The Impact on Parents of Discovering that a Child has Autism Spectrum Disorder: A Phenomenological Study of Lusaka Parents.

by

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DECLARATION

I **NYONI JOACHIM** declare that this dissertation:

(a) Represent my own work;

(b) Has not previously been submitted for a degree at this or any other University; and

(c) Does not incorporate any published work or material from other dissertation.

Signature: ....

Date: 28th July 2011.

RIGHT OF PUBLICATION

APPROVAL

This dissertation of NYONI JOACHIM has been approved as a partial fulfilment of requirement for the award of the degree of Master of Arts in Child and Adolescent Psychology at the University of Zambia.

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DEDICATION

To all parents who have children with Autism Spectrum Disorder(ASD) in Zambia, mainly to the parents who volunteered to be part of this research for the sake of their children and those who will be diagnosed with ASD. I also owe this to my second born child Sizwayo Nyoni whose life could be the gateway to many children with ASD in Zambia. Truly life is a journey, only GOD knows what is in stock for him. I dedicate this to my mother Godfridah Lungu who always valued Education despite her humble education status, my wife, Fani, and my three boys Siabonga Katisha, Sizwayo and Mphatso for their support and understanding my persistent absence from home during the study. They all gave me the strength to work harder.

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LISTS OF ACRONYMS

ABA=Applied Behaviour Analysis

ASD=Autism Spectrum Disorder

CBIA =Community Based Intervention Association.

CSO=Central Statistics Office

IEP- Individualised Education Programmes.

MOE =Ministry of Education

UN= United Nations

UNZA=University of Zambia

UTH=University Teaching Hospital

WHO=World Health Organization

ZAMISE-= Zambia Institute of Special Education.

ABSTRACT

No parent anticipates having a child with a developmental disability such as autism. The purpose of the study was to investigate and explore the impact on parents of discovering that their child has been diagnosed with autism. A phenomenological approach was used to investigate parents' *lived experiences* of raising a child with Autism Spectrum Disorder (ASD). 17 biological parents were interviewed concerning their *lived experiences* at pre, peri and post-diagnostic adjustment. In most of the families in this study, one parent had at least tertiary education. Data was collected through in-depth interviews using the Collaizi's phenomenological method later on modified by Moustakas (1994). Ten major themes were categories and each theme was illustrated by major quotations from the parents. The Themes were:(1)Making sense out of the birth of an ASD child;(2) Encounter with professionals ;(3)Parents' general knowledge of ASD and their perceptions;(4) In search of diagnosis;(5) Effects on the family;(6) Costs ;(7)Cultural beliefs ,attitude and stigmatization ;(8)Services inadequacy.;(9) Future plans, desires, hopes and fears ;(10) Parents coping strategies.

Research findings reveal that parents experienced challenges which ranged from frustration, pain, confusion, doubt and disempowerment at pre -natal ,then shock, refuting the diagnosis and having a feeling like that of losing a normal child through death. At post diagnosis, parents showed some acceptance. Young parents with first born ASD children took time to notice the child's condition as compared to seasoned parents. Parents' encounter with professionals was insufficient, coupled with inconsistent professionals' opinions which often negated parent's opinions. Access to quality service provisions such as speech therapy were insufficient and in some cases, not even available. This was due to shortage of staff, bureaucratic and red-tapes tendencies in hospitals. Parents had challenges of finding suitable schools for their children, as mainstream pre-schools and Primary were unable and often times unwilling to accommodate ASD children. Marital conflicts emerged which included separation and fighting. Single mothers suffered greater challenges as compared to married ones, as they had to mix academic life and child caring .A child's poor, social and language communication brought more frustration and stress on all parents. Parents suffered costs in social, financial and emotional domains. The costs were in form of medical bills, transport, child and parents' stigmatization, hence living an isolated life. However, parents developed various stress coping mechanisms such as empowerment, humor, openness, faith and belief in God's healing power, positive reappraisal and confrontation approaches.

There is a greater need for collaboration and partnership between multi-disciplinary professionals during the diagnostic process. Holistic assessments are recommended that evaluate autistic children and their families within their micro-, meso-, and macro-environments as all the parties consider the peculiarity of ASD as compared to other mental retardation conditions.

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CHAPTER ONE: INTRODUCTION

1.0 The Background

The major interest in this research was to find out the impact on parents of discovering that a child has autism. The first time for me to hear of the word autism was at the University of Zambia (UNZA) in 2004 when I was doing my second year of my undergraduate studies. I once visited the UNZA assessment centre and St. Mulumba School in Choma. At a distance, the children looked healthy, cheerful and lovely despite some peculiarity in their behaviour. The children seemed to be living in their own world and like strangers in their own environment. It was quite fascinating seeing them play. My quick conclusion was that children with autism have social and communication problems. Little did I know that one day I would have such a challenge of having a child diagnosed with autism. Our second son was born on 1st January, 2004. He was diagnosed with autism at the age of five in 2009. These five solid years were years of agonising, living with uncertainty and with a ray of questions without answers. What could have been the problem with the child? Who was to blame? Is there something we did not do as parents? Could it be witchcraft or Satanism? Did we disobey any cultural beliefs during our marriage? All these and many more were questions we fellowshipped with on a daily basis. We visited many hospitals and clinics, particularly University Teaching Hospital (UTH), in search of help.

One day, during our routine programme of hospital visitation, I visited the UTH Child Developmental Centre of Excellence called Community Based Intervention Association (CBIA) where I met some parents and their children with problems similar to that of our son. The question which came into my mind was how is it like in Zambia to have a child with autism? Do professionals know about this problem? If so, how far and how much knowledge do they have about autism diagnosis and treatment? Are societies and professionals concerned about the minority children with disabilities? What is the impact on parents in Zambia having a child with autism? Is there any hope for such parents towards their children? What about poor parents in the village who do not know of such disorders? What is the fate of such children and parents? Can parents access intervention programmes for their children? If yes, where in Zambia? It was against such background that when I came for my Masters programme, I decided to do an investigation on the impact on parents of discovering that a child has autism in Zambia and the after math of that discovery. I thought that a phenomenological study would really bring to light some of the challenges which parents face. It is my hope and prayer that the findings may be beneficial to a lot of professionals, particularly those from the Ministries of Health, Social Welfare and Education who may be helped to understand parents' sensitivity of having a child with Autism Spectrum Disorder (ASD) and what they go through in search of a child's diagnosis in Zambia. I preferred using the term 'a child with ASD' as compared to an 'autistic child or autism child' because firstly, this will refer to a child's condition and not the label which society may give to the child. Secondly there is a child (human being) before the condition or disorder. It is the child we must be concerned with first, rather than the label which the child may be tagged with. In this research, I was wearing two jackets, that of a researcher and a parent with a child with ASD. I tried my best to bracket my own opinions and not to impose my experiences and emotions on the respondents but to learn and appreciate what they brought out of their own experiences. A qualitative phenomenological study was used to collect data (a form of a dialogue). Phenomenological study is 'a study that attempts to understand people's perceptions, perspectives and understandings of a particular situation'. It is an approach which tries to bring something distant close, a certain strangeness overcome, and a bridge built (Leedy & Ormrod (2010:141; Gadamer 1967, 1976:22). The phenomenological method greatly allowed the researcher for a better understanding, exploration and perceptions between parent's world and that of readers.

There are certain disabilities that are not as conspicuous as others. Some of these disabilities are developmental in nature. One of such disabilities is autism which is a developmental disorder characterized by abnormalities in social functioning, language and communication and unusual behavioural interests (Mash and Wolfe,2002). This developmental disorder involves impairments in cognitive, social, behavioural and emotional growth (Halgin and White Bourne, 1993; Kendall and Hammer 1997). The Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV) of 2003, classifies autism under Pervasive Developmental Disorders. Autism Spectrum Disorders (ASD) are a collection of five developmental disorders (autistic disorder, Asperser's syndrome, Rett's disorder, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified), which are typically characterised by deficits in social-emotional reciprocity. They comprise a wide spectrum of problems, including impairment in social interactions; communication difficulties; and stereotyped patterns of behaviours and interests (Mash and Wolfe, 2002; Kutscher, 2005; Osborne and Reed ,2008)

Below is the chart on definition of ASD as adopted by Rosenberg, Westling and Mclesky (2011)

Type of ASD	**Characteristics /Definition**
Autistic	-severe development disability characterised by an early age of onset poor social development, impairments in language development and rigidity in behaviour.
Aspergers	-Sustained and often life -long impairment in social interactions and the development of restricted repetitive patterns of behaviour, interests and activities.
Rett	-It follows a typical development during first year of life. A genetic deficit, almost exclusively affecting girls. It is characterised by rapid deterioration of behaviour, language and purposeful hand movements as well as mental retardation and seizures.
Childhood disintegrative	-This is a rare condition in which a 3 to 15 years old child suddenly and rapidly loses language, social, motor and toilet skills.
Pervasive developmental disorder - not otherwise specified. PDD-NOS	-A vague designation used to describe children who resemble those with autistic disorder or Aspergers disorder but differ in a diagnostically significant way e.g. age onset.

Literature shows that no parent anticipates having a child with a developmental disability such as autism, therefore receiving news of a diagnosis of autism may be devastating, traumatising and heartbreaking, but for some, it can be a relief to have a label for their child's symptoms (Woods and Hewitt, 1989; Mariga, 1989). To date there has been little or no research in this area in Zambia. Worse still, it is speculated that little is known about autism in the Zambian society, even amongst health and educational professionals. This has been worsened by scarcity of full-scale epidemiological studies on disabilities in the third world countries, which might force planners to hypothesise disability conditions. This has been worsened by limited resources and lack of priorities by governments and the overwhelming demand for various services by the people in the nations (mainly in weak economies like Zambia). This may lead policy-makers to underplay quality service delivery to children with disabilities such as autism. Normally, such a concern may not receive much attention and be left in the hands of politicians who may make un-researched and unauthenticated statements on the number of children with disabilities. Serpell and Nabuzoka (1991:95) postulate that "identification of disabling conditions [such as autism] at an early age calls for fine-grain analysis of behavior using precisely calibrated instruments and generally presupposes a high level of specialised training".

Studies show that two of every five hundred parents in the world are likely to be biological parents of a child with ASD (Autism Association of NSW, 2001a and Committee on Children with Disabilities, 2001). In most African countries (Zambia inclusive) it is difficult to know the exact number of children with autism due to scanty statistical data available. The other reason could be due to poor obstetric and antenatal care prevailing in most developing countries, incidence of severe intellectual disability and its prevalence may be lower because such children often have associated health risk factors and are more likely to die at birth or soon after they are born as compared to developed nations whose maternal and child health services are more advanced (Tizard, 1972; Belmont, 1981; Wiesinger, 1986 in Serpell and Nabuzoka, 1991; Engle and Black, 2008)

Globally, autism diagnosis may generally take time to be discovered because of the following reasons and assumptions made by both parents and professionals:

i. Unrealistic demands and protection of the child by parents and the family.
ii. Lack of enough knowledge by both professionals and the society about ASD.
iii. Doctors' and health professionals' attitudes of 'I know better' and their assumption that parents know nothing about the condition.
iii. Cultural and religious influences and superstitions about the disorder.
iv. Continuous denial of the child's conditions by parents(Drakes,1996;Gray,2002; Rosenberg etal.2011; Bronfenbrenner, 1979)

Nabuzoka and Serpell (1989); Wood and Hewitt (1989) and Cameron (1997) all suggest that, improvement of people's perception about ASD and other disabilities has come due to:

i. Parents and professionals working together.
ii. Counseling and training provision on stress management to parents.

iii. Community participation.
iv. Individualised home-based education and care.
v. More information distributed by the media both to the general public and professionals.
vi. Parents' understanding their rights to question the doctors and professionals on what the child's problem is and the type of treatment they will administer to the child.

Early intervention programmes on children with ASD will help in school placement as stated in the mission statement of the Ministry of Education whose aim is "to guide the provision of education for all Zambians so that they are able to pursue knowledge and skills, manifest excellence in performance and moral uprightness---" (MOE, 1996: xi). This national policy statement gives a framework for who should access education in Zambia. It is clear that all Zambians regardless of age, race, creed and colour need access to education. This includes children with various disabilities, autism included. Research shows that considerable work on the physical disabilities has been done in Zambia as compared to disabilities such as ASD which deals with mental and psychological problems. Currently, the Ministry of Education has no government schools dedicated exclusively to the education of a child with ASD. Statistical data available indicates that among grade one to twelve (1-12) pupils, Zambia has over 314,143 pupils with intellectual impairment, 72,229 pupils with specific disabilities and 8,513 pupils with other forms of disability (MOE, 2008). There is no data from the Central statistics office (CSO) or at the Ministry of Education and Health for children with ASD at pre-school, primary, secondary and tertiary levels. Furthermore, little is mentioned on services provided to parents with children with ASD and how they manage to adjust to new roles upon discovering that their child has autism.

It is with such a background that the main objective of this study was to investigate the impact on parents of discovering that their child has been diagnosed with autism. This researcher further considered how helping professionals from different government institutions, NGOs and the community can improve their service provision to parents with ASD children.

1.1 STATEMENT OF THE PROBLEM

There is an increase in the number of children with disabilities in Zambia (Serpell and Jere-Folotiya, 2010, MOE, 2008, 2009).This includes Autism. Autism Spectrum Disorder may not be a well-known disability amongst professionals and the general society in Zambia and there could be no epidemiological data on the prevalence of ASD. The researcher therefore, speculates that parents in Zambia might not receive enough service support and provision from the professionals. This may therefore lead parents not meeting the child's needs, goals and aspirations. The lack of support to biological parents of children with Autism Spectrum Disorder may force parents to provide poor education, health, social and emotional development to their child, hence poor parenting method towards a child with autism spectrum disorder. The stated problem on the lack of parental support to parents of children with autism, is crucial and provides a necessity for a serious investigation on what these needs are and how parents manage and cope with them, hence gaining a better understanding of them.

1.2 SIGNIFICANCE OF THE STUDY

The future and prosperity of each child greatly depends on how parents adapt to the environment and life's situations. Most of the research works concentrate on child's intervention and how parents can help the child survival and unleash his/her potential. However, very little literature in Africa looks at the experiences which parents pass through and how they cope with stress when they have children with a disability such as autism. This study will be of great importance first and foremost, to new parents of children with autism. These parents will be availed with information that will help them understand what it takes to care for a child with ASD. Parents may later on advocate for the child's welfare in areas of research, diagnosis, interventional programmes and service delivery (from the government) which may be child-centred, accessible and affordable.

The findings will be vital to professionals from various government ministries, such as Education, Social Welfare and Health, who will be assisted to understand the sensitivity of parents with children who have been diagnosed with ASD. In the case of teachers, the research will be of great benefit to them as they are going to understand the challenges which parents with children with autism face. This, will in the end, help teachers formulate Individualized Education Programmes (IEP) appropriate for such children. The IEP may include parent counselling services in school and at home (for home-based education programmes). Other professionals like early childhood psychologists and therapists will be helped to be sensitive and be empathetic to parents with a child with ASD since these parents are at risk of higher stress and depression.

The research will help caregivers, peers and parents on modes of socialization with a child with ASD and techniques on how to communicate effectively with them. Society will be helped to understand what autism is and this may ignite many individuals to fight for their rights in health education and social welfare, which will in the long run make Zambia a conscious society on the nature and welfare of children with ASD. The outcome will be an end to discrimination and sidelining children with ASD on the basis of their disability and acceptance of them as people who can maximise their full potential and help in national development at their own pace. This will in the end act as a motivating factor for parents to open up and seek help for their child.

1.3 AIM OF THE STUDY

The aim of this study was to describe and explore how parents of children with ASD experience the diagnostic process, how they manage to adjust in different spheres of family and society life after the diagnosis has been made and how helping professionals can improve their service delivery to these parents.

1.4 THE GENERAL OBJECTIVE OF THE STUDY

The purpose of the study was to investigate the impact on parents of discovering that their child has been diagnosed with autism.

Specific objectives:

This study was guided by the following objectives:

1. Find out how knowledgeable parents were about ASD before their child was diagnosed with ASD.
2. Assess parents' reactions to the child's diagnosis before, during and after diagnosis.
3. Investigate major challenges which parents face in caring for their ASD child.
4. Establish the costs on parents with a child with ASD (psychological, social, emotional and financial costs).
5. Examine how parents manage to integrate a new role of child caring and marriage maintenance.

1.5 RESEARCH QUESTIONS.

The following questions guided the study:

1. How much information did parents of a child with ASD have about autism before the child was diagnosed?
2. What are the reactions of parents of a child with ASD before, during and after the diagnosis?
3. What major challenges do parents face in caring for their ASD child?
4. What are the psychological, social, emotional and financial costs on parents of a child with ASD?
5. How do parents of an autism child manage with the new role of child caring and marriage maintenance?

1.6 LIMITATIONS OF THE STUDY

Due to some limitation of scope in this study, the researcher did not explore in full depth all the challenges which parents undergo with an ASD child. All participants had a sound education background with a minimum of a grade 12 certificate and were all based in town. Experiences of caring for children in rural and amongst uneducated parents remain unexplored. HIV/AIDS has left many children as orphans and are kept by secondary care givers. This is another area which needs a study. Another shortfall in this scope is that results about sibling relationships with an ASD child were fully based on parent's knowledge and observation as compared from the siblings themselves.

1.7 DEFINITIONS OF TERMS.

The following were key terms which were used in this study:

SPECTRUM: It is a spectrum disorder because it includes many disorders in one. The word spectrum means an entire range of related qualities. The commonest disorders associated with Autism Spectrum Disorder (ASD) include, Autism, Aspergers syndromes, Rett disorder, Pervasive developmental disorder and Childhood disintegrative disorder.

AUTISM: A developmental disorder characterised by abnormalities in social functioning, language and communications and unusual interest.

A CHILD WITH AUTISM SPECTRUM DISORDER (ASD): This will refer to a child's condition and not the label which society may give to the child. It will focus on the child first (Human being) and not the label targeted to the child. It will encompass any of the following disorders autistic, Ret disorder, Aspergers, Pervasive development disorder or children disintegrative disorder

SOCIO - ECONOMIC: Parents status on whether employed or not and the monthly income earned by working parents.

PROFESSIONAL COUNSELLING: The psychosocial skills provided by psychosocial counselors to parents and children with autism with respect to a specific problem the child or parent is undergoing.

MULTI-DISCIPLINARY TEAMS: A group of professionals who meet to look at ways and means to help the child.

PRIMARY CARE GIVERS: This will mean biological parents of the child with autism.

PARENTS: This could be a couple or single parent but must be a biological parent of the child.

AUTISM COSTS: The term will loosely mean the impact and effects, not measurement or face value on an item, since words like psychological, social and emotional (are both covert and overt in nature) making it difficult to measure their costs on the scale.

1.8 SUMMARY OF THE DISSERTATION STRUCTURE

A phenomenological approach was used as a way of exploring, examining and describing parents' lived experiences and realities concerning the child's diagnostic processes in answering the pertinent question on' what is the impact on parents of discovering that a child has autism.' My research was deliberately focused towards biological parents because they were the best informed sources of information about the child's condition. Research of this nature may lead to information that in the long run could be useful in helping professionals, communities and Non Governmental Organizations (NGOs) to develop effective and efficient intervention models that are sensitive to the peculiar needs of parents of children with ASD.

In chapter 2, a literature review will be presented. The review focuses on what autism is, causes, diagnosis and its historical aspects. The chapter also discusses specific challenges and concerns of parents with ASD children before, during and after diagnosis. This will closely be followed by a reflection on grief over the loss of a normal child and specific vulnerabilities and needs of these parents. The chapter concludes with a review of methods which parents may employ on coping strategies and support networking groups that parents may utilise in their pursuit of a child's best way of living in the society.

Chapter 3 looks at research methods. Under methodology, the rationale, overview study of the research design, participant selection criteria, data collection, and data processing (analysis and interpretation) are discussed. Issues to do with ethical considerations are also discussed.

Chapter 4 discusses in detail results of the data analysis, interpretation process and their discussion. The researcher also looked at themes and categories that came up as results of the data processing. Themes and categories were classified under different broad areas of experiences, namely: (1) experiences surrounding the diagnostic process at pre, peri and post-natal stages; (2) effects of autism on parents' family life's activities; (3) Professional- parents relationship (4) passive impact of autism on siblings and other family members; (5) cost of caring for a child with autism ;(6) living experiences surrounding the diagnostic process, focus will be on the initial stages of sense of denial, chaos, stress and confusion associated with the birth of a child with ASD; (7) The effects of ASD on different areas of family life will be illustrated by a discussion on the influence of a child with ASD on marital relationships, parent-child relationships and sibling-child relationships. The researcher also made reference to challenges which parents of children with ASD experienced on behaviour management and discipline, as well as their search for quality and suitable type of learning institution which will have the needed resources for such children in the Zambian context; (8) On costs of caring for a child with ASD, references were made to issues to do with financial cost cumulating from medication, transport and education. Other costs to be discussed include emotional and social ones – (in the context of effects not value and measurement, as it is difficult to quantify them) (9) Cultural beliefs and community relationship, focus will be on how the community perceive ASD; (10) intervention methods and coping strategies used by parents.

The final chapter, Chapter 5, sums up all the information drawn from the research findings. In the final analysis, the chapter will provide recommendations for improved service rendering to parents of children with ASD. Some gaps in this research are identified which will serve as a good basis for further research in the field of autism in Zambia

CHAPTER TWO: LITERATURE REVIEW

2.0 INTRODUCTION

Often times we have talked about children being future leaders. As a Bemba and Ngoni proverb say "*Imiti ikula empanga*" and *N'gombe ni Matole* respectively (the trees that are growing are tomorrow's forests and you are rich if you have calves respectively). However, little is talked about on the emotional experiences of parents who care for the children. This study argues that parents of children with Autism Spectrum Disorder (ASD) may be a highly stressed group who need professional services of high quality standard.

In this chapter, the researcher explores existing literature on impacts of Autism on parents of children who are diagnosed with autism. The researcher reviewed some of the major studies done based on the methodological approaches which could have affected the results. This is because most of the literature looks at the welfare of the child and methods employed to alleviate the Child's problem as compared to considering the challenges which parents experience with a child with ASD, particularly from a developing nation point of view.

2.1 WHAT IS AUTISM?

The Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV) (2003:75) defines Autism as a developmental disability with the following characteristics:

i. Poor cognitive skills: A child has difficulties in comprehending abstract and age appropriate tasks which need much rehearsing.

ii. Stereotyped and repetitive behaviour interaction activities: These behaviours if challenged or disturbed may lead a child into tantrums. iii. The child has repetitive behaviours which include motor mannerism, sticking to one object or activity.

iv. Quantitative communication: A child has poor, disorganised repetitive language communication.

v. Qualitative social interaction: The child has inappropriate peer relationship and has difficulties to interact and communicate with peers and other members of the family and community.

Devine (2000) and Bregman (2005) describe autism as a complex developmental disability that affects normal brain development. It is a relatively rare pervasive development disorder characterized by difficulties in communication and socialization. Autism is also a neurogenetic disorder (The Committee on the Children with the Disabilities, 2001). We can therefore say that autism is a disorder which greatly affects the child's social-cognitive, communication development, and the child's behaviour and interests are not normally age appropriate.

2.2 ONSET OF AUTISM

The onset of autism also varies from child to child. Studies done in Japan indicate that some ASD behavioural difficulties were seen at 18 months and it could take five to six years to secure diagnosis. The age of diagnosis was younger if the child had lower functioning, that is having more behaviour disturbances or associated intellectual delays (Ohta, Nagaia and Sasaki, 1987). The fact that the cause is not known makes it more difficult for parents to understand the onset of autism disorder. Signs of autism vary from one individual to another. Diagnosis is usually based on careful observation as well as information provided by parents and other caregivers on the child's behaviour, communication, social interaction, and developmental levels. Diagnosis can be made by pediatricians, psychiatrists, clinical psychologists, or by a multi-disciplinary team, usually utilising an autism symptoms checklist. There are a number of screening tests or questionnaires which can be used to assess the child with ASD. These are the Childhood Autism Rating Scale (CARS), Checklist for Autism in Toddlers (CHAT), the Questionnaire on Resources and Stress (QRS-F) and the family crisis oriented personal evaluation scales (F-COPES) (Rosenberg et al, 2011; Mash and Wolfe, 2002). The question which stands out is how is diagnosis carried out in places where services might not be adequately available [Bauleni Special school, University Teaching Hospital (UTH)] and where both parents and professionals might be completely ignorant or have little knowledge on how to assess children with ASD condition? Parents in this case may probably be left with a huge task of trying to understand ASD condition and what it represents to them and the child.

2.3 SYMPTOMS OF AUTISM

Symptoms of autism typically appear before a child is 3 years old and last throughout life (Ohta, Nagai, Sasaki, 1987; Wolfe and Mash, 2002). Children with ASD can display a wide range of symptoms, which vary in severity from mild to disabling. The commonest symptoms in ASD children include:

i. Difficulty with verbal communication, including problems using and understanding language.

ii. Inability to participate in a conversation, even when the child has the ability to speak.
iii. Difficulty with non-verbal communication, such as gestures and facial expressions.
iv. Difficulty with social interaction, including relating to people and to his or her surroundings.
v. Inability to make friends and preferring to play alone.
vi. Unusual ways of playing with toys and other objects.
vii. Lack of imagination.
viii. Difficulty adjusting to changes in routine or familiar surroundings.
ix. Repetitive body movements, or patterns of behaviour, such as hand flapping, and head banging.
x. Preoccupation with unusual objects or parts of objects (Marsh and Wolfe, 2002; Sacks, 1995; Barlow and Durand, 2007).

2.4 WARNING SIGNS OF ASD

Parents need to observe the following as warning signals of autism:

i. If the child does not babble by 12 months of age.
ii. If the child does not gesture, such as point or wave, by 12 months of age.
iii. When the child does not say single words by 16 months.
iv. When a child does not say two-word phrases on his or her own by 24 months.
v. If the child has lost any language or social skills at any age (Mash and Wolfe, 2002; Barlow and Durand)

2.5 THE SEARCH FOR ASD EXPLANATIONS

Autism was first discovered by Leo Kanner and Han Spurgers in the 1940's, who identified some children who had common impairments such as poor social interaction skills, poor communication and language impairments and other ranges of stereotyped behaviours. Kanner attributed these strange behaviours to parents 'cold relationship' with their children. He called such parents as 'refrigerated parents' (Scott, Clark and Brody, 2000; Wolfe and Mash, 2002). In the past 50 to 60 years, affirmative radical interventions were used by many researchers to improve and treat children with ASD. One such approach was the removing of children with ASD from parents who were perceived to be poor child caregivers. Researchers had also to introduce a 40-60 hours treatment home- based care behavioural management programme which proved taxing on parents (Burkhardt, 2001). However, Kanner's theories like others, have been slowly discarded by latest findings which state that the cause of Autism is not known to date (Mash and Wolfe, 2002; Barlow and Durand). The popular theory on the cause of ASD is the genetic predisposition such as inherited genetic glitches and the spontaneous DNA mutations combined with environmental factors such as toxins, chemicals, or other external harmful elements.

According to Rosenburg et al. (2011), autism, a neurological disorder leads to in the shape and to differences in brain structures in most ASD children a feature not seen in most non ASD children. From the neurochemical perspective, ASD children are found to have high levels of abnormalities to the central nervous system with high level of serotonin, an amino acid-based neurotransmitter that significantly contributes to the regulation of sleep, appetite and mood in ASD children. Other than this, the following are some causal factors: problems in pregnancy and birth, viral infections, exposure to certain environmental chemicals or pollutants, or even allergies to certain foods i.e. gluten or dairy products. Other possible causes include accidents by the mothers at pre-natal, peri-natal and post-natal stages". There are also suggestions that autism may be caused by a reaction to childhood vaccines. The vaccine is a controversial one where studies showed that exposure to thimerosal, a mercury-containing preservative may lead to mercury poisoning and autism. Scientific research, however, does not support the theory that childhood vaccinations cause autism. Recent major epidemiological studies conducted in the United States, the United Kingdom, Sweden and Denmark found that children who received vaccines containing thimerosal did not have higher rates of autism (Bloomberg.com). Additionally, a major safety review by the Institute of Medicine failed to find any evidence supporting the connection. Other organizations that have concluded that vaccines are not associated with autism include the Centers for Disease Control and Prevention (CDC), the U.S. Food and Drug Administration (FDA), the American Academy of Pediatrics, and the World Health Organization. Another school of thought against the controversial thimerosal is that the chemical is no longer used in any childhood vaccines (www.Autism.about.com, 16/04/10). The above findings led to the removal of the article from public domains. The report read as follows:

The Lancet (the UK's premiere medical journal) has officially retracted a 1998 paper that was the cornerstones underlying the theory that the Measles, Mumps, Rubella (MMR) vaccine is a major cause for a huge increase in cases of autism. According to Bloomberg.com, Dr. Andrew

Wakefield's paper entitled Ileal-lymphoid-nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children "was retracted from the published record, stripping it of its scientific claims," The press release from the Lancet itself reads as follows:
'Following the judgement of the United Kingdoms' General Medical Council's Fitness to Practice Panel on January 28, 2010, it has become clear that several elements of the 1998 paper by Wakefield et al. are incorrect, contrary to the findings of an earlier investigation. In particular, the claims in the original paper that children were "consecutively referred" and that investigations were "approved" by the local ethics committee have been proven to be false. Therefore we fully retract this paper from the published record,' www.emdecinehealth.com/autism/, 16/04/10).

One set of beliefs documented amongst the Chewa people of Zambia's Eastern Province are as follows; '*Mdulo of the child'*. Mdulo is a word which means polluting the child due to mischievous behaviour of the parents. Mdulo can happen when a father commits adultery soon after the child is born and before the child is brought out of the door (*kuturuka m'chikuta*) and touches the child before the child is medically treated. The mother too can cause *mdulo* on a child if she commits adultery during menstruating period. The same can happen to a child if any man who is 'hot' touches the child (Drake, 1976). Other cultural beliefs according to my informers indicated that diseases like autism are caused by '*Kusapititsa mwana kumphatsa'*, that is, a traditional belief which says that before parents can start having sex, soon after the child is born, they need to do some rituals of bathing the child in a man's semen. Others informers said that such diseases come about due to '*Maloza chifukwa chotsa mverela adzimu ndi makolo' (a* taboo associated with lack of respect to ancestral spirits and traditional norms) if such are not done, they can lead to disabilities. Research still shows that the cause of autism is not yet known. However, modern scientific studies give some clue to factors attributed to the cause of autism - such as damage to the brain at pre, peri and post natal. The researcher explored ways on how parents expected clarity on ASD diagnosis that would give them comfort over the Childs' condition even when there is no one agreed definition and cause of ASD.

2.6 CHALLENGES FACED BY PARENTS OF CHILDREN WITH OTHER DISABILITIES

The dream of each parent is to see that the child who is born grows up to be 'normal', productive and uses all his/her potential in life. Giving birth to a child with a disability may be the beginning of another type of life in terms of child nurturing. Studies show that parents with disabled children miss a lot of opportunities which were to satisfy their personal needs such as enough sleep, leisure time, and job opportunities (Kraft and Kraft 1998). Parents with disabled children experience higher levels of stress as compared to parents of normal children (Brinker, Safer and Sameroff, 1994; Donovan, 1988; Dyson; 1991, 1993, 1997). It is still unclear on whether the situation is the same in countries like Zambia. Dyson (1991) indicates only minimal differences in terms of stress between a parent with a disabled child and that without any disability. Other studies done showed that stress between parents of a child with ASD and those without a child with ASD cannot be so minimal because autism is a disorder which is qualitative in nature (it deals with emotions that are covert and overt in nature). Hence, it leaves doubts to qualify stress as minimal without any consideration to environmental, cultural, economic status and religious belief variations. Studies have shown that most parents from rich economic status homes have higher chances of managing their stress as compared to parents from low economic status homes (Engle and Black, 2008).Another conflicting study done in Zambia by Makasa (1988) on the challenges faced by parents with mentally handicapped children showed that generally parents with disabled children showed a perfectly normal life and responses to presence of disability (meaning that though parents were disappointed with the child's disability, they achieved satisfactory adjustment to their emotional and psychological well-being). Makasa (1988) included cultural variations, onset of the problem and the degree of severity as some of the causal factors to perfect normal life on parents with disabled children.

2.7 CHALLENGES EXPERIENCED BY PARENTS WITH A CHILD WITH ASD.

Literature attests that autism has a great impact on parents and the family. Studies show that levels of parenting stress are more highly pronounced in parents of children with ASD as compared to parents of children with almost any other type of disability or health problem (Dunn et al., 2001). Autism, though a relatively rare health problem, has been known as a major problem and very expensive (Gordon, 1993). This cost comes in many forms such as, emotional, social, finances towards transport, medications, therapies and education (Hecimovic, Powell, Christensen, 1999; Richmond, 2001). The literature reviewes challenges experienced by parents in different dimensions such as discussed below:

2.8 AUTISM AND FAMILY COSTS

Dobson and Middleton (1998) estimated that the costs of parenting a disabled child are four times higher than those without any disability. Treatment is expensive; indirect costs are more so. A study done in the US, postulates that for someone born in 2000, parents would spend an estimated average life time cost of $3.66 million [over 14 billion Zambian Kwacha at the rate of K4000 per US dollar on one person] net present value in 2010 dollars, inflation-adjusted from 2003 estimate (Ganz,2007). Parents would spend about 10% for medical care, 30% extra education and other care, and 60% would go to lose economic productivity and a related study found that ASD is associated with higher probability that child care problems would greatly affect parental employment (Sharpe, 2007). Funjiura et al. (1994) s' costs measurement analysis of autism on parents' services discovered that almost all the care for people with disability was made by the parents and the family. This is supported by a study done in London, Surrey and Sussex UK by Jarbrink and Knapp (2003) under Parents Autism Campaign Education (PACE) which estimated that most of the parents could lose as far as 40 hours per week (SD = 22hours), 22 hours of paid jobs (DS = 16 hours) and 17 hours of leisure time (SD = 11 hours) [Standard Deviation]. This cost did not include materials like books, toys and computer games and other necessities (Jarbrink, 2003). A study done in Canada in 2000, estimated that the cost to the state on a person with autism was over 3million dollars (Autism Society Canada, 2001). Autism Society Canada (2001b) further estimated that each 3000 children diagnosed with autism each year ,may cost the state over $60 billion annually to care for such children. The researcher in this respect sought to explore the financial impact on parents of children with ASD in Zambia. Questions which might need pertinent answers included. What were the real financial costs which parents faced, did they have any government or nongovernmental organization support? How do they survive financial costs of caring for a child with ASD, considering the perceived varying inadequate education service provision, high poverty levels and lack of employment amongst many Zambians, coupled with keeping extended family members?

Another challenge which parents of children with ASD may have faced, were loss of social life and fun. Leisure activities such as participation in sports, clubs, weddings, picnics and attending family gatherings like funerals were affected. Parents are overburdened by the child's behaviour such that some parents have been reported to have committed suicide or have had depression leading to psychopathology. U K and Canada has seen such an increase (Robert, 2002; Brown & Braston, 1996; Autism Society Canada). Zambia may face the same stories, though few of such stories reach media attention mainly in rural areas where superstitions and traditional beliefs are strong.

There is adequate literature attributed to child costs, materials and physical aspects of the child with ASD and little is mentioned about the psychological, social, emotional and spiritual costs which parents undergo. Such costs are very difficult to quantify in economic terms. The nearest way of assessing the cost is by conducting a phenomenological study where parents have to express their *living experiences* views in a narrative manner. It is with such background that the researcher endeavoured to assess the burden on parents in caring for a child with ASD. Parents may need both emotional and financial help to manage such problems. For example, in South Africa, a family and community motivator programme was put in place whose basic premises are to help the family to work with the community in early childhood development programmes (Newman, 2007). Most developed countries have financial benefits available to assist such families.

2.9 PARENTS' REACTIONS TO CHILD'S AUTISM DIAGNOSIS AT PRE, PERI AND POST DIAGNOSIS

Diagnosis process is very important in any disorder. Diagnosis has a lot of benefits to all the three parties - parents, child with ASD and professionals. Diagnoses help professionals to have adequate classification of the presenting problem. Clinically, diagnostic knowledge of the person's type of disorder can help in planning and managing the appropriate treatment. Administratively, diagnosis helps to have knowledge on the range of diagnostic problems that are represented among the patients or clients population and for which treatment facilities should be arranged accordingly. Thirdly, Carson, Butcher and Mineka (2000:609) observed that "diagnosis helps parents and professionals to understand the nature and difficulty of needs of the disorder which needs to be understood clearly and categorised appropriately." Mental disorders like ASD are difficult to diagnose and it takes a lot of time to arrive at the final conclusion as compared to physical disorders (Carson, Butcher and Mineka, 2000).Autism Spectrum Disorder is not caused by poor parenting but it is a neurobiological disorder that has genetic basis and currently it has no cure though many people claim to have the cure (Smith and Tyler, 2010), this in itself has brought a lot of challenges to parents.

To gain a better understanding of parents feelings that they have towards a child with ASD, the following concepts will be explored, sadness, fear, guilty, embarrassment shock and many more. Literature indicates that when a child is diagnosed with an autism spectrum disorder (ASD), parents experience a range of emotional feelings. Feelings of sadness, worry, denial, anger, embarrassment, fear, confusion, guilt, concern, resentment, and shock usually occur before a sense of acceptance enters their mind (Fisman etal.1989, Bellington, Mcnally and Mcnally,2000).This state of affair make parents feel like they have lost the dream of their child. However, it is natural to go through the phase (Gombosi, 1998). Woods and Hewitt (1989) suggest that parents of children with autism spectrum disorder face a unique set of challenges that impact on their psychological adjustment. Their lives are never the same. If married, then their marriage will never be the same; it will encounter more challenges and stress.

2.5.1 Pre-diagnosis

This is the period when parents observe some peculiar behaviour in a child and seek assistance from Para-professionals and qualified professionals for assessment and diagnosis. During this stage, parents are gripped with anxiety and stress. As the child grows older and no signs of talking or age appropriate behaviors are observed mainly after one year, fear starts growing. The fear may be worsened by professionals who may fail to address concerns of the parents. At this stage, parents may question their past lifestyles and start feeling guilty as having caused the disability to the child at pregnancy stage. A study by Osborne and Reed (2008) suggested that the wish of parents during diagnosis is having a service which has a quicker process, easier, coherently structured content. Osborne et al. (2008) conducted an investigation on the impact of an ASD diagnosis for children on the levels of parenting stress in their parents. The findings on parents of eighty-five children with ASD (aged from three to sixteen years) revealed that the severity of a child's ASD predicted that their parents would first notice a problem at an earlier stage in that child's development.

2.5.2 Peri-diagnosis

Immediately the child is diagnosed, parents face another challenge of life -adjustment. At this stage anxiety may lessen though at first parents may feel shocked by the diagnosis. They may accuse themselves, members of the community, professionals and the Supreme God as the cause of the child's problem. They may start bargaining that the child will be fine if treatment is correct (Boushey, 2001). Parents' enthusiasm about the child's future slowly comes to be viewed with apprehensions as their thinking is now more about the past and the present than the future of the child; that he/she still has the potential of surviving. Such a feeling becomes worse if that is their only child. A sense of immortality encloses parents. The parents may deny that the child has autism. A second opinion will be sought from other professionals and parents may demand to be told what they do not know. Some professions may reinforce the denial and retard recovery by setting unrealistic goals and assurances. In-fighting amongst professionals also contribute to the poor recovery process (Boushey, 2001). Osborne and Reed (2008), Osborne, McHugh, Saunders, and Reed, (2008) in Osborne (2009) explained that one obvious source of initial stress for parents of children with ASD was the experience of seeking, and obtaining, a diagnosis for their child with ASD, and their contact and communication with professionals involved in this diagnostic process. It is worth exploring on whether similar challenges affected the parents of children with autism in Zambia, immediately they were informed about the child diagnosis and compare their reaction to other research findings mainly those from developed nations where there is enough literature on the subject matter.

2.5.3 Post diagnosis

This is the period after the child has being diagnosed. Gray (2002) suggests that anxiety reduces in parents if the child is placed in school and appropriate therapy institutions. At this stage parents start to interact with professionals and the family may soon settle and find ways of dealing with the child's ASD. Parents may continue seeking further explanation on the cause of the disorder. However, further enquiry may be sought by the parents on the cause of the problem, should they discover that a problem was due to negligence, say at the hospital, anger may be expressed by them. Such anger is inevitable as it is part of the adaptation process (Carr, 1989). Acceptance and maturity comes in, which brings with it the realization of personal insignificance. At this stage, parents may try to live a meaningful life by even socializing with others. This may be achieved with more support from the community and helping professionals.

If little help is given, some parents have higher chances of suffering from psychopathology (Lainhart, 1999).

2.10 DIAGNOSIS OF AUTISM

Diagnosis is very important in any disability as this helps both parents and professionals towards the child's right placement and interventional programmes. Autism diagnosis is based on behavior, not cause or mechanism (Kaplan and Sadock (2007). According to Diagnostic and statistical Manual of Mental Disorder Text revised (2005 DSM-IV-TR (2005) and WHO (1995) Autism is diagnosed according to some behavioral characteristics exhibiting in at least six symptoms which should include at least two symptoms of qualitative impairment in social interaction, at least one symptom of qualitative impairment in communication, and at least one symptom of restricted and repetitive behavior. Some of the symptoms include lack of social or emotional reciprocity, stereotyped and repetitive use of language or idiosyncratic language, and persistent preoccupation with parts of objects. The Onset of autism must be prior to age three years, with delays or abnormal functioning in either social interaction, language as used in social communication, or symbolic or imaginative play (Kaplan and Sadock (2007).

There are also several diagnostic instruments which are commonly used, these include the Diagnostic Interview-Revised (ADI-R), semi structured parent interview, and Autism Diagnostic Observation Schedule (ADOS) which uses observation and interaction with the child, Childhood Autism Rating Scale (CARS) used widely in clinical environments to assess severity of autism based on observation of children (Kaplan and Sadock (2007). In order to have quality diagnosis, there is a need to form a multi-disciplinary team of professionals. This includes special education teachers, parents, neuropsychologist, psychiatrist, pediatrician and many more. It should be noted that under-diagnosis or over-diagnosis may pause a challenge to a child. For example, if the child is under- diagnosed, he or she may not receive appropriate interventional programmes such as teaching of sign language, introducing of hearing aid and teaching parents on how to care for the child. A child with ASD may need treatment after diagnosis. The whole aim of treatment is to lessen associated deficits and family distress, and to increase quality of life and functional independence. There is no single treatment for such children. Parents and family involvement coupled with educational system are the main resources for treatment. Educational interventions can be effective to varying degrees in most children: Intensive ABA treatment has demonstrated effectiveness in enhancing global functioning in preschool children (Kaplan and Sadock, 2007; Rosenberg et al 2011).

2.10.1 Prognosis

There is no cure for ASD condition. However most children with ASD can acquire language by age 5 or younger, though a few have developed communication skills in later years. These children with ASD lack social support, meaningful relationships, future employment opportunities or self-determination. Although core difficulties tend to persist, symptoms often become less severe with age. (Rosenberg et al, 2011; Mash and Wolfe, 2002) Few high-quality studies address long-term prognosis. Some adults show modest improvement in communication skills, but a few decline.

2.10.2 Identification of Autism

There is no diagnostic test for Autism. Only guidelines for identification, assessment, diagnosis and access to early intervention for pre-school and primary school. In UK, the National Initiative for Autism (NIASA) is responsible for screening and Assessment (Frederickson and Cline, 2010). Whilst it is possible to recognize and diagnose ASD by the age of 18 months, Howlin and Moore (1997) in Frederickson and Cline (2010) state that in practice, diagnosis will only be made when the child is 24 months and the average age is 5 years old.

2.11 PARENTS' EXPECTATIONS FROM THE COMMUNITY AND THE PROFESSIONALS

Parents' expectations from the community are generally high in relation to the help which they seek to get from the community. Trigonaki (2002) wanted to find out whether the experiences of parents of a child with ASD from the outside world match with their desires on the choice theory. The choice theory looks at love/belonging, self worth/empowerment, fun/joy, and freedom and survival/health. The theory speculates that all people will try to fulfill the above needs by constructing their own unique world which consists of the people they love. The findings bring to light the fact that parents of children with ASD had their world collapsed soon after being told that their child had autism. Other findings showed that parents found it difficult to acclimatise to the situation and that their hierarchy of needs greatly differed from that of parents with normal children. Parents of children with ASD placed more emphasis on love and belonging whilst parents with 'normal children placed much emphasis on fun and enjoyment with their children. Such findings bring to light some of the experiences which parents pass through despite their needed desires for joy and fun for their children not having been met.

2.12 EFFECTS ON MARRIAGE

Enough empirical literature has been written concerning the potential marital difficulties faced by the parents of children with disabilities (Blair, 1996). These difficulties are considered to be related to their additional demands of caring for a child with disability. It is urged that often times, spouses may disagree on the mode of child treatment towards the disorder (Hall, 2000). As parents continue to interact with professionals, tension reduces and adaptation may increase, particularly for mothers who may be taking the child for treatment or clinical interventions. Difficulties in sexual relationships may result from a lack of privacy, fatigue, a sense of isolation on the part of each spouse or the fear of producing another child. Several studies have investigated the prevalence of marriage breakdown in such families. Overall, the results have been inconclusive, with reports of high rate of marriage breakdown and low marital satisfaction being balanced by findings of average levels of marital satisfaction and breakdown in other studies. One result which has been consistently found is that a stable and satisfying marriage appears to reduce the stress experienced by parents in coping with the disabled child. These findings have led some researchers to suggest that having a child with a disability in the family tends to strengthen strong marriages and weaken fragile ones (Blair, 1996; Fisman et al. 1989).

2.13 EFFECTS ON SIBLINGS AND GRAND PARENTS

Africa has communal type of life- style which is not individualist in nature. Zambia follows the same type of family system where children, grandparents and other relatives may still be under one roof. Siblings have a strong tie as the elderly siblings are the ones who normally care for the young ones. The gap the researches want to close is on whether siblings were affected by their brother or sisters' condition. How did they react? How do they cope with their brother or sisters' condition?

More of Western literatures indicate that the siblings at home may be greatly affected; this may lead to maladjustment caused by giving children a greater burden to care for their autism brother. This theme is worth investigating in societies where communal living is practiced. Since more of western literature indicates that some siblings may be so much involved in helping and assisting their brother due to our cultural setting of 'community responsibility. This could be as a way of compensation for parental disappointment of having a disabled child. Schubert's (1995) findings showed that some siblings may feel embarrassed to have such a sibling and may be aggressive to their brother or sister because of his age inappropriate behaviour (Grasberg, 2000).

Kaminsky and Dewey (2001) affirmed in their study that siblings with brothers or sisters who have ASD may develop low self esteem, less intimacy and be lonely since they cannot play well with a disordered child. Another fear which may grip the siblings is that parents may expect them to keep their autism brother and this may bring worries on whether they may find a wife or husband if they stay with an ASD adult. Further fears include siblings thinking that they may produce a child with ASD condition like their brother or sister in future (Kaminsky and Dewey, 2001; Schubert, 1995). The common Sources of Stress for Siblings might be:

i. Concern that they may have to care for their brother/sister in future.
ii. Embarrassment from friends and stigmatization for having such a child.
iii. Jealousy regarding amount of time parents spend with their brother/sister
iv. Pain and frustration of not having a normal brother to engage into daily activities.
v. Being the target of aggressive behaviours
vi. Trying to make up for the deficits of their brother/sister
vii. May be affected by the parents' perpetual worry about the child.
viii. Comments from the society about the child.
ix. Failure of the child to be self-reliant
x. Rationalizing that their sibling is normal
xi. Friends, teachers hate their brother or sister (Grasberg, 2000; Kaminsky and Dewey, 2001; Schubert, 1995 and Schubert, 1995)

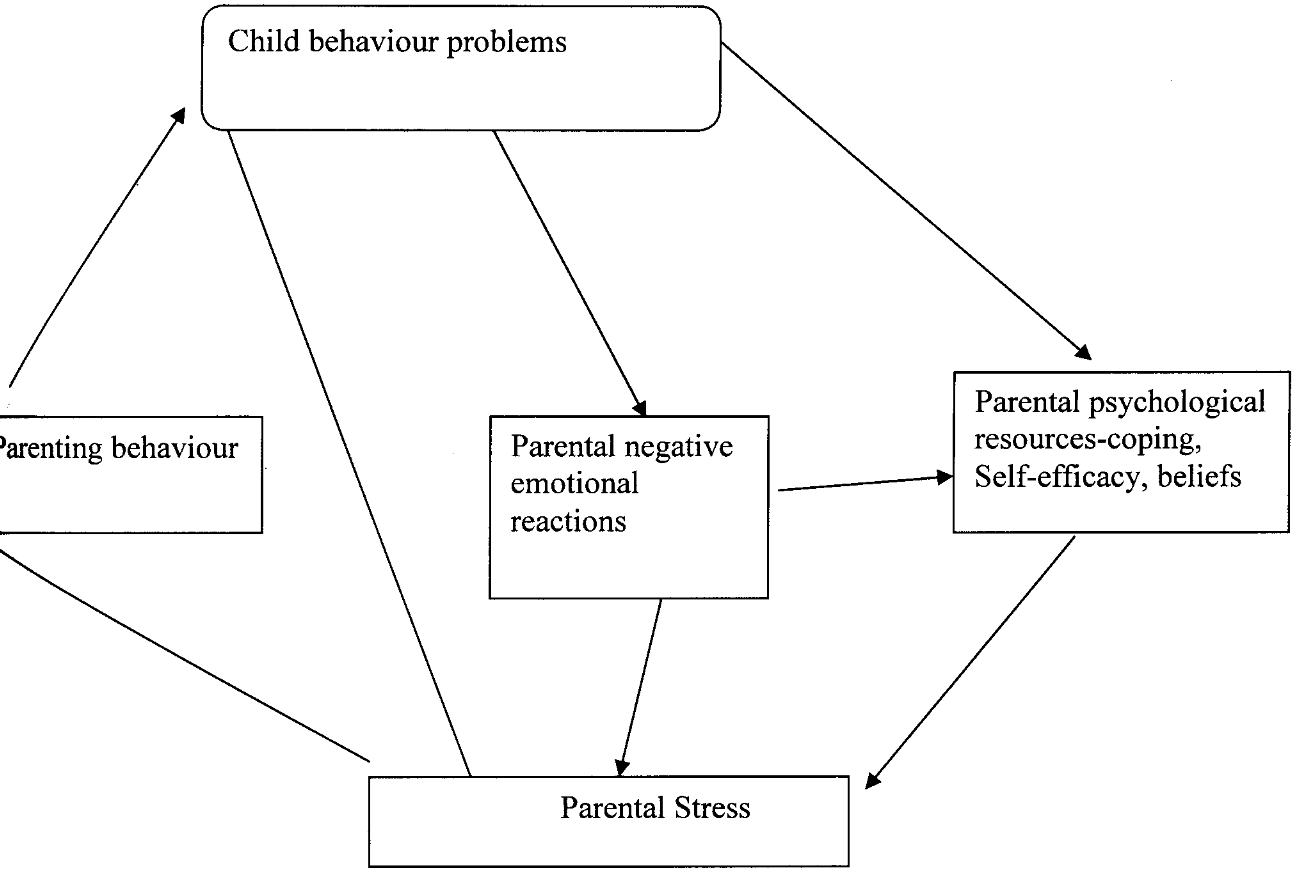
However, despite all the problems, such siblings, when they grow up, may choose careers which will help people with such disabilities or work under social welfare departments. Such children may be generally friendly to others especially people with disabilities (Kaminsky and Dewey, 2001).

In African culture, grandparents are normally given the task of caring for orphans and children with disabilities on the basis that these children give a good company to grandparents. The other reason is the assumption that grandparents can contain the problem by virtue of being experienced in child care and being related to the child (Serpell, 1982; Ng'andu, 1989). However even grandparents may be distressed for they also may feel like they have lost a grandchild whom they could freely associate or interact with.

The childs' behaviour with disability is challenging to any parent. Hastings (2002) in the study of parental stress and behaviour problems of children with development disabilities observed that children's behaviour problems lead to stress in parents and parents under stress adopt certain parenting behaviours that tend to reinforce the child's behaviour problems. He came up with a model which depicts a relationship between parenting stress, parent behaviour, and child behaviour problems in the context of development disability. See table 1.

A model of relationship between parenting stress, parent behaviour, and child behaviour problems in the context of development disability Child behaviour Problems. Parents with disabled children are greatly affected as shown in the chart below.

Figure 1.



Source: Hasting (2002).

2.14 COPING STRATEGIES TO AUTISM DIAGNOSIS BY PARENTS.

Lazarus and Forkman (1991) define coping as 'cognitive and behavioral efforts to manage, reduce or tolerate both external and internal demands that are impeded on a person and the outcome is dependent on the person's ability to overcome the situation.' Many parents use different approaches to overcome their situations. Some use positive reappraisal, confrontation, avoidance and escape avoiding. Positive reappraisal, as part of coping strategy is to have the faith and find new ways of combating the situation through creative approaches to the situation. Confrontation strategy is when a person expresses his or her anger by fighting for the rights of the child, finding a better school for the child rather than declaring that the child is not normal. Escape avoidance parents, are normally at danger, as the child's problem may lead to chronic depression and is more associated with failure to accept the child's situation (Dunn et al., 2001). Dunn et al. (2001) further state that positive reappraisal is ideal as it helps in making parents to easily accept the child's condition and move on with life. Talking about coping strategies, these may differ between men and women.

However, conflicting findings exist on whether mothers and fathers experience differing levels of emotional stress. Dyson (1997) says that there is no consistent gross difference in stress between mother and fathers. Whilst Gray (2003) agrees with Dyson and others that both parents will show emotional distress and that distress varies between a father and mother in emotional adjustment. Fathers suppress their emotions and show it through anger, rather than the sadness and crying which mothers do. Generally, fathers are reported to have difficulties in accepting the disability or disorder particularly if it occurs in a son or if the child is severely handicapped (Hornby, 1994). Furthermore, fathers are reported to experience a higher level of depression, personality and marital relationship difficulties than fathers of non-disabled children. Mothers could seek help from friends, own parents and the community for help. Studies suggest that such people who get support from the community have higher chances of managing their stress (Cameron, 1997; Newman, 2007).

2.15 TREATMENT AND INTERVENTIONAL APPROACHES

If children display some of the symptomatic behaviours just occasionally, a diagnosis of autism will not be applied. Part of the criteria for the diagnosis is that the child's abnormal behaviour is persistent over a long period of time and across many situations. So then, how can treatment or intervention be effective in such cases? It should be known that intervention does not completely cure or eliminate the condition; it only ameliorates the condition when you make the environment less challenging to the child. Studies done by Nweke and Sanders (2009) provide more insight on the impact of poor environment on children who are vulnerable to toxic effects of hydrogen, particularly during the developmental early stages of neurodevelopment stage. Children are not supposed to be exposed to modern environmental health hazards such as emissions from motor bikes, industries and mines, air and water pollutions, domestic wastes, contaminated water and food stuffs, noise and any other harmful substances, (Nwenke and Sanders, 2009). It is for this reason that we need to consider seriously the child physical and social environments during the growing stages of a child. By so doing, you will make the environment less challenging to the child with ASD. Such environmental hazards may further stimulate the child's hyperactive behaviour, resulting into more stress on parents.

A child with ASD has special needs which require both the parents and caregivers to know how to address them effectively. These special needs can be learned by adapting to systematic management techniques (SMT). Over time, parents can be said to adapt to the child's needs and the child reciprocally adapts to the care regime. As a result of such an approach of mutual adaptation, stress on both the child and parents reduces. This means that the child will experience less stress because his or her demanding behaviours are met with less resistance or hostility by the social environment. Parents too, experience less stress because the undesirable consequences of the child's behaviour are minimized and the sequence of events becomes more predictable (Reed and Osborne, 2010).

Such an adaptive pattern of parental care is analogous with providing a supportive environment for a person with mobility impairment, for example, having polio. In terms of mobility for a person with polio, a key term which is much used in service policy is 'access. Such a person can be afforded access to facilities such as slopes on cinemas or schools and shops by engineering the environment so that a wheelchair can pass through the doors or up ramps. In this respect, in spite of his/her legs being the same (his/her polio condition) the negative consequences are reduced through the provision of slopes and wheel chair. This simply means that being unable to walk does not mean that you cannot go to school or go to the cinema or go shopping. The disability will still remain the same but the handicap disadvantage is removed or at least reduced. This is what is meant by the term ameliorative intervention - an intervention that makes things better (without a complete 'cure').

In the case of children with ASD, communication difficulties many at times lead to frustration in both the child and parents, siblings and the members of the social environment. If the child's communication can be improved, then the levels of stress for all concerned will be reduced, and the situation in this case would improve (Rosenberg et al. 2011, Osborne, 2010). A child with ASD needs a different kind of intervention which has to do with communication that will enable the child to signal his feelings, desires and wants; and those feelings should be interpreted by the caregivers. In some cases, such can be achieved by teaching the child sign language.

Teaching speech with sign language is easy. Parents need to learn a few simple signs and use them when talking to their child. This is referred to as 'simultaneous communication' or 'signed speech'. Research suggests that the use of sign language increases the chance of children learning spoken language. Teaching with the Picture Exchange Communication System (PECS) is important; this involves pointing to a set of pictures or symbols on a board. Whilst pointing at the pictures, sign language and verbal communication can be combined. If well-used, this can also be effective in teaching speech www.AutismResearchInstitute.com 23/01/10). Another approach is called the Experimental Analysis of Behaviour (EAB). It involves close observation of the child's patterns of behaviour and systematic exploration of incentives, rewards and punishment (contingencies) with a view to maximising the frequency of desirable behaviour and minimising the frequency of undesirable ones (Hallahan et al, 2009). Such programs are typically unique to the individual child and can be used by his family in other social settings. Children with ASD have differences in behaviours, but there are some commonalities that allow an element of generalisation. For instance, feeding, toileting and dressing (so-called activity of daily living - ADL) are important for every child. Ritualistic behaviour is common in almost all children with ASD (Gallagher and Coleman, 2006). So what has proven effective for one case can be a valuable starting point for the design for an individualised programme plan (IPP, or IEP) for children with ASD. In the USA, IPP/ IEPS have become part of the standard promising of services of families of children with disabilities such as autism.

Professionals and parents work in close consultation to design these plans and use them to motivate the child's progress. When a plan has been agreed upon, it was agreed by all parties (doctor, school principal, social worker and parents). When parents are trained and sensitised, they advocate for better services for their children as well as lodge in legal complaints, to claim specific service entitlements (Cameron, 1997; Newman, 2007).Other therapies include, vision therapy. Children with ASD need training in eye movement such as the use of a touch in the dark room so that the child is able to follow the shadow. A one- to two-year vision training programme. This involves ambient prism lenses and performing visual-motor exercises which reduces or eliminates the problem of eye contact. There are many types of therapies for a child with ASD. These may include occupation, music, speech therapies and use of computer software activities, exercises, good nutrition and enough rest. When such intervention is done early in life, then the child and parents stand to benefit in ameliorating the problem in a child with ASD.

2.16 SUMMARY

The review of the literature has brought to light some of the challenges which parents encounter on their journey to finding a solution to their child's disability such as autism. We have looked at the historical background of autism, its prevalence, costs to the family, diagnosis stages, coping strategies and how autism also affects the family, particularly the siblings in the house. We also looked at the treatment and interventions for children with ASD.

CHAPTER THREE: METHODOLOGY

3.1 INTRODUCTION

This chapter is divided into the sub – sections, which include the following:

3.2 Research design.
3.3 Sample size, site and frame.
3.4 Modes of participant's selection criteria and procedures.
3.5 Methods of data collection and data analysis.
3.6 Ethical issues.

3.2 RESEARCH DESIGN

The methodology employed was a qualitative hermeneutic phenomenology. Leedy & Ormrod (2010:141) define a phenomenological study as, 'a study that attempts to understand people's perceptions, perspectives and understandings of a particular situation.' Phenomenology is a new scope of philosophy and has its origin in Husserl around 1889-1970. Manning (1996), says qualitative research is regarded as research that produces descriptive material based on stories. Qualitative research has elements of judgement choice and interpretations (Newman, 1994; Creswell, 2007). The aim of the phenomenological approach is "to bring to light the 'lived experiences' of the phenomenon to a description which is universal to another person, then listen to that person's dialogue and interpret what he or she is telling in a written text". A phenomenologist focuses on describing what all participants have in common as they experienced the phenomenon such as grief which is universally experienced in situations like having a child with ASD (Creswell, 2007:57). During this period, a researcher brackets, or suspends past knowledge and tries to get new insights to enrich the description of the data being collected. Bracketing is the process of setting aside one's own beliefs, feelings, and perception so as to become more open and faithful to the phenomenon (Colaizzi, 1978; Strubert and Carpenter, 1999 cited in Creswell, 2007:269). The reason for using the phenomenology approach is that it brings to light some salient features concerning the experiences of parents of a child with ASD. The phenomenological approach generated interpretive enquiries which helped the researcher collect and analyse materials with a specific context on the experiences of parents of a child with ASD.

3.3 SAMPLE SIZE, SITE AND FRAME

The initial sample consisted of 20 biological parents of a child diagnosed with ASD. Participants who took part were 17 biological parents. The three who did not take part in the research were two men and one woman. The two men could not be found at home despite several appointments due to their busy schedule at their working places. A woman was a student at boarding college away from Lusaka and could not manage to travel from Kasama to Lusaka due to transport costs. All participants were recruited within Lusaka Province. These participants were recruited from institutions where they take their children for interventional programmes and schooling. The places are UTH Special School, UTH- CBIA and Bauleni special school. The reasons for choosing Lusaka province is the fact that autism programs, clinical diagnosis, intervention and institutions of learning are found and located in Lusaka. Permission was granted from the authorities who run the institutions, who later on first contacted the participants and gave the researcher information on participant's contact addresses. The researcher further contacted the parents and appointments for dates and venues for interviews were arranged. The purposeful sampling method was also employed .This method was used because there are few diagnosed cases of autism in Lusaka. This also made it difficult to conduct a pilot study on this research project. Recruitment approach was also employed with the aim of getting more insightful data from the participants. All the participants:

1. Were Biological parents of the child.
2. Had the child once assessed by the multi-disciplinary team at UTH hospital and ZAMISE.
3. Were living in Lusaka.
4. Were willing and consented to take part in the research.

Below is the biographical data of parents and the ASD children. See figure 2 below.

FIGURE. 2.

BIOGRAPHICAL DATA FOR RESEARCH PARTICIPANTS.

ipants	**Sex**	**age**	**Home language**	**Highest Level of education**	**Occupation**	**Marital Status**	**A child with ASD**	**No. of sibling**	**Year of diagnosis**	**Child's level of education and type of treatment undergoing.**
	M	46	English/ Nyanja Tonga	Tertiary	Banker	M	F(5)	06	2006	Educ.(Ni) Speech, Physio
	F	34	English/ Nyanja, Tonga	Grade 9	House wife	M				
	M	33	Nyanja/ Bemba	Tertiary	accountant	M	M(3)	01	2009	Educ(Nil) Occupation/physio
	F	29	Nyanja	Grade 12	Court messenger	M				
	M	39	English /Bemba	Tertiary	Army officer	M	M(4)	03	2009	Educ (nil) Occupation, speech.
	F	37	English/ Bemba	Tertiary	House wife	M				
	M	35	Nyanja/ Tonga	Grade 12	Hospital assistance indoor servant	M	F(4)	01	2009	Educ (nil) Speech. Occupation
	F	29	Nyanja/ Tonga	Grade 12	House wife					
	M	34	English Bemba	Tertiary	Hospital accounts clerk	M	F(3)	00	2009	Educ (nil) Occupation.
	F	29	English/ Bemba	Tertiary	Nurse	M				
	M	34	Nyanja	Tertiary	Police officer	M	F(4)	03	2009	Educ.(nil)Speech, Occupation
	F	29	Nyanja	Grade 12	House wife	M				

	M	34	English	Tertiary	Sales agent	M	M(6)	02	2008	Educ(Level one nursery school)
	F	35	English	Tertiary	Project administrator	M				
	M	40	English Kaonde	-	-	M	M(4) M(8)	03	2009	Ed(nil) Ed(grade1)
	F	38	English/Kaonde	Tertiary	Housewife/self employed	M				
	M	33	English/Bemba Bemba	Tertiary	Electrician/ video editor	M	M(4)	00	2010	Nursery. Occupation, Speech
	F	37	English /Bemba	Tertiary	Billing officer (Unza student)	W	M(7)	02	2008	School Grade 1
	F	22	Bemba/ Nyanja	Tertiary	Student (NRDC)	S	M(4)	00	2010	Nursery. Occupation.

3.4 PARTICIPANTS SAMPLING PROCEDURE

20 biological parents and 11 children with ASD were identified at University Teaching Hospital (UTH) Special School, UTH- CBIA Clinic and Bauleni Special School.17 parents finished the research (10 mothers and 7 fathers). The reason for selecting only biological parents was to get a clear picture and first hand information and feelings of having an ASD child in the family and their day to day reflections about the child's condition. This was so because biological parents understand the child's condition better. Furthermore, biological parents are the primary care givers who face challenges from the child on a daily basis. The age range of the children was from one year to seven years (1- 7 years). This age range was preferred because most of the parents' memories about the event on the child diagnosis are still fresh, painful and parents are still uncertain about the child's welfare and future life. Moreover, this was also the pre-school stage or early childhood developmental stage which is very important to both the parents and the child.

There were eight married couples, one widow and one single mother. Seven couples were interviewed. Interviews for couples took place at their respective homes. Amongst the participants, were two female students, one widow -third year student at UNZA and the other was a third year student at NRDC. The age range for respondents was between 46 years – (male) and 22 - years (female).The average age for mothers was 29.3 years whilst that for their husbands was 35.5 years (see figure 2 above). The children's age ranged from 3 years to 7 with an average age of 5. All men and six women interviewed were in formal employment. The other 4 women were house wives. An interview guide was used to guide the researcher during interviews. 22 interviews were conducted, five interviews were conducted from focus groups. The first focus discussion group (A) had 12 participants. These were parents with first born children diagnosised with ASD. Group (B) comprised parents who had other children diagnosised with ASD apart from the first born. The initial number was 8 only six participated. Group (C) comprised seven parents who were coming from low economic status categories. The fourth group was for parents from high economic status group. In this research, they were no members coming from this group. The final group, group (E) comprised all parents who took part in the research (take note that some of the parents were found in more than one group. For example, a parent from group B could also be found in group C again.) During the interviews, the researcher could ask for the child to be nearby the parents whilst the interviews were going on. The researcher's assumption was that this could help parents reflect more on challenges which they underwent and are still undergoing with the ASD child. Parents could mention the names of the doctors, psychologists, teachers and some schools whom they met during their search for diagnosis and quality services. The researcher omitted the names and gave all respondents pseudonyms names to protect their anonymity. Interviews were conducted in fluent English, Chinyanja or Chibemba or a combination of the three. The three mentioned languages are the commonest languages used in Lusaka as a means of communication.

To start the interview, the researcher would always introduce himself and explain about the research being carried out, its importance and relevance to society. The researcher then informed parents on the importance of their informed consent towards this research and he also talked about confidentiality. Permission was granted from the participants to tape -record the interview. Written consent forms were given to each participant to sign and one copy remained with them .Soon after an introductory interview, parents were asked to talk about their experiences of the phenomenon as indicated on the pre-planned interview check-list below (though not restrictive of the order)

i. Chronological experiences as constructed by the parents as they make sense of the birth of a child with ASD.
ii. Their ideal professional and government services to both parents and children with autism
iii. Their general perception and knowledge of autism.
iv. Their personal desire about treatment, intervention, education for children with ASD.
v. Reflection and the meaning of their experiences and what these experiences represented to them as they search for a diagnosis and services.
vi. Costs of caring for a child with ASD.
vii. Their desires for their child and plans for their child
viii. Their initial feelings about the condition and the coping strategies.

Each parent was interviewed once with a minimum of 2 hours and maximum 4 hours. Focus group sessions were conducted once. The following were the focus groups:

i. Group one consisted of parents of ASD children whose child was their first born.
ii. The second group - parents who had a child with ASD but not a first born
iii. The third groups - parents of middle economic status
iv. The fourth group had parents of low economic status.
v. The last group had members from all the groups.

In the sample, there were no children who were found from high economic status group)

3.5 Focus Group

During the focus group meetings, the researcher could meet the participants and introduce the topic on what is it like to have an ASD child? Each focus group would allow participants share their experiences with others on what they have gone through with their ASD child and how they were coping with the challenges. After each person had spoken, other parents could ask questions or contribute on what they saw as common challenges with their children. During this period the researcher was recording and guiding the group so that they do not move away from the topic under discussion.

In the final group, group E, all the parents came together .Parents shared their challenges and what they considered to be the best way forward for their children in areas of education and health provision. After each interview (Group and individuals) participants were requested to fill in their biographical data and that of their child. At the end of the interview, the researcher briefly explained that he also had a child with autism. The researcher's assumption of informing the participants at the end of each interview was to avoid participants' having a pre-conceived mind toward the topic which might have made participants withhold some important data. All the interviews were done within 2 months. In the third month participants were invited again for any latest information which they needed to inform the researcher apart from what was already discussed or talked about through emails and phone.

3.6 DATA COLLECTION

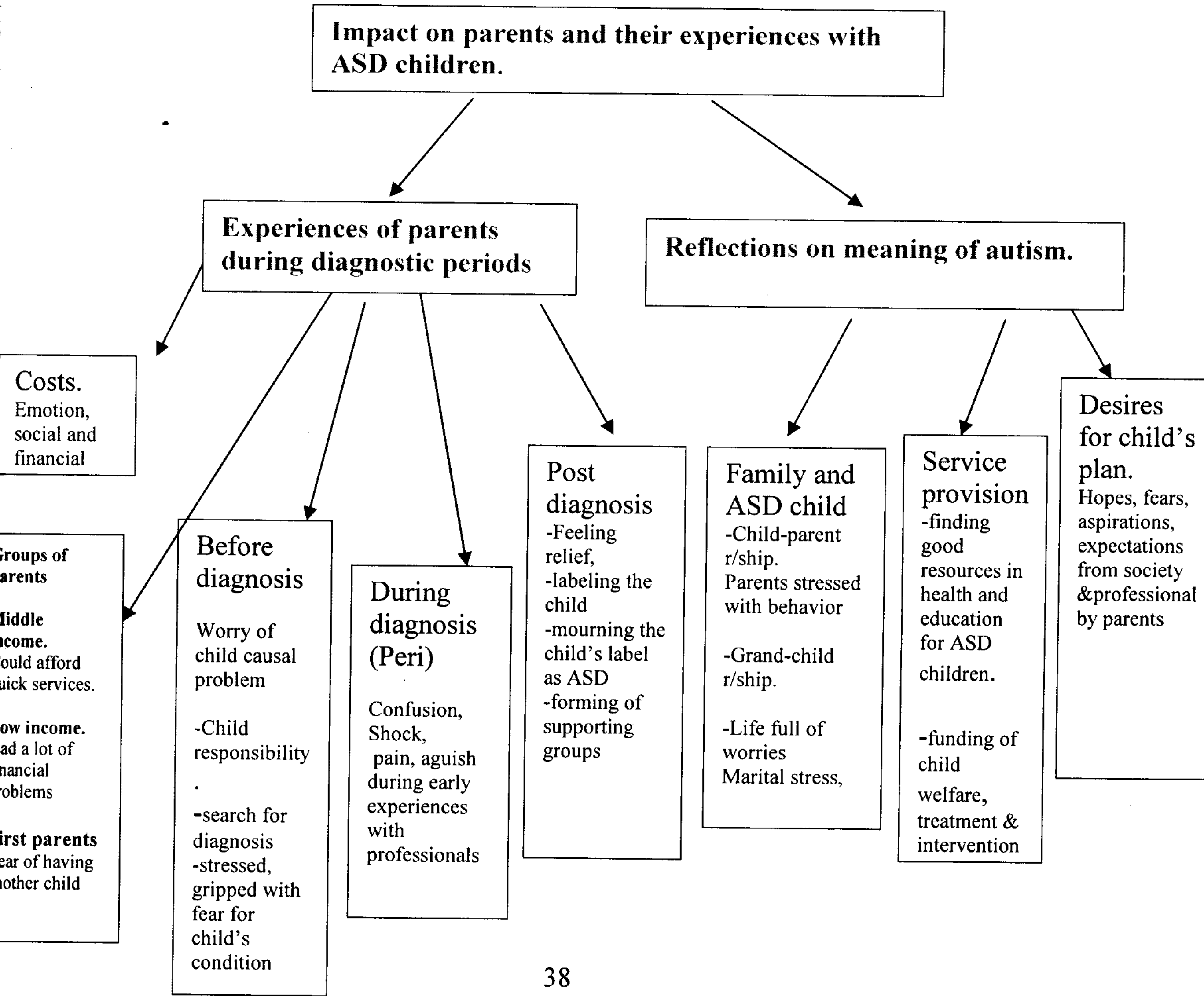
3.7 INTERVIEWS

Semi-structured and face to face in-depth interviews were used to collect dated. De Voss (1998) suggests that face to face interview is important because it helps the researcher to enter into the feelings of the client (empathy), semi-structured interviews is good because it is flexible and allows the researcher to gain full participants experiences, whilst spoken interview brings the experiences of the client closer to the person, unlike structured or written interviews. A semi-structured interview guide was drawn. The researcher used non - standardized interviews which allowed participants to tell their stories in any way they wanted. This was after participants understood the researcher's question: What is it like to be parents/parent of a child with ASD? Or tell me in your own words about your experiences as a parent with a child with ASD. This mode of data collection is in line with phenomenological study approach which has a philosophy of 'live the experiences'. Interviews were conducted either at the home of the client or at an agreed place. Interviews could last 60-240 minutes depending on the participant's amount of data which they wished to share with the researcher. Participants were free to call back by telephone or email the researcher, after remembering some more information concerning their experiences with their child. Only two parents called and one female student e-mailed me.

3.8 DATA ANALYIS

The Collaizi's phenomenological method was employed, [which was later on modified by Moustakas (1994)]. Moustakas methods were preferred because, they focus less on the interpretation of the researcher and are more on the description of the experiences of the participants. Moustakas focuses on one of the Husserl's concepts of the epoch (bracketing) in which the researcher set aside their personal experiences as much as possible to take a fresh perception towards the phenomenon under study (Cresswell, 2007). In this method, the researcher read through all scripts several times so as to obtain an overall feeling for them. Thereafter, the researcher looked at each transcript and then got significant sentences and phrases that were directly looking at the experiences of parents with children with ASD. Meanings were formulated from the significant statements and phrases. The formulated phases were clustered into themes which were common to all participants' transcripts. Later on, the results were integrated into an in-depth, exhaustive description of the phenomenon. When all the descriptions and themes were obtained, as a way of conclusion, the researcher approached some participants for the second time. The aim of approaching participants for the second time was for further verification and validity of the findings. New data that came up during this period was included in the final description

Figure3. Results of data analysis and interpretation.



3.9 ETHICAL CONSIDERATIONS

1. Permission was obtained from The University of Zambia Research Ethics Committee.
2. All participants (parents) were asked to sign a printed consent form which provided the aim of the study and the form clearly stated that participation was not a forcing matter but free and voluntary.
3. Participants were free to refuse or drop out of the research during the research project.
4. Participants were informed that a feedback would be given on the outcome of the results. A summary of the results would be made available to participants and the institutions were the researcher recruited the participants.
5. Privacy and confidentiality of the data was taken into consideration. All names of participants were disguised and the transcripts were coded to avoid putting name of participants. The participants were assured that the tape recorded information were only for academic purposes and were to be carefully secured and later on after some time will be disposed off.
6. Potential risks which might cause shame and embarrassments to clients and the society were avoided at all costs.

CHAPTER FOUR: RESULTS AND DISCUSSION

INTRODUCTION

This chapter comprises a detailed discussion of the results of the data analysis and interpretation process. The themes and categories that resulted from the data processing were grouped into ten themes. The ten themes had also its sub themes plus five focus groups. The ten themes were:(1)Making sense out of the birth of an ASD child;(2) Encounter with professionals ;(3)Parents general knowledge of ASD and their perceptions;(4) In search of diagnosis;(5) Effects on the family;(6) Costs ;(7)Cultural beliefs ,attitude and stigmatization ;(8)Services inadequacy.;(9) Future plans, desires, hopes and fears ;(10) Parents coping strategies. Interviews were also conducted with each participant and each respondent was free to use their language of choice. The data collected was transcribed from tape- recorded verbatim, daily notes and all significant statements and phrases. Interviews conducted in Chibemba and Chinyanja were translated into English. Some words and sentences were left in their local languages in order to maintain the original meaning. All interviews were translated word by word after listening and re-listening to them. This helped the researcher to come up with themes from the topics of discussion. All Significant statements or sentences were extracted with their formulated meanings.

The findings were tabulated in form of a story or report. This approach was used to maintain the originality of the participants' anecdotes and experiences so that a true reflection is reported. Later on, all the formulated meanings were clustered and the results were put into themes as follows:

1. Making sense out of the birth of a child with Autism Spectrum Disorder
2. Encounter with professionals
3. Parents general knowledge and their perceptions of Autism.
4. In search of diagnosis.
5. Effects on the family:
6. Costs.
7. Cultural beliefs, attitudes and stigmatization.
8. Services inadequacy
9. Future plans, desires and fears .hopes

10. Coping strategies.
11. Group discussions.

Theme 1. 4.1 MAKING SENSE OUT OF THE BIRTH OF AN ASD CHILD

This theme explores early recollections of couples' anticipation when they were expecting a baby. Parents also briefly talked about the child's birth and the delayed developmental milestones. Results in this theme indicated that six of the ten mothers reported having had no reference of any problem during pregnancy or at birth. Only four mothers had some slight observation, which included, one parent giving birth to a blue baby through a Caesarean section whilst two mothers had long labour pains of two hours to 2 days. The other mother gave birth to a child whose umbilical cord was hanged around the neck. Apart from these few observations from the four mothers, all participants reported that their children were born healthy, cried at birth, had normal weight and soon after giving birth their parents were discharged from health centers.

4.1.1 Sentiments from parents who experience problem-free pregnancies

Six parents reported no reference of any problem during pregnancies and at birth. Parents reported that they did not notice any delayed developmental milestone in the child with ASD condition until around six months to one year. However, parents did not have any clue that the child would have any disability condition such as autism. Comments like'*...James, 4 years was born normal, did all his milestones on time. He crawled on time. He walked at 1 year 2 months but that didn't worry me because the first born was like that*.'

Mrs. Mubanga[1]

.... When I was pregnant, he was just okay and the months were fulfilled very well. I gave birth at UTH. Otherwise the baby cried normally when he was born. There was a period of time that passed before medical staff got their equipment so that they come and use them but he cried normally. They said everything was normal and we were discharged the same day I delivered. So I didn't pay particular attention then until after six months ..... (Mrs. Mumbi)

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[1] All names of participants, location, work places were changed for ethical reasons. Use of names from various places does not mean that all participants interviewed were coming from the said provinces or are prone to ASD. These are purely names which the researcher used with no connection to the tribe, individuals or province and are there for only academic purposes.

Siabonga is the first born and he will be turning 7 years soon. At birth everything was just normal. He grew up and did so fast. I think his milestone were way ahead. Like by 6 months he could crawl, sit and he could say mama, dada and then by nine months he could run around.

Mrs. Muzemba

The cause of ASD is still inconclusive and observations from the above parents still confirm that the cause of autism is still a mystery. All the six mothers experienced problem-free pregnancies and yet their children were diagnosed with autism. Current results are consistent with Hallahan, Kauffman & Pullen (2009) and Rosenberg, Westling & Mcleskey (2011) who observed that it was difficult to determine the cause of autism in children. Scientists have however, established some causal factors to ASD which are linked to neurological, biological, immunological and other Peri-natal factors (Kaplan & Sadock, 1998).

4.1.2 Sentiments from parents who experienced problems during pregnancies and at child's birth

Four mothers experienced challenges when giving birth. Problems included having long labour pains, cesarean sections and giving birth to a child with an umbilical cord hanged around the neck. Despite the said challenges, none of the four mothers associated the child's condition to Autism Spectrum Disorder.

I had BP. ...the child was supposed to be born on Christmas day but because of BP, they operated on me on 12th December, that's when she was born. But after one month, she developed a running stomach (diarrhea) and began to look pale and weak. After about another month, we took her to the hospital.... After about four months, we took her for a test and she was found HIV-positive ,and we started giving her ARVs after one year.

Mrs. Mulenga.

I got married when I was 31 though there were complications. I had two days of labor pains until he was born. He was OK and we were even discharged.

Mrs. Musole.

She is the second born in the family. She was born quite alright but the umbilical cord was around her neck. Unfortunately it was during a health workers strike, so we had two ladies who were giving birth so there was only one nurse. I just saw my baby with the umbilical cord around her neck. The nurse told me to remove it from the neck of the baby, and I did, but she cried. She started talking the first sounds ta ta ta, mama mama and name calling recalled Mrs. Mwange

Kaplan & Sadock (1998) observed that children with Autism Spectrum Disorder have been found to have significantly more minor congenital physical anomalies than their normal siblings and that there are a lot of pre and peri-natal pregnancy complications in mothers with ASD children. Some of the complications may include maternal bleeding, respiratory distress syndrome and anemia during the neonatal period. Such are on a higher side as compared to normal children. In the present research, no mother, even those who had complications when giving birth, attributed their minor complications to ASD condition. However, results are similar to observation made by Kaplan and Sadock(1998).

4.1.3 Frequent use of drugs by mothers during pregnancy

One mother reported frequent use of drugs during pregnancy. When asked on whether she ever attributed the use of drug to the cause of ASD Childs' condition? The response was negative.

Lucky enough one of the neighbors was a clinical officer, so she prescribed some phenigan to help stop the vomiting, which didn't work because I vomited it out as well. I would vomit everything water, I had a very hard time holding down anything but I was given vitamin b complex injection for appetite, so even if I vomited, most of the time I still held down something.

Ms. Mwila

Kaplan & Sadock, (1998) observed that there was a high incidence of medication usage during pregnancy in mothers of ASD children. For example, in the present study, Ms. Mwila revealed that most of the time she was on medication .

4.1.4 Multiple consultations by parents

The data collected reveals that desperation and professionals' inconclusive advice made parents seek for a second opinion. The other reason brought forward by parents in the study were that diagnosis could take long followed by too many assessment processes and long hours of waiting at the hospital and between assessment and next appointment.

Anxiety for an immediate answer on the cause of the child's problem forced some parents to use unconventional methods of removing tongues ties so that the child could talk. For example, tongue tie cutting were normally done at home by herbal and spiritual leaders or elderly people who claimed to have knowledge about them. One parent believed the child condition was due to witchcraft, hence believing the advice from a *profita* who told him to get hot water from Chinyunyu hot spring in Chongwe district and then mixed it with Vinegar as the remedy to the problem. Parents' desperation could worsen by over-assurance promises by health professionals. It is important to note that multiple consultations is a good step taken by parents, however, some of their consultancy had no professional research credibility to give them a good diagnosis over the child's condition. Cosser (2005) postulate that parents frustration comes about by seeing many professionals and spending a lot of money, then they don't get help from the professionals.

...last year I was going for treatment in Botswana and South Africa. I wanted to get a second opinion because he had stopped responding to his name, unlike when he was a baby. He was also very hyper. I took him to a speech therapist who suspected that it might have been autism but wanted confirmation by a psychologist

When we took her to the hospital they said that she didn't have a tongue tie. I work at the clinic, Chawama health centre, we have an elderly nurse who is specialized in this. So she invited us to go to her home. When we went there, she checked her and said she's got those things around her tongue, they call them 'amasasala' (Tongue ties). They had to cut them. ..... We also took her to a very old man who was a clinical officer he also knows these things very well. When we took her there he said they've cut them but they cut was too much "she will talk just be patient*

Mr. and Mrs. Mpundu.

4.1.5 Parents' frustration with the child's behaviour

Results on the study showed that parents suffered frustration and at times could not understand why a small baby could behave in such a manner of throwing tantrums, repeating words and poor communication skills. Reflections from parents like Mrs. Mwaba gives a picture on the impact on parents of discovering that a child has autism *'The other experience is when she's playing with other children, she can't play like them, you give her a toy at times she will throw it away, you try this she does the same. Sometimes you wonder, 'what can I do?' Such kinds of questions come. She can't say wee-wee, she can't say poopoo, she will mess herself anytime anywhere, sometimes she will just go on the table and sit there and wee-wee....when you buy him toy cars, he was just interested in the wheels, flipping them. He loved cars till today, and at school whenever he sees a car he would want to go into that car and go wherever in that car. So he would just cry throwing tantrums and pulling other children's hair. Mrs. Muzemba*

In the present study it was observed that parents attested frustrations and stress towards the Child's' inappropriate behaviour. Donovan (1988) indicated that parents of children with autism experience greater stress than parents of children with mental retardation and Down syndrome. For example, a child with autism may not be able to express his or her basic wants or needs. The child's frustration can lead to aggressive or self injurious behaviuors that threaten their safety and the safety of other family members (e.g. siblings. Since children with ASD have deficits in social skills, such as lack of appropriate playing habits. These act as sources of stressful events for families. Data collected showed the mother of two children with ASD (like others too) struggled on daily basis to get the children sleep, stop crying and running about in the house or eat a wider variety of foods. All of these deficits and behaviors are physically exhausting to parents and they emotionally drain them.

4.1.6 Parents' reflecting on the early years of the child with ASD

All parents said that it was difficult to understand the 'strange' child's developmental milestones and the world in which their children were 'living and operating in'. Participants described the times as hard moments, because the child behaviour was peculiar and difficult to make meaning out of it. Mr. Mushota had this observation, ... *'the child lost interests in many things, could isolate oneself, was withdrawal, and lacked appropriate communication and language skills. We started noticing some peculiarities on my son when he was three years old.... He could wake up very early and sleep very late without it having any impact on him. You will think that maybe he's tired but then he could continue running around.*

....So we just saw that she started crying abnormally sometimes uncontrollably. Crying could even go up to an hour.

Mrs. Mwange.

...being our first born, we were anxious to see our daughter talk to us. But nothing was happening...

Mr. and Mrs. Mpundu.

Then I noticed something, it was between two and three years old when he just started shunning people, enjoyed being alone and singing a lot. But at two, he stopped talking and we were looking forward to hear him speak....

Mrs. Muzemba

There was one time he should have been two or so years old. I can't remember what I stopped *from doing and he burnt his hands on the table. So I thought that was very odd for a child ...*

Is. Mwila.

I remember Siabonga used to cry, he could cry from 24hrs to 06hrs crying. He cried for four months continuously every night. When he starts crying the chair would even shake. We were all wondering and getting mad on him, so I could just grab him and nurse him until 06hrs then he could sleep. He could just sleep for an hour.

Mrs. Muzemba

4.1.7 Summary

The theme has highlighted how ASD children develop during pregnancy and the first three years of life. Some parents reported that their children seemed different at birth. Such a condition is called as early-onset autism. Other parents report that their children seemed to develop normally and then had a major regression resulting from the characteristics of autism, usually around 12-24 months. This condition is said to be late-onset or regressive autism. However, many parents reported that there was completely normal development (e.g., speech, behaviour, social) until sometime between 1 and 2 years of age. The findings clearly show that much still remains to be learnt about the cause of autism, and it still appears most reasonable to suppose that ASD begins with certain broad indications of neurological, biological, immunological and peri-natal factors s some of the causative factors (Hallahan, Kauffman & Pullen, 2009; Rosenberg, Westling & Mcleskey, 2011).

Theme 2: 4.2 ENCOUNTERS WITH PROFESSIONALS

theme 2, the study looked at the relationship that existed between parents and health helping ofessionals during the time when parents were searching for a childs' diagnosis. All parents in s present study had an interaction with health professionals. The road to child diagnosis started h assessment at UTH, then Zambia Institute of Special Education (ZAMISE) for school cement and finally Community Based Intervention Association(BCIA) clinic for therapies ectively. Parents were given an assessment form from the speech center, which indicated the ssment procedures and the type of professionals to visit (see attached appendix 7). According e researchers' observations on the assessment form, the design of the form had little help in iding quicker methods of diagnosis for a child with ASD. It is more based on school ment than ways of early child identification on ASD. Helping professional do not use any e ASD instruments as discussed earlier on (See page 13) for child assessment.

Parent's first instance of help was from the family members' particularly elderly parents, then the community and finally health professionals. This then could be the beginning of a long painful, frustrating, tiring journey in search for a meaningful diagnosis from health professionals. Researcher's findings revealed that parents' relationships with professionals were extensive, inconclusive, frustrating and time consuming. Most parents said that they had a rough experience of hospital life, particularly with appointments of which some could last 2 years to 3 years before seeing a doctor again. Participants in the current study, attributed part of their frustrations to the child's inability to communicate effectively and behave appropriately in public places like hospital where you need to have patience waiting for a turn with a doctor or health worker.

Another cause of frustration, stress and pain to participants were lack of enough knowledge by professionals about ASD, shortage of qualified human resource who can be specifically assigned to children with ASD. All except two participants in this study, reported predominantly negative experiences as they interacted with a variety of helping professionals in the specialties of psychology, neurology, psychiatry, speech, nursing, general doctors, and health registry officers. However, parents expressed satisfaction with services and reception at CBIA, the centre of child excellence, where occupational therapy and physiotherapy is conducted. (Participants only concern about CBIA was, shortage of man power and little time of therapy services. For example, parents could meet the therapist once in a week for just an hour for at least six weeks and that could be the end of therapy sessions, then another new group could start.)

Parents' observations were that some professionals brushed aside their concerns on the child's lack of communication skills and age inappropriate behaviours. Professionals could call a child 'late bloomer' or 'still young'. The behaviour by professionals made parents perceive their concerns as often dismissed as products of worry rather than serious concern and observations.

At UHT we were given some forms for assessment which made us see different doctors at clinic 6 and 7. No proper answer was given on the problem of the child until we were directed to JK's physiotherapy clinic(CBIA) where they started doing some speech therapy. So we came back, we stayed but nothing...

When I went to the hospital, I was told that the child lacks parental guidance. I was working in the hotel industry and my husband was a business man. I was so hurt by those remarks and I even stopped work. The hospital gave me a two-year appointment. I vowed never to have another *child again.*

Mrs. Mwanza (a mother of two children with autism)

They (helping professionals at scanning lab) were rude and I felt discouraged. I went searching for the prescribed drug in town but there were nothing till I found that it was K380 000 in Lusaka Chemist. Because we delayed, we found it finished and the next person who had it said he was selling it at K500 000. After we managed to get the medicine, we did the scan. There was nothing found.

Mrs. Mwaba.

Burkhardt (2001) states that negating parents' needs may bring more pain, anguish, helplessness and despair and contributes to parents' feeling of anger and dis-empowerment. Osborne and Reed's (2008) findings, in England on parents' perceptions of communication with professionals during the diagnosis of autism , showed that, if the contact with professionals was particularly stressful or aversive, it may lead to any subsequent teaching intervention being less successful than it might otherwise have been. It may also lead to negative feelings and lack of trust concerning those professionals. Professionals need to know that these parents are already stressed by other environmental factors such as job loss, economic and political tensions, family matters, coupled with the child's condition. Brinker, Safer and Sameroff (19940);Donovan (1988) and Dyson (1991, 1993, 1997) confirm that parents with disabled children experience higher levels of stress as compared to parents of normal children. Smith (1994) examined the quality of medical care, as experienced by 128 British families of children with autism. His observations were that despite the improvements, there is still a problem to get right support from the professional and right diagnosis during the early years.

Osborne and Reed (2008); Osborne, McHugh, Saunders, and Reed, (2008) in Osborne (2009) explained that one obvious source of initial stress for parents of children with ASD is the experience of seeking, and obtaining a diagnosis of ASD for their child and their contact and communication with professionals involved in the diagnostic process. Gray (2002) further observed that during this time of interaction with professionals, many parents undergo a great deal of frustration and pain of not having a concrete answer from professionals. Osborne and Reed (2008) suggested that the wishes of parents during diagnosis as they meet with professionals was having a service which has a quicker process, easier coherently structured content . Serpell and Nabuzoka (1991:95) postulate that "identification of disabling conditions [such as autism] at an early age calls for fine-grain analysis of behaviour using precisely calibrated instruments and generally presupposes a high level of specialized training". It is with such a background that even in this research, parents needed a quick intervention approach toward their child's condition. Present findings indicate that participants strongly felt that professionals were punishing them by giving them long appointments when in fact a child was physically fit and whose diagnosis was not yet established. They observed that the process of diagnosis took so long that it brought more pain than the needed answers. As much as I do agree with participants, it is cardinal to note that ASD condition is still a new phenomenon amongst helping professionals in Zambia and any quick diagnosis without proper investigation may disadvantage the child who could have received inappropriate intervention programs such as sign language.

4. 2.1. Professional contradicting reports

Parents observed that professionals could give contradictory reports which were perceived as lack of knowledge about ASD. The one probable cause of contradictory reports could be attributed to inconsistence of professionals working with the child (changing of professionals on duty dealing with the patient case). Another observation was the poor hand- over of case history and documents of the child with ASD by both doctors and registry officers. This meant that each time parents visited the hospital, they were either attended to by the same or another new doctor, nurse or clinical officer who may not really understand the historical background of the case. Parents had no right of demanding for the old doctor but to accept the health worker on duty on that material day of appointment. Another observation was that professionals could argue on the cause of the child's condition in the presence of parents. There is a need for professionals to avoid arguing in the presence of clients as this erodes parent's confidence in their work. Follow-up cases with other multi-disciplinary working group need to be encouraged to avoid conflicting reports as observed in this research. Comments like those from Mrs. Mubanga who said that. *'There was a conflict between the occupational therapist who felt it was behavioural challenge and Dr. A, who thought that it was autism' … I had two reports but what was important was that intervention for a child with autism and behavioural challenge were the same.*

….we went to the female Dr. B who had said that it was delayed speech. Then she said that if the

child continues being hyper, she was going to put him on medication that would reduce the hyper. .. but JK and her group from CBIA said that children can't be put on medication coz it would worsen the problem; and they could later on be drug addicts. That's how we stopped going for appointments. On that group of people who advised against the use of drugs was a speech therapist, and that's what we started with for therapies.

Mr. and Mrs. Muzemba

.... Interestingly the staff at the hospital would argue about the child's condition as they also didn't know what was wrong.

Mr. and Mrs. Mumbi.

4. 2.2 Long appointments:

Parents complained of long appointments given to them by professionals which could take long to have the next appointment with doctors. This brought anxiety, disempowerment and stress on parents. The researcher's observations were that such long appointments are made by professionals due to high population of patients and few medical workers to attend to them. This has been caused by brain drain syndrome where most of the qualified staff have left the country for 'greener pastures', putting more pressure on few doctors. There is a need for government to reduce the ratio gap between patients and doctors for quality services. The most affected people are the parents from low socio-economic group who cannot afford high cost medication from private health centers.

At the hospital, they would give you an appointment for two months and tell you to come after two months and the child kept growing bigger. They needed to have 100 samples since the reactors were expensive to be used on only one patient. So we kept on waiting. That is when they said that we could go to Kanza Laboratory ,a private lab. We went there and tested. We brought the results back and they told us that it was just OK. Otherwise if we kept going there they would have just been telling us that the results were not ready.

Mrs. and Mrs. Mwaba.

.. I could have appointment of two months or so but if you met caring people they would reduce it to even 3 weeks. They told me to go to the speech and hearing centre that is clinic 6 and 7 respectively.... I made an appointment at clinic 6 and 7 for 3 months. I delayed to reach clinic 6

and 7. "Then babwela ba nipasa appointment ya two months inangu imagine" (They gave me a two months appointment again... can you imagine?)

Mrs. Mwansa.

..but the other clinics like 6 and 7 it was quite terrible; the appointments were at 07 hours, so we were told to come before that, around 6 hours. One day we even came earlier around 5:30 hours but still we found that there were a lot of people who were ahead of us. You can imagine from 05.30 hours we came to see the doctor around 14 hours. Then they tell you that 'no the doctor can't see any more patients so you have to come after 2 or 3 weeks on another day'... So you can imagine the anxiety ...when you change one appointment you also change the others which are in front(Mr. Mushota).

Mrs. Mwange gives a reflection in this story of one typical example of parents' experiences in Zambia at UHT on the road to diagnosis of ASD ....'*they recommended that I go to UTH to see neurologists. We went and booked. We were told to come after three months, the appointment date came, and I went there, met with the doctors at neurology. They examined her; they were many with the student, learning from her like "a child like this is it normal? What and what they examined her.*

Then they told me to go to the speech and hearing centre. So we went thinking that we are going to speech and hearing center only and we'll get help, they said you have to go and book clinic 6 and 7. We were directed as to where it was as you know UTH is big and it was late around 12 hours and the workers were going for launch and 15hrs they knock off, so I had to rush, and found that's when they are locking the office. ... I had to book their 3 months. I went home waiting for the appointment. I went to clinic 6 for hearing tests, checked the mouth and nose, but they didn't say what the baby had. They rang the bells for her, audio gram they played it in her ears so that she can tell if she hears anything, but the baby can't speak. There was no recording on the chart, because they didn't know if she was hearing or not. So they just wrote hearing is not good.

We went to the psychiatric; they asked some questions like 'amazi tundila tundila? (Does she often urinate in her pants?). By then she used to urinate abnormally of which I thought she wasn't okay. I explained all these. So they said she needs special education. We came from there. Anyway I was lucky coz while they were on the windows, they heard her crying. So what I used *to do was if I go there I tried to explain that the baby cries. So I beg of you to explain why this is so. At least you squeeze me somewhere; I can see there a lot of people waiting to be attended to, but please bear with me. Then they accepted. Sometimes I could lie saying the doctor said it should not take three months appointment no. just a month. They could say no there are so many people; I could just say that's what I was told they need fast results for the baby to see how she is. Sometimes they could squeeze you maybe two weeks, four weeks just like that. At last they got used with me such that whenever I go there they could just book for me. So there at clinic six they wrote down some papers and there at clinic seven. They gave me a same day appointment for both clinics.*

I told them and they told me to cancel one appointment. Somehow God told me not to cancel the appointment, then I just went back home. So I had two appointments on one day and I left the papers for speech and hearing at clinic seven, the other file at clinic six. I just told some one that if you hear this name just say she's nursing the baby outside. Those people come late there, you come around 05:00 hours but they come around 10:00 hours, the baby would have cried enough. So I stayed at clinic 6 and could go and check there. Clinic 6 they called me and asked "your friends have the papers from speech and hearing center what about you?" I have left it at clinic seven, WHY? They need to sign, she has to be admitted. She needs to be checked, visual assessment, because they were looking for the source, why she was crying. ' So madam, you need to go and get that copy.' Said the doctor. I said OK, let me go get it there, left the line, and went to get the copy. When I reached clinic seven, just at the door they called, Mary Mwange,I just had to rush inside.' it's me.' I said.

They got the paper and signed. She will be admitted. Come tomorrow early in the morning before 07:00 hours, before the doctors go to the wards, failure to which you will be sent back, even five times you will be going back as long as you don't come early. Besides sleeping there they refuse, they chase. So I got the paper and went back to clinic 6, and gave them. They attended to her, that's how quick it was. I went back waiting for her to be admitted ku (at) C 23. Then in April we went to be admitted, that was rain season. But there they said the doctors have already gone, just go back. I thought all the way from home come here just to be told you are late? I tried to go to the clinics to talk to the doctors in charge, but they said no! You are late; just go back its fully booked. They gave me another appointment. I went back, the actual day *came I went early on the morning as you know we come from a far place, and transport is a problem. So I had to make efforts and arrived in time. They admitted her, we were there for a day, and the following day she was supposed to go to the theatre".*

4. 2.3 Parents commendations to helping professionals

Some parents narrated that they had no problem with professionals since they followed appointments dates regardless of the time frame.

Well, I had no problem with doctors; I just kept the appointment date and time, (though appointments could be long). All doctors and nurses were good to me and reception was fine.

Ms. Mwamba and Mrs Mweni.

The place where they do physiotherapy,that side people were very helpful and we never even...spent time there. It was quick and the service was so excellent, not clinic 6 and 7.

Mr. Mushota.

4. 2.4 Professional knowledge about autism

Parents further felt that many professionals in the health and education sectors had little or no knowledge of ASD, its onset, cause and early signs:

They would have told me what was wrong if they knew. I used to ask them, but they never said anything. They ruled out brain damage as there was no accident during pregnancy, birth was normal and he did not suffer any accidents afterwards. They also recorded that everything was normal and they just wanted to keep monitoring him without knowing what was wrong. It pains to have no clear answer in such a situation.

Mrs. Mumbi

To put it straight forwardly, there are very few people who know about autism. We have tried taking him to Maina Soko, our military hospital but the doctors or nurses have no clue about autism. They may provide physiotherapy but that is a very little component for him. He is active, what is needed is therapy for autism conditions.

Mr. Mubanga.

When parents were asked on whether regular teachers know about ASD condition. Parents said no except for special education teachers '*... no in fact I was the one who was telling them except for the last one. (Teachers)When I told her she said she had heard about it and she even started doing research about it. Whenever she heard or read anything on autism she shared with me.*

Mrs. Mubanga

4. 2.5 Lack of empowerment of parents by professionals

Present findings revealed that parents felt that they were not fully empowered with knowledge and information about autism by professionals. These findings are different with the cases in South Africa and Canada (Autism South Africa, 2000 and Canadian Autism Society, 2000) which advocate for the provision of practical information on autism and related topics .They both advocate for empowerment and information to form the foundation of intervention programmes and be directly aimed at parents with ASD children. It is important that parents should be empowered with knowledge on areas of what autism is, its causes, practical guidelines on how to assist their children with ASD across a spectrum of problematic behaviours, early signs of autism in children, how parents can cope with challenge of caring for an ASD child and information regarding educational resources and training programmes for children with ASD. Professionals need to be sensitive to parents' need and try at all cost to empower parents with provision of a full program on counseling. Professionals need to employ a collaborative parent-professional model where parents are recognised and appreciated as experts of their children's need and to actively participate in their children's treatment (Rosenberg, Westling, Mcleskey, 2011; Hallahan and Kauffman, 2009). Parents further observed that their opinion needed to be respected and understood as they were the major stake holders in the right provision of the child's services.

When I told the doctor that the second born child seems to have the same problem, he shouted at me and told me never to compare a first born condition to the younger one. I knew the condition having experienced it with the first one.

Mrs. Mwanza.

I then noticed that he had lost some of his speech and I thought it was due to the medication. I just decided to take him back and they said it was the effect of the drugs and said we should give him sweet things to help the medication clear. But I doubted that because he was already 1 year 6 months s (Mrs.Mulenga.)

4. 2.6 Parents' ideal professionals

The dream of each sick person is to access quality health services from qualified professionals. Parents in this research talked about their preferred type of professionals. Here, the researcher wanted to find out from parents about their expectation from professionals.

Participants summarised their ideal professional and services as follows:

i. Visitation from the professional who will help me with management style for my child's condition.

ii. Speech therapist that can be very accessible.

iii. Professional home- based care services adding to the schools for ASD children.

iv. A professional who will treat me equal and will be friendly.

v. Having an autism centre strictly for children suspected to have ASD .If you have a problem you don't need to go through all the process with the child as if he has a disease.

vi. Assessment should be near to my home where my child home is.

vii. Community based assessment where if I have a problem, I can go and see someone since he knows the report of my child.

viii. We need a multi -disciplinary team which is readily available or what I call, the all- in-one doctor where you find at one place or centre a psychiatrist or psychologist or medical person on board with the educators.

ix. A professional who is well versed in autism and has the passion for such children.

4.2.7 Summary

From participant's comments, the researcher concluded that the relationship between the parents and professionals is vital during the diagnosis process. 90% of participants reported an initial tendency among helping professionals to negate and brush aside their concern and reports of development delayed milestones of their child with ASD, leading into participants' having a sense of helplessness and hopelessness. This further contributed to increased couple's sense of anger, pain, loneliness and disempowerment. The findings revealed that most professional opinions were often confusing, contradictory and not definitive and at times vague. This made some parents seek a second opinion from other professionals either by transfer or due to personal efforts, resulting in the loss of trust in helping professionals and further doubt their final findings about the condition. It is therefore important for professionals to work hand in hand with parents and treat them as equal partners in areas of treatment, intervention and behaviour management. The 'I know it all' attitude by some professionals towards parents' grievances and observation on their ASD child, does not help in diagnosis process but further discourages parents, making it difficult to achieve the needed goal of child interventions.

Siklos and Kerns(2007:10) attributed some causal professionals' delayed factors towards early diagnosis to:

i. Limitations of the assessment.
ii. Lack of assessment measures for preschool children,
iii. Limited time available for assessment,
iv. No assessment taking place on time and dependence on only parents' reports.
v. Lack of specialised professionals to recognise early signs of ASD children.
vi. Shortage of specialised services

Theme 3: 4.3 PARENTS GENERAL KNOWLEDGE OF ASD AND THEIR PERCEPTION

This theme considered parents knowledge about ASD and how gradually parents adapted to the new scientific term of autism as a way of defining their child's problem, a concept which they never heard about it before. The findings indicated that all parents showed ignorance of ever knowing what autism is before the child's diagnosis. The majority learnt of it when the American group of students conducted a workshop on autism at UTH. One parent read about it in the newspaper and another learnt of it through the wife. The newest respondent to a have a child diagnoses with autism heard of it from CBIA. However, after learning about it, many parents searched for more information on the Internet, friends and books to have a wider understanding of the condition.

We learnt about autism at the workshop organized by some Americans -that's when we knew that there was something like autism.

Mr. and Mrs. Mumbi

I learnt about autism through my wife.

Mr. Mubanga

I got it from the newspaper in Times of Zambia where an article was found.

Miss. Mwila.

Actually it was at the last assessment, because everybody was mentioning the word hyperactive *and delayed speech that's what they used to say, but when we finally came here we found the ladies at physiotherapy centre(CBIA) and some other specialists who were here, that's when they mentioned that he has a bit of autism. I didn't understand the word, but I just said anyway if that's what you say then do what you have to do because all I need is for him to have a better life.*

Mr.Mushota(The researcher interviewed him after a week of a child's diagnosis)

4. 3.1 Parent's definition of Autism

Soon after learning the scientific word *autism*, some parents were able to define the term *autism* loosely. Mr. Mubanga's remarks were that the best description of ASD was '*to let that person observe my child's behavior. It will be difficult to define it, I will just show that person my son and tell him to just observe him for only five to ten minutes and see his behaviour.*'

Mr.Mubanga

As at now I wouldn't explain, but if they ask me in reference to my son I would say like somebody who is hyperactive, but then he's unable to speak fluently, to communicate with the people fluently, like pronounce words correctly and make sentences that are meaningful. That would be my basic explanation of autism.

Mr. Mwaba, and Mr. Mushota.

*It's a disease with unknown origin(*Mr. Sitwala)

4. 3.2. Summary

Parents' results indicated that they had little knowledge on what autism is before a workshop that was conducted by some Americans. Others learnt about it from their spouses and only one said she read it in a news paper. There was much search for knowledge on the Internet, books and friends by parents on what autism immediately after they learnt about it and soon after the diagnosis.

Theme 4. 4..4 IN SEARCH OF DIAGNOSIS

There are three major stages of diagnosis. Namely:

(i) Pre-diagnosis stage: During this stage an account of parent's experiences was explored in finding out what could have been the child's problem. Here the researcher considered helping professionals and unsupportive professionals to parent's vulnerability and their fears and confusion.

(ii). Peri diagnosis (during diagnosis): The sub theme reflects on how parents reacted to the news immediately the child was diagnosed as having autism

(iii). Post diagnosis. In this theme more emphasis is based on parent's reflection, and acceptance of the child's condition. Labeling the child and creating a relationship with the child.

4. 4.1 Pre-diagnosis stage

The pre-diagnosis stage is a very crucial stage as this is the time that parents start a long journey of interacting with different professionals in search of a solution to the child problem. Parents in this study showed a degree of confusion, stress, anxiety and emotional hardship coupled with financial hardships. Findings further show that parents moved to many places in search of help for their child with ASD. Some had to seek Chinese medicine. Fear anxiety, desperation, panic and grief gripped parents on what could have been the problem with their child. Participants' reflection showed that they really needed an agent answer to the Child's problem, resulting into seeking help from any source such as, elderly parents in the community, healthy professionals and traditional doctors. Three parents who had first born children suspected foul play on their children. Parents who were first born and had a first born son were more affected as they felt like they had lost a child who could carry their name and duties since there is a traditional attachment to a boy child who is still believed to be the heir to family estates. For example two fathers named their children after their names (junior) .Sentiments like *'He used to complain that his first born was not* ***well*** *and he would complain as he is the firstborn too'* indicates a traditional family attachment.

We first had to ask some parents after observing that the child is not talking. At first we took it lightly then time passed no change. We started panicking ... We would just cry with my husband. My mother is the one who would calm us down. We were told by a profita[2] *that if we take her to*

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[2] A profita(prophet) is a spiritual leader who uses both spiritual and traditional rituals to heal people.

the UTH she would die and that is why we delayed even in taking her to the hospital. We suspected foul play by people, so it pains us(Mr. and Mrs. Mweni)

Others said he had a tongue-tie. We once took him to a traditional healer who gave him some African medicines.

Mrs. Mwanza

'we moved a lot with the child seeking for help. Someone tried to introduce us to Chinese medicine as we thought activating his brain cells would help. It was our hopes that if the brain cells were active, we would see our child behave normally.

Mr. and Mrs. Mwale

Inadequate knowledge about the disorder may have made parents still feel that there could be a drug which could just trigger the child's brain and make the child normal, as is the case with malaria or an injury on the body. Research shows that there is no cure for ASD to date (Mash and Wolfe, 2002; Kaplan and Sadock, 2007; Rosenberg et al, 2011). In the present study, most parents did not know what the child's condition was (autism is still a new vocabulary item in Zambia) and did not associate the child's behavior to ASD signs, making it more difficult to understand the child's condition. These findings are different from those of Collins and Collins (2001) who postulated that parents with ASD children have to experience a "journey out of denial." However, in this study parents were still in the state of uncertainty, confusion marred with suspicion of foul play on the child. Parents felt that the child was still young and all behavioral problems will soon disappear as the child grows. However parents began to have more questions and concern as time passed. It brought about panic, wanting to find the sudden cause of the child's inactivity and age inappropriate behaviours, hence seeking for second opinion. Gary (2000) affirms that parents undergo some emotional hardships and stress.

4.4.2 Peri diagnosis (during diagnosis)

The theme reflected on how parents received the news immediately they were informed that the child was diagnosed with autism. In the present study parents reaction varied and ranged from relief, confusion, denial, fear for the future of the child in areas of education and self reliance. When asked about how they received the news of the child diagnosis, parents gave the researcher varying reactions. Two parents who had more than one child with a disability (Mr. Mulenga and

Mrs. Mwanza - deaf child and another child with ASD respectively) had a mild reaction as compared to those whose child was the first one to be disabled. Parents, who had read something about the child's suspected condition of ASD, received the news in a calmer manner as compared to those who were getting it for the first time. The data findings are similar to Hornby(1995)'s results who stated that parents reaction to a child's disability is not uniform and the adoption process to loss was not a clear-cut as simply moving from one stage to the other would suggest. Hornby (1995) further postulates that a reaction to a loss of a child due to a disability varies according to time, events and space.

4.4.3 Pain and Anguish

Some parents felt some strong shock waves, a feeling of something blocking their throat over the news about the diagnosis:

The first child, it was painful and I had vowed not to have another child, but having another child with the same condition has just made me strong now.

Mrs. Mwanza

I was devastated, it was difficult to accept. I read somewhere that it was genetic so I suspected my wife and I pondered whether I should divorce her. This was all mental battles and I didn't tell her about it. .. I was sad and after thinking that the developed world didn't have any medication devastated me more....

Mr. Mwale.

It was bad, my world was small and I just looked at the doctor, or was it a nurse .I never said anything because they didn't explain more about. I felt cold, something blocking and choking my throat...

Ms. Mwamba.

4. 4.4 Taking the news calmly

Some parents in this result took the news calmly. However, My perception is that the calmness was more ironical in the sense that they might have been shocked and dumb -founded hence the calmness. Studies show that if such parents are not counseled, they are likely to suffer from psychopathological disorders in the near future. Bronfenbrenner (1979) states that some people may take shocking events calmly based on their strong religious belief and cultural background. Mrs. Mubanga and Mr. Mulenga took the news calmly based on their past experiences thus having some knowledge about the condition before hand and caring for two disabled children respectively. Mr. Mulenga quoted saying *'I took it calmly. I have another child with a similar problem, so it wasn't the first time but I ask myself why me'*. Calmly could mean shock, denial and surprise at having two children with different disabilities. His sentiment of saying *"why me"* may mean more of being shocked than facing reality to the condition.

4.4.5 Blaming God

Mrs. Mweni felt that it was a punishment from God and God does not love her. *'I just feel bad. There is nothing I can say. I feel God hates me and he can't forgive me.'*

4.4.6 Post diagnosis. In this theme more emphasis was placed on parent's reactions, their acceptance of the child's condition labeling the child and creating a relationship with the child and professionals.

4.4.7 Relief: child labeling

In my pre-diagnosis discussion, I highlighted challenges which parents went through during diagnosis period. This was a long lonely journey by parents which brought with it pain, anxiety and discouragements. Data collected revealed that, soon after the child was diagnosed, parents had to come to terms with reality and found the way forward for their child. Parents further interacted with professionals, searched for more answers on the Internet, books and from fellow parents with similar children and inquired further on issues to do with child management.

Labeling of the child with ASD to some parents brought a relief, as parents were now able to look for the child services such as education, speech, occupation and other forms of services which would benefit the child. However, Hall (2000) warns that caregivers' relief over the arrival at a diagnosis should not be mistaken for gratefulness. She suggests that parents' relief may merely result from the fact that, by comparison, they have not received news of a life-threatening situation in their child, such as a brain tumour. Her finding agrees with such comments from Mrs. Mwila in the current study who said…' *It's difficult. You know as a mother... When I come back home I would like my child to do things the way other children were doing them at work. But I can't see that in my child, you know it's very painful and again it's depressing. But you know once I went to UHT I met other mothers, parent guardian and stuff like whose children disability is worse than that of my child, at least now I have started to adapt to this situation. And the most important thing is I have accepted the condition of my child and now* *at least am healing a bit unlike those days.*

Mrs. Mwaba

Gascoigne (1996) postulates that despite children having being diagnoses at an early stage in life, this did not make emotional experience fade in life and their adaptation and acceptance stages of the child's disability, was not in strict phase of events. The data collected in the present study indicated that parents' adaption to child's labeling and its relief still varies and their emotional experiences have not completely faded away. Parent's emotions were still fresh and vivid about the child's disability. Most parents in the research said that their belief in God helped them to accept the child's disability. For example, Mrs. Mwansa said *"Sometime back I used to ask myself why it is like this, but this time no, because I have now seen other children who are worse than this one. So I have come to learn to leave everything in God's hands*". The adaption method employed by respondents in this research is supported by Bronfenbrenner (1979)'s ecological model which states that ,religious beliefs have a part to play in how families cope with a disabled child .He further states that if the family believe that it's a gift from God then they can easily accept the situation and if they see it as a punishment due to their past sins, acceptance delays .Data collected revealed that families expressed their strong faith in God this may have quickened their acceptance of the child's condition.

4.4.8 Signs of relief

After diagnosis most parents felt a sigh of relief especially after being told the child's problem as compared to not knowing the childs' disability condition.

We feel much of a relief, what we were looking forward to is for somebody to tell us what could have been causing our son to have such a challenge and it was a kind of a relief that at the end of it, after going through all the assessment, somebody had to come up with something they had diagnosed him with and they gave us hope that after going through these sessions they might help and put him back to where he's supposed to be.

Mr. Mushota.

I just accepted the situation positively. There is no way I can run away from the situation. So I have just taken it positively.

Ms. Mwamba.

4.4.9 Husband's acceptance of the child's condition

Some men in the current study took time to accept the child's condition as compared to women. The probable reason could be that women do share their grievances with their fellow mothers and are ever with the child. So, there's that strong attachment bond between the child and mother as compared to a father.

He has not accepted and hides their condition. He doesn't like that they be beaten and often times he complains that he can't take them anywhere. Maybe he has to be talked to but he does not want to stay for therapy.

Mrs. Mwansa

4.4.10 Summary

The above discussion has given us supporting evidence that all parents with a child diagnosed with ASD were affected in one way or the other by the child's condition. It is important to be very conscious on the initial relief on parents. This might just mean that parents felt a sense of relief because their child was'normal' in the sense that he had no brain damage or any serious disease like brain tumor. There was a relief in the sense that when they looked at other children as compared to theirs, they felt much better hence the acceptance. However, parents still felt a sense of loss like that of losing a child through death. Participants expressed varying emotions that were associated with stages in the grief cycle, namely, initial shock and denial; anger and resentment; depression; and eventual acceptance. Helping professionals need to assist parents with ASD children during this period through counseling and addressing their emotions of loss and grief, encouraging families to take time to heal, and by providing them with facts about autism, assurance of a child's future, informing them about services available for such children and its importance to widen parents knowledge on other related disabilities.

Findings showed that parents of first born children with ASD took notice of the problem a little bit late and still believed that the child was still young. However, as time passed by, all participants in the present study experienced internal conflicts ,denial and acceptance.

Theme 5: 4.5 EFFECTS ON THE FAMILY

The theme considered the effects of a child with ASD to the parents and siblings in relation to time and energy. The birth of a child in a society normally brings joy to couples and the extended family and the community at large. Any strange happening in the family cause uncertainty in the family, mainly if it had to do with a disability. Superstition, finger pointing, witchcraft, blaming

God, spouse, or past life activities come in. All such, dominate parents' mind. During this period parents need to also adapt and adjust to daily routine as the child's disability take more of their time as compared to the normal child.(Cosser,2005).If this is not well handled, the child's disability can split the family .

R: Tell us about your marriage. How was it like when you were expecting Kelvin?

Actually it was very exciting, and its one thing I kept looking forward to. I remember escorting my wife to every antenatal clinic. I wanted to learn whatever there was to learn, what to expect when and what until he was born. Actually, she was taken in the morning. I was there the whole day. And just when they told me to go home and rest to come the following day, I left, that's when she delivered. I had to be called back that she had given birth to a baby boy. It was 11 March, 2006 around 19:00hours.

Mr. Mushota.

4.5.1 Marital Conflicts

In this study, findings varied. Most parents in this study said they were greatly affected at the initial stage but presently, the child's condition has cemented their relationship, though some men had to go on separations, and two almost divorced their wives. The most common cause of conflict was related to the extreme demands on time and energy that the children with ASD made on parents. This gave parents little or no time to spend as a couple. Participants also reported that their partners particularly husbands felt neglected and unloved as a result of the time that their wives spent attending to the needs of the children with autism. Participants expressed their perceived impact on the marital relationship as follows:

i..Most fathers did not want to have another child, they were afraid of having another child with ASD.

ii. Husbands wanted to give the best to the ASD child in terms of financial resources.

iii. Husbands thought that the child's condition has to do with the wife's parent's background.

iv. Wives believed that their husbands have not fully accepted the child's condition.

The results collected showed that fathers took long to accept the child's condition and hardly talk about it to friends or at their working place. In this research, the word 'love for the child' overshadowed a lot of activity in parents' lives such as social functions. Comments like...*you* *have seen the way she is (pregnant), I was against this, and actually I'm not happy. I tried to talk to her so that maybe she could abort, but she refused. I brought in my mother-in-law, my mother...she also became against. My idea was, we still have this problem, and we still have Mary to look after because she is always like a baby. But here we are, we are bringing another child into this world...To be honest, I'm not happy, I'm against this.* Complained Mr. Mulenga. Such comments showed that husbands were having a second thought of having another child. Mr. Mwale was hesitant to have another child basing his fear of having a child with similar condition"*I have a baby now but I was fearful that even other children would be like him. I just used to ask God and pray that I don't I have a child like that again as the cost of having a child like that is very high .Often he would just be crying, even in the night from mid night to even 2 a.m. I was so irritated that I slapped him once and a quarrel ensued between my wife and me.*

It was difficult and my husband didn't want it because when I fall pregnant Helen did not talk and or go to the toilet. I just used to carry her on my back and her father did not want us to have another child.

Mrs. Mweeni.

4.5.2 Couples 'Relationships

Participants in the present study acknowledged some problems in the first initial stages being so strong, mainly amongst men. Two men once divorced/separated with their wives. 31% of the 17 respondents felt that their increased stress had an adverse impact on their marriage. The majority of respondents in the study felt that their marriages were strengthened by their experience of caring for a child with ASD. Mr. and Mrs. Mumbi said that their relationship brought them together. '*No! No! No! Actually, in fact it brings us a bit closer to each other. Sometimes we, you know, have problems in marriage because of him, and especially when he starts throwing tantrums here and there you find that, even if when you are sitting in the bedroom there, the other one was in another room you find that we would come together and see what is wrong with him and see how we can help him. It has helped us get a bit closer.'*

Literature indicates that when there is a child with a disability there is a degree of marital conflicts which comes aboard. (Blair,1996; Osborne and Reeds,2008.) However, Blair (1996) and Fisman et al. (1989) suggest that parents with a disabled child had their marriage strengthened. Considering variations in literature on marital relationship between couples, it was difficult for the researcher to deduce what caused parents marriage to get strengthened as this was beyond the scope of this study. However, it could be speculated that their cultural and religious belief played a major role.

4.5.3 Single parents

Single parents had a greater challenge of caring for the child with ASD as compared to marriage couples. This was observed during interviews and how emotional they could be when they thought of their child and challenges they faced.(See chapter 5 for more).A single mother who was ,a worker, student and also a window with another sibling, reported that life was rough as she had to meet financial costs of her education as a self –sponsored student, tuition fees for her grade 12 daughter ,daily transport (booking taxi) to take the ASD child to school, house rentals and her demanding job as billing officer where she needed to be in the field most of the times-away from home.

....*Awa life iliko badi mwandini.(*life is hard for me*) As you can see, I am a window who just lost my husband, a mother of two children including this one Mike, then my job is demanding. I've to go to school ,care for the child with ASD and my daughter too, I need money for their school tuitions ,transport and packed meals for their school, then I have to think of house rentals which are ever increasing each day. As single money with one small salary ,its rough and tough going .At times you know, I feel like giving up life but again, I fear on who will care for my children if I kill my self? So ku kosafye you know...* (just have to be strong*).*Ms.Mwamba.

Another single mother a student at NRDC ,mother of first born child with ASD said that life was challenging, mixing school with child caring, coupled with fear of the child's daily life when she was out at school. She said that on several times she wanted to stop school so that she could concentrate on child- care since often times the child was cared for by her mother and auntie when she was in school*.

... *'You know the child was recently diagnosised .I used to think too much about my child that at times I could start crying whilst in class then, I could just live the lecture room and rush to my room and cry. Ba roomie(bed mate) and mum have been so helpful to me, had it not been for them, I could have stopped school along time ago. Anyway, I am much better now, as you know ASD is just a diagnosis ,it's not the end of the world for my child'*

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*The first time the researcher met the child, the ASD boy was with grandmother who had brought him for therapy at CBIA, later on I made an appointment with the mother Ms.Mwila

Such a situation forced the participant to be home every weekend to go and care for the child. The researchers' perspective is that Ms.Mwila's emotions were quite strong because she had the child whilst young and at school in grade 12 and then the child has no father to care for him except Ms.Mwila's mother and the family.

4.5.4 Effects on siblings

In the present study, all parents had some difficulties in child caring which also affected their family. Parent's joy suddenly turned into fear, concern, worry and despair on the child's condition as the child could not do other activities as anticipated by a normal child. This brought stress, negative emotions which even affected their formal employment.

One father once said '*I was so excited to have a baby boy whom I named after my name James, but suddenly the child's behavior brought some emotional reactions'* Despite the negative behavior shown by ASD children, their normal developing children demonstrated love, protection, concern and certainty that their brother or sister will one day be fine. However, when the siblings were told about the diagnosis, all siblings reported signs of hope for their brother or sister. Few normal children showed sadness or depression towards their ASD sibling. Despite this, most children could still ask their parents soon after returning from the hospital on whether the doctor had said that their brother or sister would talk again. One male parent expressed concern on the siblings who complained of getting tired playing and looking after their brother who needed attention each minute. Another couple expressed concern about the aggressive behaviour or bullying that their child with ASD demonstrated towards a much younger sibling. Mrs. Mwansa reported on how the step-brother could beat their child with ASD every time they were playing. In this report only one mother confessed having never asked the children on how they felt about their sister

Awe apo peve nikalibe kuwafunsapo mwamenne amanverela mwee. But since wenze kuona mwanene enze udwalira, wanamujaira so chabe. (I have never asked the children how they feel towards their sibling but since they could see how she suffered from the condition. They are used now with her).

Mrs. Mulenga.

Okay aha...well they have accepted the girl...There are times when she likes playing a lot. The problem is that we cannot let her play alone minus someone watching her, which the other friend *has to be there when she is playing, she has to leave whatever she is doing to watch her. So it's like they get tired of her. So those are some of the challenges for these guys but otherwise they have accepted the way*

Mr. Mulenga

It was difficult for our dependents to accept. But we educated them about his condition and since we as parents are not always home, we told them to take care of him. We convinced them that if they helped, he would be OK. They have adjusted and my sister-in-law has been very helpful.

Mr. and Mrs. Mwale.

They love her and are good to her. They even take care of her because they know her condition. They like her, they understand that she is sick and do not even beat her. Sometimes I would tell them am giving away Grace because she had troubled me but they said we will pick her and take care of her. When I told (Mrs. Mwamba) them they should look for their own place they insisted it was their fathers' place and he will allow my child to stay.... They know that she has also the right to live and she will be OK.... One time, elder brother came home and the friends were laughing that his sister does not walk. He felt hurt and remarked that God will burn them. In instances like that I just encourage them.

Mr. and Mrs. Mwaba

... 'so will he talk when he comes, will he?' (from therapies at the hospital) so they are looking forward to for the time that he will talk. 'Even after that medicine he can't talk.

Mrs. Mwaba.

....my girl who is in grade 12 came back from the party crying that the friends were laughing at the brother for the mess he made at the birthday party. 'Mum , never ever ask me to go to the party with him.....its either I remain or I go without him .I feel bad when I see my only brother like this, I just have to stop going for parties so that I remain with him. I love him. (starts sobbing again) MS. Mwamba.

4.5.5 Summary

The above discussion has demonstrated how different family subsystems are greatly affected by having an ASD child in the family. The most common cause of conflict in the marital relationship is related to the extreme demands on time and energy that the child with ASD made on parents, which gave them little or no time to spend as a couple. A parent-child relationship with normal developing children was difficult to predict on whether it affected sibling. (There is need to out carry a study on this) Normal developing children demonstrated more love, protection than anger or resentment toward children with ASD sibling because maybe of the society set up which emphases playing together in the community, hence, reduction in tension on children. Resentment by normal children towards children with ASD was partially reported which may have come about due to poor communication with the child with ASD and embarrassment which comes about when a child with ASD behaves inappropriately in the presence of their peers such as grabbing other friends toys, running all over and crying for toys which they want and not wanting to share it with others. The findings have shown that it is also common for older siblings with ASD to be aggressive to young ones.

Theme 6: 4.6 COSTS

This theme looked at some of the challenges faced by parents as they care for the child with autism. The findings revealed that all the parents faced a lot of financial, social and emotional challenges before diagnosis and after the diagnosis. One couple were suspected to be a thieves when they were taking a child to Chainama Hospital around 01. 00 hours a.m. They were caught by the police officers for shishita (loitering) Vagabond police crime). However, upon realisation by police officers that they were carrying a sick child; they helped the couple to transport the child to the hospital. One finding was cases were two mothers had to stop work because of the demands of caring for the ASD child. Most parents encountered challenges in keeping maids as they could not cope with the child's behaviour hence stopping working. On cash, only one couple recounted seeking assistance from the social welfare department once .Parents complained of high costs of the drugs and lack of transport for taking the child to the hospital. On social aspects, many parents said they forgone a lot of social activities such as weddings, church services. Parent's bemoaned lack of special schools since there was only one recognised boarding house at Bauleni which has limited spaces. This means that parents have to meet the cost of transport to school on a daily basis and been the only known school.

One couple complained of high expenses of taking their child to a private school. Mr. Mweni was twice fired at his working place for spending more time caring for the child with ASD. In this present study, two mothers were denied any opportunity for outside employment due to their child's disability. They had to stop work. Another mother said the child's condition has prevented her from finding formal employment and this has also restricted her hours and/or type of employment or work to do. Despite the fact that most parents are in formal employment, participants reported restricted hours of working and little time of serious concentration to work. One mother talked of ever receiving reports that a child has done this and that and another one complained of ever going to pick the child at school during peak hours of traffic jam(morning and lunch time)resulting into having few hours working for the company.

Present findings are related to Montes and Halterman (2008) who says that ASD is associated with higher probability of child care problems which greatly affect parental employment. Funjiura et al (1994) in Japan did a costs measurement analysis of autism on parents' services and discovered that almost all the care for people with disability is made by the parents and the family. Gray (2002:281)s' longitudinal studies showed that parents found it difficult to have a career job with ASD children .A study done in Canada in 2000,estimated that cost to the state of a person with autism was over 3million dollars (Autism Society Canada ,2001b).

Another challenge faced by parents is loss of Social life and fun. Leisure activities such as participation in sports, clubs; weddings, picnics and attending family gatherings like funerals were often affected. According to Roberts (2002) in their UK study. Parents may really be over burdened by the child's behaviour such that some parents have been reported to have committed suicide or have had depression leading to psychopathology. The trend has been the same in Canada too (Autism Society Canada) In the present study all mothers hardly go to church and social functions for fear of embarrassment by the ASD Child. All Parents indicated higher degree of pain, depression, anxiety, anger frustration at the cost of child care. Parents lost a lot of time whilst caring for the ASD child mainly in treatment and behavioral management. Jarbrink and Knapp, (2003)'s study under Parents Autism Campaign Education (PACE) on time lost by parents with children ASD was estimated that parents could lose as far as 40 hours per week [Standard Deviation] (SD=22hours), 22hours of paid jobs (SD = 16 hours) and 17 hours of leisure time (SD = 11 hours). This cost did not include materials like books, toys and computer games and other necessities, (Jarbrink, 2003).Data collected indicated that participants had faced social, economic, emotion and financial impacts particularly when seeking for services at UTH and special schools.

4.6.1 Financial costs

The data collected revealed that parents of children with ASD suffered a lot of financial loss which were in form of transport, hospital bills and buying of toys and food since some children were found to be selective to food stuff. Other financial loss came about due destroying of items by the child for both the home and other people '… *My friend, we have spent a lot of money that unfortunately we don't count. It's not that one day we want to claim the money we have spent, but what I know is that we have spent a lot. Just to give a picture, from the time she was born, she could only take one type of milk...so you can imagine spending almost K80 000 in every two days that took us almost three years, then there is up keep, hospital bill....But I don't look at that, I look at the future of the girl. I would do anything for her to be independent.*

Mr. Mulenga

4. 6. 2 Loss of jobs and money

Three mothers stopped working in order to care for their children; one participant lost the job twice for taking more time caring for the child. One mother complained that she cannot find a job because; no one could care for her child.

I was fired twice for the love of my daughter. .. We suffered and had no money. He would borrow K2000 and take her to the hospital .We used to eat the cabbages from there. I made a friend there and she would encourage me to finish the treatment. When we were discharged we had no transport money and had to walk from UTH to Matero. (about 20 kilometers)

I can't find a job and do my own business. I go 2-3 times to the hospital and can't wait for a month end salary.

Mrs. Mwaba.

4.6.3 Emotional costs

Feelings of Grief. Parents of children with autism are grieving the loss of the "typical" child that they expected to have. In addition, parents are grieving the loss of lifestyle that they expected for themselves, the now ASD child and the family as a whole. The feelings of grief that parents experienced can be a source of stress due its ongoing nature. Theories of grief suggest that parents of children with developmental disabilities experience episodes of grief throughout the life cycle at different events (e.g. birthdays, holidays, social events and unending care giving) which trigger grief reactions (Hornby,1994).Researchers have indicated that experiencing "chronic sorrow" is a psychological stress that can be frustrating, confusing and depressing. ...

'It's frustrating, tiring and how I wish he knows how I feel too sad. Mrs. Mumbi

.....usually when am alone thinking I just get some frustrations, and sometimes there is the question 'why did it have to be my son?

Mr. Mushota

4.6.4 Social trauma

The early signs of parents' withdrawal from society start slowly by first avoiding social contact of the child with other members due to the child routine behaviour and programmes. Parents slowly start counting the social benefits of going out or remaining home. Data collected indicated that parents' social costs ranged from enduring the behavioural disturbances by a child with ASD to comments from the society, which created a greater sensitivity on parents with ASD children resulting into their perception about society to change. Many parents with ASD children feared comments from other people in the society who perceived them as those that don't know how to care for their child with ASD. One such example comes from Mrs.Mumbi's experiences with the police. This was her lamentation:

'I have had this experience about three times. My son could jut open the gate and go outside. He went for over 45 minutes. I was there asking where he was. Coz I always wanted to know his where about. We started looking in the house and he was not there. Then we realized the dogs were not in the yard and the gate was open. I said 'oh my God he's gone', we went the other side and he (son)went the other way. I went with the baby on my back and I didn't have shoes and it was hot. That was a bad experience and it was the first time him going out and disappears. And all the time he leaves home he had no shoes and we found him on the middle of the road wanting to go into a car because .He loves cars. A lot of people started screaming, "they will bash the baby!" the taxi drivers got him and I was on the other side. Meanwhile I called the father and informed him that the boy was missing. He rushed from work. Those guys took him to the nearest Police station just there and he started troubling the police holding the radio, answering, and things like that. And they were very surprised. When I went through Burma Road asking people if they had seen the boy.

When I reached at the same bus stop, the taxi drivers told me they had taken him to the police station. We got there and we were questioned by the police, "you're a bad mother!" I tell you I cried that day and I will never forget it. "You know that this child is retarded and you think that *one on you your back is better, you leave this one not cared for."Shouted at her one police officer.' I just said to me 'they don't know what I go through' and my husband was there to calm me. They got the statements and told me that I was going in the cells. At last they told my husband, "you know you should man you house, these people you ask to look after your children are all useless. In fact you should whip them all; they are not doing a good job. Because you are working for them and you give them your child and they just leave him to wander."*

They discharged us but it was not the end. He ran out again. This time I was locking but there was a little girl and I could tell her to lock the gate. We don't know where Misheck passed, he's so fast. Now we know the side he runs to. It was because I used to park the car at the Police station there, so he would go there, if he searches and mama's car is not there, he starts wandering looking for the other car. This time it was the bus driver who took him to the police. When I saw him he ran away from the police and they started chasing him themselves. Then there they said to me "you are back again madam, sit behind there!" This time I didn't say anything I just said let them talk. So they talked and talked until they were fed up and said "ok just go" as usual I was bare footed with a child on my back. Those were my biggest challenges, going and wandering wherever. So I resorted to putting something written on his wrist or neck to say, 'this is Misheck house number so, so, so. Take him back.' Then when I said I want to make a name tag for Mischeck they could say no, what are you saying to the people. I just said I have this problem people should know about it, the community and all they see is 'why is that boy kept locked in the gate all the time, he can't play with other children. Because if you take him out to the others children, he will just run and wander about. To you it may be a bad idea, but it will help him and even one day if the cops see the house number they will say 'ok there is an improvement now' the mother did something about it. He has the contact number, the name and others, meaning, they are telling us that this child does not speak, he's from this place, and let's take him back.'

Mrs. Mumbi

Such challenges like those faced by Mrs.Mumbi forced parents mainly women to drag into personal private lives. This shrinking of social contact by parents represented a loss to self on the parent as a social being.(see more comments in 4.7.2)

.... It is worse when you visit other people's homes, when you go to church, they invite you for a wedding, some parties then just at that moment he would behave like that; people would turn, "what is wrong with the child, what have you done to him", "no give him what he wants" but then you don't know what he wants. So sometimes, we have to let some functions pass without going there...' bemoaned Mrs.Muzemba.

When parents were asked on whether they had any experience where maybe they went out for a social function then faced some problems with child with ASD?

...Several times, sometimes it's not necessarily going out to a function but just maybe take him for a walk in the street because he likes cars a lot. So maybe he would see some of these pirate taxis parked along the road and he would want to go there, so when you say no he will throw a tantrum. Or sometimes he would pass pa ka 'ntemba' (a make shift shop) and he wants something from there and you say no, he will throw a tantrum.

Mrs. Mumbi

4.6.5 Summary

In the above discussion, I have highlighted some of the challenges which parents went through in areas of social, emotional and financial costs. All parents acknowledged having difficulties in financing their child's health services and education. Parents went through frustration on the child's poor mode of communication, behavior and reactions from the community towards the child. Transport costs were another bigger challenge. The recent findings are similar to Bradshaw and Lowton (1978)who discovered that the socio-economic status of a person with a child with special needs has an impact on the stress levels of the parents. Bronfenbrenner (1979) postulated that the economic situation of the society in which the family lives will affect how families cope with special needs children. The Observations by Bronfenbrenner (1979) has some bearing when we compare the health service provision in Zambia according to the economic situations, where most of the medical materials, equipments, specialized human resource like speech therapists are not available. The positive part on the parent's side was that they have learnt to be patient.

Theme 7. 4.7 CULTURAL BELIEFS, ATTITUDES AND STIGMATIZATION

This theme looks at the comments from the society and cultural beliefs on the cause of ASD. Results showed that both parents and the community had strong superstition on witchcraft, taboos and failure to accept some traditional norms and beliefs. Further findings showed that some elders in the family attributed the child's disability to failure by parents not following traditional sexual practice norms. One parent was told that the child was weak because they did not do the rituals of *Ukutwala ku mwenshi* (similar to mdulo). *When I consulted with parents they said it was not normal as they said since it was flesh; it needed to take 3 days to fall off....Others concluded that we didn't do mwambo (traditional child cleansing).Culturally, it is believed that when a child is born when you resume intercourse with your wife, the first semen that you ejaculate should be applied on the child's forehead that is what they call* ***Ukutwala ku mwenshi****.*

Current research findings showed that despite parents being educated and Christians ,they still suspected witchcraft or foul play on their child with ASD.

(Okay aah, (laughs)...that you can't rule out... (more laughter). As a person who was brought up in Africa , a black man, who has been to a village, I can't rule out witchcraft. Though we tend to say let's leave everything in the hands of the Lord, sometimes such feelings are there.

Mr. Mulenga.

One parent attributed the child's condition to 'juju' business popularly known as ' sanda bana business' (ritual business)in the compound where the child was being used to boast some people's businesses '*...They said it was witchcraft. Whenever she would fit, some said bamusebenzesa (they are using her at night for work). We used to pray. But her father said nituntemba (juju business)*.....recalls Mrs. Mweni

4.7 .1 Prayers

In this study one respondent said that he was told by a pastor who attributed the child's condition to the name given to the child. The participants had some misgiving to such logic by the pastor which was difficult to prove. However, prayer and belief in God helped parents accept the child.

Some pastors would say his behavior is associated with his name because he was named after the father's late brother. Yes. So they say it has something to do with ancestral spirits something like that,... and then a traditional healer said no it has something to do with witchcraft or something like that...

Mr. Mushota

"*...we have taken them for prayers which did not work. I didn't want any tattoos on my child. I even took him to the witch doctor who told me that my aunt was responsible. He wanted me to do rituals which I didn't want to do*" explained Mrs. Mwansa.

4.7.2 Comments from the community

Taking an individual with autism out into the community can be a source of stress to parents. People may stare, make comments or fail to understand any mishaps of behaviors that may occur. For example, children with ASD have been seen taking a stranger's food right off their plate. As a result of these potential experiences, families often feel uncomfortable taking their child to the homes of friends or relatives. This makes holidays a difficult time for these families. Parents of children with autism may experience a sense of isolation from their friends, relatives and community. In the present research, parents complained of humiliation from the society due to the child's behaviour. Mrs. Mulenga Narrates on how the child brought an embarrassment at the kitchen party and cafeteria shop.

'Last year I went for a kitchen party and he was running around getting people's drinks. It was so embarrassing. Worse yet some women took me aside and rebuked me that I had let him get spoilt like that. I was so devastated and cried. It was too bad that I don't even like talking about it. ....I also remember one time in an eating place. One family left because they felt offended. He loves phones and one time in Shoprite he rushed at someone and grabbed their phone fortunately it was someone we knew. Otherwise with other people are helpful and have been able to help him. Then humiliation from people when you go somewhere and you find a group of people they start asking; what is wrong with this child? He does not talk or walk, what happened? Some start laughing and say we have spoilt the child. It's painful.'

*When I went for a funeral and I was feeding her, most people said that she is too old to be fed and am just spoiling her. God has given me this child and I won't neglect her. I had stopped walking with her but when I saw all the children at UTH I thanked God for Grace. Sometimes call boys(*boys who shout for buses to win passengers and at the same time are street vendors*) ask why I make her wear glasses and some pass silly comments but I just ignore(* Mrs. Mwamba)

"You know that this child is retarded and you think that the one on you your back is better, you leave this one not cared for." I just said to myself, 'they don't know what I go through'...

Mrs. Mumbi

4.7.3 Summary

The above findings have indicated some of the challenges and comments which came from the community. All parents reported stigmatization and lack of enough knowledge about ASD by the society. (Gray 1993b) postulates that parents with ASD children normally face stigmatization from the community. It is therefore important that the community is made aware about autism through various media to avoid stigmatization from the community. However, data collected indicated that some parents were able to ignore comments from the society and went on with life. The reaction from parents to society varied from one respondent to the other. Some parents are still bitter with comments which came from the society, whilst others have forgotten or just ignored them.

Theme 8. 4.8 SERVICES INADEQUACY

In this theme, I looked at the services provided by the government to children with autism. All participants during interviews said that services provided to their children were not enough or adequate. Such findings were consistent with Hanlon and Hanlon (1996) who conducted a survey on services provided to ASD children and concluded that most parents said that support and services were not enough in Ireland for children with autism. The situation could be probably a lot worse in Zambia where there are few doctors with little knowledge on what autism is, services and equipment for assessments are hardly available and there is no government funding or support to parents with ASD children.

4.8 .1 Health services

Parents in the study complained of the red tapes in service provision and inadequate qualified human resource in many fields and lack of enough materials and equipments for ASD children. Mr. Mulenga sums it up like this: '*The government should give attention to children with autism just as they help the deaf, blind and lame, HIV/AIDS people, they should also give us help with what we need. It is not enough. Sometimes when we take him for physiotherapy, the nurses could have a long queue but would not be attending to any. A lot of people still don't know so there is need for sensitization ...I wouldn't pick my daughter alone because she is not alone in this fight.. We need the government to help train people on this problem. They are not enough. Sometimes they even say she has to go to India or china. If they can take them or bring them here it would be better.*

Mrs. Mwange.

There are no professional clinical psychologists to give a full professional counseling, so people like church members who used to say that he is going to be OK. Often times I would just pray to God.

Mr. Mwape.

The services are not enough, can you imagine, they just rang a bell to her ears for hearing test and results were not even recorded.

Mr. and Mrs. Mpundu (health workers)

4.8 .2 Education provision

Present research findings indicated that Zambia falls short of programmes suitable for children with autism. Parents in the present study recorded worry about finding an appropriate school. However, before diagnosis, most parents took their children to normal pre-school where they changed one school to the other due to rejection of their child by teachers and administrators. All participants repeatedly needed to move their children from one preschool or day-care centre to the next, since these facilities were either unable or unwilling to manage the child with ASD's behavioural problem or meet the child's special needs.

We took him to a normal school but there were a lot of complaints and after a term they did not want him anymore. I was told that he disturbed the classes. I was very frustrated and upset; I took all the uniforms and locked them away, I don't even want to see them again. I never knew about the special school and when I found out I was very happy and knew that he had a chance of getting an education. When I saw the children with autism I was very encouraged and felt better'. Recalls Mrs. Mwansa. Participants frequent change of schools were not only traumatic for the children concerned, but parent's also experienced emotional turmoil as the search for appropriate resources began anew each time the child was chased from school. In Lusaka, there are limited schools that enrolled children with ASD and most of these are run by private organizations such as the church. When parents where asked about the availability of schools for their children, all the parents complained about lack of exclusive schools run by government for children with ASD '... *It is not sufficient. Because there is only one school where you can take children like my child here in Bauleni. So if you are from Copper belt or Western for example, you can't benefit'* observed. Ms. Mwiinga

Participants stated that schools which are in private hands were very expensive costing as much as K4 million–7 million per term, making the schools to be elitists in nature.'*....but there is a school, Baobab, I went there but it's very expensive 'sitigakwanise' (We cannot afford). Even doctors said that there he can catch up fast manje kaili nkani ya ndalama (The challenge we* *have is where to get such colossal sums of money) it was 7.5 [K7.5 million], we can't manage' Complained Mrs. Mulenga* .The impact in this case as reported by parents is lack of schools for their children and lack of enough money to send their children to better school. All parents wished the government could help them with funds for the child education as it is in developed nations like Canada. ....(Autism Society Canada,2000).*I hear like in developed countries, such children the government pays for their education There is no funding towards the education of such children in Zambia.'* Said *Ms. Mwila.* Parents in the study complained that ASD is not given the attention which is given to diseases like HIV/AIDS and other physical disabilities

4.8.3 Mainstream schooling

There were conflicting views on this topic, some parents were of the view that their children should be in mainstream classes to avoid labeling of the child as "disabled or special child". Their thinking was that this could lead to stigmatization. Another school of thought from parents was that such children need to be on their own due to high numbers of pupils in classes of public schools with a minimum of not less than 60 pupils per class in Lusaka.

.... but there were too many in one class and the teacher couldn't take care of his special needs .

Mrs. Mwale.

Actually, he went to school this term. We changed the schools he has been going to another school just in the same area, we noticed he was kind of being neglected, that's how I would put it

4.8.4 Summary

The above theme explored the challenges which parents encountered as they searched for suitable early childhood education and primary education for their children with ASD. Many mainstream preschools and schools were unable to meet the special education needs of these children, and were often unwilling to accommodate ASD children because of their behavioral problems. Parents are faced with limited resources for their child; they also have limited options for schools as there are only a few well known and established special schools in Lusaka strictly for disabled children. These are Bauleni, UTH, Still Waters and Chainama Day Care Centre. This has added further financial burden on transport costs and packed meals for a child. Health services are few which deal with children with ASD. Parents felt that there is too little equipments for testing and assessing their children in public hospitals.

Theme 9: 4.9 FUTURE PLANS AND DESIRES, HOPES AND FEARS

This theme considers parents' desires, hopes and fears about their children. Most of the parents in this study, still had hope that their child will be normal one day and will play and function like any other child. Parents' fear was seeing their child not live a normal life when old. Another common fear from two mothers was death, if they die, they don't foresee their father or close relatives managing her ASD child. Participants' desires were to have better services for their children from an early age. One mother emphasized the need for more research in this field. Most parents have high hopes that their child will be normal or slightly near normal.

4.9 .1 Parents main concerns

Parents showed concern in various areas such as provision of the services, lack of assistance care givers and lack of enough information about ASD conditions in Zambia. They were also concerned about the future of the child, stigmatization, environmental hazards and the education of the child. Parents also dreamed of care givers who could assist them to care for the child. *I need someone to watch them 24/7. My life is on standstill but if I can get relief I would appreciate. I would love schools to be put up for them. If they can even have baby classes I would be thankful,* said Mrs. Mwansa.

The only challenge I have is that I find myself doing everything and there are no services. I wish if there can be training for all care givers it could be better

Mrs. Mwansa.

4.9 .2 Fears from the parents

One of the greatest fears which made the world of parents collapsed was the fear of their death. Mothers were so afraid of who could accept to live and care for their child when they die. Another fear was whether the child would outgrow the challenge one day. Such concern still showed that some parents still believed that one day their child will be normal, this is despite knowing that ASD is a permanent condition.

Will he outgrow this and be independent.? I always worry about where he is. In Ndola, I found him in a drum of water and half his body was submerged with his head sticking out. If I had delayed he would have died. Before intervention he was never scared of anything which was worrisome but today at least he is fearful of danger.

Mrs. Mubanga

When I die, I don't know who will take care of him. And when he is at school I am fearful. My boys are not fearful to things: This boy once drowned at my sister's place. The maid jumped in the swimming pool but could not swim but my bother-in-law jumped in and rescued them both... I was worried that he could have died. These children are not fearful...

Mrs. Mwansa.

I sometimes say that maybe it's going to take him a bit longer time than I expected. That's my only fear. Sometimes I fear for him that he might get older than this and not be able to communicate fluently with his friends and they will start discriminating him, laugh at him things like that. I have a friend who has a speech problem and sometimes tells me stories of how people make fun of him and how he had to develop a thick skin for him to be where he is now. Even now he is not able to communicate; when you are talking to him you have to pay attention to him. That has been my fear that it might take him longer than we expected.

Mr. Mushota.

4.9 .3 Parents hopes

Hope is very important in life as it adds value to life. It gives someone a mind of certainty for things not seen but having faith that all will be well. It also creates other avenues on how to help the child. Parents in the current study have hope that one day their child will be normal to near normal, the child will read and write, socialize normally ,get a job, get married and be loved. Cosser (2005) states that it is the dream of each parent to see their child love and be loved.

I hope one day he will be close to being normal or normal. I know he is a bright child when I compare him to other children. I just hope he can sit in class with other children and express himself normally.

Mr. Mumbi.

That they have a bright future, I want them to talk. I want them to be educated I plan that he goes to school, gets to college, and starts work so that he gets independent and be responsible.

Mrs. Mwanza.

You sit and look at him, as a father it affects you and I think about what will happen to him 10 years from now. I don't mind if he is quiet or won't want to socialize but I would want that he will be able to express himself and stand for himself.

Mr. Mubanga.

4.9 .4 The parental desires on treatment.(Gaps in services)

The general findings showed that there was no direct funding or services offered to parents with ASD by the government. In the literature review, parents complained of poor professional-parent relationships and inadequate services.

I desire for a larger percentage of funds to be allocated to the health sector in the budget so that if we have of course the medical personnel and the equipment and the infrastructure and necessary facilities they would be no need for people to go out coz my feeling right now is really if you have to manage a child who is autistic you would have to have a lot of money because you would have to maybe take them out. Ms. Mwila

4.9 .5 Intervention programmes

In the present study, all parents desired for better interventional programs for their children. Parents felt that the intervention programs provided were in adequate and slow. During the time of this study, six parents were still taking their children for therapies at CBIA.

I read a lot on his condition. We have an activity schedule for him that spells out every activity for the day. When he wakes up he must know that he should bath, eat, go to school, sleep and so on which I learnt even at the workshop. We are trying to mentor him to have all these activities and help him lead a normal life.

Mrs. Mubanga.

It's usually just playing with him, giving him puzzles and toys and trying to work on his communication and perception skills. They said they will work on his speech problem later, but for now they are going to give the communication and perception priority. Yesterday was his second session; so much emphasis was on changing his food stuffs because they said autism goes with nutrition. They didn't really explain they just said it goes with autism (Mr. Mushota)

There is enough research evidence which indicate that providing early intervention and identification is essential (Gordon and Browne, 2004) For example, early intervention in education does optimizes long-term prognosis particularly children with ASD who may develop symbolic language before the age of 5.These children stand a better chance of better prognosis (Gordon and Browne, 2004). Early intervention may enable children to reach important milestones; research has shown that children who receive early intervention are more likely to develop communication skills and fewer out-of-control behaviours. Furthermore, researchers have variously suggested that the primary deficit in autism is accounted for by deficits in language, arousal modulation and sensory responsiveness, theory of mind, motor functions and social/emotional (Pierangelo and Giuliani, 2009:187; Gordon and Browne, 2004). Children need to be assessed in areas of behavior using instruments like the draw-a-person screening procedure for emotional disturbances (DAP:SPED) (Pierangelo and Giuliani (2009:187)

Theme 10: 4.10 PARENTS' COPING STRATEGIES

This theme concerns ways in which parents coped with the situation of having an ASD child in the family. The term strategies in this research are defined as ways, methods and approaches which parents used to care for their children. Participants explained that it was difficult to totally accept the child's condition, as each day had its own problems and challenges. The challenges were further compounded by non- availability of trained counselors to equip them on stress management and coping strategies. Parents attributed their coping strategy to a strong belief in God as the giver of life and the healer of all lives. Others talked about a strategy called empowerment. Many mothers further said that they managed their emotions by talking about the child's conditions to other members of the public. Knowledge exchange with other parents were in a similar position greatly helped them. Both fathers and mothers said they dealt with challenges as they came (living in the moment and taking one day at a time is their ideology). Planning for the future or planning a head of the child greatly helped them to cope with the situation. Such findings are consistent to those of Gray (2003) who conducted a qualitative analysis of the role of gender and coping among parents of children with autism. His findings showed that there are similarities in terms of practical or problem-solving coping strategies, between both male and female caregivers of children with ASD, in that they both used anticipation and planning as well as dealing with problems as they happened as their most popular practical coping strategies. Boyd (2000) advocates the use of respite care services in ASD parents as a way of alleviating stress, by introducing time-out to replenish their own energy.

4.10.1 Love from ASD children

Mrs. Mwansa said that the ever present and love from the children gives her strength .This was when she was asked on how she really love her two ASD children if she feels they also show signs of love to her. She said '... *I think they also give me the energy. They love me around and* *when I'm not around they get depressed.*

Mrs. Mwansa.

4.10.2 Comfort from friends

Some parents found comfort through friends who now understand their challenge and the childs' condition and also that the child is able to go to a special school.

Good friend who can show empathy with you help in reducing stress. We have our childhood friends who are doctors and we talk about our problems. Generally friends have been there for us through out.

Mrs. and Mr. Mubanga

There was one time when I went to a kitchen party with him and he was so hyper active that he went taking other peoples meats. Then one woman came and blasted at me saying, "is this (Devil)child yours, he came from that womb" then I broke down and cried and started shouting at her. But there was a doctor who knew his problem so she tried to explain to them his problem. But now if am confronted like that I can be able to tell them his problem.

Mrs. Mulenga

4.10.3 Comfort from God

Parents found more comfort in religious belief .This is belief that you need to accept a gift from God regardless of the Childs' condition. All the participants claimed to be Christians and have a faith in God. Their strong belief is that one day their child will be fine and a solution will be found. This according to the researcher gives parents comfort.

*But knowing God and believing in him has brought a lot of comfort. Especially that the Bible says when God gives you something he never adds sorrows, that's why his name is Mapalo(*blessings*), it's a gift from God. I believe it's just time and definitely things are going to change for the better.* (Mr. Mushota)

Parents observed that there was a need to respect a child with ASD.Ms Mwila draws her strength from the fact that ASD is not a killer disease .It is just a condition and there was no need to stigmatise the child or parents.*She remarks:, '.... Life is still a struggle you know he's a boy who's just been diagnosed, but I always tell people that diagnosis is just a name it's just a name, ok so don't look at the word diagnosis, do not look at the word autism, all you have to always look at is a boy who can do anything. Diagnosis is just a word which is supposed to be brushed* *aside and look at the positive aspect of the child and how you can help him. Like I gave an example HIV/AIDS, it's just a word others have been able to live with it for over 20 years, but those who are in denial it has become a reality."*

4.10.4. Parents daily care strategies for ASD children

Each child needs parental care from the attachment figure mainly the primary care giver. If the care is not enough, children may be affected and be insecure children. Even the disorganised insecure child needs parental care to help him/her change for the better. Parents in this study have used many strategies to cope up with ways of child care as discussed above.

I wake up before they do so that they eat. I bath them, which they love. They love watching cartoons on TV so they don't bother me. By 20:30 they are tired and I have to sleep with them and that is when they rest. My day is programmed so I'm up by 4 a.m. to make snacks and when they are up they go to school

Mrs. Mwansa

Only we have a bit of a problem on meal times, yes. When he's very hungry, he would sit and concentrate and eat on his own. But if he's not, you have like to guide him, force him to eat but then he would be running around, he would pick one thing, goes eats, stops eating it would take maybe an hour or an hour and a half for him to finish, and especially when he's with the mother. Otherwise bathing time, he enjoys bathing very much so we never had problems with bathing. Sleeping times like I mentioned earlier, sometimes he doesn't sleep early he takes a long time, and especially when the job that I do, especially the editing part of it, you find that am editing the whole night, so he would be with me sitting and watching.

Miss. Mwila

4.10 .5 How parents communicate with the child

Findings revealed that parents still had challenges in communicating with the child. In this research, no parent mentioned of using sign language to communicate with the child. At first, before parents knew the childs' condition, they had tough time to communicate with the child who could only cry or throw tantrums if he or she needed something. However, parents reported some improvement in the communication after attending a workshop on autism where they were taught on how to communicate with the child. Parents have come up with methods of communication, by drawing routine picture charts .Two parents explained that the child moves with a picture diary where he or she can points at the things he needs and are slowly becoming independent in basic communication. Literature indicates that children with ASD face a big challenge with communication skills, many children repeat the words and speech in form of an atonal voice (Rosenberg, Westling and Mcleskey, 2011). Due to poor communication skills, this leads children to also get isolated, discriminated against and to throw tantrums as a means of getting what they want in life. It is the duty of parents to teach children different ways of communication such as use of picture exchange, sign language and many other meaningful ways of communicating (Mash and Wolfe 2003).

He speaks, he can understand, only certain things that he misses but mostly he understands. The difficult part has been him communicating back that is what has been giving us a lot of problems... So we've drawn out some diagrams in the house, if he wants water, if he wants to go to the toilet, so he has picked up. But even at first when he was just about a year, we taught him how to ask for water he would say water, when he wants to go to the toilet he would say wee-wee, yah but certain times he would not say it he would just start crying so he will cry and starts pulling down the pant, so then we would know that he wants to go to the toilet. Water nowadays he would just go pick up the cup and the container and bring to you then you will know that he wants water. If he wants juice he would just point where it is coz we just put it on top for fear coz he used to pick and make his own juice. So he will take you to the kitchen while crying and point where the juice is then you know that he wants juice, but there are certain things where he can't point at so we used to have problems coz he will just be crying, so now we would try to figure out looking at time, what he's doing then you will know that maybe what he's looking for is this

Mrs. Mumbi.

4.10.6 Summary

In this theme, parents used many methods of coping with an ASD child was discovered. Knowing the child's condition has helped them to be sensitive to their child's welfare and understanding what is right for their child. This gave parents a sense of empowerment. Present *findings are similar to Dunst and Trivent (1996)'s model of empowerment that suggests that* empowerment ideology is the belief that people have the power and strength to become competent. Parents used humor, self appraisal, openness to the society, seeing other children who have more challenges than their child and the belief in GOD. One parent attributed his resilience to his job as a soldier which demands to be strong as a way of coping with challenges. Parents also said they were slowly accepting societal criticism and stigmatization towards their child. Dunn etal (2001) called such approaches as positive appraisals.

4.2 Group discussions

The researcher looked at challenges which parents faced from different categories ranging from parents who had a first born child with ASD to parents whose child was not the first one. I also looked at challenges which parents from low social and middle income passed through during diagnosis stages.

These focus groups had different parents from different social and economic backgrounds. Each parent (both mothers and fathers) brought in their experiences of their child. Some parents had more than one child with ASD, others had more than one child with other disabilities and to some it was their first time to have a child diagnosed with ASD. The dynamism of these focus groups brought in a rich in-depth history of the parents' challenges with ASD children .Findings showed that all parents had similar observation towards their child behaviour .The impact of discovering that a child had ASD were similar . This included birth of the child, discovering that child had ASD, meeting professionals, diagnosis stages, coming to terms with the diagnosis, in search of service provision and coping strategies with stress.

During the focus group discussions, the researcher observed some unique experiences too on some parents. For example, parents who had a first born child with ASD took time to notice the child's condition and had a higher chance of wanting to divorce their wives as compared to other groups. Furthermore, parents from lower income brackets faced a lot of financial challenges during the prognosis stage. Despite the differences, some common traits of similarities were observed which came up too in the final group where all the parents met and shared their challenges. Similarities which came out included, their ASD child's poor communication skills, isolation, tantrums and phobia to some stimuli. Others felt need for a channel or organisation which can speak for their children's rights and condition, school placement challenges, long period for ASD to be diagnosed, financial and emotional challenges. Parents' acceptance of the child after diagnosis was noticed, though some parents are still in the denial stage.

Another important observation during discussion meetings was that generally parents were excited to meet with other parents who had similar problems like that of them and were able to share their lived experiences of caring for a child with ASD. At first, some parents were hesitant to open up and share their challenges particularly in the first discussion group, but as they continued meeting in other different groups were they had again similar challenges, for example, some parent who had a first born child diagnosised with ASD were also found in a category of low social income status. As they again met for the second or third , they became more open. A group were all parents met was quite exciting, as all parents were open enough to share their problems from the child's birth, to search for diagnosis, school and community comments. Most parents learnt more from friends on what they did not consider as a signs of a child being ASD. As each parent was narrating the challenges they under went with the child , for instance , when one parent mentioned that the child could just cry the whole night and day and could also just look at the objects for a long time without wanting any disturbance. If you disturb him or her ,he would throw violent traumas. Many parents could be seen agreeing with them and could be heard saying 'that is exactly what my child was doing".

Marriage couples were greatly attached by stories from single parents who were observed to have faced a lot of challenges. Single parents could not hold their tears as they narrated their ordeal with the child. This also made some marriage couples particularly first born ASD parents shed tears too. However, by the end of the meeting parents consoled each other, cooled down and became more determined to fight for the rights of their children .The main counselors during the discussion were parents with more than one child with a disability who challenged everyone to be strong and accept the child as a gift from God. Finally parents exchanged their contact addresses and phone numbers. They also agreed to form supporting groups which could advocate for the rights of children with ASD and sensitise the community and government through electronic and print media on what ASD is and how to accept such children and their parents in order to help them reduce the stress they face each day.

CHAPTER FIVE: SUMMARY, CONCLUSION AND RECOMMENDATIONS

5.0 INTRODUCTION

The general objective of the phenomenological research was to examine, explore and describe the impact on biological parents of discovering that a child has Autism. I explored their living experiences before, during and after diagnosis, and how they adjusted in different areas of family life after the diagnosis was made. Other areas explored included effects of an ASD child to other siblings, challenges from society, cultural and traditional beliefs about ASD, services provision in Zambia and parent's desires, hopes and fears about their child and how to cope with them. This goal was attained by conducting a series of semi-structured interviews with biological parents of ASD children, who voluntarily participated in this research. All participants in this researched were recruited within Lusaka province. Themes and categories were fully discussed and evaluated in relation to the present literature.

5.1 SUMMARY AND CONCLUSION

Firstly ,six mothers gave birth normally and only four said had some slightly observation during the child's pregnancy or child's birth. However, no mother attributed ASD condition to their problems during pregnancy and at birth delivery. The results are consistent with findings by Rosenburg et al, (2011) who postulated that it may take time for parents to know that their child has ASD since the cause is not known.

Secondly, participants perception about professionals was that of not generally being helpful toward their child assessment and diagnosis since appointments could take long to be honoured. However, Smith and Tyler (2010:21), Siklos and Kerns(2007:10) attributed professionals' delay in early diagnosis to limitations of the assessment , lack of assessment measures for preschool children, limited time available for assessment, no assessment taking place on time and dependence on only parents' reports, lack of specialized professionals to recognize early signs of children with ASD and shortage of specialized services. Construction of Specialist medical centers for children with pervasive developmental disorders where research on autism in Zambia can be carried out could be a good idea .Such a centre may also act as a resource centre for all Autism related conditions.

Thirdly, three-quarters of parents had no knowledge of what autism is. They learnt about the scientific term autism through a workshop conducted by some Americans .Only one parent once read it in the newspaper. Lack of information, poor sensitization to the public followed by traditional beliefs like *Mdulo and kupitisa mwana kumphatsa, Maloza, witchcraft'* as recorded by Drake (1976) and my informers respectively could have caused this lack of knowledge. There is a need for more sensitization by government and its agencies on what ASD is, how to know the signs and measures which need to be taken at an early stage of child's life.

During the search for diagnosis for the child with ASD, many parents faced challenges such as fear, grief shock denial and finally acceptance of the child diagnosis .Brinker, Safer and Sameroff(1994) and Donovan(1988) highlighted similar results ,they observed that immediately the child was diagnosed, many parents were shocked, refuted the diagnosis. In this research ,parents whose child were first born took time to notice the disorder whilst older couples with other siblings were early to notice delayed developmental milestones, this could be attributed to their experience of child care. Parents with two or more disabled children received the news of the diagnosis with more calmness as compared to other groups(first parents and older parents). However, Hall (2000) warns that caregivers' relief over the arrival at a diagnosis should not be mistaken for gratefulness. She suggests that parents' relief may merely result from the fact that, by comparison, they have not received news of a life-threatening situation in their child, such as a brain tumor. The pain and anguish is still with them (Gascoigne (1996).Promotion of counselling services to parents is needed because lack of it may lead to psychopathological problems in parents or suicides.

On effects on the family, about 80% of the parents were married. All married couples acknowledged that the presence of an ASD child had two -fold effects-it brought unity and also fear of having a second child. This fear was high in parents whose child was the first born with ASD condition. Marital conflicts were observed accumulating from time and energy consumption by parents, particularly mothers who were so obsessed with child's care at the expense of bed and marital matters. Single parents had a greater challenge as they did not have any intimate to help them. One single mother (a student at NRDC who also had a first born child with ASD) said that life has been a challenge mixing school with child caring coupled with fear of the child's daily life when she was out at school. She said that on several times she wanted to stop school so that she could care for the child as often times the child was cared for by her mother and auntie when she was in school. Another single mother a student at University of

Zambia (UNZA) who had a second child diagnosised with ASD recalls that life was rough with her as she was under pressure with school work, her job as billing and she also lost the husband. On siblings, normal children showed love to their sibling though at times they demonstrate anger or resentment toward the child with ASD. Often times, siblings felt ashamed or embarrassed playing with their ASD brother or sister as a result of his or her peculiar behaviours and the constant reminder by parents to check on him or her.

Self esteem is vital to the development of positive attitude of the child and the self. Low esteem will normally have a negative implication when it comes to child care and sourcing for the child's resources. When parents were asked to reflect on their emotional, social and finances costs of caring for a child with ASD. Parents expressed sadness about the high cost in caring for a child with ASD. In this research, parents could not quantify their financial costs spent on the child as it was huge and did not keep any records of their expenditure since all the funding came from personal meager resources or relatives and friends who could help at times. If we are to follow findings by Dobson and Middleton (1998) who estimated that the costs of parenting a disabled child are four times higher than those without any disability, then parents suffered a great deal of cost to care for a child up to the age he/she is at. Mothers in the present research said they generally experienced greater stress due high responsibility in caring for a child with ASD as compared to male partners.

On services, respondents felt that there was a serious shortage of human resources in therapy services, such as speech, occupation, counseling and music. The most affected parents in the study due to shortage of human resource were parents from lower socio-economic status. The findings are consistent with the position taken by Engle and Black (2008). Early intervention programmes are vital for the child's treatment and promotion of home based care (Serpell and Jere-folotiya 2010; Gordon and Browne, 2004). Education services are a challenge to parents since there are no suitable preschools for children with ASD. Mainstream preschools and primary schools were unable to meet the special education needs of their children, and were often unwilling to accommodate them because of the child's behavioral problems. The probable cause could have been teachers' lack of knowledge on what autism is lack of access to the national curriculum for children with ASD. Smith and Tyler (2010:21) observed that the major barrier to academic and social inclusion of students with ASD is lack of access to the general curriculum and the inclusive environment which helps the child with ASD in social aspects of his or general education This may result in parents blaming themselves for not solving the child's problem, some parents may fail to come to reality and further blame themselves if the child's education goals are not met or achieved.

A literature reveals that there are many approaches which can be used to educate children with special needs. This includes multi-disciplinary teaching techniques which integrate training in auditory, applied behavior analysis management, communication, speech therapy, play therapy, music therapy and many more. It is generally recommended that within 6 weeks of diagnosis, pre-school children should have access to a trained professional skilled in ASD in each local area. The professional should set up an Individualised Education Programme (IEP) either at home or nursery to develop communication, social and cognitive skills. This should be with the help of the parents and teachers who will implement the plan.(Cameron, 1997 and Newman, 2007).There is a need to have a specific ASD child's programme which should run for at least 15 hours per week -25 hours for 2 weeks(Frederickson and Cline,2010).Teachers should develop knowledge and understanding about individuals' needs. Teacher professional development is a responsibility that all teachers need to learn about specific disorders .This helps them teach appropriately according to the disorder. This is more encouraged in inclusive learning (Rose and Howley, 2010)

Parents coping strategies included taking one day at a time and planning ahead, empowerment, humor, openness, being part and parcel of interventional methods. Cameron, (1997) and Newman (2007) advocate for home based education which is lacking in Zambia. However, it can be perceived that parents cope with stress through their faith and belief in God's healing power as suggested by Bronfenbrenner (1979). Professional opinions expressed during the present findings matched those reported by Boushey (2001) who states that the diagnostic process was sometimes vague, confusing, and contradictory and non-definitive. In Zambia, this may have been caused by the fact that the scientific term autism is little known amongst professionals and some may just speculate that it is autism or the commonly popular behavioural problem in early childhood -Attention Deficient Hyperactive Disorder(ADHD) .There is a need for a good and warm relationship between parents and helping professionals as postulated by Osborne and Reed(2008).The perceived professional delay in diagnosis may have being caused by poor patient-doctor ratio. Zambia has fewer health professional as compared to the population. Many specialized health professionals have left the country for *greener pastures*. Furthermore, participants may not understand that mental disorders are difficult to diagnose and take a lot of time to arrive at the final conclusion as compared to physical disorders (Carson, Butcher and Mineka, 2000).There is need for practicing medical practitioners, pediatricians, and teachers to improve their technical knowledge at identifying ASD condition at an early stage of child's development. The training of teachers, doctors, and nurses should have a sense of urgency by considering the stressful nature of the condition on parents of a child with ASD who is normally emotionally unresponsive. Practicing professionals can assist parents to overcome challenges by providing effective strategies such as counselling and home based care education.

Parents still had a ray of hope for their children, as they still believe that one day their child will be normal to nearly normal. Their hope is that one day the child will be loved and be independent. Parents fear their own death because they don't know who can keep such a child and still give figure any one in their parents surround

All the mothers interviewed easily accepted the condition by means of talking about it with other members in the community and confrontation approach. Confrontation strategy is when a person expresses his or her anger by fighting for the rights of the child, finding a better school for the child rather than declaring that the child is not normal. Results indicate that 50% of fathers took a long period of time to accept the child's condition and they hardly talk about the child's condition to friends. Parents further narrated some challenges of disciplining the ASD child. This resulted into parents getting frustrated, as beating or shouting at the child does not work. Parents hardly go for social functions due to criticism, stigmatization and behavioral challenges from the child. To help mitigate such a challenge, parents need training and sensitization on coping strategies on stress. This may help parents advocate for better services for their children as well as lodge in legal complaints, to claim specific service entitlements.

It is the researcher's hope, prayer and conviction that this study will serve as an important and valuable information for professionals working with children with ASD children particularly teachers and health workers. It is also my conviction that parents of both ASD children and those who may join the ASD family will benefit from this information

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5.2 RECOMMENDATIONS

5.2.1 Construction of Specialist Medical Centers for children with pervasive developmental disorders where research on autism in Zambia can be carried out. The place can also act as a resource centre for all Autism-related conditions.

5.2.2 There is a need for practicing medical practitioners, pediatricians, and teachers to improve their technical knowledge at identifying ASD condition at an early stage of child's development. The training of teachers, doctors, and nurses should have a sense of urgency by considering the stressful nature of the condition on parents of a child with ASD who is normally emotionally unresponsive. Practicing professionals can assist parents to overcome some challenges by proving effective concreted strategies such as:

1. Developing patience in the knowledge about ASD conditions also make parents understand that child development is gradual.
2. Close observation on the child's behaviour as a source of understanding.
3. Planning of multi-professional support groups to relieve the pressure on single parents.
4. Sharing experiences with the parents in a loosely supervised support groups.

Such strategies will assist both professionals and parents to easily identify systems, warnings and quickly refer the child to specialists or formulate intervention programmes for them.

5.2.3. Parents need an intense professionals-Parents model approach, where professional counseling services and other support like emotional, social and finances are provided to them. This will empower parents with information and resources, and employ a collaborative parent-professional model, whereby parents will directly be involved in child treatment and recognised as experts on their children's behaviour.

5.2.4 Home-based care education and intervention approach need to be encouraged. Parents may greatly benefit from professionally run support groups where they can share challenges and experiences.

There is need to build schools for children with ASD which are well-equipped with materials resources that may help in behaviour modification and skill learning. The school needs to be staffed with specialists in speech therapy, child and clinical psychology, occupation therapy; behavioural management therapy, music and these personnel need to be stationed in schools and hospitals or Autistic centers. Affordable schooling and available schooling is needed in Zambia in all the districts.

5.2.5 The governments need to have empathy for ASD parents and children by allocating funds in the national budget for parents and children to meet the costs of services in Zambia.

5.2.7 There is a need for nationwide assessment sensitisation health survey to parents on ASD condition and diagnosis. This information will benefit government to know the exact numbers of children with autism and will help in planning for their services and resources.

5.2.8 The government needs a serious affirmative action on quality health services in Zambia and remove the weak red-tapes bureaucratic tendencies in health provision. Zambia like any other third world countries has a lot of health challenges such as high diseases caused by lower levels of control on the physical environment. For example, heaps of garbage, poor water and sanitation in shanty compounds, heavy mineral explorations, high uncontrolled pollution from industries and careless tree cutting. All such leads to pollution of the environment, hence health hazards and diseases.

5.2 9 Another challenge is low levels of specialised technical professional staffing due to poor enumeration, forcing professional going for 'greener pastures' (brain drain). The quality shortfall of professionals affects all sectors of health regardless of the health problem.

5.2.10 There is needed to support special schools with more grants as it is normally at the mercy of donors. The grant which the school receives is the same as other normal primary school. The grant is less than K4, 000,000 per year. The money is not enough considering the fact that the special needs children need a lot of education materials and toileting materials.

5.2.11 Special allowances and incentives need to be introduced to motivate special education teachers and doctors who will work with Special children in both schools and hospitals. This will avoid brain drain.

5.2.12 There is a greater need for collaboration and partnership between multi-disciplinary professionals during the diagnostic process. Holistic assessments are recommended that evaluate autistic children and their families within their micro-, meso-, and macro-environments as all the parties consider the peculiarity of ASD as compared to other mental retardation conditions.

5.5 FUTURE RESEARCH AREAS

There is need to have such future studies in Zambia that will directly aim at siblings phenomenological challenges with their brothers and sisters who live with a child with ASD. Other future research can include all the ten themes, their categories and sub-categories. For example (1) Financial cost of caring for the child from birth to schooling time and beyond; (2) how to educate adolescent ASD children; (3) career path for ASD children in Zambia.

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Appendix 01

The University of Zambia
School of Humanities and Social Sciences
Department of Psychology, Postgraduate Studies 2010

TITLE: THE IMPACT ON PARENTS OF DISCOVERING THAT A CHILD HAS AUTISM: A PHENOMENOLOGICAL STUDY OF LUSAKA PARENTS.

Informed Consent Form

I/we---the research participants in the study: **'The impact on parents of discovering that a child has an autism'** through UNZA permit(s) **Nyoni Joachim,** the researcher, to interview me/us and audio-tape the interviews for the transcripts purposes. These audio tapes and other documents will be confidential and they may only be used by **Joachim Nyoni**. I/we are aware that I/we have the right to discontinue with the project at any time and this will not affect my/our access to services for my/our child or my/our relationship with the researcher and professionals.

Date: ---

Signature of parent one ---

Signature of parent two ---

APPENDIX 02

A. PARENTS BIOGRAPHICAL DATA

1. Name--- (pseudo)
2. Sex ---
3. Age---
4. Occupation---
5. Marital status--
6. Highest level of education---
7. Year when the child was diagnosed with autism---------------------------------------
8. Date of interview---

APPENDIX 03

B. CHILD BIOGRAPHICAL DATA

1. Name--- (pseudo)
2. Sex ---
3. Age---
4. Occupation--
5. Education highest level --
7. Year when the child was diagnosed with autism--
8. Services provided---
9. Date of interview---

APPENDIX 04

C. FOCUS GROUPS DATA SHEET

1. Name of the group--

2. Date of the group interview--

3. Participant's name---

4. Gender--

5. Marital status--

6. Number of children with autism---

7. Children's /child's name with autism date of birth-------------------------------------

8. Gender of the child---

9. Name of the school the child is attending---

APPENDIX 05

D. QUESTIONS GUIDE FOR THE RESEARCHER.

The in-depth question:

What is it like to be parents/parent of a child with Autism Spectrum Disorders(ASD)? Or tell me in your own words about your experiences as a parent with a child with ASD.

Supplementary questions:

1. What situations have greatly affected your experiences of having a child with ASD?

3. How would you describe an ASD child?

4. What feelings come into your mind when you mention or see a child with ASD?

5. What meaning does autism disorder have in your life?

6. What mental images do you have for a child with ASD?

7. Does having a child with ASD affect your family life? If so how?

8. What has been most helpful in your life with a child with ASD?

9. Has having a child with ASD influenced your personal growth?

10. What has been your experience with professionals?

11. What are the most prevalent feelings you have experienced towards an autistic child's diagnosis such as aggression, anxiety, disappointment, grief and pain?

12. What are the costs (financial, social, and emotional) of caring for a child with ASD?

13. What have been the reactions from the community in relation to cultural beliefs about children with ASD?

APPENDIX 06

E. SEMI-STRUCTURED INTERVIEW GUIDES

INTERVIEW 1:

EXPERIENCES UP TO AND INCLUDING THE DIAGNOSTIC PROCESS

Researcher introduces self and summarises the aim of the study and ask participant to complete and sign the consent form and the biographic data.

1. Biographical data (name, age, employment, highest level of education, home language, marital status).

2. Family size (occupation of parents, birth order of children)

3. How did you experience [name of autistic child] as an infant and baby? What was s/he like as a baby and before going to school? What do you remember most as you think back to that time?

3. How did it come about that you decided to seek for professional health assistant. Explain to me about this time in your family's life.
4. Who first mentioned the word autism?
5. How would you describe the diagnosis process? What did that diagnosis mean to you? What was particularly difficult during this time and was helpful?
6. How were your feelings like when you reflect back during this stage? What came into your mind immediately you were told about the diagnosis and what thoughts and concerns ran through your mind as you tried to understand your child's condition?

- Arrange time for the second interview, (if there is still time, Researcher goes to second interview).

INTERVIEW 2:

PARENTS COPING STRATIGIES AND ADJUSTMENT

[Start questions with: *How have you experienced...; What is your understanding of...; Please tell me more about...; What was it like...; What do you remember most...; What was most helpful...; What made it difficult...; What (if anything) would you have done differently...; What sense did you make of...]*

1. Describe your daily programme at home after [child's name] was diagnosed with ASD. How is this different now from how it was when s/he was first diagnosed? Is there any difference in the daily activities such as meals, bath time, using the toilet, bedtime, and fun activities? What difficulties did you encounter? What helped?

2. What coping strategies did you use to manage the demands on your time and energy? Where did you run to for help? And what or who was most helpful in coping with the demands of raising a child with autism?

3. Tell me about your experiences, struggles and eventual adjustment in terms of:
3.1. Your child's education .
3.2. Effective methods of behaviour control and discipline; and
3.3. The impact of the ASD child on other siblings and family members.
3.4. Cultural beliefs and community's attitude toward the child.

The researcher wills Summaries the main areas covered in the interview. Arrange time for the third interview:

INTERVIEW 3

PARENTS,FEAR,HOPES , NEEDS, CONCERNS AND SUPPORT SYSTEMS

[The researcher will start questions with: *How have you experienced...; What is your understanding of...; Please tell me more about...; What was it like...; What do you remember most...; What was most helpful...; What made it difficult...; What (if anything) would you have done differently...; What sense did you make of...*]

1. As you reflect back to everything that you have been through with [child's name], what was it that you felt you needed for your child. What were the main challenges you faced?
2. How do you feel about the resources and support systems available to parents of ASD children in Zambia? Where there any formal support from the government? What do you still need? Suggest on how you feel the services available to parents with ASD children can be improved?
3. How do you look at [child's name's] future? What are your major concerns about him/ her? What gives you hope?
4. What are some of unresolved issues or problems about your child's condition which you feel still needs attention?

The researcher will summarise the main areas covered in the interview. He will ask the participants to share anything else about their needs, concerns, or thoughts about available resources and support systems that they regard as important or that the researcher did not ask about.

The researcher will thank participants for their willingness to share their experiences. Obtain postal address or telephone number to provide summarised details of the major findings and recommendations of the study at the completion of the research to participants who want this inform.

Number ....X X

MULTIDISCIPLINARY SPECIAL NEEDS ASSESSMENT SERVICE
HEARING AND SPEECH CENTRE (UTH)
LUSAKA

NAME OF CHILD:... X X ....

SEX: ...M...

MOTHER'S LANGUAGE: ....Bemba.... OCCUPATION ..Nurse..

FATHER'S LANGUAGE: ...."................. OCCUPATION .Engnire..

NAME OF PARENT / ~~GUARDIAN~~: ..L. mwape mutale ......

RESIDENTIAL ADDRESS: .. X X

TEL/CELL: .... X X ....

RELIGION: .... X X ....

HEALTH AUTHORITY CARE FOR CHILD (GOVT, MINE, RAILWAY, PRIVATE ETC)

....Lewanika Hospital Govt ....

....

REASON/S FOR ASSESSMENT:

1.......Autism..

2..

3..

4..

DECLARATION

I the undersigned DECLARE that the above information is true. I have / will supply / supplied all the necessary information regarding the child. I at any time, physical, mental or other conditions arise that make the child's enrolment, removal or transfer from school necessary, this will be accepted by me. I .... further agree to accept the results of the assessment.

SIGNATURE: .... RELATIONSHIP ....MOTHER....

WITNESS: .... X X X X ....

ADDRESS: ....UTH. SP. SCH. ....

....

OCCUPATION: ..Specialist Teacher. ....

DATE: 05/01/2010

CONSULTANT: x x x x

CONTACT NUMBER ……………………………

SOCIAL HISTORY

A. FAMILY STRUCTURE

i. Number of people in the family: 6
ii. Adults: 3
iii. Siblings: Male 1 Female –
iv. Does child stay with [✓ both parents] / single (father or mother)? yes
v. Does stay with other relatives other than biological parents? ……………
vi. If yes, why? ……………
Age of (a) Mother 30 (b) Father 40 (c) Guardian ……

B. ECONOMICAL STATUS OF FAMILY

i. Are parents / parent / guardian in gainful employment? [✓ Yes] / No
ii. Type of employment Nurse
iii. If no, how do you earn your living? ……………

C. FAMILY INTERACTION

i. How do you cope with this child?
very well.
ii. What have you done to help this child?
Took him to the Hospital.
iii. What is the attitude of the other children towards child?
Its goods

EDUCATIONAL LEVEL: [✓ (a)] University (b) Secondary (c) Primary (d) Never been In school

FAMILY LINK TO COMMUNITY RESOURCES

i. Do you take this child to hospital? [✓ Yes] / No
ii. If not why? ……………
iii. Does this child go to school? [✓ Yes] / No
iv. If not why? ……………

RECOMMENDATIONS:
Further investigations.

SIGNATURE …………… DATE 05/01/2010
OCCUPATION Specialist Teacher.

Clinic 2

PAEDIATRIC REPORT

i. Pregnancy: was it normal? Normal
ii. If not, what were complications? nil

iii. Where was the child born? [✓ (a) Clinic] (b) Hospital (c) Village / home (d) BBA
iv. Birth was it normal? Normal
v. If not what were the complications (prematurity, breech, caesarean etc)

v. Birth weight: 2.7kg
vi. Any abnormal happening soon after birth (e.g convulsions, jaundice, slow to breath) nil
vii. Has the child suffered any disease? Please give details (e.g smallpox, mumps, TB, meningitis etc) nil

ix. Has any other member of the family suffered from a similar disease? Yes / [✓ No]
x. Was the child involved in any accident?
a. During birth No
b. After birth yes; Electrocution at 1yr 2m

xi. Has the child been vaccinated against any of the following?
1. BCG [✓ Yes] / No Date:
2. Measles [✓ Yes] / No Date;
3. DPT [✓ Yes] / No Date:
4. Meningitis [✓ Yes] / No Date:
5. Mumps Yes / [✓ No] Date:
6. Polio [✓ Yes] / No Date:

SIGNATURE DATE 06/01/2010
OCCUPATION medical doctor

ZAMBIA CHILDREN'S CLINIC
06 JAN 2010
UNIVERSITY TEACHING HOSPITAL
BOARD OF MANAGEMENT
P/B RW 1X, LUSAKA

Zamise

PSYCHOLOGICAL PROFILE

A. DEVELOPMENTAL BACKGROUND

i. when did the child start:
a) Talking (a) about 11 months B) Sitting 6 months C) Crawling 11 months
b) Walking 13 months
Child's ability to communicate: verbal & gestures

D. PERSONAL SOCIAL SKILLS

Ability to interact with others – He interacts with peers below his age most of ~~them~~ the time. He is not fightful.

2. Activities for Daily Living skills

i. Toileting – goes to toilet by himself.

ii. Domestic skills – Baths for himself, feeds for himsel

MOTOR SKILLS

Fine Motor Skills:

i. Does the child use a turning motion with a hand while turning door knobs, screwing lids of jars? Yes, he does eg. closing and opening door.

ii. Is he / she able to pick small objects with hands or fingers? Yes, he is.

C. ADAPTIVE

Imagination / Initiative He is able to avoid dangerous ob

1. Does the child put things away where they belong? Yes, he does, he even cleans his plates and cups after a meal.

2. Problem solving skills Not much.

3. Is this child functioning like other children of his age group? Yes / ~~No~~
Explain He ~~is~~ needs assistance in behaviour modification – He should be discouraged f making unneccessary movements.

4. Is this child suitable for school or education? Yes / ~~No~~
Explain Yes, in a special class for children with ADHD and autism.

GENERAL REMARKS / RECOMMENDATIONS: We recommend that XXXX be placed in a class of children with Learning Disabilities esp. autism and ADHD.

REPUBLIC
SPECIA
ASSESSMENT CENTRE
P.O. BOX 320081, LUSAKA.

SIGNATURE XXXXXX

DATE 06 JAN 2010

OCCUPATION Assessment Coordinator/Senior Lecturer

Clinic 6

PSYCHIATRIC PROFILE

Does the child do any of the following:

i.	Sucks thumb or fingers	Yes	Sometimes	[✓ Never]
ii.	Is overly dependent on others	Yes	Sometimes	[✓ Never]
iii.	Withdraws	Yes	Sometimes	[✓ Never]
iv.	Wets bed	Yes	Sometimes	[✓ Never]
v.	Exhibits eating disturbances	Yes	Sometimes	[✓ Never]
vi.	Exhibits a sleep disturbance	Yes	Sometimes	[✓ Never]
vii.	Cries or laughs too easily	Yes	Sometimes	Never
viii.	Exhibits excessive unhappiness	Yes	Sometimes	Never
ix.	Is too impulsive	Yes	Sometimes	Never
x.	Has poor attention	[✓ Yes]	Sometimes	Never
xi.	Is overly active	[✓ Yes]	Sometimes	Never
xii.	Has temper tantrums	[✓ Yes]	Sometimes	Never
xiii.	Has negativistic or defiant	Yes	[✓ Sometimes]	Never
xiv.	Teases or bullies	Yes	Sometimes	[✓ Never]
xv.	Does cheats or steals	Yes	Sometimes	[✓ Never]

Is the child emotionally stable or not? A.D.H.D

RECOMMENDATIONS: To Special School

MINISTRY OF HEALTH
UNIVERSITY TEACHING HOSPITAL
06 JAN 2010
CLINIC 6
PSYCHIATRY CLINIC
LUSAKA

SIGNATURE

DATE 06.01.2010.

OCCUPATION Psychiatric Specialist

Clinic 7

VISION – EYE SPECIALIST REPORT

1. Are there any observable physical defeats?

2. What are they?

3. Can the child see? Yes

4. Can the visual acuity be assessed? NO

5. If so? VAR:

VAL: ....

6. **Fundus:** Normal

7. **Remarks / Recommendations:** Special school

SIGNATURE ....

DATE 6/01/10

OCCUPATION Ophthalmologist

REPUBLIC OF ZAMBIA
MINISTRY OF HEALTH
UNIVERSITY TEACHING HOPSITL
06 JAN 2010
CLINIC 7
EYE CLINIC
P/BAG RW1, LUSAKA

Clinic 6

E.N.T SPECIALIST REPORT

1. Was the child born deaf or delayed in speech? NO
2. Has the child got delayed speech? YES
3. Are there any other children in the family who are deaf or have delayed speech? NO
4. Is there anybody on either the father or mother 's side who has had hearing problems? NO
5. Has he / she suffered from any disease before? HE WAS INVOLVED IN ACCIDENT IN 2002
6. If the child was not born deaf, when did he / she develop a hearing loss? N/A
7. Has the child suffered from discharging ears? At what age did this happen? NO
8. Have you taken your child to a hospital or doctor because of ear trouble? Where and when? NO
9. Recommendations: Special School

REPUBLIC OF ZAMBIA
MINISTRY OF HEALTH
UNIVERSITY TEACHING HOPSITAL
06 JAN 2010
CLINIC 6
P/BAG RW1, LUSAKA

SIGNATURE ....

DATE 06 - 01 - 2010

OCCUPATION ....

10/2010

AUDIOMETRIC PROFILE

[illegible]
ds meat

AUDIOLOGICAL REPORT

e bared
vo.ps
rde

EAR CONDUCTION:
Right ear o-o/red
Left ear x-x/blue

BONE CONDUCTION:
Right ear (……/ red
Left ear (……/blue

95 the
ny box pure-
nc sounds
all frequencies
head
8, at
stance,
Response
good
ause he
ned his
d toward
object

Not heard

0						
10						
20						
30						
40						
50						
60						
70						
80						
90						
100						
110						
120						
125	250	500	1000	2000	4000	8000

rding
1. Reliable response ( ) Fairly reliable response ( ) Unreliable response ( )

te mother
2. Is hearing normal in:
   (a) Both ears? ……………………………………………………
   (b) One ear? ……………………………………………………

boy
hees
3. Speech - which words is child able to say……………………………………
……………………………………………………………………

ulte
DATE: ……………………………………………………

ds
ough
OCCUPATION: ……………………………………………………

on we
SIGNATURE: ……………………………………………………

e [illegible]
dance
diological
[illegible]

4. Recommended Hearing Aid, Type :
……………………………………………………

ly
5. Recommended by: ……………………………………………………

ms to be
in normal hearing limits in
o test
audiology Technician
Siwakai

DATE: ....

OCCUPATION: ....

SIGNATURE: ....

main physio

PHYSIOTHERAPY

1. DEVELOPMENTAL HISTORY

At what age did child sit unsupported 6 months
At what age did child crawl unsupported 8 months
At what age did child walk unsupported 1 1/12

2. ACTIVITIES OF DAILY LIVING (ADL)

Eating:	[✓ Feeds self] / fed
Drinking:	[✓ Drinks alone] / can not drink alone / looses a lot of fluids
Toilet:	[✓ Trained] / not trained
Undressing:	[✓ Able to] / unable to
Dressing :	[✓ does alone] / needs help / fully dependent

3. PHYSICAL EXAMINATION

From lying to sitting	[✓ Able to] / unable to
Sitting:	[✓ Sits alone] / sits with support
Rolling / turning:	[✓ Able to] / unable to
Four point kneeling	[✓ Able to kneel alone] / able to kneel when placed / Able to kneel with support

Head :	Head control in prone	[✓ good] / poor
	Head control when pulled to sitting	[✓ good] / poor
	Head control in sitting	[✓ good] / poor

Long sitting:	Unable / [✓ able to long sit] because
Crawling:	[✓ Able to] / unable to / bottom shuffers
From sitting to standing -	with support / [✓ able to] / unable to

Standing:	[✓ stands alone] / stands with support
Step:	takes assisted steps / takes a few steps alone
Walk:	[✓ walks alone] / walks with help
Balance on one leg:	unable to / [✓ able to]

4. USE OF HANDS

Can grasp and release – with right hand / with left hand / [✓ with both hands]

Can not grasp

Can reach out for objects – with right / with left / [✓ with both]

Bilateral hand skills – [✓ good] / poor

Hand regard – [✓ good] / poor

5. ORAL : [✓ Good oral control] / dribbles

6. Associated impairment : Hearing / vision / [✓ Speech] / Epilepsy

7. POSTURAL TONE:

Normal

SIGNATURE: ... X X XX ...

DATE ... [illegible] ...

OCCUPATION ... Physiotherapist ...

UNIVERSITY TEACHING HOSPITAL
DEPARTMENT OF PHYSIOTHERAPY
06 JAN 2010
PRIVATE BAG RW 1X, LUSAKA

MULTIDISCIPLINARY SPECIAL NEEDS ASSESSMENT SERVICE
HEARING AND SPEECH CENTRE (UTH)
LUSAKA

X X X ……………………………………………
X X ……………………………………………
X X ……………………………………………

TO WHOM IT MAY CONCERN

Re: Assessment [redacted] and request for placement ~~for~~ of
… X X X [redacted] in a special class for childr
with learning difficulties.

This serves to inform you that the above mentioned person has been assessed and below are the summary comments of the assessments:-

	AREA OF ASSESSMENT	SUMMARY COMMENTS
1	Paediatrics summary	ADHD
2	Social History summary	He is able to socialise with his peers
3	Psychological profile summary	He seems to have mild autism.
4	Psychiatric profile	A-D-H-D
5	Vision	Normal
6	E.N.T summary Report	Special
7	Hearing / Audiometric summary	Normal hearing [illegible]
8	Physiotherapy summary	No gross motor defects [illegible]
9	Academic profile	He was at Lewanika Hospital special school for 1yr

In general, X X X ………… has major difficulties in the following areas of function:
1 Attention Deficit Hyperactive Disorder
2 Autism
3 Behaviour Problems
4

We therefore recommend that Kafula Mutale be placed in an appropriate special school / institution for children with Learni Difficulties

Yours faithfully

X X X

X X X X

SIGN

REPUBLIC OF ZAMBIA
INSTITUTE OF SPECIAL EDUCATION
06 JAN 2010
ASSESSMENT CENTRE
P.O. BOX 320081, LUSAKA.

UNIVERSITY TEACHING HOSPITAL
06 JAN 2010
PSYCHIATRY CLINIC

N.B X X X X should be brought for comprehensive assessment – using

mmunications should be addressed to
e Headteacher
el: 222268

In reply please quote
No.........................

REPUBLIC OF ZAMBIA
MINISTRY OF EDUCATION

LEWANIKA TEACHING UNIT
P.O. BOX 910147
MONGU

30 Nov. 2009.

The HeadTeacher
UTH Teaching Unit
P.O. Box
Lusaka.

Dear Sir/Madam,

RE: TRANSFER LETTER FOR

The above mentioned pupil has been transfered to your school on parental request.

Please Kindly make your own assessment and placement in Grade 2/Level 2, next year 2010.

PEROSAL PARTICULARS OF THE PUPIL

NAME / GRADE	Y.O.B	RELIGIOUS DENOMINATION	1ST YEAR ENTRY INTO SCHOOL	CHARACTER	ACADEM PERFORMA
GRADE 1 / LEVEL1	2001	CATHOLIC	2008	Good.	Average He need more hel

As a school, we shall be very grateful to learn th
he has been offered a place at your school.

Yours faithfully,