and religious beliefs, they and their children are stigmatized and discriminated against to a point where some of them consider suicide. Therefore, their way of eliminating the stigma and its consequences on their lives; like being emotionally stressed and having suicidal thoughts, is to disregard society's negative attitude towards them and their children and concentrate on loving their children and living a happy life. These were evident when Attaah and Cynthia reported that they ignored negative attitudes and behavior from people so they can be emotionally stable and refrain from the thought of killing themselves or their children. They rather choose to accept their children as they are and love them.

These revelations confirm that in their quest to cope and manage their children's condition, parents look on the bright side of life by thinking positively about their children and disregarding negative public behavior towards them (Depape & Lindsay, 2014; Glazzard & Overall, 2012). These highlight the fact that society's action and beliefs have immense influence on parents who have children with ASD, and these attitudes force these parents to take drastic decisions for their wellbeing and that of their children.

CHAPTER SIX

6. Conclusions and recommendations

This final chapter revisits the entire research process and summarizes the findings and discussions of this study. Also, it outlines the contribution this study has made to existing literature and recommends potential areas to be investigated for future studies as well as recommendations for policy makers and stake holders of education in Ghana.

6.1 conclusions

The present study investigated and described parental experiences of raising a child with Autism Spectrum Disorder in Ghana. This was necessitated by the limited qualitative research available on this phenomenon in Ghana and the whole of Africa. Thus, this study was undertaken to attempt to bridge the gap between the number of qualitative research available in Ghana on ASD and the rest of the world. It commenced by giving a background information about autism; a pervasive neurodevelopmental disorder existent in individuals who exhibit characteristics of some sort of impairment in their communication, and social behavior, and exhibit patterns of behavior that are repetitive. It is a condition, whose global prevalence according to the WHO 2013 epidemiological data, is estimated to be one person in 160. Despite this high prevalence rate of autism across the globe, it was observed that little information is known in Africa regarding this condition, specifically in Ghana: where the belief in religion and cultural superstitions regard children with autism as children from the rivers or the forest sent to parents who had committed some sort of sin and were being punished by the gods or God for their inequities, thus the parents were stigmatized and discriminated against.

Here, it was observed that the laws of Ghana mandated all children below the age of eighteen to access basic education irrespective of their physical or intellectual disabilities, yet parents who had children with ASD could not access basic education for their wards. Existing research proved that parents who had children with ASD were highly stressed and stigmatized therefore they devised various strategies to help them cope with the situation. These, also necessitated the conduction of this research so that not only would it investigate, explore and describe what parents experiences are when raising a child with ASD in Ghana, but it would also contribute to the discourse surrounding this subject by providing empirical academic literature that would provide an in depth and more detailed account of the phenomenon. It was observed that the Ghanaian society shunned and discriminated against parents who had children with ASD based on their religious beliefs and socio-cultural perceptions therefore, Avoke's (2002) religious or magical model of disability which sees disability as evil imposed on an individual from the gods or a deity and Oliver's (1996) social model of disability which views disability as all the things that impose restrictions on disabled people, were employed to explain this phenomenon in the Ghanaian context.

The study, guided by the constructivist tradition and the interpretive paradigm of research, used qualitative case study research method to closely investigate, explore and describe the afore mentioned phenomenon. Here, multiple case study was chosen as the type of case study employed for the research. This was because like case study research in general, multiple case study facilitates the exploration of a phenomenon within its context using a variety of data sources thereby ensuring that the issue is not explored through one lens, but rather through a variety of lenses which allows for multiple facets of the phenomenon to be revealed and understood. Thus, the study collected empirical data from five parents and three heads of institutions; who were included to enrich the data and verify parents' assertion of difficulties in seeking basic education for their children with ASD. The data was gathered through interviews, field notes and a research diary. This was supplemented with short policy contexts of the legal framework regarding the education of children as a whole and the education of

children with disabilities in Ghana in order to have knowledge of what the policy and the law said and what was reported by parents. Later, the data gathered were analyzed using thematic analysis.

The findings of the study revealed that religion and the belief in the supernatural played dominant roles in the day to day lives of people in the Ghanaian society. Thus, while caring for their children who have ASD, parents in Ghana experience stress emotionally, financially, and on their marital life. In addition, they experience stigma by the belief in spirituality which regards them as causal agents of their children's condition, and they are stigmatized by virtue of their association with their children with autism. Further, it was evident that despite the existence of laws that required them to freely gain access to basic education for their children, they found it difficult when accessing basic education for their children who have autism. Due to these experiences, parents were reported to have coped with the situation by seeking spiritual support, seeking family and friend support, educating themselves about the condition, changing their lifestyle to accommodate the needs of their children with ASD and disregarding negative social attitudes towards them.

Ultimately, these experiences shared reveal a phenomenon within the Ghanaian society which the religious model of disability and the social mode of disability has helped in understanding and explaining. It is evident that the origin and the rationale behind the superstitious nature of the Ghanaian society and their behavior and perceptions regarding people with ASD emerges from a socio-cultural perspective of constructing meaning which is embedded in their way of life. Albeit, acknowledging that Ghana is a very religious country and religion and socio-cultural belief systems play significant roles in the lives of Africans, and also acknowledging that spirituality is envisioned to be a process through which one continuously negotiates and meditates within and between complex and contentious social, cultural, medical, and religious constructs that inform lived experiences (Mitchell, 2013 p.232), the Ghanaian society cannot be expected to suddenly change their way of life and way of constructing meaning, by the enactment of policies and interventions that are foreign to them, but with education, and continuous sensitization, the people would come to the realization that spirituality may not always have the answers. Thus, it is time for them to gradually incorporate other ways of constructing meaning in certain aspects of their lives. Likewise, parents in Ghana cannot be judged for their actions, inactions and some of the drastic measures they took to manage their children's condition; like seeking spiritual help, because that is what they believed in and it contextually enables them to manage the situation.

6.2. Recommendations

Based on the empirical nature of the study, I believe this research has contributed knowledge to qualitative discourse about parental experiences of raising a child with autism in Ghana. Therefore, based on the findings of this paper I recommend that:

The medical model of disability which sees disability as a result of some physiological impairment due to damage or a disease problem (Llewellyn, & Hogan, 2000), could be considered as an alternate theory by future researchers who would like to investigate this phenomenon in the Ghanaian context. In that, although the models of disability used in this study explained the origin and the rationale behind parents' report of name calling, stigma and difficulty in accessing basic education for their children who have autism, it failed to explain why parents were stigmatized as causal agents of their children's autistic condition by virtue of a medication they took while pregnant and it also failed to explain how some parents in the study like Gifty relied on the medical diagnosis of their children's disability to refute claims that their children were spiritually possessed but had a medical condition called Autism Spectrum Disorder.

Further research should be conducted on this subject to explore the alleged killing or abandoning of children with autism in Ghana in this 21st century; an outmoded tradition which was presumed nonexistent in our modern times, and legally forbidden due to fundamental human rights that give every individual the right to life.

Also, I recommend that parents in Ghana should be supported by the government with social support systems like a stipend for children who are unable to gain access to education in the limited government assisted schools to attend the private institutions. Also, although there has been some of sort of education about ASD on radio and televisions stations in Ghana, people are still ignorant about the condition, therefore I recommend that the government, members of the community knowledgeable about ASD and non-governmental agencies should all join together to create awareness and educate the public frequently about the condition in order to reduce the stigma and help transform people's mindset about ASD

Finally, educational policy makers and implementors of educational policies should acknowledge the existence of some sort of gap between policies enacted and its implementation because the enactment of policy is not always linear and rational; policy work is often a piecemeal process of fixing problems. …. there is a feedback process or a process of complex iterations between policies and across policy ensembles that generate forms of institutional transformation and regeneration (Ball, 2015 p. 309). Therefore, policy makers in education and implementors of educational policies should periodically have a round table discussion and appraisal of existent policies and its implementations to ascertain how best to bridge the gap between the policies enacted and the implementation process.

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Appendices

Appendix 1:   **Letter to parents and heads of institutions**

To whom it may concern
Dear Sir / Madam,

<div align="center">

PERMISSION TO CONDUCT RESEARCH

</div>

My name is Eugenia Allotey, a master student in the Department of Education and Special Education at the University of Gothenburg, Sweden. I am studying International Master's Programme In Educational Research and I recently started work on my master thesis. I would like to research parental experiences of raising a child with Autism Spectrum Disorder (ASD) in Ghana. This involves interviewing parents, and institutional heads.

This is to contribute empirical studies on parents' experiences of raising a child with autism in Ghana and to enable parents' voices to be heard and draw the attention of relevant stakeholders to their experiences and the experiences of educational institutions as a whole. I will therefore be grateful if you could please permit me to interview you and one of your teachers in other to gather data for this research. Kindly be assured that this research will adhere to the codes of ethical conduct of conducting social research.

I look forward to hearing from you soon. Thank you.
Yours sincerely,
……………………
Eugenia Allotey
Telephone: xxxxxxx
Email: xxxxxxxxx
International Master's Programme In Educational Research
Department of Education and Special Education
University of Gothenburg
Sweden.

Appendix 2:   Informed consent

<u>Informed Consent Form</u>

My name is Eugenia Allotey, a master student in the Department of Education and Special Education at the University of Gothenburg, Sweden. To finalize my studies, I am writing my thesis about parental experiences of raising a child with Autism Spectrum Disorder (ASD) in Ghana, and I will like to invite you as a parent, head of institution or teacher to participate in this study. You are being invited to take part in this research because your experience can contribute immensely to existing knowledge about experiences involved in raising a child with ASD in Ghana. Please sign the certificate of consent located at the last page of this document as prove of your voluntary participation in the study. Kindly be assured that this study has the full support of my institution and it will adhere to the codes of ethical conduct of conducting a scientific research. Below provides more information about the research.

Objective of the study
The objective of this study is to find out parents' experiences when raising a child with autism in Ghana. It is to explore the themes of stigma, stress, access to basic education and coping strategies employed by parents to manage the situation. And to draw the attention of relevant stakeholders to their experiences and the experiences of educational institutions as a whole.

Procedure and duration
The research involves interviews which will be recorded if agreed on and last for a duration of about twenty-five (25) to thirty-five (35) minutes. This will be conducted on two separate occasions. The language of communication will be English or any of the Ghanaian languages understood by participants and the researcher.

Benefits
This study is expected to bring help to participants, by letting their voices be heard and by motivating policymakers to enact laws that outline support and intervention centers for these parents and to also, review the policy and supervision of Inclusive Education and Special Education in educational institutions in Ghana.

Risks
Some of the topics to be discussed may be sensitive hence you may feel uncomfortable sharing such information. Please note that it is fine if you do not wish to answer or discuss any topic that makes you uncomfortable.

Confidentiality
The information collected from this research will be kept anonymous and confidential. Only the researcher will have access to your name and the information you provide. This will be kept private and locked with a password and may be destroyed after two years.

Sharing the results
The findings from this research may be published electronically by Gothenburg University Library as a master thesis. It may also be published as an article in a scholarly journal or presented at scientific conferences. Further, electronic copies can be given to participants on request.

Right to withdraw
You may stop participating in the interview while it is ongoing. Also, you will be given an opportunity to review your remarks and do modifications where necessary. You may withdraw from the study before it is presented to the University of Gothenburg.

Certificate of consent
I have read the foregoing information, and I consent voluntarily to be a participant in this study.

Name of Participant   _____

Signature of Participant   _____

Date   _____

I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.
Name of Researcher   Eugenia Allotey_____
Signature of Researcher   _____

Date   _____

Appendix 3:   Interview guide parents

<u>Interview guide for parents</u>
1. Which part of Ghana do you live at?
2. Can you tell me a little about the child in your family who has ASD? Age, sex, etc
3. How are you related to the child? parent or care giver?
4. When did you notice the difference in his/her development?
5. What did you do?
6. Was your first impulse to seek for Medical or spiritual help?
7. Has your child been diagnosed? When where, by whom?
8. What are your experiences of caring for your child with ASD?
9. Has your life changed since you discovered the child has ASD? How?
10. Are you working?
11. What have you gained from caring for your child with ASD?
12. Have you lost anything while caring for him or her? What have you lost?
13. What are your experiences about the social perceptions of your child with ASD?
14. Do you have support from the society?
15. Do you feel your child is accepted in society?
16. What sort of support do you wish for?
17. Is your child currently schooling? If no, why?
18. If yes, is the school a mainstream or special needs school? boarding or day?
19. Tell me about your experiences when seeking education for your child? (before and after diagnosis / symptoms)
20. Is the school close to your home or far from your home?
21. Has there been significant changes in your child since he/she started schooling? If yes what are they?
22. Has there been significant changes in your personal life and family life since your child started schooling? If yes what are they?
23. How do you cope with your child's situation?
24. What are your future hopes for your child?

Appendix 4: **Interview guide special needs school**

<u>Interview guide for head of institution, Special Needs school</u>

1. How long has the school been in existence?
2. Is the school private or public?
3. How long have you been the headmaster/mistress or principal of this institution?
4. Tell me a bit about yourself.
5. How long have you been in the education sector?
6. What level is the first class in this school?
7. What level is the last class in the school?
8. How many children can your institution admit? And how many do you have in admission?
9. What is the educational policy concerning education for children in general and children with special needs?
10. What is the process and criteria for admission in the school?
11. Does everyone who seek for admission for their ward gain admission? If no, why?
12. Do you admit all groups of children with special needs? If no, which group of special needs children do you admit?
13. Do you have children with autism in your institution? How many?
14. What do you understand by ASD?
15. How do you support children with autism?
16. Are the teachers provided with training that enables them to care for these children?
17. Do the children with autism complete their education or they exit midway? If they exit midway, please tell me why?
18. Do you feel you could have done more to keep the child in school if you had help?
19. What help do you need as an institution to help carter for children with ASD?
20. Are those who complete able to be integrated into the society

Appendix 5:   Interview guide regular school

<u>Interview guide for the head of institution (regular school)</u>

1. How long has the school been in existence?
2. Is it a private school or it is a public school?
3. Is it a special needs school?
4. How long have you been the headmaster/mistress or principal of this institution?
5. How long have you been in the education sector?
6. What is the process for admission in the school?
7. How many students do you have in your school?
8. How many students can your school admit?
9. What class is the entry level in your school?
10. What level is the last class in the school?
11. Do you admit children with special needs?
12. How do you support children with special needs?
13. What does the educational policy say about inclusive education?
14. Are the teachers provided with training that enables them to care for children with special needs?
15. Have you ever admitted a child with autism? how many?
16. What do you understand by ASD?
17. Did the child exit at the last level or s/he exited midway?
18. Can you please tell me why?
19. Do you feel you could have done more to keep the child in school if you had help?
20. What help do you need as an institution to help carter for children with ASD?

Appendix 6:   Except from field notes

Interview with head of institution C

- **How many children can your institution admit? And how many do you have in admission?**
  My institution currently has in admission 165 students, but we can admit up to 300 students, we have the infrastructural facility, but these kids cannot do certain things on their own, so we need people to assist, and that is where we have a challenge. The problem is we do not have enough personnel to help care for these children and give them the needed help. Once we don't have those personnel it is extremely difficult to admit more children. The government is responsible for providing the personnel but at the moment we are understaffed.

- **What is the educational policy concerning education for children in general and children with special needs?**
  In Ghana, we have the FCUBE policy which states that every child of school going age shall have a constitutional right to education. This is for every child in Ghana, so it does not matter if the child has a disability or not and there are other laws like the Education Act …… which talks about inclusive education. But honestly this is a challenge for the public schools because they also have same challenges as we have such as inadequate personnel and things like that. ………….

- **What is the process and criteria for admission in the school?**
  The procedure for admission is for parents to be referred to the school and then we would also refer parents to send their children to the National Assessment and Resource Center so that an assessment can be done to find out the level of the child's spectrum. Parents would then have to wait for the report from the center and then they can give it to us, and we can admit the child based on that report.

Appendix 7:   Except from research diary

6 - 2 - 19

Reflection on Interview with Gifty

I am surpised she mentioned that people still send their children to the villages and abandon them in this modern world. Well she says its rumour that she heard, I hope this is just a rumour. But I can't stop thinking of it because I believe there is an iota of truth in every rumour. (•̀ ⌣ •́)

8 - 2 - 19

Reflection on Interview with Cynthia

It is hard trying to surppress my feelings and thoughts about parents sending their kids to spirtualists and p. healing. They say it is expensive yet they keep going. As an educational researcher I know that is not the right option but it would be unethical to point it out to parents.

16-2-2019

Reflection on interview with Atteah

This is the second time a parent has mentioned that she contemplated suicide. The issue of emotional stress is great. Cynthia also said she nearly bought poison to drink sometime ago. At least I am glad they were able to suppress such feelings and have come to the realization that their lives are more precious.