

**PHYSICAL AND PSYCHOLOGICAL IMPACT OF CHILDREN WITH
AUTISM DISORDER ON SCHOOL AND FAMILY HOUSEHOLD IN
KENYA**

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**A Research Project Report Submitted in Partial Fulfillment of the Requirement for The
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DECLARATION

This research project is my original work and has not been presented for a degree in any other university.

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DEDICATION

To The Almighty God who gave me the physical and mental strength to accomplish the work as required. To my loving children, especially my elder son who is autistic and my husband Mr. Ramkumar who gave me time, support and opportunity to continue my studies. I appreciate each and every member of my family for their patience, understanding and motivation which inspired me to achieve my goals. May God bless all of them and sustain them with strength and healthy life.

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Glory and Honor be to God because of His doing.

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ABBREVIATIONS AND ACRONYMS

ASD Autism Spectrum Disorder

PDDNOS Pervasive Developmental Disorder Not Otherwise Specified

SPSS Statistical Package for the Social Science

ABSTRACT

The general purpose of this study was to investigate on the physical and psychological impact of children with autism disorder on family household and the strategies that could be used to improve or identify the coping strategy for the family and involve more effectively in the child's development and education. the study had five objectives, namely, to establish how the child diagnoses ASD causes relationship conflicts within the parents, to examine does ASD affects the well-being of the mother greater than other member of the family, to evaluate how ASD impact on the psychological well-being of the siblings living, to examine how the sigma affects the parenting responsibilities in the upbringing a child in Kenya diagnosed with as and to establish how the learning of the autistic child affected by the parenting stress. In order to achieve the objectives of this research, samples were collected randomly from family members affected by as and questionnaire filled to obtain data. The findings indicated that mothers' social life especially their daily routines are affected due to autistic children. It is accepted therefore that that autism has caused stress in their marital relationship as well as affecting relationship with other children. The findings also conclude that siblings get depressed due to autistic nature of their sibling. Moreover, when parents are highly stressed, they may fear allowing their child to go to school. This affects learning and development of behaviour with their peers. Finally, parents with autistic children have never knew what autism is as well as the cause for their child's condition. This has been left to be explained in terms of taboo, stigma and speculations. The study recommends that mothers with autistic children should undertake formal training in order to learn nature of therapies necessary for their children. Moreover, autistic children should not be isolated but rather be integrated with other siblings in order to learn appropriate communication and life skills. Furthermore, the government through education should organize training programs geared towards eradicating

stigma and taboo related to children with autism. Finally, the education providers should provide the autistic children with a conducive learning environment

CHAPTER ONE

INTRODUCTION

1.1 Background of the Study

Autism Spectrum Disorder refers to a cluster of compound neurological disorder and the signs are present since early infantile. ‘The word “spectrum” states to the inclusive array of signs, skills, and stages of disability in operational that can happen in people with Autism Spectrum Disorder’(Development, National Institute of Child Health and Human, 2016).”ASD is a disorder with varied level of symptoms diagnosed in the early childhood, some being additional severe than others. Mostly the symptoms are difficulties in communication, social skills, behavioral and emotional impairments, as well as sensory dysfunction and it varies from one individual to other” (Weiss & Lunskey, 2011). These symptoms really affect the relationships with the peers and they are not able to form meaningful interactions. They are both verbal and non-verbal, lot of modification is needed in their both learning and daily routine. “psychologist may characterize children with autism who exhibits stereotypic behavior or motor movements for the sake self-stimulation such as shaking, hitting head or on substances, self-injurious, tip toeing, jumping and rotating” (Mays, Beal-Alvarez, & Jolivette, 2011). Individual identified with autism are mostly viewed by their age mates as communally disobliging or aloof. Several years there has been an opinion, the birth of a physical or intellectual/ neurological disorder represents stressful involvement with lot of burdens and considerable challenges to the family and it might also distress their somatic and mental well-being (Sola Carmona, Lopez Liria, Gongara, Aguilar parra&Salido Campos, 2016).Mainly in low confidence in one’s own abilities/worth, high levels of nervousness,

unacceptable behaviors and psychosocial difficulties due to the reduction of societal and domestic relationships (Sola Carmona et al.,2016). In addition economic status of the family is also affected negatively. The financial and moral burden in caregivers of disabled children increases and the care of disabled children become a burden which cannot be overcome by the families (Tursuslu, Merve, &Demet, 2015). These stresses in families affect the children progress in the development and education.

ASD is a lifelong neurological disorder where family is the main key funding system for those children. “Having a child with Autism Spectrum Disorder is often conceptualized as a risk factor in terms of family well being as there is an additional stress placed on the family relationship as well as family roles and responsibilities”(Gardiner &Iarocci, 2015). “The devastated process related to the delivery of a child with disorders is problematic for the families’ feeling bad or weeping the death of the happy moment (delivery of the new born) on the other hand struggling to agree to take the ‘incomplete’ baby. Though the families have the chance to hold and love their baby, the life completely changes unexpectedly and harshly”. (Hooyman &Kramer, 2006, p. 200). Anxiety and depression squeezes the family system.

The word "stress proliferation" has been castoff to express psychological influence of children with ASD on caregivers and school, particularly the stress handled by the parents. Benson (2006), an expert in the arena of ASD articulates: "Stress proliferation [is a process that] occurs when an original stressor or set of stressors in one area of life stimulates added stressors in other life areas"(p. 686). He also states, He conjointly states, "The initial stressors in one space of life have the management and adversely distress the activities, roles, and relationships in different domains to that they’re straightly and indirectly connected, new sources of stress may be created" (Benson, p. 686).

This analysis is preponderantly on the result of physical and psychological impact of youngsters with autism disorder on faculty and family home in African country. Addressing and treating the family stress will support them within their family quality of life or well-being and in participating themselves in the intervention program of the kid, provide full participation within the development/ education of the kid. Families of youngsters with autism Spectrum Disorder in African country conjointly expertise common challenges together with stigma, lack of acceptable treatment, finance and caring burdens (Newton. G, Rimba, Mapenzi, Kihara, Vijver & Abubakar, 2016).

1.2 Statement of the Research Problem

An autism diagnosis changes the life of both the family and the diagnosed immensely (Paltrow, 2015). Families with a baby identified Autism Spectrum Disorder need to apply range of skilled services like occupational therapy and diet therapy and some adjustments in daily life routine for behavior management of the child which has possible welfares for folks; but, these facilities additionally place stresses on folks to access as a results of navigation and participation (Hodgetts, McConnell, Zwaigenbaum, & Nicholas, 2016). This provides physical and psychological stress in parents and stretches into relationship imbalance within the families. Upbringing a child with Autism spectrum disorder puts larger tension on parenting skills. “Parenting tension ascends once the parent’s observe the burdens on their role as parents exceed their means and to cope with them” (Miranda, Tarraga, Fernandez, Colomer& Pastor, 2015). Mainly parent’s acceptance on their child’s autism diagnosis comes at different time, different ways and the finance causes conflict in the couple system and affects their marital relationship (Paltrow, 2015). “Siblings are affected to bound level like small parental attention, further responsibility, nettlesome behaviors and communication difficulties” (Ward, Tanner, Mandlaco,

Dyches, & Freeborn, 2016). Parents of children with autism in Kenya try and use all their earnings in providing the professional services to their child with autism. The disorder persists lifelong and on the other hand parents originate themselves with no money due to the struggle they go through in providing services to the child. (Gona,et al.,2016). Parent's area unit unable to go away their homes thanks to caring responsibilities towards their kid with autism. These caring responsibilities semiconductor diode to lack of adequate time for paid work, home domestic chores and alternative activities (Gona,et al.,2016).

1.3 Purpose of the Study

The purpose of the research was to assess physical and psychological impact of an individual with autism disorder on school and the family household.

1.4 Objective of the Study

1. The analysis was divided by the following goals
2. To launch how the child diagnoses ASD causes relationship conflicts within the parents.
3. To examine does ASD affects the well-being of the mother greater than other member of the family.
4. To evaluate how ASD impact on the psychological well-being of the siblings living.
5. To examine how the sigma affects the parenting responsibilities in the upbringing a child in Kenya diagnosed with ASD

6. To recommend and establish how the learning of the autistic child affected by the parenting stress.

1.5 Research Questions

The study was guided by the following questions:

- i) Does parenting stress causes relationship conflict between father and mother of the child diagnosed Autism Spectrum Disorder?
- ii) Does parenting stress causes relationship conflict between father and mother of the child diagnosed Autism Spectrum Disorder?
- iii) Does psychological well-being of the siblings living with Autism Spectrum Disorder manifest only negative outcomes?
- iv) Does stigma associated affect the parenting responsibilities in upbringing a child in Kenya diagnosed with Autism Spectrum Disorder?
- v) Does the development/education of the autistic child is affected due to parent's personal stress?

1.6 Significance of the Study

This analysis is to comprehend what extend the influence of diagnosis ASD can have on parents and siblings, how these parents can be assisted to decline the volume of stress. This study will concentration the influence of ASD has on parents and other family members like siblings and grandparents precisely, emotions they go through and causes that origin stress in a family directly influenced by ASD. The stigma in our country toward such disability also has a strong influence

in the parental stress. The current research available will be examined as well as interviews of families who have an individual with ASD. By the end of this analysis it will give clear understanding about the support these parents need or wanted. It will also assist to understand is it the understandings with the family member are the societal taboo. When we realize the stress and assist them through professional services it can guide them to work effectively in the child's learning.

Lastly, the research will assist upcoming researchers to make references on this effort with the goal of structuring more information in the arena of parental stress and autistic child development or education.

1.7 Basic Assumptions of the Study

This research will assume that:

1. The entire family member under investigation have ASD child in the family.
2. All respondents were cooperative and provided reliable responses.

1.8 Limitations of the Study

There were a number of challenges which were faced in this study. They included:

The immediate family members and their conflicts are only included in this study. Although there is a lot of possibility for the extended family members also affect due to ASD. A child to have an independent and accepted life in this society all the members of the society must be involved in the study. As the immediate family member is the initial and close social member of the society and affected more we are including only them in this study.

Limitation can be the acceptance, if the family members are under denial it will not be easy for them to express cooperatively and to distinguish the stress due to ASD and other problems.

Sibling confusion with the personal bias instead of personal experience and the researcher personal experience.

Limitation of time limited the questions to 10 and rural county participant was limited because of only four participants.

1.9 Delimitation of the Study

The delimitations are the constraints set by the academic professional to smear the possibility of the research (Cohen, Manion & Morrison, 2007). This research is delimited to physical and psychological impact of children with autism disorder on family household.

1.10 Definition of the Concept

In 2015, we understand autism based on the characterization delivered by the American Psychiatric Association. In the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders, “Autism Spectrum Disorder encompasses Autistic Disorder, Asperger Syndrome, Pervasive Developmental Disorder Not Otherwise Specified, and Childhood Disintegrative Disorder” (American Psychiatric Association, 2013). “Symptoms embody deficits in social interactions, communication, sensory dysfunction and restrictive and repetitive patterns of behavior and interests” (American Psychiatric Association, 2013). Social problems embody the deficits in interaction, unimaginative or repetitive behavior, deciphering facial features, developing meaningful relationship and non-verbal communication. Social issues include the deficits in interaction, stereotypic or repetitive behavior, interpreting facial expression, developing meaningful relationship and non-verbal communication. (American Psychiatric Association, 2013).

The following terminologies have been well-defined to heighten the information of the readers and to deliver them with a healthier understanding of this study.

Asperger's Syndrome: “A part of autism spectrum disorder with in which children are challenged with organization, verbal quality, hopelessness, violent behavior in change of routine, and have a tendency for restricted and repeated behavior, but unlike other forms of ASD, these children acquire social and communication skills by the level of adolescent ” (Willis, 2006).

Autism: A district of autism spectrum disorder within which someone exhibits distich impairment like social, communication, behavior and sensory dysfunction principally this disorder is confirmed at the first age (Willis, 2006).

Autism spectrum disorder (ASD): “A broad term that is employed to explain autism disorder and four alternative disabilities that have effects on individual capability to mingle, converse, and react to one's environment” (Willis, 2006).

Childhood Disintegrative Disorder: A progressive deterioration part of autism spectrum disorder in which the child’s development is normal and later loses the acquired ability or the mastered skills are forgotten”. (Willis, 2006).

Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS): A part of autism spectrum disorder sometimes it is also misunderstood with typical autism, but the criteria exhibited by the individuals are not absolutely like the autistic child who is identified at the age of early age”. (Willis, 2006).

Rett’s Disorder or Rett's Syndrome: This is more common is girl and it is a degenerative form of ASD. (Willis, 2006).

Stress: Affected by an emotion which causes tension physically and mentally ensuing from aspects that incline to alter an existing stability (Merriam-Webster, n.d.).

Stress proliferation: “A method once someone is associate effect on by an external agent and it adds the strain of the individual, which might be either by an inventive agent or a set of stressor”. (Benson, 2006).

1.11 Organization of the Study

This analysis is accessible in five dissimilar chapters. Chapter one highlights the background of the study, statement of the matter, analysis objectives and queries, significance of the study, scope and limitations of the study, assumptions of the study, theoretical and abstract framework of the study and operational definition of terms. Chapter two presents relevant literature on physical and psychological impact of youngsters with autism disorder on family social unit. Chapter three presents information on analysis vogue, location of the study, target population, sampling techniques and sample size, analysis instruments, information assortment procedure and information analytical techniques. Chapter four explores analysis findings, interpretation and discussions whereas chapter five provides the outline, conclusions, recommendations and suggestions for more analysis.

2.1 Introduction

Autism, also known as Autistic Spectrum Disorder (ASD), is demarcated as a behavioral disorder that disturbs the function of the skills like motor, neuropsychological development, social/emotional interaction, intellect, and communication in children (Pinto, Muniz, Torquato, Barros, Collet, Neusa, Reichert, Silva, Neto, Lino de & Mendonca, , 2016). Its etiology remains unknown; but, it's presently thought of a syndrome of multi-causal origin that involves genetic, neurologic, and social factors of kids, nowadays there square measure and calculable seventy cases of ASD for every 10,000 inhabitants worldwide, and its fourfold additional common in boys (Pinto, et al. 2016). "This condition activates fluctuations in the family life since the progress of the child needed to be closely monitored and it causes influence because the family must do alteration in their daily schedule and accommodate roles, which affects work, income, and inter-family relations" (Pinto, et al. 2016).

2.2 Mothers Wellbeing

Though there square measure goodly analysis targeted on the upbringing of a baby with identification of autism spectrum disorder influences on the parent psychological Eudaimonia is extremely very little. These researches have methodically appraised the connections with agreeableness systems and mothers psychological Eudaimonia. Following identification skilled services square measure required to be started by the fogeys (Hodgetts, et al, 2016). They need to give three to four therapies at a time every day. "The child's exceptional condition necessitates that parents specially mothers accept the loss of the perfect child and look for managing approaches to deal with the upcoming reality" (Paulyane, Gomes, Leonardo, Lima, Mayza, Bueno, Liubiana, Araujo, Nathan, & Souza, 2015). "Autism Spectrum Disorder exercises sturdy management on family dynamics, succeeding in caregiver overload, particularly in mothers

(Paulyane, et al, 2015). Autism spectrum disorder exercises strong management on family dynamics, ensuing in caregiver overload, especially in mothers (Paulyane, et al, 2015). Difficult behavior conjointly develops the psychosocial stress of care giving primarily on mothers United Nations agency bear inconsistent burden of care giving (Bello-Mojeed, 2016). The role of mothers as medical aid givers places them in an exceptional position within the delivery of intervention for youngsters with ASD (Bello-Mojeed, Ani, Lagunju, & Omigbodun, 2016). "Mothers participation in the remedies of their children with ASD has a probable advantage in developed child result, dropping related maternal/family stress, refining care giving skill including identification of possible functions of the aggression" (Bello-Mojeed, et al, 2016). The level of challenge might vary depending on the severity but the autism related issues and dealing with them are similar from severe to high functioning autism and the mothers are challenged by the load of their multiple roles in dealing with the accepting their child for who they are and at the same time wishing the children typical growth and development (Safe, Joosten & Molineux, 2012). Mother's role is very critical in the life of the child with Autism. She plays major role especially in the early stages she has to adapt lot of changes in life which could lead into stress her in many ways.

2.3 Marital Conflicts

"A child with ASD can stress marital relationship and reduce marital fulfillment "(Rivers & Stoneman, 2003). Parents of children with ASD demonstrate anxiety and marital disappointment than others with different disabilities. (Bedesem, Boyd & Mancil, 2009, p. 523). After the diagnosis is complete and if the child is diagnosed with Autism, parents will often come with the play "blame game" in which parents repeatedly engage themselves in blaming each other for the cause of the child's ASD. As specified by Willis (2006, p. 200), mostly this is the time the

marriages breaks develops anger against the couples and affect the interpersonal relationship. "Having autistic child always predicts poor father involvement and emphasizes the provoking effect of autism to the marital relationship."

Becoming a parent itself is a big turning point for a couple and making adjustment in the development of the child and the relationship between the couple is a new task and lot of involvement is needed. This adjustment worsens when the child has disability and the transition of relationship becomes challenged (Rudy, 2015). Strains and everyday life stresses challenge relationships suffer from lack of attention, lack of time and energy for personal, marital and family activities (Rudy, 2015). They are also socially isolated and this isolation affects any entertainment for them. Sometimes it becomes impossible for the couples to understand each other and it becomes devastating pain (Rudy, 2015). There is no latest study in the rate of divorce but Naseef and Freedman (2012) said there is 80 percent of divorce rate among parents of children with autism. Most of the Autistic children will have sleeping disorder and the burden of staying whole night awake goes to the mother and the dad earning. They don't know how many days these will continue the frustration of excess sleepless night and the finance expenditure mostly brings conflicts within the parents (Sicile-Kira, 2008). The parenting stress mainly leads into the cause of the marital conflict between the parents of the child with Autism Spectrum Disorder (Lai, Goh, &oei, 2015).

2.4 Parental Stress

The primary stressor for the parents is the inability of expressing the basic needs. Children with ASD expressive and receptive language are disabled and it frustrates both the parents. They will not be able to clarify the needs of the child and the child will also feel frustrated as parent are not understanding even their basic needs like hunger, tired, thirst sad and happy. Such circumstances

lead to extreme aggressive behavior. “Parents expertise worry and concern that their child is also doubtless injured as a result of usually, they cannot communicate verbally and are highly vulnerable” (Autism Society, 2011).

Secondly taking the kids publically or society, community support or creating the individuals within the society to grasp the kids may be a task. Parent become hesitant in socialization that not solely have an effect on the kids social skills it conjointly have an effect on the fogeys socialization. (Autism Society, 2011).

Thirdly folks concern for the child’s future welfare “Future care giving presents stress in folks as a result of in sure circumstances, there are not any different members of the family capable of usurping once the fogeys don't seem to be to any extent further within the state of caring for his or her child” (Autism Society, 2011)

Fourthly the monetary aspects, ASD kids are costly the services required for the kids are costly. “On the opposite hand if one parent must surrender his/her job to assist with caretaking, this will be financially nerve-wracking because it leaves one parent to support the whole family” (Autism Society, 2011).

2.5 Wellbeing of Siblings with ASD brothers or sisters

The sibling relationship, next to parent it is one of the long lasting relationships in human life (Deater-Deckard, 2002). Social skills are initiated by the sibling and the sibling relationship is unique and significant within the family system it supports the social skills perfectly and promptly (Knott et al., 1995). The interactions among siblings provide a matchless opportunity for children to learn about themselves and others. Additionally, these relationships provide one of the first chances for children to learn about appropriate play, communication, and interaction (Barnes

&Austin, 1995; Brody, 1998; Knott et al., 1995). Through repeated interaction, siblings serve as teachers for their brothers and sisters. These encounters with one another provide the opportunity for children to practice on their communication and social skills (Brody, 1998). For instance, the conflict that siblings experience can serve as practice for the conflicts that may be experienced later in life. Abramovitch, Pepler, and Corter (1982) showed that children develop a style of social exchange with their siblings which they subsequently use with their peers. Sibling relationships can be seen as a safe haven in which to have successes and failures when learning to develop social skills. The social skills achieved through sibling interaction are used throughout life in other social relationships (Brody, 1998) and when children do not have siblings in the home, they miss the opportunity to practice these skills.

The impact on siblings with autism spectrum disorder is moreover equally positive and negative, in positive characteristics includes maturity, accountability, self- concept, less arguing and rivalry, respect for the person with ASD and acceptable sibling relationship (ward, et al, 2016). However they also have negative attributes which includes fear of frightening or violent behavior, decreased sibling intimacy and social emotional difficulties (ward, et al, 2016). When it comes to adjustments, each and every single person of the family need to adjust which could affect their independent life. How the adjustment is taken and the side effects of it are depended on the individuals also. The result of this particular qualitative descriptive study encourages education and coping skills for the siblings (Ward, et al, 2016). There are some studies which has proved male siblings have more severe impact than female siblings, older sibling more than young sibling (Walton & Ingersoll, 2015). So the impact on the sibling is also needed to be studied and look into the coping skills which could assist the lives of these kids also continue in a peaceful manner. When each and every individual on the family is given proper education and coping strategy the

child with Autism will not be consider as burden and their process towards development will also get better. If these issues are not consideration the siblings might end up with hatred toward the child with Autism Spectrum disorder, not only addressing the level of stress educating and deriving coping skills is also important.

2.6 Taboo in Autism

Understanding of Autism in Kenya or in general Africa is not accurate; there is lot of lack of awareness and limited access to needful services which can improve the life and prognosis in children with autism. Single parenting or divorce, needs for childcare and financial issues also gives negative effect (Gona, et al, 2016). Stigma in Kenya encounters lot of distress for these parents who isolate them from socialization and the fear facing the society make this parent to end up with severe anxiety and depression. Stigma includes Labeling, stereotyping, separation, status loss and discrimination (Gona, et al, 2016). The study was done only in two counties like Mombasa and kilifi. Further studies is needed to cover major cities like Nairobi or even comparative studies between rural and urban study can help us to know more about the condition of autism in Kenya, including the taboo towards the Autism Spectrum Disorder. The sampling was also purposive convenience sampling if the sampling done in special schools there could be possibility for randomization among the sample and there could be variation in the result. Although in coastal areas they got two different cultural samples Kenya as such has lot of different cultural population and it will be better if the study was between rural and urban ethnicity may be the result will be different. This particular study by (Gona, et al, 2016) says about everything like taboo, parental stress, sibling stress but the samples are limited in two counties. Further study will help us to understand more and help is deriving coping strategy.

2.7 Conceptual Framework

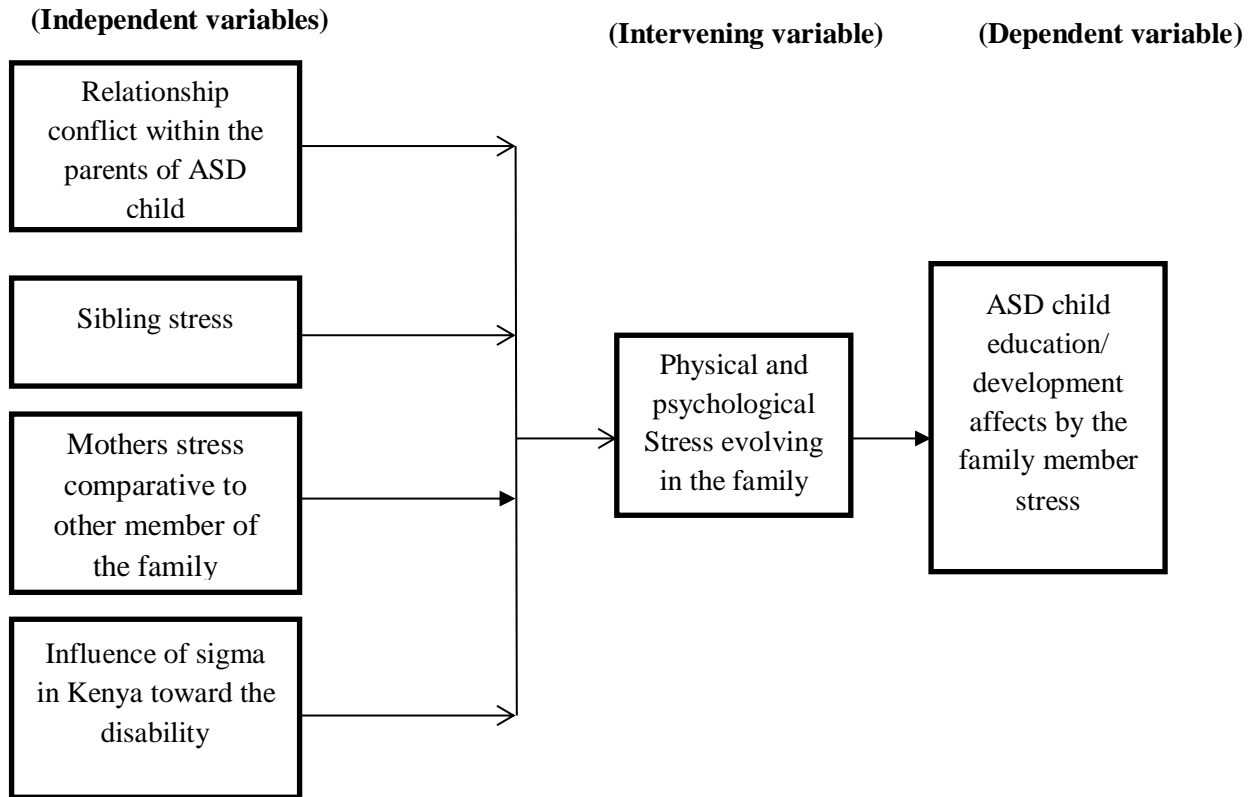


Figure 2. 1Conceptual Framework

Figure 2.1 show independent variables of the study which were Relationship conflict within the parents of ASD child, sibling stress, mothers stress comparative to others in the family and influence of sigma towards the disability. The dependent variable of the study is the outcome caused by the independent variables this was autistic children education and development affected by physical and psychological impact of children autism disorder on family household.

2.8 Summary of Literature Review

This chapter is all about the major impact of autism on families, well-being of the mother, sibling, conflict between the parent and the effects of taboo in child with autism in Kenya. Predominantly the study is on the mother's wellbeing because in most of the cases mothers play the role of primary

caregiver and the level of the stress they undergo is excess compared to others. Siblings' adjustment in their daily living and the outcome of the adjustments. How it disturbs the relationship between the parents and finally does taboo in Kenya has any influence on the development of the children with Autism spectrum Disorder.

3.1 Introduction

Methodology could be a method or strategy used at intervals a discipline to regulate information, acquired information and through this chapter we are ready to see the ways investigator utilize during this study. This chapter presents the methodology that guided the study. Specifically, the chapter outlines thematic division just like the analysis vogue, study location, target population, sample size and sampling procedure, analysis instrument, validity liableness of the instruments, information assortment techniques, information analysis techniques and ethical issues.

3.2 Research Design

Research design states to the techniques used by the examiner to identify a sample, administer the tools and evaluate the data (Ogula, 2005).The study involved the use of descriptive survey design, which was useful in collection of statistical data for in-depth study of physical and psychological impact of the children with autism disorder on the family household. The study employed a mixed method comprising quantitative and qualitative approaches suitable for questionnaires as research instruments to collect in-depth data on impact of the autism disorder on the family house hold (Creswell, 2003; Kenya Institute of Management Training Series, 2011).

3.3 Target Population

“A target population is that the larger cluster engaged by the investigator want to use findings” (Fraenkel and Wallen, 2006, Gravetter and Frzano 2009).“Outline population as entire set of people of interest to an investigator. The population of this study is that the members of the families have a baby diagnosed with autism Spectrum disorder. The targeted population is that the parents and also the siblings of the kid with autism. The accessible population is parents and siblings of special schools in Nairobi and participant parents of the awareness program in rural area conducted by Special Education Professional (Nairobi) organization.

3.4 Sample Size and Sampling Procedures

Researcher recruited each eight participants through convenience sampling from four special schools in Nairobi and 6 participants from Kiambu County to understand the taboo or cultural impact. Samples that are voluntarily available and convenient for the researcher are defined as convenience sampling (Monette et al., 2008). Researcher recruited parents and siblings who has autistic child from special schools at Nairobi, parklands, each special school to determine their perspective on the child diagnosed Autism and its impact on the family and 6 participants from the Kiambu County who has autistic child to determine the taboo. Totally 38 participants participated in the research.

Gay (1998) reasoned that approximate 10% to 20% sample of the entire population could be adequate representative. Thus out of the 10 special schools four were selected to participate in the study. Also 36 family members of ASD children were selected to participate in this study. Table 3.1 presents the summary of the respondents.

Table 3. 1 Sampling size

Sample type	Parents	Mother	Sibling	Total
School 1	3	3	2	8
School 2	3	3	2	8
School 3	2	3	3	8
School 4	3	2	3	8
Kiambu County	2	2	2	6
Total	13	13	12	38

3.5 Research Instruments

The Questionnaire and interview schedule was used to accumulate data on physical and psychological impact of children with autism disorder on family household. Questionnaires were acceptable for this analysis as a result of its economical in aggregation information from several respondents, consumes time and its additionally scale back an excessive amount of movement for the research worker from one respondent to opposite (Borg, 1998). The respondents were additional ready to fill in info in namelessness to avoid associate in nursing evitable worry of victimization.

3.5.1 Instrument Validity

Validity of a probe instrument is that the extent to that a probe instrument measures what it absolutely was designed to live, whose validity was examined by the consultants within the space of study (Kothari, 2004; Mugenda and Mugenda, 2003; Orodho, 2009). The analysis instrument was piloted by administering questionnaires to a convenient sample of ASD relations from one among the special school with ASD students at Nairobi. The results was wont to create valuable judgement particularly on the content validity to confirm that it might be in concordance with the objectives it absolutely was designed to live (Kothari, 2004).

3.5.2 Instrument Reliability

According to Cohen, Manion and Morrison (2007), reliability is an extent to which an experiment, test or any measurement procedure yields the same results on repeated trials. A pilot study was conducted whereby the researcher tested both the questionnaires and interview guide prior to embarking on data collection. Test-retest method was used to test the reliability and validity of the

instruments. Test-retest technique involved administering the same instrument twice to the same group within two weeks.

3.6 Data collection procedure

The researcher obtained authority to conduct the research through an introduction letter from the University of Nairobi. The researcher then sought permission from head teachers of the sampled schools to administer the instruments.

3.7 Data analysis Technique

Data analysis involves process raw facts, figures and numerals into meaty data by sorting, coding, cleaning and processing and deciphering knowledge (Cohen, Manion & Marrison, 2007).

The data was analyzed victimization descriptive statistics. A quantitative knowledge collected from closed-ended form things was scored and conferred victimization descriptive statistics in a variety of percentages, tables and charts (Creswell, 2003). The quantitative data was categorized and organized based on objectives of the study for analysis using Statistical Package for Social Sciences (SPSS), version 20.

3.8 Ethical Considerations

Ethics could be branch of philosophy that guides one's behavior and therefore the ethical values that required to be applied (Mugenda and Mugenda 1999). A research tool note of the following:

1. That the researcher didn't consult with another person's work as his/her own while not acknowledging the author or offer false analysis methodology and results.
2. The researcher was an honest person, didn't manage the analysis for self- benefit or the analysis to make a negative influence on alternative people's lives.

3. The data's collected by the analyzer is real didn't use them to abuse or stigmatize people/person.

The researcher sought permission from the government authorities and also the head academics of select schools before involving the relations of the kids diagnosed with ASD. The researcher explained to the pinnacle teacher and also the relations that the participation was voluntary. They were issued consent to sign. They were assured of confidentiality and no components of individual identification would be tried. The researcher did not raise embarrassing queries or create statements that will interfere with the conceit of the respondents even as Gay (1996) advices. A letter of introduction was bestowed to the pinnacle academics of the known special schools to function an indicator of the supposed analysis and also the explanation of the study.

4.1. Introduction

The determination of the study was to assess physical and psychological impact of individual with autism disorder on the family household. This section therefore presents data analysis related to; how ASD affects the well-being of the mother greater than other member of the family, how ASD impact on the psychological well-being of the siblings living, how the learning of the autistic child affected by the parenting stress and finally Taboo towards Autism.

4.2. Response Rate

The original sample size for the study was 38 clearly show the initial sample size. Table 4.1 illustrates the response rate.

Table 4. 1: Response Rate

Questionnaire issued	Questionnaire returned	Return Rate
38	38	100%

According to Table 4.1 all the questionnaires were filled and returned. The response rate was 100%. This implies that the findings were adequately representative.

4.3 Demographic Data

The respondents' demographic information was analyzed with respect to their stratification. The finding is presented in Table 4.2.

4.3.1 Respondents Category

An analysis was computed to show respondents category. The finding is presented in Table 4.2.

Table 4. 2: Respondent Category

Respondent category	Frequency	Percent
Mothers	11	29%
Siblings	12	31.5%
Parents	15	39.5%
Total	38	100%

From the finding, it was noted that mothers who had autistic children were 29% as their siblings were 31.5% of the total sample. Finally, parents with autistic children constituted 39.5% of the total sampled population.

4.4. Descriptive Analysis

Descriptive analysis was computed using percentages. The finding is shown in subsequent tables.

4.4.1 How Autism Spectrum Disorder affects the well-being of the mother

Descriptive analysis was computed to determine how Autism Spectrum Disorder affects the well-being of the mother. The finding is presented in Table 4.3.

Table 4. 3: Effect of Autism Spectrum Disorder on the well-being of the Mother

Statement	The feel or the known informatio n is less (%)	The feel or the known informatio n is moderate (%)	The feel or the known informatio n is strong (%)
Did your social life affect because of your child with autism?	36.4	18.2	45.5
Did you react negatively when you were informed about your child’s condition?	45.5	18.2	36.4
Were you aware of autism before your child’s diagnosis?	63.6	9.1	27.3
Did the diagnosis change your expectation on your child?	45.5	18.2	36.4
What kind of sources you child is receiving in the need of development?	36.4	36.4	27.3
Did autism affect your daily routine?	45.5	18.2	36.4
Did it affect your relationship with other children?	63.6	18.2	18.2
Did it cause stress in your marital relationship?	63.6	18.2	18.2
Did you use support system for you both to be strong?	45.5	36.4	18.2
Have you learnt something from raising a child with autism?	36.4	18.2	45.5

The study showed that majority of respondents (45.5%) affirmed that their social life had been affected because of their child with autism. This view was supported by 36.4% who reported that they reacted negatively when they were informed about their child’s condition. The findings also revealed that 63.6% were unaware of autism before their child’s diagnosis as well as that 45.5% reported that the diagnosis did not change their expectation on their child.

Specifically, the findings showed that 36.4% reported that autism affect your daily routine while only 18.2% aver that autism has affected their relationship with other children.it was noted that 18.2% affirmed that autism has caused stress in their marital relationship. Equally, the findings showed that 45.5% had limited information on use support system for related to autistic children. By and large, 63.7% of respondents aver that they have learnt something from raising autistic child.

4.4.2 Impact of Autism Spectrum Disorder on psychological well-being of the siblings living.

Descriptive analysis was computed to determine How Autism Spectrum Disorder impact on the psychological well-being of the siblings living. The finding is presented in Table 4.4.

Table 4. 4: Impact of Autism Spectrum Disorder on psychological well-being of the siblings living

Statement	The feel or the known information is less	The feel or the known information moderate	The feel or the known information is strong
Have you ever got depressed due to sibling autism?	33.3	50.0	16.7

Did your sibling diagnosis autism affect you?	66.7	16.7	16.7
Did you see difference in sibling from other peer group of his/her age?	25.0	41.7	33.3
Do you ever felt embarrassed of your sibling behavior while growing up with him/ her?	33.3	33.3	33.3
Do you feel having an autistic sibling affected your relationship with parents?	41.7	33.3	25.0
Is your relationship with your sibling is positive?	8.3	25.0	66.7
Having sibling with autism strengthened your family bond?	33.3	58.3	8.3
Have you ever thought what will happen to your sibling in future, once your parent will not be able to care for him/her?	75.0	16.7	8.3
Have you ever met about other siblings with autism?	91.7	8.3	0.0
Have you ever received any support find meaning and acceptance in having sibling with autism?	83.3	16.7	0.0

From Table 4.4, it was noted that up to 50% of respondents affirmed that they had ever got depressed due to sibling autism. This was supported by 16.7% who confirmed that the sibling diagnosis of autism affected them. It was observed that 41.7% moderately observed differences in their sibling from other peer group of his/her age. This could be explained in terms of the nature effect of autism. However, the finding showed that 33.3% reported that they did not felt

embarrassed of their sibling behavior while growing up with him/ her. This view was also maintained by 41.7% who felt that having an autistic sibling affected your relationship with parents.

Moreover, 66.7% reported that their relationship with their sibling is positive despite the disorder. Similarly, 58.3% aver that having sibling with autism had strengthened their family bond.

The study also found that 75.0% of respondents hadn't ever thought what will happen to their sibling in future, once their parent will not be able to care for him/her. it was noted that 91.7% asserted that have never met other siblings with autism as well as receive any support find meaning and acceptance in having sibling with autism (83.3%).

4.4.3 Effect of Parenting Stress on Learning of the Autistic Child

Descriptive analysis was computed to determine How the learning of the autistic child affected by the parenting stress. The finding is presented in Table 4.5.

Table 4. 5: Effect of Parenting Stress on Learning of the Autistic Child

Statement	The feel or the known information is less	The feel or the known information is moderate	The feel or the known information is strong
Did you react positively, when you heard your child need to undergo multiple therapies?	54.5	27.3	18.2
Does your reaction to the diagnosis delay the child's intervention?	18.2	45.5	36.4

Did it took long time for you to accept?	45.5	36.4	18.2
Do you feel your personal stress affected the child's development or learning?	36.4	27.3	36.4
Do you believe school is only for academics?	63.6	9.1	27.3
Do you think autistic children also learn in school?	54.5	9.1	36.4

According to Table 4.5, it was noted that 54.5% of respondents did not reacted positively when they heard their child needed to undergo multiple therapies. However, 45.5% and 36.4% aver that their reaction to the diagnosis did not delay the child's intervention. The finding also showed that 45.5% maintained that it took long time for you to accept the situation. Furthermore, 36.4% felt that their personal stress affected the child's development or learning but never believed that school is only for academics (63.6%). Generally, 36.4% of respondents reports that autistic children also learn in school.

4.4.4 Effect of taboo on the Parenting Responsibilities in the upbringing a child in Kenya diagnosed with ASD.

Descriptive analysis was computed to determine how the taboo affects the parenting responsibilities in the upbringing a child in Kenya diagnosed with ASD. The finding is presented in Table 4.6.

Table 4. 6: How the taboo affects the parenting responsibilities in the upbringing a child in Kenya diagnosed with ASD

Statement	The feel or the known information is less	The feel or the known information is moderate	The feel or the known information is strong
Do you know what Autism is?	100.0	0.0	0.0
What kind of intervention you started when your Child was diagnosed with Autism?	0.0	100.0	0.0
Are you aware of the cause for your Child’s condition?	75.0	25.0	0.0
Have you manifested any ritual you have done to cure your Child?	50.0	50.0	0.0
Did your family react positively with the diagnosis of your Child?	25.0	75.0	0.0

Table 4.6 shows that all the respondents (100%) never knew what Autism. However, they were aware what kind of intervention they started when their Child was diagnosed with Autism (100%). Moreover, 75.0% were not aware of the cause for their Child’s condition. Despite this finding, respondents were divided (50.0%) whether they have manifested any ritual done to cure their Children. Finally, 75% of respondents affirmed that their family reacted positively with the diagnosis of their Child. However, 25% never reacted positively with the diagnosis of the Child.

5.2. Summary

5.2.1 How Autism Spectrum Disorder affects the well-being of the Mother

Mothers with autistic children generally face innumerable problems regarding their Children's wellbeing. The study showed that majority of respondents (45.5%) affirmed that their social life had been affected because of their child with autism. This view was supported by 36.4% who reported that they reacted negatively when they were informed about their child's condition. This implies that when mothers' social life especially their daily routines are affected due to autistic children, they could impact negatively in their well-being. Specifically, it was noted that 36.4% of respondents agreed that autism affect their daily routine while only 18.2% aver that autism has affected their relationship with other children. It was noted that 18.2% affirmed that autism has caused stress in their marital relationship. Equally, the findings showed that 45.5% had limited information on use support system for related to autistic children. By and large, 63.7% of respondents aver that they have learnt something from raising autistic child. This view agrees with that of Paulyane *et al.*, (2015) who asserts that the interaction of parents with specific manifestations of Autism Spectrum Disorder in their children can often lead to the family's marginalization regarding social life.

5.2.2 Impact of Autism Spectrum Disorder on psychological well-being of the siblings living

Siblings share a unique and important relationship within the family unit and are important to one another in the process of learning social skills (Knott et al., 1995). From the findings, it was seen that up to 50% of respondents affirmed that they had ever got depressed due to sibling autism. This was supported by 16.7% who confirmed that the sibling diagnosis of autism affected them. It was observed that 41.7% moderately observed differences in their sibling from other peer group of his/her age. This could be explained in terms of the nature effect of autism. This suggests that the

tendency of sibling to undergo depression and stress due to their autistic child was inevitable. This view is in line with ward *et al.*, (2016) who opines that the impact on siblings with autism spectrum disorder include siblings negative attributes which such as fear of frightening or violent behavior, decreased sibling intimacy and social emotional difficulties.

Despite this challenge, 33.3% reported that they did not felt embarrassed of their sibling behavior while growing up with him/ her. This view was also maintained by 41.7% who felt that having an autistic sibling affected your relationship with parents. Moreover, 66.7% reported that their relationship with their sibling is positive despite the disorder. Similarly, 58.3% aver that having sibling with autism had strengthened their family bond. This resonates with studies which suggest that positive attributes includes maturity, responsibility, self- concept, less quarrelling and competition, admiration for the person with ASD and satisfactory sibling relationship (ward, et al, 2016).

5.2.3 Effect of Parenting Stress on Learning of the Autistic Child

Children with ASD are both expressive and receptive such that language is disabled and it frustrates both the parents. According to the finding, it was noted that 54.5% of respondents did not reacted positively when they heard their child needed to undergo multiple therapies. However, 45.5% and 36.4% assert that their reaction to the diagnosis did not delay the child's intervention. The finding also showed that 45.5% maintained that it took long time for you to accept the situation. Furthermore, 36.4% felt that their personal stress affected the child's development or learning but never believed that school is only for academics (63.6%). This finding implies that when parents are highly stressed, some may fear allowing their child to go to school. This view agrees with Autism Society report (2011) who observes that parents experience worry and concern

that their child may be potentially harmed because often, they cannot communicate verbally and are highly vulnerable.

5.2.4 Effect of taboo on the Parenting Responsibilities in the upbringing a child in Kenya diagnosed with ASD.

Upbringing a child diagnosed with ASD in most African communities is regarded a taboo. There is lack of awareness and limited access to needful services which can improve the life and prognosis in children with autism. According to the findings, all of the respondents (100%) never knew what Autism was as well as the cause for their Child's condition (75.0%). However, they were aware what kind of intervention they started when their Child was diagnosed with Autism (100%). Despite this finding, respondents were divided (50.0%) whether they have manifested any ritual done to cure their Children. Finally, 75% of respondents affirmed that their family reacted positively with the diagnosis of their Child. However, 25% never reacted positively with the diagnosis of the Child. Stigma in Kenya encounters lot of distress for these parents who isolate them from socialization and the fear facing the society make this parent to end up with severe anxiety and depression. Stigma includes Labeling, stereotyping, separation, status loss and discrimination (Gona, *et al*, 2016).

5.3 Conclusions

The study concludes that mothers' social life especially their daily routines are affected due to autistic children. It is accepted therefore that that autism has caused stress in their marital relationship as well as affecting relationship with other children. The findings also conclude that siblings get depressed due to autistic nature of their sibling. Moreover, when parents are highly stressed, they may fear allowing their child to go to school. This affects learning and development of behaviour with their peers. Finally, parents with autistic children have never knew what autism

is as well as the cause for their Child's condition. This has been left to be explained in terms of taboo, stigma and speculations.

5.4 Recommendation

The study recommends that:

- i. Mothers with autistic children should undertake formal training in order to learn nature of therapies necessary for their children
- ii. Autistic children should not be isolated but rather be integrated with other siblings in order to learn appropriate communication and life skills
- iii. The government through education should organize training programs geared towards eradicating stigma and taboo related to children with autism.
- iv. The education providers should provide the autistic children with a conducive learning environment

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APPENDIX I: INFORMED CONSENT

Dear parents and siblings, my name is Girija Ramkumar student of University of Nairobi. I am doing a research study, Impact of Autism on the families. The purpose of the study is to improve the well-being of the family member with autistic child through analyzing coping strategies for them which can support them in their well-being and involve more effectively in the development of the child. You have full freedom to decide in participation of this research study. Even before starting the interview I'll explain clearly about all the information expected in this study. With your permission I'll wish to record our conversation.

The Risk of this interview could be the confidentiality. I promise all the information given by you will be confident between you and me. The interview might take maximum 45 minutes including the time you might spend to fill in the questionnaire. I selected you to know your experience of Autism in your family and your support for this study will assist us to understand more about the impact of autism in the families. The questionnaire will be produce during the interview. The benefit of this study will help us to find more about the coping strategies for the families with autistic children.

I agree to participate in this study. I read the above information and I was also read. I was given chance to ask questions and the answer given was satisfactory. I volunteer to participate in this study.

Name of the participant:

Name of the researcher:

Signature of the participant:

Signature of the researcher:

Date / Month and year:

Date /Month and year:

APPENDIX II: QUESTIONNAIRE FOR MOTHERS

– Rate Yourself 1- 10 for Each Question

1. Did you react negatively when you were informed about your child's condition?
2. Were you aware of autism before your child's diagnosis?
3. Did the diagnosis change your expectation on your child?
4. What kind of sources you child is receiving in the need of development?
5. Did autism affect your daily routine?
6. Did it affect your relationship with other children?
7. Did it cause stress in your marital relationship?
8. Did you use support system for you both to be strong?
9. Have you learnt something from raising a child with autism?
10. Did your social life affect because of your child with autism?

APPENDIX III: QUESTIONNAIRE FOR SIBLING.

Rate yourself 1-10.

1. Did your sibling diagnosis autism affect you?
2. Did you see difference in sibling from other peer group of his/her age?
3. Do you ever felt embraced of your sibling behavior? Growing up with him/ her made you embarrassed?
4. Do you feel having an autistic sibling affected your relationship with parents?
5. Is your relationship with your sibling is positive or negative?
6. Having sibling with autism strengthened or weakened your family bond?
7. Have you ever thought what will happen to your sibling in future, once your parent will not be able to care for him/her?
8. Have you ever met about other siblings with autism?
9. Have you ever received any support find meaning and acceptance in having sibling with autism?
10. Have you ever got depressed due to sibling autism?

Please answer the question in the blank sheet behind.

APPENDIX IV: QUESTIONNAIRE FOR TABOO TOWARDS AUTISM.

Rate yourself 1-10.

1. Do you know what Autism is?
2. What kind of intervention you started when your Child was diagnosis Autism?
3. Are you aware of the cause for your Child's condition?
4. Have you manifested any ritual you have done to cure your Child?
5. Did your family react positively with the diagnosis of your Child?

APPENDIX V: QUESTIONNAIRE FOR THE CHILD'S EDUCATION AND PARENT'S PERSONAL STRESS.

Rate yourself 1-10.

1. Did you react positively, when you heard your child need to undergo multiple therapies?
2. Does your reaction to the diagnosis delay the child's intervention?
3. Did it take long time for you to accept?
4. Do you feel your personal stress affected the child's development or learning?
5. Do you believe school is only for academics?
6. Do you think autistic children also learn in school?