ROLE OF COUNSELLING SERVICES ON PARENTS WITH CHILDREN WITH DISABILITIES IN LUSAKA, ZAMBIA.

BY

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DECLARATION

I, Maria Musuka, do hereby declare that this dissertation is the result of my own work and that it has not been previously presented at any level at this or another university except in the case where acknowledgement has been quoted in the study.

Signed…………………………………………………Date…………………………………..

DEDICATION

This dissertation is dedicated to very special people in my life who I denied my presence each time I sneaked away to study: Chioni, Viston, Tasila, Samson, my brothers and sisters, namely Charles, Cyprian, Dominic, Cecilia, Adrian, Kafa, Ngawa and Alida. Above all, this dissertation is dedicated to my mother Veronica and my father Samson, who gave me the best foundation in my education.

CERTIFICATE OF APPROVAL

This dissertation of Maria Edina Mwanza Musuka has been approved as partial fulfillment of the requirements for the award of the degree of Master of Education in Guidance and Counselling.

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Abbreviations and Acronyms

AIDS	Acquired Immune-Deficiency Syndrome
CBT	Cognitive Behavioral Techniques
CPRC	Community Parent Resource Center
CBR	Community-based Rehabilitation
CSO	Central Statistics Office
CRPD	Convention on Rights of Persons with Disability
ELM	Effective Life Management
HIV	Human Immune-Deficiency Virus
IDA	International Disability Alliance
MCDSS	Ministry of Community Development and Social Services
MoGCSW	Ministry of Gender, Children and Social Welfare
MoDEA	Ministry of Disability and Elderly Affairs
MoE	Ministry of Education
MCH	Malawi Council for the Handicapped
NAMR	Norwegian Association for the Mentally Retarded
PPP	Parent to Parent Programme
PPP	Parental Positive Perceptions
PTC	Parents Teachers Conferences
PTI	Parent Training and Information
SBFC	School-Based Family Counseling

SRF	Sue Ryder Foundation
UNCRPD	United Convention on Rights of Persons with Disability
VIM	Vereniging voor een ge Integreerde op voeding van Mongoloide Kinderen
WHO	World Health Organisation
ZAPD	Zambia Agency for Persons with Disability

ABSTRACT

Every parent has great dreams and expectations of a healthy, bouncy baby in their marriage. These dreams are shattered when the baby is born with a disability. There is shock and grief and this disappointment is harder in Africa where some societies still believe that it is an abomination and punishment from the gods for something sinful that the family had done. Thus such parents and their siblings face social stigma, exploitation, and discrimination. The grieving of parents of children with disabilities is common and universal. Counselling services assist grieving parents to heal and come to terms with the situation. Counselling helps parents of children with disabilities to be empowered and understand the human rights, know the channels to seek justice and stand up to fight in order to enable their children access the social facilities in all dimensions of life. When the parents are healed and live fulfilled and self actualized lives, then their children with disabilities will benefit and grow up to live quality lives.

Counselling is not a new concept in Africa; it is as old as Africa itself. The wisdom and knowledge imparted by elderly men and women on the younger members of the society was part of continuous guidance and counselling in preparation for the future. Counselling was available to all at different stages of life. However, there is a contrast as regards counselling parents of children with disabilities because of the cultural beliefs in Africa. The communal aspect of ‘I am because you are” “umuntu” is overshadowed and there are negative attitudes towards people with disabilities. This causes grief and anguish that need counselling services.

The purpose of this study was to find out the role of counselling services, whether there are institutions that offer counselling services to parents of children with disabilities, do parents of children with disabilities receive counselling services and how effective these are in Lusaka. The study sample was 17 parents of children with disabilities. A purposive sampling technique was utilized due to rich-in-depth information that was to be obtained for the researcher. The interviews carried out with these parents at Hidden Voice revealed that most of the parents of persons with disabilities do not have counselling services and face attitudinal barriers that is behaviours, perceptions and assumptions that discriminate against persons with disabilities including prejudice, low expectations and even fear within their communities. Negative attitudes about their children‘s disabilities impact on all aspects of their lives and so need counselling services and empowerment in order to cope with the situation appropriately.

Finally, recommendations were made to the government, non-governmental organisations and to the parents of children with disabilities.

CHAPTER ONE

INTRODUCTION

1.0 Overview

This chapter discusses the background to the study, the statement of the problem under study and its purpose, the objectives of the study and the research questions. Thereafter, the chapter confers the significance, delimitations and limitations of the study, theoretical framework and finally the operational definitions. The aim of this paper is to discover the role of counselling services for parents of children with disabilities and ways of resolving this problem by using methods of educational research. The paper will define the problem and identify the research topic which will guide the discussion.

BACKGROUND TO THE STUDY

Globally a human being is born with inherent dignity that gives him or her immense value, this means that universally, it is accepted that a human being has dignity. No physical disability reduces the value of any human being. The Universal Declaration on Human Rights (UDHR) www.un.org. states clearly: all human rights are indivisible, whether they are civil and political rights, such as the right to life, equality before the law and freedom of expression, economic, social and cultural rights, such as the rights work, social security and education. The parents of children with disability and their children are naturally included in without exception. The concern for children with disabilities in Africa is animated by the communitarian dimension. Parents take care of children with disabilities because of the spirit of ubuntu demands that even children born with disabilities be taken care of. However it has not been a simple task traditionally, because in the past, a child with a disability was seen as a bad omen. The change has been due to gradual education on the dignity of each child.

Parents of children with disability in Africa may not be aware of UDHR or Convention on the Rights of a Child (CRC) like the right to freedom from torture or to freedom from cruel, inhuman or degrading treatment or punishment. http://en.m.wikipedia.org. In Africa, a child is a price of great value. The birth of any child is filled with hope and enthusiasm which is short lived when a child has a disability. When a newlywed couple announces that they are expecting a baby the good news spreads like wild fire. When the baby is born, it completes the circle and brings so much joy. Initially, the parents have hopes and dreams of a ‘normal’ and healthy baby. When a family gives birth to a disabled child, they are devastated, all the dreams are shattered and sorrow and grief creeps in the home. Hence the need for an outlet, the role of counselling services plays a vital part in restoring the parents to their original state.

Acceptance of a child who has a disability becomes a hitch and there are various questions that arise to try and explain the situation. In the African context, children represent the satisfaction and completion of social and cultural expectations. Children symbolize the unification of different ancestral spirits and the continuation of the family name. A person was not generally considered an adult until they had married and had children. It was then that they could qualify to the next stage of eldership. Burke (1987) denotes that the desire for children has always been the main motive inspiring the African to marry. Personal fulfillment for the African is achieved very principally in having offspring through which one expresses and perpetuates oneself. Children have always been regarded as a prolongation of self and therefore, in some way, a fulfillment of immortality. A man who had no child would consider himself dead and finished. Thus a child with a disability questions the essence of this belief, the potency of the father and raises suspicions as to what the couple had done to deserve such an abomination. Therefore, explanations are sought.

One of the explanations to the cause of disability in the African setting is attributed to witchcraft or anger on the part of ancestral spirits. One of the parents is viewed with suspicion and blamed for the misfortune on the family through adultery or some other sinful act. This is what brings repulsive feelings among parents of children with disabilities. They are wounded and their future becomes bleak. Taylor, (1982), states that the feeling of isolation at the time of diagnosis is almost universal among parents of children with disabilities. The parents have to adjust to a wide variety of emotional and psychological problems when first confronted with the failure of their reproductive expectations. Counselling is a formal procedure or transaction in which both counsellor and parents aim to find a mutually acceptable plan of adjustment. Parents need support to cope with their own personal inadequacies as well as with the needs of the child. Counselling services must be a continuous process, in which the parents can learn to accept the child as different.

Taylor, (1982) categorised into stages the kind of grief felt by parents of children with disabilities; The feelings of fear, grief and shock, denial, numbness, depression, and finally, adjustment. The passage through these stages takes time and may occur differently in different families. Grieving brings out the "feeling states" of denial, anxiety, fear, guilt, depression and/or anger.

Fear of the unknown future is a common emotion. The parents may ask themselves questions like, "Will he ever learn?" "Will he go to college?" "Will he or she have the capability of loving and living and laughing?" Fear brings out the issue of fight or flight. The flight takes you into denial and the fight gives you the energy to reattach and generate new dreams.

Counselling services help a parent realise that fears of the future can immobilize someone. Living with the reality of the day at hand is more manageable if one throws out the "what-ifs" and the "then-whats" of the future. Even though it may not seem possible, good things will continue to happen each day. Worrying about the future will only deplete the limited resources. The parents can be helped to carry on, have enough to focus on and get through each day and live one step at a time when they undergo conselling.

Guilt and concern often come in the form of questions about whether you, the parents, caused the problem especially parents with a strong background that believes that a disability is punishment from God. They may ask questions like "Did I do something to cause this?" "Am I being punished for something I have done?" "Did I take care of myself when I was pregnant?" "Did my wife take good enough care of herself when she was pregnant?" A lot of self-criticism and remorse comes from questioning the causes of the disability. "Why me?" or "Why my child?" Counselling services help parents talk about the guilt feelings and assure that parents are not afraid to confront beliefs about what caused the child to have a disability. Counsellors will help parents realise that their beliefs have no effect on what happened in the past, or what may happen in the future. They may come to realize that their actions were not the cause of the child's disability and this will help them to move forward.

Depression can make parents question whether they are competent, capable, valuable, and strong. It is a part of the grieving process that leaves feelings of sadness and isolation among parents.

Counselling services offer skills that help parents cop with depression and anxiety, they help you to know that what you are feeling has been experienced by many, many others. You can start to calm your depression and anxiety through the support of other parents who know what you are going through.

Denial and anger upon learning that the child may have a disability, is common. “This cannot be happening to me, to my child, to our family.” Denial rapidly merges with anger, which may be directed towards the medical personnel who give you the information about the child’s problem. Anger can also hurt communication between partners or with grandparents and extended family members. Early on, anger may be very intense because it is triggered by the feelings of grief and terrible loss. Hess, (2004).

The counselling service practitioners may help parents understand that feelings of denial and anger are inevitable and to be expected when you realise that you must revise the hopes and dreams you had for your child. Recognizing your denial and anger is a valuable first step in learning how to let go of them. Getting outside help from health professional is necessary. There will be that assurance that life will get better and the day will come when you will feel positive again. By acknowledging and working through your negative feelings, you will be better equipped to meet new challenges, and bitterness and anger will no longer drain your energies and initiative.

Healey, (1996) echoes Taylor’s findings and confirms that there are stages through which parents experience when their child has been diagnosed with a disability. It should be born in mind that not all parents go through the stages in the same way as all parents are different and arrive at the acceptance stage differently. Nevertheless parents need support in order to heal. Firstly, they may be shocked, cry, feel dejected, and experience physical outbursts. Secondly, they may deny and suggest various actions to avoid the reality, sometimes they may even ‘shop for cure’ and bargain their situation.

Anger may follow, which may be expressed outwardly or rage or simply become withdrawn from intense feeling of guilt. They may even verbally attack anyone who might be blamed for their unfortunate circumstance. Healey, (1996) states that this is a positive point to reach in the process of adjustment and may now become defensive if attacked. Some may feel resigned or slip into depression, with feelings of shame and guilt, hopelessness and anxiety stemming from a new overwhelming burden of responsibility. At this point others may retreat or attempt to hide the disabled child especially from friends during social encounters. This is perceived as the first sign of beginning of acceptance. They have reached an unconditional positive regard for the child. They begin to understand and appreciate the child. Thus they need to strengthen their skills in coping with the child as well as meet life’s demands. This is where parents need assistance to go through the different stages in order to heal.

Families with a child who has a disability have special concerns and often need a great deal of information: information about the disability of their child, about school services, therapy, local policies, funding sources, transportation, medical facilities, and much more. Hess,(2004). This is where parents support groups or a center where parents congregate and share concerns is necessary. This is what this paper is about, are there established institutions with professionals in counselling skills and services for such parents around Lusaka?

In the field of teaching, teachers have encountered several disabled children in the classroom environment with different ranges and degrees of disabilities. Some have experienced children who are deaf, those with cerebral palsy, ADD, dyslexia, and many other disabilities.

What is noticeable over the years is that during Parents Teachers Conferences (PTC), most parents of the children with disabilities tend to use this opportunity to discuss and express their own feelings and anxieties about their disabled children, their anger and frustrations in dealing with the daily chores and demands of raising a child with disabilities. Thus the PTC turns out to be a counselling session because the focus is shifted from discussing the progress and achievement of the child and directed on the challenges that the parents experience. Although it is reasonable time to discuss both child and parents issues to form a link between home and school, counselling services need time and a favorable environment.

The researcher's long experience of counselling some parents of children with disabilities prompted this research. As a secondary school teacher and now a primary school teacher there has been vast experience of many children with disabilities in school. There has been counselling instances to both parents and children. This is because of the challenge of reaching out to console them and in the process, get into a counseling session unintentionally. One year there was a girl who had multiple disabilities and had speech problems. Another year there was a boy who had ADD. Recently, there was a boy who had hearing aids and has since moved to the next grade. Currently, there are two children, a boy and a girl. The boy has multiple disabilities and the girl has cerebral Palsy. All these children have had informal counselling from their teachers. However the concern is counselling services for the parents of these children. Having been in direct contact with these parents, it has been proven beyond doubt that these parents need ongoing counselling at different stages of development of their children because the degree of disability changes as the children develop.

Upon inquiry from these parents whether or not they go for counseling at all, their responses are that they do not undertake counselling services. The girl with cerebral palsy had to travel to India where she underwent an operation known as stem cell therapy and she came back a new girl, able to write better. When the school inquired about how they came in contact with the professionals in India; they related that some family members in India informed them about it. They too confirmed that they did not know of any parents support groups for parents with disabled children or any institution where parents with disabled children received counselling services. This has prompted this research, to find out the role of counselling services and whether there are places where these counselling services are offered in Lusaka.

The parents discuss how difficult and expensive it is to find some professionals to handle their children's conditions. The hospital plays a big role in attending to the needs of the children with disability. As the number of children with disability is increasing in schools as the populations rise, more children with disabilities will be enrolled. More so now, with the Ministry of Education promoting the policy of inclusion in schools, inclusion as Ndhlovu, (2008) states, means a place where every pupil belongs, is accepted, supports and is supported by his/her peers and other members of the school community in the course of having his/her educational needs met. The Ministry of Education (1996:69) strategy of providing education to pupils with disabilities which states that, 'to the greatest extent possible, the Ministry will include pupils with special educational needs into mainstream institutions and will provide them with necessary facilities. However, where need is established, the Ministry will participate in the provision of new special schools for the severely impaired.' An excellent policy, though the children may experience their own individualized challenges depending on their impairment, there is certainly an attempt by government to better the lives of children with disabilities. This means the numbers of children with disabilities in the mainstreams will go up as the citizens get to understand the policy and demand for the rights of the children with disabilities. What is striking, however, is that there is no statement to cater for the parents of these children. Are there institutions that offer counselling services to parents of children with disabilities in Lusaka?

The counselling institutions in Lusaka, such as Zambia Police Victim Support Unit, Kara Counselling Center, Training and Resource Centre, Serenity Harm Reduction Programme Zambia (SHARPZ), Mental Health Users Network of Zambia (MHUNZA), Africa Directions, Envision Zambia and Comprehensive HIV/AIDS Management Programme (CHAMP) do not have a counselling provision for parents of children with disabilities, neither are they included on their programmes. For instance Kara Counselling (which has since shut down) and CHAMP specialize in HIV/AIDS counselling, and SHARPZ specializes in drug addicts, is there a place that specializes in counselling parents of children with disabilities? Hence the quest to ascertain the existence of such an institution in Lusaka, therefore, there is a knowledge gap that needs investigation. Are there institutions or centers where parents of children with disabilities receive counselling services?

STATEMENT OF THE PROBLEM

Parents Teachers Conferences (PTC) is meant to discuss children's academic performance and achievements in order to gauge the progress of a child; the center of attention must be the child. However, more often than not, parents of children with disabilities tend to discuss the challenges that they experience in raising a child with disabilities during PTC, deviating the focus from the child to the parents. The role of counselling services for parents of children with disabilities is vital in that the parents regain their personal identity and physical as well as emotional health in order to properly look after their children. The parents also feel skilled and informed about the balance between caring and parenting, maintaining family life and positive adjustment of siblings. In Lusaka, it is not known if counselling services for parents that have children with disabilities are there reason being most parents tend to utilize the Parents Teachers' Conferences for counselling by asking a lot of questions and finding consolation.

Where is the forum or places allocated where opening up and sharing of problems by parents whose children are disabled are done? A sanctuary or safe haven, where parents of the children with disabilities can gather in a relaxed atmosphere and open up about their fears and hopes about their disabled children. Therefore, this study seeks to fill this knowledge gap.

1.3 PURPOSE OF STUDY

The purpose of the study was to ascertain the role of counselling services on parents of children with disabilities at Hidden House School in Garden Compound, Lusaka District. This is so because parents who unexpectedly have a child diagnosed with a disability have a traumatizing effect like that of learning of a death of a family member. Receiving such news can produce an overwhelming surge of emotions of shock, disbelief, anxiety, fear, despair and a miserable life. Such news shatters the lives of many parents and for luck of information about where to go or what to do; some parents find Parents Teachers Conferences an ideal place to vent out there feelings and concerns. By establishing the prevailing situation about roles of counselling services for such parents, policies can be augmented and enlighten the burden for such parents.

1.4 OBJECTIVES OF THE STUDY

The study was guided by the following three research objectives.

I. Establish whether there are institutions that offer counselling to parents with children with disabilities.
II. Ascertain whether parents of children with disabilities receive the services in counselling.
III. To determine the benefits of counselling services to parents of children with disabilities.

1.5 RESEARCH QUESTIONS

The study was guided by the following three specific research questions reflected by the three objectives stated above.

1. Which institutions offer counselling services to parents of children with disability?
2. What counselling services do parents of children with disabilities receive?
3. How beneficial are counselling services to parents with disabilities?

SIGNIFICANCE OF THE STUDY

The significance of the study is that, the findings would help the policy makers come up with policies that would enhance the creation of institutions that would cater for counselling services for the parents of children with disabilities. The information could be utilized to lobby the government or donors and other well wishers.

This study would be valuable to school administrators to direct parents with disabled children to the appropriate institutions where they would seek help. At such counselling institutions, the parents can meet other parents and specialists responsible for supporting them. Assistance can be obtained through brainstorming ideas for how to respond to difficult situations, carve out plans to sort out their thoughts about their children and make plans to take positive action. As for teachers, they may direct parents who might be hopeless to seek help from this well established institution other than be a counselor to parents in the classroom during PTC where time is limited.

Tools can also be learnt for improved communication and parenting skills. They may also receive feedback as to whether they may be over or under reacting to their child's disability from parents dealing with similar problems.

Referrals can also be gotten to therapists or patient programmes in the area that other parents know are effective and share information about books, websites, magazines and other helpful parenting resources as well as receive help in times of crisis.

The parents of disabled children will attain the assistance that they need from the institutions and learn how other parents in similar predicaments handled their situations. Solace and peace of mind will follow naturally by the fact that they are not alone. Therefore, they can laugh with other parents about the silly things disabled children can do in a serene environment and their children will be better taken care off.

The information can be utilized to lobby the government or donors to come up with policies that will help parents of disabled children to overcome the situations they unexpectedly find themselves in. Such facilities, if created would be sanctuaries for such parents. They would find peace and consolation as they mingle and express themselves.

Finally, the government would be helped by realizing the negligence in providing institutions for counselling parents of disabled children. In the long run policies can be put in place and a national budget created for such a noble course.

1.7 DELIMITATION OF THE STUDY

The study area is defined as the geographical location in which the research is conducted. From Maxwell's (2005) analysis, it is a particular social setting where something actually happens. The Study was undertaken in Lusaka District of Lusaka Province, in Garden Compound in Zambia. This location was preferred because of its proximity to the researcher. Within Garden compound there is a school called Hidden Voice for only children with disabilities and that is where the study was conducted. The children in the school have myriad of different disabilities. The researcher's interest was in the parents of these children.

1.8 THE LIMITATIONS OF THE STUDY

According to Best and Kahn (1998), limitations are conditions beyond the control of researchers that may place restrictions on the conclusion of the study and its application to other situations. The main limitation to the study was that some parents felt ashamed or embarrassed to discuss their children's predicament and were not free to share in a group. Therefore individual interviews were very helpful to such parents. Some parents felt stigmatized and sometimes needed to be psychologically ready to go out with their disabled children. To get them to accept to participate in the research needed time and persuasion. Although this was a foreseen hindrance to the study, by widening the number of respondents, the expected number of parents with children with disabilities was arrived at. The other impediment was that fewer than the expected number of parents turned up for focus group discussions. These limitations limited the chance of generalizing the findings.

1.9 THEORETICAL FRAMEWORK

Parents experience trauma when they discover that their child is disabled. The well-being of a child who is disabled centers on parenting capacity. Therefore, quoting the theory of Rogers (1977) on the importance of the self actualizing in forming a self concept, the parents need to be counselled in order to attain full potential and self actualisation. If parents get healing through counselling, then they would be able to reach their congruence and self awareness, be fully functional and give their children optimum service.

1.9 OPERATIONAL DEFINITIONS

Disability: According to Mutswanga, (2010) the term disability summarizes many different functional limitations occurring in any population. Such persons may be disabled by physical, intellectual or sensory impairments, medical condition or mental illness. Idea Partnership, (2004) summarizes disability as a particular act that someone has problems performing, like reading a book, running or dressing because of impairment. It goes on to say the result of any physical or mental condition that affects or prevents one’s ability to develop, achieve or function in educational and social settings within the normal rate of growth and development.

A child with disability: According to Idea Partnership, (2016) a child with a disability means a child evaluated as having a mental retardation, a hearing impairment including deafness, a speech or language impairment, including blindness, a serious emotional disturbance, an orthopedic impairment, autism, traumatic brain injury, a specific learning disability, deaf-blindness, or multiple disabilities, and who by reason thereof needs special education and related services.

Parent: A caregiver of the offspring in their own species. In humans, a parent is the caretaker of a child, where "child" refers to offspring, not necessarily age. A biological parent is a person whose gamete resulted in a child, a male through the sperm, and a female through the ovum. Lewis, (2012).

A parent of a child with disability: A parent whose child who has a disability.

Counselling: Counselling is a mutual helping relationship between a person in need of help (client) and a trained counsellor, Ndhlovu, (2015:59). And according to Shertzer and Stone(1974:20) in Ndhlovu (2015:59) says “counseling is an interaction process which facilitates meaningful understanding of self and the environment and results in the establishment, and or clarification of goals and values for future behaviour.

CHAPTER TWO

LITERATURE REVIEW

2.0 Overview

The previous chapter introduced and presented the background to the problem under study with regards to the places for counselling available to parents of children with disabilities in the area around Lusaka, Zambia. This chapter presents a review of the literature relevant to the study. As Bell, (1993) affirms that Literature review involves reading what other people have written about a writer's area of interest, gathering information to support or refute writer's arguments and subsequently writing about findings. These will have to be analysed providing an originality of a writer's research.

Similarly, this chapter highlights and reviews what is happening in some of the countries as regards the care and concerns of parents of children with disabilities. How their needs and concerns are catered for to cushion some of the challenges that such parents experience in raising their children who are disabled, hence the reason to establish whether there are institutions that offer counselling services to parents with children with disabilities and to ascertain whether parents with children with disabilities receive counselling services in Lusaka District. Are there any foundations in Lusaka where parents of children with disabilities can go for guidance and counseling as well as consolation, care or even just to meet other parents in similar circumstances? The researcher approaches the review from the general point of view, international level, analysing the scenario in different countries about places for counselling of parents with disabled children and then at regional level and specifically in Zambia.

2.1 INSTITUTIONS THAT OFFER COUNSELLING SERVICES.

2.1.1 Globally

To introduce this section there is a story told by Hess, (2004)**.** The story is entitled a Trip to Holland and the author is unknown. In a nutshell it's about a person who has spent months if not years planning a trip to France only to find out that as the plane lands at the airport that she is not in Paris at all, but in Amsterdam! It's not that Holland is a bad place, it's just a different place, necessitating that this individual now learn a whole new language and meet a whole set of people that she most certainly would not have met had it not been for the sudden change in flight plans. The story talks about the fact that there are actually many wonderful things in Holland, but it also honestly reflects the hurt, the pain, and the disappointment about a trip that suddenly and for no apparent reason went off beam and ended up far from the original destination.

Many parents of children with disability do not know where to start when they find out their child is disabled. They are lost like in the story of the plane landing in an unexpected destination. They have no idea what support is available, what they are entitled to, or what to do when they cannot access the help they need especially in the developing countries. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is very clear about negative attitudes and erroneous beliefs about disability which bring about stigma and discrimination. Stigma may be defined as an attribute possessed by a person or group that is regarded as undesirable or discrediting. On the other hand discrimination may be defined as any distinction, exclusion or restriction based on disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights. It includes all forms of disability discrimination and is worded broadly so as to cover not only discrimination experienced by persons with disabilities but also their families.

The UNCRPD describe disability as an evolving concept of a social nature. Families remain the first and most immediate environment where children with disabilities can develop their potential and enjoy a fulfilling life. Thus parents of the disabled children must be fulfilled and living a quality life in order to fulfill their obligation of bringing up their children satisfactorily. It has been recognized by many researchers that having a child with a disability, whether mental, physical, or both, increases stress experienced by the family (Abrams & Kaslow, 1977). Parents of children suffering from disabilities report "lower satisfaction with their parental role, lower self-efficacy, higher levels of depression, lower marital satisfaction, and higher rates of divorce" (as cited in Shechtman & Gilat, 2005). The turning point in these families' lives is when they first hear that their child has a disability. The child may be diagnosed as an infant, or their disability may reveal itself slowly as they age. Regardless of when this information is revealed to the parents, it can have a significant effect on their family dynamics. Fantasies of cheering for a son whose playing football, or watching a daughter walk across her high graduation stage as valedictorian are shattered (Ziolko, 1991). The discrepancy between their child's real self and their expectation become hard to bear.

The amount a family is being affected can be judged by "sleep disturbances the child's disability might cause the parents; physical burdens related to dressing, lifting, feeding, and so on that an illness or disability might create for the parents; complicated diets which require extra time; extra housekeeping which might be necessary; financial stress and strain; adaptations that may be needed in housing and furnishings; and the unpredictability of the disease or disability" (Ziolko, 1991). The greater these areas of the lives of the family members are affected, the greater amount of stress and burden that the family experiences. Sometimes the burden placed on the family member will escalate into occasional outbursts of anger towards the child, thus promoting a painful cycle of resentment, guilt, overprotection, and permissiveness (Abrams & Kaslow, 1977).Counselling services are needed for parents of children with disabilities to gain their lives back and take care of their children appropriately.

The United Convention on Rights of Persons with Disability (UNCRPD) states that family is entitled to protection by the State to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities. Article 5 says the state must respect the rights and responsibilities of parents while Article 8 commends awareness-raising at the family level. Article 18 recommends parental responsibilities and Article 23 respect for home and the family, intended as the right of children. Thus a parent who is shuttered and in shock may not be in a position to perform the duties expected of her/him, hence the need for counselling services in order for them to heal.

There were moves occurring to recognize and help meet the rights and needs of parents of disabled people. One way in which countries have responded to the United Nations request is by forming Community Based Rehabilitation (CBR) which emphasises on integration and provides an opportunity for people with disability to have full participation and equalisation of opportunity within their society. During this process, the people with disability are exposed to day-today risks. This equips them with confidence and teaches them skills to negotiate and overcome problems and achieve their own rehabilitation through self-help.

CBR has been implemented in many parts of the world. The World Health Organisation (WHO) published a manual to train local supervisors and family members of disabled people to become involved with CBR, Helander, et al., (1989). The WHO model in CBR has placed a strong emphasis on medical rehabilitation. The International Labour Organisation (ILO) has placed more emphasis on vocational Rehabilitation and community integration. In 1994, the ILO, the United Nations, Scientific and Cultural Organisation (UNESCO) and WHO came together and drew up a joint position paper on CBR based on their similarities of approach. Their joint paper defines CBR as: a strategy within community development for the rehabilitation, equalisation and opportunities and social integration of people with disabilities. It is achieved through the combined efforts of people with disabilities, their families and communities and the appropriate health, education, vocational and social services. (ILO, UNESCO, WHO 1994, P. 1) CBR therefore is one avenue in which the parents of disabled children can access counselling services within the community. The most important stakeholders in CBR are people with disability and their families. Due to the fact that parents of children with disability are directly involved and work together with the community, the influence on the programme is strong and positive. As they organise the CBR programme, their own needs for counselling will be included and fulfilled. Thus through counselling services, the parents of children with disability would heal and arrive at their own quality life and self actualisation in conformity with the theoretical framework.

According to Ofori-Addo, (1991),the UN General Assembly declared 1981 the “International Year of Disabled Persons" and in 1982 adopted a World Programme of Action Concerning Disabled Persons. The purpose of the World Programme of Action was to provide effective measures for prevention of disability, rehabilitation and the restoration of the goals of full participation of disabled persons in social life and development, and of equality. This means ensuring that the opportunities available to disabled people were equal to those available to everyone else, and that disabled people have an equal share in the improvement in living conditions resulting from social and economic development, thus reducing the stress on the parents.

At the International level De Carpenter (1991) discusses INITIATIVES as an international organization which operates from the United Kingdom but works in many developing countries. The organization supports professional and parents for the disabled especially hearing and deaf in their attempt to increase public and government awareness and involvement. Having Partners from countries all over the world, De Carpenter (1991) explains that INITIATIVES grapples daily with maintaining good communication between the Partners and the Secretariat in the UK. Poor communication and transport infrastructure are the main problem, with lack of telephones, faxlines and reliable postal systems, poor roads and long distances in many developing countries. There, people rely more heavily on face-to-face meetings and often prefer this method of communication as they counsel and empower parents with children with disabilities. The INITIATIVES workshops provide this personal contact and for this reason is a vital element of the network's provision. The INITIATIVES network has proved valuable not only to those directly involved in its activities but to a wider community of the parents of the disabled.

One of the examples of countries in the world that have formed strong organisations for parents of children with disabilities, with the intention of empowering them in order to help their children is India. Parivaar Bengal, a National Confederation of parents Organisation was formed in 1995. It has over 222 parent organisations covering 28 states and 3 union territories have come together. This organisation is recognised by the government of India. They have various national and international partnerships. The organisation believed that an empowered parent: knows the rights of her/his child with disability, knows about existing facilities and services for his/her child, knows what is good and wrong for the child and is confident enough to say “No” to what is wrong, can guide and gain the goodwill of other parents and the local community, explores national laws and policies to find out how they protect and serve her/his own child and others, knows the channels whereby to seek justice for her/his child, understands that their child needs assistance and support to benefit from the same environment as others, has the courage to promote inclusion in the family, community and seek to enforce this in the local and national government, understands that a child with disability deserves the same dignity as other children and understands the concept of human rights and social justice. Kundu, (1995)

The research in Netherlands by De Wit-Gosker (1990) reports that in June 1986, the parents of children with disabilities formed the Verenigingvooreenge Integreerde op voeding van Mongoloid e Kinderen (VIM) to lobby for the support and integration of children with Down's Syndrome into mainstream education. Six years later, in June 1992, the VIM had grown to a membership of 340 families all helping each other. Meeting regularly and voicing out their needs. The VIM argued for better state support for integrated education, lobbying the Dutch Ministry of Education for extra resources. It organised training for parents in taking care of their children, and has an advocacy role in promoting the views of its members to educationalists, policymakers and the general public. Due to the fact that Parents of children with disability were in the forefront, it had a positive effect in their children.

In Jamaica, Thornburn (1998) in his research reports that Parents' Association for Handicapped Children was determined to keep the spirit of the project alive. They had taken the responsibility of educating other parents of disabled children and help alleviate their burdens. They managed to maintain the community clinics and decided to embark on a parent education programme. The Parents' Association applied for a Community Education Grant from the Jamaica-Western New York Partners which was awarded in July 1983. This enabled the Association to run four parent training courses in the parish which were attended by over 50 parents and many other interested people.

As a direct result of the courses, the Association expanded, with a rapidly growing membership. At the Annual General Meeting in August 1984, Thornburn (1998) members agreed that a Community-based Rehabilitation (CBR) Programme should be established. Grant applications to the Christoffel Blinden Mission in Germany for the CBR programme and to the Norwegian Association for the Mentally Retarded for development of the Association were both successful, and 3D Projects began in February 1985. Thus the stigma and low self esteem of the parents of children with disabilities was done away with or at least reduced tremendously.

There was a campaign in Austria for the integration of children with special needs by parents and teachers. It took ten years to achieve its aims and for the first time parents with children with disabilities were able to make real choices about the education their children received. As Volker Rutte (1998) writes in 1993, the Austrian government passed a law enabling the parents of children with special educational needs to choose whether their child is educated in a special or a mainstream elementary school. Parental participation was mandatory and as Rutte (1998) affirmed it, parental involvement is essential and a child will not be considered for integration until the parents register at the local elementary school. Thus when parents of children with disability unite and fight for the rights of the children, they achieve the goals and the benefits are innumerable in their favour.

This project recognized the importance of the family, with optimistic and hopeful parents. The Volker Rutte (1998) noted that the parents of children with disability were accepted and received continued counselling. Their positive outlook gave them confidence and they had a forum to express themselves and remain strong.

Another report involving sanctuary places for parents of children with disabilities was from Anhui Province Integrated Education Project in the People's Republic of China. This APIE project involved the integration of children and inclusion of their parents in the system. Holdsworth (1991) confirms that the teachers involved aimed to rebuild family confidence and hope, and to involve families in the work of the school. The child was fully recognised and one of the goals of the project was to promote partnership between teachers and families. This helped to ensure that the demands on the child were consistent and that the skills she/he learnt were transferable and of use in both school and the home. The parents met regularly to discuss their problems and had group counselling sessions. In the absence of diagnostic tests which were appropriate culturally, the observation skills of both teachers and parents were vital for appropriate goals to be set for the child and individual learning programmes designed. Holdsworth, (1991) states that Family contact was maintained through home visits by teachers and school visits by families. Families were encouraged to become fully involved with their child's individual learning programme, to meet with other families and to take part in seminars and meetings as full members of the project.

In Guyana, the research by O’Toole (1991) reveals that it is now recognised that many of the social and emotional needs of parents can best be met by participation in an informal voluntary association with other parents of children with special needs. The nature of this partnership must emerge from the parents and reflect their needs and interests. Few of the parents in the Guyana Community Based Rehabilitation (CBR) programme had met other parents of disabled children before the programme began. The great majority who took the opportunity to meet other parents found this contact very helpful and they found comfort in the knowledge that they were not alone. The CBR committees were trying to facilitate the development of a local network of families who could provide mutual support for one another. Such a network could provide a formidable force in working for change in developing countries. O’Toole,(1991)continued to say that effective participation cannot he brought about by political pressure or insistence from external providers. People will become involved only if they feel that they are genuinely being consulted about their needs. Effective consultation may be the key to change as the community learns to solve its own problems. The members on the various CBR committees need to improve their skills in consultation, develop their management ability and become more sensitive, as they listen to others in these places.

Another skill that is promoted is the Effective Life Management (ELM). Parents typically find it difficult to accept that their child is not developing ‘normally’ (Gray, 2006). Therefore, they need to be empowered to manage and cope with the change in family dynamics within the home Sicile-Kira, (2003). In this regard the work of Scorgie, Wilgosh, Sobseyand McDonald (2001) focuses on Effective Life Management. This is a skill that enables parents to live full lives with the disabled child, understanding and accepting the situation. In a similar vein Hastings and Beck (2004) suggest the use of what they refer to as Cognitive Behavioral Techniques, including problem-solving, cognitive restructuring, and monitoring of thought and feelings to effectively manage life like any other family without a disabled child. Parental Positive Perceptions are strongly related to managing and coping with a disability (Hastings, Allen, McDermott & Still, 2002). Grant and Whittell (2000) also emphasize the Positive Psychological States of parents as being important in helping them to cope. A contented and fulfilled parent will give the best assistance to the disabled child. Carter and Evans, (2008) articulate that if the parents are facing problems, it can have a severe impact on the learner’s school achievements. Happy parents will assist the positive performance of a disabled child.

In South Korea, Yim, Moon and Yung Lee (1996) found out that the mothers of children with disabilities suffered from serious psychological distress in the initial diagnosis of the child’s disability. Psychological distress included depression, anxiety, hostility and phobic anxieties. In the same vein, Yim et al (1996) discovered that the severity of the child’s disability had little influence on the degree of the mother’s initial psychological distress. In other words there were no significant differences in terms of psychological distress between mothers assessed at initial diagnosis and those assessed later in the child’s development. Thus psychological distress is usually not resolved even after diagnosis and thus there’s a great need for psychosocial counselling to ensure that the mothers of children with disabilities can cope with the stresses of caring for a child with a disability. Parents typically find it difficult to accept that their child is not developing normally; therefore they need to be empowered to effectively manage and cope with the change in family management within the home.

Parents are overwhelmed by the challenges associated with disabilities and by their emotions. Instead of feeling alone, other parents can be invaluable sources of help and information. Having access to information may be critical in maintaining a stable and healthy family life. Thus institutions for counselling services or parents support groups can organise early intervention services for infants and toddlers and education services for preschoolers and school aged children through their sharing.

Current studies have shown that there are parental needs at the time of diagnosis that are not being met and that parent contact with professionals must not end with the diagnostic period, but must continue, as it has been proven that parents who belong to the support groups enhance the development of their disabled children. The child's adjustment, advancement and rehabilitative progress is affected by the parents' strength, weaknesses, and emotional reactions. Parents need continuous support through counselling services that can be arranged by parents themselves in the parents support centers.

Research in Bangladesh has proved that parents support groups and counseling services to parents of disabled children have assisted in the development of children with disabilities. They showed tremendous progress in their development. In the Journal Intellectual Disability Research, (1999:89 - 113) a home based family focused counseling scheme providing support for English and Bangladeshi families of children with intellectual multiple disabilities, mothers and children in intervention groups showed significant and positive changes compared to randomly allocated controls. The greatest benefits were derived by the more deprived and initially less well supported Bangladeshi families. Mothers changed positively in ratings of perceived support and family functioning, and in their construction of their children, themselves, husbands and family relationships. Although systematic teaching was not included, their children also showed improvements in development progress and behaviour problems. This led to massive campaign on the promotion of institutions to counsel parents with disabled children.

Ziolko, (1991) stated that approximately 30% to 40% of the children born would suffer from a significant long-term disorder some time during their first 18 years of life. Whaley and Wong, (1982) went on to say that was a huge number of parents with disabled children. Although some families with disabled children manage their lives as effectively as other families some such families may require counselling services and therapy to facilitate integration of the disabled child into the family. Harris and Fong, (1985).The parents of disabled children are part of our lives and there is need to put structures in place. Arrangements of places that will assist in putting parents of children with disability back on track with life are a necessity in every country.

The United Kingdom has many centers that deal with parents of children with disabilities. One such centre specializes in strengthening the bond between husband and wife of the disabled child. And the author Butler (2013) states that Relationships matter. When they work well, they are vital source of support and protection against life's stresses and strains. All relationships go through periods of change and challenge. Parents caring for a disabled child have to adjust to new roles, and may have different expectations about their child. They also have to cope with significant emotional, social, physical and financial pressures. Many parents find these experiences bring them closer together and make their relationship stronger. The institutions that offer counselling services may not be cheap but it is worthwhile to undergo a healing process as the benefits outweigh the costs.

Marriages undergo change with the birth of a child, any child. But when a child in the family has special needs, this change may be even more profound. As Kelly Harland puts it, "How unexpectedly it all unfolds. One moment, you and your lover are singing along in bad Italian with Venetians in a crowded bar…….red wine pouring out of nowhere. And the next minute, the two of you are filling out disability forms for your tiny son." Harland, (2002:33) what a challenge! Getting the old life back along with the new arrival that is demanding is the role of counselling services and who wouldn't want that.

Many parents have found it is necessary and helpful to seek joint counselling. Through this process, they grow to understand each other's needs and concerns more fully and found ways of discussing and resolving their differences. As one parent says, "We steer a rocky ship, my husband and I…We have had to check in with the therapist, sometimes once a year, sometimes once a week. We've experienced a hard distance between one another from time to time, as Will in all his complexity takes over every spare second of our lives. We have hung on, though. Our hearts are bonded by something that goes even deeper than love." (Harland, 2002:33) the bond of an unexpected disability.

The parents of handicapped children have to adjust to a wide variety of emotional and psychological problems when first confronted with the failure of their reproductive expectations. Counselling is a formal procedure or transaction in which both counsellor and parents aim to find a mutually acceptable plan of adjustment. Taylor (1982) argues that parents may need support to cope with their own personal inadequacies as well as with the needs of the child. Counselling should be a continuous process, in which the parents can learn to accept the child as a different rather than as a lesser person.

About 6 million kids in America receive special education, according to the U.S. Department of Education. One out of every 10 children under the age of 14 has some type of special need, which includes any physical, cognitive, or medical disability, or chronic or life-threatening illness. That is a numerous number of parents with children with disabilities. Fortunately the United States of America has counselling service centers for parents of children with disabilities in all the states. In fact it has been discovered that every state in the USA has multiple homes, under different names, such as Parents' Sanctuary, The Peace Haven or Solace that deal with parents that have disabled children. The starting point in the United States is the Parent Training and Information (PTI).Each state has at least one PTI program. If you're looking for resources in your state and community, you simply call the state's PTI. The PTI can also give you information about disabilities, the educational rights of your child, or strategies for being an effective advocate for your child. Brown, (2014).

Similarly, some states also have what is known as Community Parent Resource Center (CPRC)**,** which is funded by the state to serve a particular high-need area or audience. http://www.parentcenterhub.org/find-your-center. Another organization is The Parent to Parent Programme (PPP). The PPP on the other hand matches in one on one relationship for sharing information, experience and emotional and practical support. Families with disabled children may experience negative attitudes from others, leading to social exclusion of the whole family, including siblings. The cultural community to which the child belongs may have different responses to disability; the parents may have to cope with additional negative and stigmatising beliefs about causes of disability as well as managing the situation within the family, hence the need for support in all dimensions.

When families join a parent group, they can meet other families with similar needs. Parent groups can serve many purposes, but one of their most important can be to introduce families to others like themselves. When families with similar concerns meet, there is a sense of community, and understanding. They create a place where they can laugh about the same things, where you can discuss the same problems and possibly help each other.

Here are some quotations from some parents with children with disabilities in some centers: "This experience we did not choose, which we would have given anything to avoid, has made us different, has made us better. Through it we have learned the lesson of Sophocles and Shakespeare that one grows by suffering. And that too is Jessy's gift. I write now what fifteen years past I would still not have thought possible to write; that if today I was given the choice, to accept the experience, with everything that it entails, or to refuse the bitter largesse, I would have to stretch out my hands, because out of it has come, for all of us, an unimagined life. And I will not change the last word of the story. It is still love." Park, (1982).

Another touching quotation is "I would sometimes retreat to my "tower" and pretend that I had no responsibilities other than to amuse myself with a good book or a soothing tape. The respite usually did not last more than a half hour, and it was never enough, but it helped me break the "martyr" pattern of thinking I was required to live and breathe only for my children……. It was important to remember that I was Kate, a person, with lots of abilities and interests that did not all coincide with my role as Mommy. I came to realize that a little selfishness is not a bad thing. If I could enjoy myself more, I could enjoy my children more. McAnaney, K.D. (1998). Kate appreciated the services of parents support groups. It was a get away from all the cares and concerns of raising a disabled child. Offloading the burdens is what counselling services are all about.

Kate talks about reading a book and taking a walk, things that could be done at a center with other parents. A lot of activities can be done to get away from the burden and enjoy life. Meeting for lunch, getting away for a few hours together, sharing an activity. Talking to each other and really listening are also important—and conversations do not always have to revolve around the children in the family. Finding other topics to discuss can do much to revitalize parents.

2.1.2 African perspective

In the traditional African societies, there is a myth that a family that bears a disabled child is an indication that either the father or the mother had sinned against the gods and was being punished by the gods. They needed to appease the gods by sacrifice. So the disability in the family brought about guilt and shame to the parents in the community. As if this was not enough burden for the parents, they need to deal with the actual disability in whatever form it takes. Travis, (1986) stated that the affliction on the parents includes sleep disturbances the child's disability might bring about, physical burdens related to dressing and feeding. Other challenges include complicated diets which require extra time to prepare as well as extra house cleaning which might be needed. In another view, challenges also emanate from the adaptations that may be needed in housing and furnishings as well as the unpredictability of the disability.

Support for parents of a child with disability is crucial in ensuring that the child's specific needs are appropriately met, both before and after the child enters formal schooling. Hastings et al, (2002) discusses Parental Positive Perceptions as a necessary skill for the proper administration of a disabled child. Parental Positive Perceptions are strongly related to the parent managing and coping with a disability. South Africa promotes School-Based Family Counseling (SBFC) to both the child and the parent. Professional intervention pertinent to SBFC is helpful in this regard. The parents of children with disabilities have a place within their reach to seek assistance from professionals like psychologists and psychosocial counsellors. It is the responsibility of the school to provide an environment that supports the presence of the multi professionals within the school.

Around 63% of Nigeria's population lives in abject poverty. Many thousands live in shacks without the basics like clean water and sanitation, needed to provide stability. This situation has an adverse effect on programmes of counselling services to parents of children with disability. Coping Skills Models is one of the initiatives Nigeria embarked on to provide services to parents of children with disabilities. In general, Andazi and Amwe (1995) confirms that these interventions have used the ideas from stress and coping theories to inform parent training in problem solving and decision making, communication skills, skills in accessing and utilizing social networks, and coping strategies such as positive self-statements, self-praise and relaxation. These models focus on services that take a holistic approach to parent support. One of their strengths lies in their ability to work with parents to determine their needs and to provide opportunities for parents to access a range of other services like counselling.

In Counselling Intervention Programmes Andazi and Amwe (1995) stressed the need for intervention programmes for families of children with special educational needs through counselling, social services, family education, skill training and advocacy activities. They pointed out that an enlightened society should give parents new and expanded roles in their handicapped child's education and care. Parents are also expected to function effectively as decision makers and teachers.

The Importance of Parent Support Services Research indicates that parents of children with special educational needs children are particularly vulnerable to stress, for example, high levels of distress have been found in up to 70% of mothers and 30% of fathers of severely children with special educational needs (Sloper and Turner, 1993) in Andazi and Amwe (1998). In addition, both the general psychological literature and specific studies of children with special educational needs show that parental distress and family functioning impact on children in numerous ways, affecting their cognitive, behavioural and social development. Thus, lack of parent support and high levels of parental distress will affect the child's well-being. Therefore, parents need to be on top of things and their best.

However, Nigerians with disabilities continue to face social stigma, exploitation, and discrimination. In fact, in most communities, children with disabilities are perceived as a financial burden because they are unable to contribute to the family economy like their peers without disabilities, some of whom assist their parents by going out to the streets to sell various food items, clothing, and general merchandise (Ebigbo & Ebigbo, 1992). According to the World Bank, Nigeria has an estimated population of over 162 million, as of July 2011 (The World Bank, 2012). The Nigerian National Assembly (2013) estimates that there are over 20 million people living with disabilities in the country today. To make matters worse, many parents in most parts of Nigeria are illiterate and consequently need to be given factual information about causes of disability, skill development, how to use existing resources, ways by which they could help and similar concerns. Parents training can take many different forms depending on the needs of particular families. Parents may require to be taught how to assist their child master basic academic skills.

Consequently, many families are known to reject their children with disabilities, forcing some of these children to roam the streets begging for alms, or to die as they become exposed to the elements. The reasons for the abandonment of the children are not implausible. Often, family members become fixated on the myths that only emphasize the embarrassment of giving birth to a child with a disability, and attributing such disability to the anger of the gods or their ancestral spirits. Because of these erroneous ideas, children with disabilities may become ostracized and denied their fundamental human rights. Therefore, It matters as much how Counseling Services for Parents of Children with Learning Disabilities Family counseling offers parents help in accepting the problems, in developing empathy for the child, and in providing a beneficial home environment.

On the contrary, Namibia's policy to Empower and support people with disabilities to fully participate in all aspects of society has raised the pedestal of parents of children with disability. The government is fully involved in providing the children themselves and their parents special assistance according to their needs. The 2001 Population and Housing Census indicated that people with disabilities in Namibia numbered around 85 567, or 4.7 % of the total population, distributed almost equally between females and males. The number of disabled is higher in rural areas than urban areas. There are no statistics on the numbers of children with disabilities. The Ministry of Education reported (2007) states that out of a total of 570 623 learners, 29 853 learners (5.23%) had disabilities. Within Namibia's schools, 1 524 students with disabilities are catered for in eight special schools. These students get a modified version of the school curriculum MoE (2007).

Namibia's National Disability Council Act (No. 26 of 2004) creates a council tasked with monitoring the implementation of Namibia's National Policy on Disability. This policy, which was adopted by Cabinet in 1997, identifies children with disabilities as a key target group. International Disability Alliance (IDA) (2004).

The Convention on the Rights of Persons with Disabilities was ratified by Namibia in 2007. One of the key principles of this Convention is respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities. The Convention includes several specific provisions on non discrimination and protection of the rights of children with disabilities to family life. Children's needs are also explicitly addressed in provisions on education, health and sport and recreation, IDA (2004). Namibia has also ratified, allows for individual complaints to the Committee on the Rights of Persons with Disabilities.

Despite its international agreements in the domain of human rights, Angola is still lacking as far as the implementation of these laws is concerned. If it is still struggling with the implementation of basic human rights, what more the rights of persons with disabilities, let alone the parents of children with disabilities?

Although the organisation like Open Society Foundation, disability and Social Response in Southern Africa, Leonard Cheshire Disability and Norwegian Peoples Aid organisations have worked with local organisations in Angola, there has been limited implementation of disability rights projects in Angola. Furthermore, there does not seem to be any academic institutions openly supporting the work of Disabled People Organisations (DPOs). There is no legislation pertaining solely to persons with disabilities. However, a successful outcome would be its implementation at domestic level, along with more co-ordination with local DPOs. Luacuti, (2010).

DPOs in Angola seem to be doing effective work in the area of disability. However, most organisations lack proper institutional backing by government. Such effectiveness is also compounded by a lack of technical expertise on the ground, compounded by a massive brain drain, which hampers the effectiveness of established organisations which support the disability rights frameworks, inhibiting them from fully and effectively lobbying government institutions.

Furthermore, there seems to be a difficulty with communication between DPOs already operating in Angola and those in the region, due to a gap in the technical and informative skills held by the leadership of a great number of DPOs in Angola. This has hampered adequate and valuable communication and sharing of best practices with other DPOs in the Southern African region.

The research conducted regarding persons with disabilities in Angola has revealed that DPOs in Angola suffer tremendously due to a lack of technical expertise. Such a deficit minimises the way in which these organizations' vision and objectives are disseminated to the public and interested parties. Kotze (2015).

The Angolan Department of Education undertakes the education of children with disabilities. Furthermore, the Ministry of Education and Social Integration works in collaboration in the area of education. This collaboration also includes education by providing an environment for learning of those with disabilities. Luacuti, (2010).

Despite the Constitution of 2010 which protects the fundamental rights of all citizens, persons with disabilities still face a number of challenges. First, access for persons with disabilities to the labour force remains difficult. Persons with disabilities still face grave discrimination in obtaining employment, and in situations where they do find employment, the work environment is not conducive to them to work adequately. Although article 3(1) of the Labour Law promotes the principle of equality, no mention has been made of this where persons with disabilities are involved.

Second, a social stigma exists, namely, that persons with disabilities are not entitled to legal recourses but, rather; the little that is being done is an act of charity. In interviews conducted by the Open Society Initiative, interviewees stated that the integration of persons with disabilities within broader society should not be one of charity, but rather one of human rights.

Lastly, another major challenge, encapsulating the above two, pertains to access to justice of persons with disabilities. Angolan society is not very open to the needs of persons with disabilities, despite there being legislation that speaks in the language of equality. In reality, this is not the case.

The lack of education among persons with disabilities is also a major contributing factor, which prevents them from understanding their legal rights. Thus Angola is still struggling with the basics in the implementation of counselling services for parents of children with disabilities.

Munthali and Tsoka (2013) in Malawi reported that a number of institutions provide services to persons with disabilities. They include government ministries - the Ministry of Gender, Children and Social Welfare (MoGCSW) and the Ministry of Disability and Elderly Affairs (MoDEA) and departments, including state-sponsored service providers like the Malawi Council for the Handicapped and the Sue Ryder Foundation and disabled people’s organizations. All these offer policy formulation, advocacy for the disabled, coordination and monitoring and evaluation. However, there is very little or no consideration for the parents of children with disabilities. This is the dark area this paper is trying to establish. Are there any places in Lusaka where parents who have children with disabilities go for counseling?

2.1.3 Zambia

Very little is known about Counselling services for Parents of children with disabilities in Lusaka. It would be wonderful to learn that such services exist not only in Lusaka but in the whole country of Zambia. The counselling locations in Zambia such as Zambia Police Victim Support Unit, Kara Counselling, Training and Resource Centre, Serenity Harm Reduction Programme Zambia (SHARPZ), Mental Health Users Network of Zambia (MHUNZA), Africa Directions, Envision Zambia and Comprehensive HIV/AIDS Management Programme (CHAMP) do not have a counselling provision for parents with disabled children.

The mother body for social services in Zambia is the Ministry of Community Development and Social Services, Community House, Sadzu Road, Lusaka. Counselling in this ministry is done at different levels, and cuts across all kinds of counsel. The Social welfare Officers provide counselling to parents or guardians of the juveniles undergoing rehabilitation on the need to maintain contact with children or dependants in institutions to help in preparation for eventual reintegration into the community. However, the Zambia Agency for Persons with Disability (ZAPD) takes care of counselling matters for persons with disability. The Ministry of Community Development, Mother and Child Health (MCDMCH) is entrusted with formulating policy for people with disabilities. ZAPD has the responsibility to co-ordinate the implementation of the National Policy on Disability and acts as an advisory body to the Ministry. Therefore, they are mandated to counsel parents of children with disabilities. The number of such parents is immense. According to the World Health Organisation (WHO), about 2 million men and women in Zambia are disabled.(Korpinen2013). That means there is twice as many parents of the disabled out there who need counselling. Since it takes a woman and a man to have a disabled child, then the estimate of the affected parents can be pegged at 4 million.

The research done by Ndhlovu, (2008) data revealed the following challenges faced by children with disabilities in Zambia; inadequate funding to schools, long distance to schools, non user friendly infrastructure, inadequate appropriate teaching and learning materials and lack of skills in sign language and braille by teachers for communicating to pupils with disabilities especially those with hearing and visual impairments. In order to address the above stated challenges, the respondents and informant suggested that Ministry of Education should ensure that infrastructure is modified so that it is accessible by all pupils. Ndhlovu, (2008) continued to say there was need for empowerment of parents of children with disabilities. Parents of children with disabilities indicated that they need to be empowered so that in turn they support their children with disabilities. There would be need for them to come together in groups in order to heal first from the trauma of having disabled children themselves as part of the package of empowerment. For instance, the Central Statistics Office (2003) reported that there were 256,690 persons with disabilities in Zambia. Out of this number, 43.2% had no formal education, 39.7% had primary school education, 14.5% had secondary school education, 1.3% had A level and another 1.3% had attained tertiary education. This number would increase if the centers for parents of children with disabilities were established and functional to empower the parents.

All these problems definitely have a direct effect on the care takers who are parents of the children. Hence the need to have centers to counsel the parents first and foremost to enable them recover from the shock and bounce back to life to give full support to their children. Through these centers they would lobby the government or Non-Governmental Organizations to look into the needs of their children.

Many factors can influence the well-being of a family. One factor is certainly the emotional and physical health of the parents. Parents are definitely the heart of the family. They are the ones who deal with the issues associated with their child’s disability. They also maintain the household, working to pay the bills, shopping, cooking, cleaning up and taking care of other children. Is it any wonder that many parents of children with disabilities report times of feeling overwhelmed?

Therefore, it is very important for parents to take some time to care for themselves as individuals and counseling institutions would provide some of the psychological and psychosocial needs. Such basic needs like getting enough sleep, eating regular meals, taking a short walk, and doing the things that they really enjoy, even if they can only squeeze them in occasionally in their own free time is so beneficial.

2.2 SUMMARY OF LITERATURE REVIEW

In the Literature review the issues of counselling for parents of children with disabilities have been analysed from the global perspective, African perspective and the Zambian scenario. The research looked at how overwhelming it can be for parents to learn that they have a disabled child and how the challenges can be overcome if the parents undergo counselling and belong to parents support groups. The benefits of these parents support institutions are numerous and so many parents have testified that these centers can be sources of information for early intervention, solace for parents and support may be critical in maintaining a stable and healthy family life where a child with a disability can grow and attain quality life.

CHAPTER THREE

METHODOLOGY

3.0 Overview

The previous chapter looked at the literature relevant to the investigation of institutions of counselling services for parents of children with disabilities. In this chapter the researcher studied the population, the study sample and procedure, data collection methods, ethical consideration and the chapter summary.

3.1 Research Approach

The approach to the research is qualitative approach because it was found ideal due to the fact that it revealed people's deep feelings; it was humanistic and inquired into their opinion in finding out the insights. The qualitative approach also found out more about the parent's emotions. As Anderson and

Arsenault (1998) cited that qualitative research is a form of inquiry that explores phenomena in their natural settings and uses multi-methods to interpret, understand explain and bring meaning to them. The advantages were quite clear as the qualitative approach allowed for in-depth study and flexibility and broad coverage since it was dealing with human beings who could express themselves. Care was taken as the number of interviewees was small, therefore there was no generalization. The qualitative approach gave a more complete picture but was limited to specific people and time.

3.2 Research Design

The study employed a case study of parents of the disabled children at Hidden Voice School in Garden Compound in Lusaka. Yin (1994) defines a case study as an empirical inquiry that investigates a contemporary phenomenon within its real life context especially when the boundaries between the phenomenons are not clearly evident.

To investigate the mentioned problem of the role of counselling services for parents of children with disabilities, the researcher case studied one school called The Hidden Voice in Garden Compound of Lusaka. As Cohen, et al, (2000) says; to collect information from one school for the handicapped children in such a way that the knowledge gained will be representative of all the departments under study.

3.3 Study Population

There are several schools handling children with disabilities in Lusaka District. The University Teaching Hospital, Cheshire Homes and Bauleni Community Center just to mention a few. The Hidden Voice School was strategically selected because it was the most appropriate from which the sample of parents with children with disabilities had to be drawn. As Oswala (2001) cites that a study population is a well defined collection of individuals or objects known to have similar characteristics. It is therefore a collection of people, items, or events about which the researcher wants to make inferences. The population therefore, comprised of parents of children with disabilities at Hidden Voice School.

3.4 Study Sample

Sampling is getting evidence from a portion of the whole population in the expectation and hope that what is found in the portion would be representative of the population. Merriam and Simpson (1995) defined sampling as a strategically and systematically identified group of people or events that meet the criterion of representativeness for a particular study. Out of the many parents of children with disabilities in different schools, the study concentrated on one particular school of the disabled children. Hidden Voice School has a population of 30 children, thus 30 families in total. The target sample was 20 parents.

3.5 Sampling Techniques

Sampling is the procedure of selecting elements from the total population. Amin (2005) asserts that as much as possible, most characteristics of the population should be represented in the sample selected. With reference to sampling techniques, these are methods that are utilized to select a sample from the population by reducing it to a more manageable size, Saunders, Lewis and Thornhill, (2007. According to De Leeuw, Hox and Dillman (2008), sampling techniques are used when inferences are made about the target population. A purposive sampling technique was preferred for this research. All the parents at Hidden Voice School have children that are disabled; therefore, rich in-depth information that is of interest to the researcher will be obtained.

3.6 Instruments for data collection

Semi-structured Interviews and Guide and Focus Group Discussions were administered on the parents of children with disabilities. The research was qualitative in nature as it examined the perceptions, opinions and attitudes of participants.

3.7 Procedure for data collection

An official introductory letter was obtained from the Directorate, Institute of Distance Education Studies at the University of Zambia. This, together with a letter from the researcher to the Director of Hidden Voice School was submitted to the school office. The researcher was introduced to the participants. The semi-structured questionnaire and individual and group interviews were used to collect information from the respondents. The interviewees were parents of the children with disabilities from Hidden Voice School.

Permission was given by the Director of the school to interview parents. All the parents were invited through letters to attend the Focus Group Discussions which were held at the school on Thursdays. Thursday was the most appropriate day for the researcher. Different numbers of parents came on different days while 17 parents were consistent. Parents were assured that they would not be identifiable from the interviews and that any potentially identifiable features would be removed from the transcript. The responses to the interviews were dependable.

It was important that the parents were informed well in advance about what was going to happen as informed consent was important for ethical reasons. Some parents are particular and protective of their disabled children; they had to be psychologically ready to share their views. Secondly, anonymity and confidentiality were explained to mean that it would not be easy to know which participant the researcher was discussing in the findings. The respondents needed protection so that they were free to disclose without embarrassment or intimidation, as their privacy was respected and not encroached upon.

An in-depth Group Focus Interview was conducted on the selected parents of the children at Hidden Voice School. The interviews produced data at a specific point of time thus the researcher was able to find out what parents of the disabled children think at that point in time and inform whether there were places they go to for counselling services.

Individual personal interviews were conducted. These were Semi structured interviews carried out on 17 parents individually from Hidden Voice School. Interviews were very reliable as that provided first hand information and had direct communication with the respondents and was able to see their facial expressions. Cohen et al, (2000), states that “interviews can also give deep information and insight for the specific purpose of obtaining research and relevant information”. Semi-structured interviews were utilized as in which case there were questions ready but gave a chance to be flexible by adding in some supplementary ones. In the structured interviews there is tight control and standardized responses, therefore, there was not going to be chance to ask the respondent any other questions or clarify queries.

A letter of acknowledgement and gratitude was written to all the parents who participated in the interviews and sent to the school.

3.8 Data analysis

The data collection was on going as the interviews were carried out and analysed according to the objectives and questions. Verbatim information was written down and expressions noted and analysed and interpreted critically. The School Director accommodated and facilitated the meetings with the parents by providing one of the classrooms within the school. The information from the interviews supported the research when recommendations were made.

3.9 Ethical considerations

In this research it was important that certain ethics and protocols were adhered to. Ethics are guidelines to human behaviour, procedures or rules that are generally followed to distinguish socially acceptable behaviour from that which is generally unacceptable, (Anderson & Arsenault, (1998). The protocols are general agreements, in this case between the researcher and the respondent. As Bell (1999: 38) describes, certain professional bodies and societies have their own guidelines, which may include issues such as deception concerning the purpose of investigations; encroachment on privacy; confidentiality; safety; care needed when dealing with children and much more. The researcher settled on four of the ethics to be used in this research as proposed by Bell, (1999: 45- 46) and those were:

“Speak to the people who will be asked to cooperate.” The respondents had to be identified and an explanation given about the research, which was going to be carried out. They, according to the research ethics, were supposed to know what was happening to them.

“Maintain strict ethical standards at all times.” It was important for the researcher to consult the supervisor should there be an observation that the research was not developing well.

“Decide what is meant by anonymity.” It should not be easy for any reader to know in the research which person or participant the research was discussing. This was explained to the respondents so that they were not scared of the exercise or incase the findings were in the negative, such a research should not bring embarrassment to the respondents. Above all, there was no encroachment on anyone’s privacy.

“Decide whether participants will receive a copy of the report or see drafts or interview scripts.” The participants were not promised a copy of the report or see drafts. There were quite a number of ethical guidelines and protocols, which could not be exhausted in the section hence the choice of the few that have been discussed.

3.9 Conclusion

This chapter highlighted the research design, the population and sample. It further considered the sampling techniques and the instruments for data collection. Finally, the procedure for data collection and data analysis were looked at closing with the ethical consideration. This was for the purpose of coming up with a comprehensive methodology befitting the topic.

CHAPTER FOUR

PRESENTATION OF FINDINGS

4.0 Overview

The previous chapter considered the methodology utilized in the collection and scrutinizing of the data. The information was collected from the parents of the children with disabilities from Hidden Voice School. This chapter presents the research findings in line with the research questions. The questions were:

1. Which institutions offer counselling services to parents of children with disability?
2. What counselling services do parents of children with disabilities receive?
3. How beneficial are counselling services to parents of children with disabilities?

4.1 Institutions that offer counselling services to parents of children with disabilities.

Table 2.Parents who attended the hospital (Number of parents - 17)

Attended Hospital	**Frequency**	**Percentage**
Went to the hospital	16	94
Did not go to the hospital	1	6
Total	17	100

Out of the 17 parents that participated in the study 16 (94%) went to the hospital. Basically, all the parents visited the hospital except 1 (6%) did not visit the hospital.

There was only one parent who did not go to the hospital. She visited a diviner instead. She was reluctant to do so, but her parents insisted. So they went to Chongwe to some remote village beyond

Chalimbana. They were told that the grandmother, who had since died, demanded the child to be named after her, and when this failed she inflicted the disability. There was a renaming ceremony when they returned home. After narrating the story she concluded by saying:

Up to now my child is still crippled. The only hope I have now is in God.

They shared that when they discovered that their child was disabled, the first thing they thought of was visiting the nearest clinic or hospital for help. The medical personnel attended to the child but the parents themselves were not addressed. No counselling services were offered to them.

The parents said, when a child was prescribed physiotherapy, the parents continuously took the child on a weekly basis or monthly basis for therapy. Otherwise they were given medicine and went back for review. One parent narrated that she kept going for physiotherapy but the child was deteriorating. Eventually she gave up as it was expensive to book a taxi since the child's condition needed special care for mobility. Her final resort was to bring the child to Hidden Voice School. None of the Hospital personnel followed her up or bothered to find how she was doing.

The parent said:

No one felt mercy on me as I struggled with my son. The only consolation was prayer. There was nowhere to go and nothing else to do.

4.2 Counselling services parents of children with disabilities receive.

Table 2. Parents who received help (Number of parents - 17)

Answers	**Frequency**	**Percentage**
Alone in handling their children	9	53
Helped by own parents in handling their children	5	29
Helped by the church in handling their children	3	18
Total	17	100

Out of the 17 that participated in the study, 9 (53%) did not receive help. They were alone in handling their child with disability, 5 (29%) were helped in handling their child by their own parents while 3 (18%) were helped by the church.

One of the parents said:

"I wake up early in the morning to prepare my daughter for school. I carry her on my back to and from school every day. No one helps me and I am tired. The government must chip in to help us."

The two parents said that the members of their church had been very supportive and the priest provided pastoral counselling to the whole family. One of them had this to say:

"When the priest visited my home, it was a big relief. He always encouraged me and my family and that gave me strength."

One of the parents whose parents helped said:

"My parents and family has been there for me and we share duties taking care of my son. My worry is that I do not know where to take him after Hidden Voice because he is now over twenty years."

4.3 Benefits of counselling services to parents of children with disabilities.

Out of the 20 targeted parents 17 came for the group discussions:

Table1. Parents who received counselling services (Number of parents - 17)

Counselling Services	**Frequency**	**Percentage**
No counselling services	15	88
Counselling services from the church	2	12
Total	17	100

Out of the 17 parents who participated in the study 15 (88%) parents agreed that they did not receive counselling services after discovering that their child was disabled. 2 (12%) received counselling services from their church.

4.4 Help from an NGO

The parents narrated how some two years before, a Non – Governmental Organisation called up a meeting for all the parents at the school to register their children. The parents were promised that their children would be sponsored and adopted so that the burden would be lessened. Names were taken and the parents held meetings to see how the project would go. A few months down the line, there was a rumor that some children were selected on the list and others left out because some parents bribed the people who were running the project. The majority of the parents, whose children were not picked got frustrated and left the group. Eventually the group was divided and eventually dismantled.

One parent complained and said:

“There was corruption involved and some of us who had no money to pay were left out. Up till now the NGO has never come back to explain what happened.”

One parent narrated that:

“Nimaukakuseniseni, kusambikanakudyesamwanawanga kuti ayende ku sukulu. Nikasiliza namupapa na kumupeleka ku sukulu masiku onse. Nalema.Government iyenela kutithandiza.”

“I wake up early in the morning to prepare my daughter for school. I carry her on my back to and from school every day. No one helps me and I am tired. The government must chip in to help us.”

‘I am used to my son being stared at like a circus by kids, but adults who gaze at us just drive me crazy. Children don’t understand but adults who stare, it’s unforgivable. I find that very rude’

One parent shared that the son was restless and very disruptive.

He behaves strangely and I require eating double amounts of food for strength to take him out. He looks like any other child but behaves funny. He might suddenly start bunging doors or anything he lays his hands on.How can I feel free takinghim out? It is so embarrassing.’She started to cry but quickly recollected herself. "I'd feel hundreds of pairs of eyes on us – all watching us, all judging us for being disruptive and difficult," This, she says, is what you are up against when you have a child with special needs: other people tend not to be very kind. Which is particularly awful "because you've already got so much on your plate as it is, and if people just gave you a bit of space and support, it would go a long *way. But the opposite is more often the case: you're struggling to start with, then people knock you down further. They make assumptions about you, they find you wanting, they treat your child as though he or she is dangerous or badly behaved. It's so bad, so hard to deal with, that I have friends with special needs kids who don't even take them out any more.*

Hiding children in the homes is quite common. The incidences of hiding children in homes were confirmed in a research in Malawi. However, in some cases parents lock their children in the house in order to do productive work. Some children may require so much care that the parents are unable to work. Another parent confirmed the fact that it is a cumbersome responsibility that does not require worsening by prejudices within the community.

The truth is that it's incredibly tough to have a child with a special need. In many cases, it's a 24/7 job and to have to suffer the prejudices of others on top of that is just too much. I feel that there is something wrong about the way we look after our most vulnerable in our society. I did not decide to have a lame child but God almighty game as a gift to take care of. People need to change their behaviour towards us.

The parents who received formal counselling services in this study got it from the church. The church is a source of pastoral counselling and spiritual support as the following parent confirmed.

The organisations at the parish where I pray usually have projects to carry out and one of the tasks is to identify and visit people in need. "A little bit of help goes a long way," she said. "One time the team came to my home. My child became excited and he was all over, they sat down with me and chatted. They did not complain about her. I hugged them and felt consoled. I felt someone was on my side rather than the usual wall of hostility.

Many parents agreed with this statement that the biggest difficulty about life with children with disability was the negative attitudes of others. The judgment and unkindness encountered from strangers that decide for themselves that the disabled child is a badly behaved child with an inadequate mother. One parent echoed that one day in a queue at a till a father who was standing next pushed his glasses down to the end of his nose and sat there staring at her son in evident disapproval. She felt like heading across to shout and swear at him, but she held herself back.

What do people think gives them the right to behave that way? And the irony is they think they're making a judgment on my child's bad behaviour.

A young couple with twins had this to say;

What we'd like people to understand was that these were their children. This was their life. It's not a bed of roses, but we try to make the best of every day. What would be nice is if people were kind and considerate once in a while, and gave us a bit of space. We're dealing with issues that most people haven't got a clue about, and it's disturbing when you get someone coming up to you and saying, he needs a clip round the ear when one of them has a tantrum.

Another parent contributed that:

'If my child and I could ask the rest of us to do just one thing, it would be to stop staring. "It's fine to do a double take, but once you've taken in that our children have a disability, get on with what you're doing. It doesn't give you the right to gape," Beyond staring, what angers me is when strangers ask about my child. They say, what's wrong with her? And I say nothing's wrong with her. She's fine." I say it so sarcastically that they go away with my message.'

Another mother shared positively about the church:

It's not a tragedy,' she said, that her child had a disability. "We don't need pity; we're a very happy family and we just want to get on with our lives. I hate people calling me 'special' or thinking I somehow have extra qualities that enable me to deal with all this. The truth is that when it happened to me, I thought I couldn't cope. The pastor at my church helped me, and he still helps me. I don't know what I would have done without the church.

Another painful thing to many parents was the assurance from people that all will be well. That the child would heal soon enough, or would walk soon or talk soon whatever the situation would be, when the parent knew the condition and what it entailed.

Some parents said that time and empathy from some family members consoled them.

It was an experience that never left you. Sometimes I would wake up sweating, startled from night mares. Then I tried to imagine how the burden of having this disabled child would go away. The reality would then hit me hard; it was not going away soon. And I would cry.

Some other answers were that the embarrassment and humiliation does not go away.

It is like you have been stripped off all your clothes and everyone is ridiculing you. I stopped chatting with my neighbours and each time I was passing by I felt they were staring at me and pointing fingers.

The other parent said:

It was hard enough to have a deformed child, but harder still was when your partner was mute, no communication and you do not know what he or she is thinking.

Two parents said that their husbands left them. Since they were not in any gainful employment, it became so unbearable. One of them went to live with her parents and the other started selling at the market while her older child who was 12 years old stayed home with the disabled one. The one who moved in with her parents said:

My husband left me because he believed that I was bewitched. But now I have a two year old child who has no disability.

Parents expressed exhaustion as one of the consequences of raising a child with disabilities. People are not willing to help; perhaps they have no idea about what the parents are experiencing. This is what the parent said about tiredness:

I am tired. Parenting is already an exhausting endeavor. But parenting a special needs child takes things to another level of fatigue. Even if I've gotten a good night's sleep, or have had some time off, there is a level of emotional and physical tiredness that is always there, that simply comes from the weight of tending to those needs. Hospital and doctors' visits are not just a few times a year, they may be a few times a month. Therapies may be daily. Paperwork and bills stack up, positioning him to sit a certain way and taking him to school. This is not to mention the emotional toll of raising a special needs child, since the peaks and valleys seem so much more extreme for us. I am always appreciative of any amount of grace or help from friends to make my life easier.

The second parent was envious of the ‘normal’ children. She obviously brought out a point that is so hard to talk about:

I am jealous. It’s a hard one for me to come out and say, but it’s true. When I see a 1-year-old baby do what my son can’t at 4 years-old (like walk), I feel a pang of jealousy. It hurts when I see my son struggling so hard to learn to do something that comes naturally to a typical kid, like chewing or pointing. It can be hard to hear about the accomplishments of my friend’s kids. Sometimes, I just mourn inside for Jacob, “It’s not fair.” Weirdly enough, I can even feel jealous of other special needs kids who seem to have an easier time than Jacob, or who have certain disorders like cerebral palsy, or autism, which are more mainstream and understood by the public, and seem to offer more support and resources than Jacob’s rare condition. It sounds petty, and it doesn’t diminish all my joy and pride in my son’s accomplishments. But often it’s very hard for me to be around typical kids with him.

The next parent appreciated meeting other parents in the same predicament and sharing their stories, the sincerity and catharsis brings out so much healing to many parents in similar situations.

I feel alone. It’s lonely parenting a special needs child. I can feel like an outsider around mothers of typical kids. While I want to be happy for them, I feel terrible hearing them brag about how their 2-year-old has 100 words, or already knows their ABCs Good for them, but it’s so not what my world looks like. It’s good to connect with other special needs mothers, with whom it’s not uncomfortable or shocking to swap stories about medications, feeding tubes, communication devices and therapies. Even within this community, though, there is such variation in how every child is affected. Only I understand Jacob’s unique makeup and challenges. With this honor of caring for him comes the solitude of the role. I often feel really lonely in raising him.

Anxiety and worry, this echoes the fears of so many parents out there, but when they meet other parents with their children in the same predicament, the worries and fears melt away. This parent had this to say:

I am scared. I worry that I’m not doing enough. What if I missed a treatment or a diagnosis and that window of optimal time to treat it has passed? I worry about Jacob’s future, whether he will ever drive a car, or get married, or live independently. I am scared thinking of the hurts he will experience being “different” in what’s often a harsh world (not to mention that I fear for the physical safety of the person *who inflicts any hurt upon my son). I am scared about finances. Finally, I fear what will happen to Jacob if anything were to happen to me. In spite of this, my fears have subsided greatly over the years because of my faith, and because of exposure to other kids, teenagers, and adults affected with Jacob's disorder. When I met some of these amazing people at a conference last year, the sadness and despair that I was projecting onto Jacob's future life (because it was so unknown) melted away when I saw the love and thriving that was a reality in their lives. The fear of emotional pain (for both me and Jacob) is probably the one that remains the most.*

The next parent brought out the ridicule; negative attitudes alluded to that brought out the worst in parents and hidden thoughts about expectant mothers. The parent had this to say:

I wish you would stop saying, "retarded," "short bus," "as long as it's healthy... " I know people usually don't mean to be rude by these comments, and I probably made them myself before my son was born. But now whenever I hear them, I feel a pang of hurt. Please stop saying these things. It's disrespectful and hurtful to those who love and raise the kids you're mocking. As for the last comment, "as long as it's healthy," I hear a lot of pregnant women say this. Don't get me wrong, I understand and share their wishes for healthy babies in every birth, but it's become such a thoughtless mantra during pregnancy that it can feel like a wish against what my son is. "And what if it's not healthy?" I want to ask. My response: you will be OK. You and your child will still have a great, great life.

One parent shared about true feelings being expressed about being human and experiencing challenges in life, like longing to do the things she likes. She said:

I have been challenged and pushed beyond my limits in raising my son. I've grown tremendously as a person, and developed a soft heart and empathy for others in a way I never would have without him. But I'm just like the next mother in some ways. Sometimes I get bad-tempered, my son irritates me, and sometimes I just want to flee to the spa or go shopping. I still have dreams and aspirations of my own. Sometimes it's nice to escape and talk about all these other things. And if it seems that the rest of my life is all I talk about sometimes, it's because it can be hard to talk about my son.

There is always a lot going on in the mind of a parent with a child who has a disability. It may all not be shared. This parent had this to say:

I want to talk about my son. It's hard to talk about my son. My son is the most awe-inspiring thing to happen to my life. Some days I want to shout from the top of a building how funny and cute he is, or how he accomplished something in school. Sometimes, when I'm having a rough day, or have been made aware of yet another health or developmental issue, I might not say much. I don't often share with others, even close friends and family, the depths of what I go through when it comes to Mabvuto. (Pseudo name). But it doesn't mean that I don't want to learn how to share our life with others. One thing I always appreciate is whenever people ask me a more specific question about my son, like "How's Mabvuto's sign language coming along?" rather than a more generalized "How's Mabvuto?" which can make me feel so overwhelmed that I usually just respond, "Good." Starting with the small things gives me a chance to start sharing. And if I'm not sharing, don't think that there isn't a lot going on underneath, or that I don't want to.

Another parent said:

Raising a special needs child has changed my life. I was raised in a family that valued performance and perfection above all else, and unconsciously I'd come to judge myself and others through this lens. Nothing breaks this lens more than having a sweet, innocent child who is born with impairments that make ordinary living and ordinary "performance" difficult or even impossible.

The next parent shared about her redefined concept of true love with the experience of a child with disability. She had this to say:

It has helped me understand that true love is meeting someone child or adult, special needs or not exactly where he or she is no matter how disabled they are. Raising a special needs child shatters all the dreams that we idolize and build our lives around, and puts something else at the core: love and understanding. I may have it tough, but in many ways I feel really blessed.

This chapter considered the verbatim of the parents interviewed. Obviously the parent's lives are shattered and need healing. Assistance from institutions or individuals is also required. The fact that the parents of children with disability require the community, the government's genuine concern and Non-governmental Organisations on board to assist is expressed in the cry of the parents of children with disabilities at Hidden Voice School.

CHAPTER FIVE

DISCUSSION OF FINDINGS

5.0 Overview

The preceding chapter presented the results from the interviews. The following chapter will undertake to discuss the findings of chapter four in regard to the objectives set at the initial stage of the research.

5.1 To establish whether there are institutions that offer counselling to parents with children with disabilities.

From the findings of the Focus Group Discussion and individual interviews, all the parents disclosed that there were no such institutions where parents of disabled children go for counselling services. The only place that the parents of the disabled children go to is the hospital and the church. They expressed that it would be a good idea to speak to someone influential about their situation to set up one.

5.2 Ascertain whether the parents of children with disabilities receive services in counselling.

From the findings it is clear that most of the parents of children with disabilities did not receive counselling services, therefore the majority are neglected. According to the Ministry of Sports Youth and Development, Zambia Association for Persons with Disability (ZAPD) is authorized to counsel Parents of children with disability, and 15 parents out of 17 never received counselling from ZAPD, this therefore means there is no institution to go to for counselling services. If ZAPD has a responsibility to counsel parents of children with disabilities, then why haven't these parents been visited?

ZAPD has a team of counsellors that used to go round to offer counselling services to schools that have children with disabilities. The disparity is that Hidden Voice School parents have never been visited by this team and they have never heard about it. Therefore, there are no places available for counselling for parents with disabilities in Garden Compound where the school is situated.

All the parents of the children at Hidden Voice have no formal link with each other. It is each one for himself and God for all. They hold no meetings apart from Parents Teachers Conferences, when they meet the teachers on individual basis to discuss the progress for their children. A sheer greeting at drop off and pick up times is not enough to understand how the other one feels or how they are managing with the burden of a child who is disabled. Clearly, the parents of Hidden Voice need to organize themselves in such a way that they form a strong bond that can stand up for themselves and their children, to be heard so that their needs can be addressed.

All the parents of the disabled children at Hidden Voice said they never met to discuss their issues or indeed support one another in any way. They dropped off their children in the morning and picked them up later in the day. As they dropped their children and fetched them, they informally greeted each other. The only persons available to them were the two teachers at the school.

One parent that has shared her personal experience of being a mother of a child with cerebral palsy was Darla in her book, Clayton (2011), stating that there may be no one else with the same problem as your child, but there are certainly people with challenges. It pays to find those people and make friends with them. The parents need to know that they too deserve to be cared for in spite of being placed in a position to care for others nearly constantly. The parents may not be perfect, they make mistakes but no one's perfect. People must change their negative thinking.

A parent with a child with a disability is a superhero in his/her own right. She may not leap buildings in a single bound or run faster than a speeding bullet but she is a superhero none the less. Every day she manages situations that a regular parent would think are impossible. She stretches tight muscles, remember pills, inject and infuse medicine. She holds hysterical children during horrendous medical procedures. She deals with tantrums and melt downs. And most often manage not to have a tantrum or melt down herself. She encourages her child to do things doctors told her they would never do but never gave up hope. She is a therapist, nurse, doctor, friend and confidante. She is not a regular parent. Clayton (2011)

Clayton accepted the situation and realised her own self actualisation through counselling therapy. She got her life back after going through a rough time.

The old belief that having a child with a disability was considered as an omen, as a result of having offended the ancestors and they show their anger by inflicting disability of one kind or another could still have deep roots in the society. This could be why parents of people with disabilities in at Hidden Voice School are neglected. As one parent narrated:

"Bena banthu baitana bana ati cilema ,nthawi zina ati silu, cibaba."

"Some people ridicule the children by calling them names like the lame one or mad one. It's painful.

Some African beliefs promote the stigmatization and marginalization of people with disabilities through exclusion and depiction of them as objects of pity or ridicule and as victims of evil forces. Ndhlovu, (2016). As such one had to appease the spirits of the ancestors who unfortunately had no power to heal the disabled person. However given the communitarian dimension of African societies which emphasized the need to take care of each family member, there were cases of disabled people being cared for. The same Ndhlovu (2016) indicates: alternatively, other African beliefs inculcate positive and empathetic moral and ethical teaching aimed at empowering those living with disabilities by depicting them as full human beings who have the same rights, obligations and responsibilities as ‘normal’ persons.

Two parents were rejected by their own families while five got help from their families and the church. In the African perspective of ‘I am because you are’, ‘ubuntu’, which is the communal support of life in contrast with the Western World of ‘individualism’, surprisingly does not apply when it comes to children with disabilities. The parents of children with disabilities are traumatized not only due to the fact that they have a disabled child, but also due to the family and community’s negative reaction. Disability is associated with negative perceptions resulting in stigma, discrimination, exclusion and violence, as well as other forms of abuse of persons with disabilities. This is traumatizing and devastating to the parents. The myths surrounding the people with disabilities, e.g. being cursed, bewitched, misfortune, sub human and many more do not make the situation any better.

Worse still, there are no special needs facilities to cushion the daily chores both at the school and at home. Consequently, parents with disabled children need not just counselling services but also innumerable services. They experience a lack of support and local services are denied them this brings a lot of frustration.

5.3 To determine the benefits of counselling services to parents of children with disabilities.

The two parents who received counselling from the church testified that they benefited and were able to look at the situation of having a disabled child from a positive point of view. One of them said:

“Nina mvela bwino ,nakuona mwana wanga kuti nimphatso, osati tembelelo.”

Translated as; “I felt good, such that I regarded my child as a gift instead of a curse.”

All parents admitted that there was no place to go to for counselling of parents of children with disabilities. Thus it was not easy to determine how effective the counselling services were. The effectiveness of counselling places was established from previous researchers like Beresford et al (2007) who confirmed that parents with children with disabilities gained so many positive outcomes from the counselling places. The role of taking care of the child with disability dominates the life of the parent, which means their own identity is lost. Through counselling they would regain and maintain their work interests and personal relationships. The parents will learn to be physically and emotionally healthy in order to properly look after their child. They will know how to handle lifting, sleep problems, and the chronic care and supervision needs of the child as these threaten parents' physical and emotional well-being.

Three parents were helped by the church and five were helped by their own parents in handling the children with disabilities. Accepting and adjusting to the child's diagnosis is an on-going emotional task that can be reduced by ongoing professional counselling and the medical attention, appropriate equipment, suitable housing and skills in dealing as well as help with the child's problem. Thus support and contact with other parents is critical. Research has proved that parents support groups and counseling services to parents of disabled children have assisted in the development of children with disabilities. They showed tremendous progress in their development.

According to Beresford et al (2017) Parents' information benefits were diverse the balance between caring and Parenting maintaining family life, positive adjustment of the other siblings in the home, managing financial resources, gaining knowledge to properly care for and bring up their child and the rest of the family can also be shared and so many other benefits to reduce stress on the parents and include fun in their lives in order to live "normal" lives.

Summary

The objectives set out at the initial stage of the research were to establish whether there are institutions that offer counselling services to parents of children with disabilities. From the findings, the majority of the parents take their children to the hospital where the children are attended to. The focus at the hospital is on the child and the counselling needs of the parents are ignored. Apart from the parents who underwent counselling from their priests, basically most parents of children with disabilities were denied counselling services. The parents who were counselled testified that they benefited from the experience. Parents experience trauma when they discover that their child is disabled. Clearly, a parent who is unstable due to the trauma of the circumstances that she finds herself in may not be at her best in taking care of the child. She/he may be considered disabled in a way. The well-being of a child who is disabled centers on parenting capacity. Thus the child with a disability may not get the best from such parents. According to the theory earlier quoted, Rogers (1977) on the importance of the self actualizing in forming a self concept, the parents need to be counselled in order to attain full potential and self actualisation. If parents get healing through counselling, then they would be able to reach their congruence and self awareness, be fully functional and give their children optimum service.

CHAPTER SIX

CONCLUSIONS AND RECCOMMENDATIONS

6.0 Overview

To wrap up, we briefly consider the preceding chapters. Chapter one looked at the introduction to the study while chapter two discussed the Literature Review. In chapter three the methodology applied was studied and chapter four reviewed the findings of the study. In chapter five, the researcher discussed the findings and finally this chapter will provide personal about the outcome of the study and the conclusion and recommendations to the community, NGOs and the government at large.

6.1 Conclusion

The purpose of this study was to find out the role of counselling services and whether there are institutions that offer counselling services to parents of children with disabilities and the effect. The interviews carried out with these parents at Hidden Voice revealed that most of the parents of persons with disabilities do not have counselling services. The institutions, other than the hospitals where the parents go to seek medical attention and receive incidental kind of counselling are minimal. It is not all the parents who receive counselling from their pastors at their respective places of worship. Thus the majority of the parents with disabled children in the study area lack counselling services. As a result their parenting capability is not optimal. The theory of self actualization is not realised, therefore the child with a disability gets minimum attention.

There were some incidences of rejection expressed by parents and attitudinal barriers that is behaviours, perceptions and assumptions that discriminate against persons with disabilities including prejudice, low expectations and even fear within their communities. Negative attitudes about their children‘s disabilities impact on all aspects of their lives and so need counselling services and empowerment in order to cope with the situation. However, there are no places to go to for such counselling services apart from the few parents who admitted that they had pastoral counselling from their priests. I strongly feel that every parent with a child who is disabled has the right to undergo counselling to enable them to cope with the situation and have a positive attitude towards the upbringing of the child.

Attitudes to disability are not always uniform within a region or even within a country. Different groups or individuals may have beliefs about disability that vary from those held by wider society and beliefs may vary even within small communities and within families, but the trauma is common and universal at all times. Healing is necessary for these parents to live life normally again while giving their best to their child with a disability. It is important to note that, although false perceptions and beliefs about disability are often difficult to overcome, beliefs can change and evolve over time. When more and more people become sensitized and more informed about the feelings of both the parents of children with disabilities and their children, there will be empathy and understanding. This attitude will have a positive chain reaction in that people in different states of life will provide inclusive environment for both people with ability and those with disability.

6.2 Recommendations

The following recommendations are directed to the parents of children with disabilities, the community within which parents of children with disabilities live and the Government and Non-Governmental Organizations.

1 The government, NGOs should find ways to empower the parents of the children with disabilities to enable them to stand up on a platform to share what they experience and what their needs are. One of the good practices in Zambia is The Mental Health Users Network of Zambia who have provided a forum for users of mental health services to support each other and exchange ideas and information through peer support that helps combat internalized oppression and shame. The organization champions the human rights of people with mental disabilities and works with government departments national and international NGOs and the media to fulfill its objectives. WHO (2010)

2 The Government and NGOs can work through the strong voice of the parents of children with disabilities to create the needed places for counselling. Leadership structured from national level to the grassroots, since parents with disabled children are found at all levels of life. In that way, national programs which involve parents of children with disabilities will bring awareness to all the stakeholders to come on board.

3 Advocacy activities including mobilizing and sensitizing communities around people with disabilities by parents groups. The parents of children with disabilities can work together with Zambia Association for Persons with Disability to identifying their needs and lobby for rights and services required for them and their children.

4 When the parents are empowered, they can work with the media to carry out Intensive community sensitization programs to reach out in both towns and rural areas, to teach people about the values and potentials of the disabled people. Reporters can also play an important role in investigating and publicizing abuses experienced by persons with disabilities. To do so journalists themselves may need training in disability awareness and the rights of persons with disabilities. In some cases persons with disabilities are taking this on. For example, to empower and promote awareness of the capabilities and contributions of Persons with disabilities.

5 The communities must be educated about the rights of the people with disabilities as stipulated by the United Nations.

6 Parents should make the children play different games and this could be part of rehabilitation. As the children are playing, the parents could use that time to meet other parents and strategise the way forward to solve their needs.

7 The parents must make time to enjoy their kids. It is very important to make time to play. Engage with them with what is important to their world. Recreation is good for the soul and body. Mpofu et al (2016) contends that leisure and recreation is designated to improve cognitive and coping skills in individuals with special needs. Leisure and recreation therapy services develop the skills needed to enhance functional independence for community living and to promote a higher quality of life for the individual and their family. Recreation therapy services provide individuals with disabilities mechanisms to prevent declines in physical, cognitive and psychosocial functioning and as a result reduce the need for health care services. http://www.atratr.org/ In fact studies show that recreation therapy helps:

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APPENDICES

Semi-Structured Interview questions for individuals and Focus Group.

When did you know that your child had a disability?

Who did you talk to about the disability?

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Where did you go for help?

Who was there to help you?

What was your spouse’s reaction?

What were the reactions of other people like friends and neighbours?

What were your feelings, fears and anxieties? E.g. anger, self pity, indifferent, sad.

Did you receive any counselling services?

How do you feel now?

Do you know of any centre that offers counselling services for parents of children with disabilities?

Did you get to meet other parents with children with disabilities?

Would you like to meet other parents in a similar situation?

What would be your advice to other parents in similar situations?

Is there anything that you would like to add?

THANK YOU FOR PARTICIPATING IN THE INTERVIEW!

Some quotations from the parents

“No one felt mercy on me as I struggled with my son. The only consolation was prayer. There was nowhere to go and nothing else to do.”

“When the Pastor visited my home, it was a big relief. He always encouraged me and my family and that gave me strength.”

“My parents and family has been there for me and we share duties taking care of my son. My worry is that I do not know where to take him after Hidden Voice because he is now over twenty years.”

‘It was an experience that never left you. Sometimes I would wake up sweating startled from night mares. Then I tried to imagine how the burden of having this disabled child would go away. The reality would then hit me hard; it was not going away soon. And I would cry”

“I wake up early in the morning to prepare my daughter for school. I carry her on my back to and from school every day. No one helps me and I am tired. The government must chip in to help us.”

“Nimauka kuseniseni, kusambika nakudyesa mwana wanga kuti ayende ku sukulu. Nikasiliza namupapa na kumupeleka ku sukulu masiku onse. Nalema. Government iyenela kutithandiza.”

“I wake up early in the morning to prepare my daughter for school. I carry her on my back to and from school every day. No one helps me and I am tired. The government must chip in to help us.”

“Bena banthu baitana bana ati cilema ,nthawi zina ati silu, cibaba.”

“Some people ridicule the children by calling them names like the lame one or mad one. It’s painful.

“Ninamvela bwino ,nakuona mwana wanga kuti nimphatso, osati tembelelo.”

“I felt good, such that I regarded my child as a gift instead of a curse.”