

**CHALLENGES OF PARENTING CHILDREN WITH INTELLECTUAL
DISABILITIES:**

A CASE OF

SELECTED PARENTS IN LUSAKA DISTRICT ZAMBIA

BY

HANSANGU C. MILAMBO

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requirements for the award of a degree of Master of Education.**

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DECLARATION

I, Hansangu C. Milambo, do declare that this dissertation represents my own work and that it has neither in part nor in whole been submitted for award of any degree at the University of Zambia or any other University.

Signed:

Date:

DEDICATION

This dissertation is dedicated to my lovely wife Lillian who was deprived of my attention during the study, and my children: Chabota, Alimwi, Mwiinde and Luyando for their encouragement and support given to me throughout the study.

APPROVAL

This dissertation of Hansangu C. Milambo is approved as a partial fulfillment of the Requirement for the award of the degree of Master of Education (Special Education) of the University of Zambia.

Examiners' Signatures:

Signed: Date.....

Signed: Date.....

Signed: Date.....

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ACRONYMS

ID	Intellectually disabled
MoE	Ministry of Education
WHO	World Health Organization
UNO	United Nations Organization
CSO	Central Statistical Office

ABSTRACT

The study sought to establish the challenges that parents, guardians and caregivers of children with intellectual challenges go through in the process of raising their children. The researcher used both qualitative and quantitative methods in which a case study research design was employed. A sample of sixty parents was used in Lusaka District. The findings revealed that parents, guardians and caregivers had problems as regards the unacceptable behavior from their children. Some families were reported to have been socially isolated and suffered stigma. Marriages were stressed and some broke down. Intellectually disabled children also created anxiety among siblings. Besides that, parents, guardians and caregivers had economic hardships to meet the daily needs of these children. A number of them were found to be out of formal employment and were finding it hard to meet the needs of the children. It was also found that, the inevitable role by parents, guardians and caregivers to look after the intellectually challenged children in a more of perpetual manner, hindered them from full participation in income generating activities which they undertook before the birth and eventual diagnosis of these children with this condition. Furthermore, other parents, guardians and caregivers were reported to have lost formal employment for the sake of taking care of the intellectually challenged children. The study showed that parents, guardians and caregivers had developed some strategies that helped them to cope with the situation of living with intellectually challenged children. Some of the strategies include beliefs in God, comfort from friends and planning for the children in advance. The study also revealed that parents, guardians and caregivers were negatively perceived by the community and members of the public at large. The parents and guardians were held responsible for the conditions of their children and it was in some quarters of society believed that, the parents and guardians due to the love of money caused the conditions of the children. The parents and guardians further received terrible remarks from some sections of society for the perceived failure to control their children emanating from their disruptive behavior in the community. The researcher, therefore makes recommendations as follows; close observation on the children's behavior as a source of understanding can be helpful, planning for multi-professional support groups to relieve the pressure on parents, sharing experiences with the parents in a loosely supervised support group is also ideal for the parents and need for a nationwide assessment sensitization health survey to parents on the condition and diagnosis.

CHAPTER ONE INTRODUCTION

1.0 Overview

This chapter contains the background to the study, statement of the problem, purpose of the study, research objectives, research questions, and significance of the study, limitations, delimitations and definitions of terms.

1.1 Background to the study

It is not a wish of any parent to have an intellectually challenged child. However, due to reasons beyond any human intervention, parents may find themselves in a situation where they have to contend with raising an intellectually challenged child. An intellectually challenged child may be described as that child who is having problems with the development of cognitive and learning capabilities (MOE, 2005). These individuals are also referred to as mentally challenged or mentally disabled. The defining factor here is the fact that they have intellectual, cognitive, developmental as well as learning disabilities. Due to the fact that this disability is affecting the brain and general body development, they are also sometimes physically disabled.

Parenting an intellectually challenged child poses huge challenges to parents. It calls for a very well organized plan and strategy to overcome and to cope with parenting a child with special needs. But how do you tell that your child falls in the category of intellectually challenged individuals? Is it obvious to tell? Some of the outstanding signs among others include intellectually challenged children experiencing delays in many areas of development. Some children, for instance, take too long in learning spoken language, social skills, and simple problem solving skills as well as delays in learning self-care skills such as going to the toilet (Heward, 2006).

Gombosi (1998) states that it is estimated that world-wide up to 20 % of children suffer from debilitating intellectual challenges. Intellectual challenges pose a significant concern that include learning disorders, depression, psychosis, pervasive development disorders, and anxiety disorders, conduct disorder, substance abuse and eating disorders. Living with such children can be very stressful for parents and caregivers in the family. Therefore, determination of challenges of living with these children is important in the process of finding ways to help or support caregivers to provide proper care for their children.

One of the most replicated findings in family research is that 1-2% of the world's population have intellectual challenges, with higher prevalence rates reported among children and adolescents and in lower income countries (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011). The median prevalence for intellectual challenges has been estimated at 6.2/1000 (Elsabbagh et al., 2012). Between 40-67% of children with pervasive developmental disorders also have intellectual challenges (Blair, 2003).

Given the current global fertility rate of 2.5 (UNICEF, 2011), this suggests that between 1 in 50 and 1 in 20 families with children in the world have a child with intellectual challenges. It is also indicated that 90% of the world's children aged 0-14 live in low or middle income countries (World Bank, 2012). International Human Rights Conventions recognize the right of children and family life in the community (United Nations, 2006). In the vast majority of instances, children with intellectual disability are cared for by their parents who (along with other family members) serve as their most constant and life-long caregivers. They play a critical role in shaping the development and life experiences of their children with intellectual challenges.

In many contexts, caring for intellectually challenged children also becomes the responsibility of their siblings and extended family members taking on caring roles,

especially when parents are no longer able to render the necessary care that children with intellectual challenges require. While families supporting children with intellectual challenges are first and foremost families, they may in some cultures differ from families who do not include a child with disabilities in some important ways. These include: increased risk of exposure to socio-economic disadvantage, exposure to disability-related discrimination, coping with exceptional and prolonged caring tasks, complex interactions with disability services, and continuing to provide support into later childhood, adolescence and adulthood (Dyson, 1991). Many of these differences are also shared by families supporting a child with other types of disabilities and are likely to vary as a function of social/cultural context and the nature/severity of the child's impairment.

According to the 2010 national census, the proportion of the population with disabilities at national level in Zambia was 2.0%. The proportion in rural areas was higher than urban areas at 2.4 and 1.4 percent, respectively. Western Province had the highest proportion of the population with disabilities at 2.9% while Lusaka Province had the lowest with 1.3 percent. The median age for the population with disability was 35 years. Physical disability was the most common type of disability at 32.7%. The major cause of disability was disease at 35.2%.

The literacy rate for the population with disability at national level was 58.6%. Lusaka and Copperbelt provinces had the highest proportions of the population with disabilities who were literate, with 73.6 and 73.1%, respectively. Eastern Province had the highest proportion (45.2%) of the population with disabilities who could not read and write. The proportion of the population with disability that had never attended school was higher (34.4%) than that of the population without disability (20.9%). The highest level of education attained by the majority of the population with disabilities, whether living in rural or urban areas, was primary education. Out of the population of the disabled, 90.9% were employed. Of these,

52% were self-employed and 35.2% worked as unpaid family workers. Agricultural-related occupations made up 83.3% of the disabled population employed.

Currently, available statistics from Central Statistical Office (CSO) indicate that among grades one to twelve pupils, Zambia has 32,360 male, 17,878 female pupils with intellectual disabilities in grades, 1-9, which gives a total of 50,238 pupils, 392 male, and 486 female pupils with intellectual disabilities in grades 10-12, giving a total of 878 pupils. The total for the male pupils stands at 32,752 and 18,364 female pupils giving a total of 51,116 pupils with intellectual disabilities (Ministry of Education, 2009).

Furthermore, having a child with intellectual disabilities can have profound effects on the family and may place a set of extra demands, challenges and burdens on the family system as well as on the disabled child. Kirk, Gallagher and Anastasiow (2000) point out that such experience affects the dynamics of the lives of parents and other members of the family in different ways.

Belington, McNally and McNally (2000) observe that raising a child who is intellectually challenged requires emotional strength and flexibility. The child has special needs in addition to the regular needs of all children, and parents can find themselves overwhelmed by various medical, caregiving and educational responsibilities. Whether the special needs of the child are minimal or complex, the parents are inevitably affected. Support from family, friends, the community or paid caregivers is critical to maintaining balance in the home. Parents and guardians play a major role in helping children grow and develop to their full potential.

As children grow in families, they most significantly depend on their parents or guardians for basic needs support such as food, shelter, education, protection, and care at all times and especially during these difficulty trying moments and times of crisis. Intellectual challenges in childhood and adolescence can be chronic and very disturbing, requiring proper attention,

help and support from caregivers. Thus, parents or guardians and relatives living with children with intellectual challenges have additional responsibilities and roles to care for them as they do for other healthy children. The importance of family support for the growth and development of children and the role it plays as a determinant of whether children will receive appropriate care or not, cannot be overemphasized.

From the past until at the time of this study the World Health Organization (WHO) Mental Health Programme has not given due weight to child and adolescent psychiatry as compared to adults and the elderly. Yet from a demographic and epidemiologic point of view, intellectual challenges in children and adolescents represent an area that needs proper attention. It is already estimated that up to 20 % of children and adolescents in the world suffer from debilitating intellectual challenges (Thompson, 2000).

There are various ways in which child and adolescent intellectual challenges can be considered. One way is looking at these disorders in a priority manner based on their frequency of occurrence, degree of impact, therapeutic possibilities, and long term care effects (Kraft & Kraft, 1998). From this perspective, child and adolescent intellectual challenges that pose a significant concern include learning disorders, depression that normally affects the parents to the children. Others include psychosis, pervasive developmental disorders, anxiety disorders, conduct disorder, substance abuse and eating disorders.

Physical exhaustion can take a toll on the parents of intellectual challenged children. The degree of this is usually relative to the amount of care needed. Feeding, bathing, clothing and moving a child is much easier physically than doing the same tasks for someone who is old enough. The intellectually challenged child may have more physician and other health-care appointments than a typical child and may need close medical monitoring. He may also need

to be watched to avoid inadvertent self-harm such as falling down stairs or walking into the street. These additional responsibilities can take a physical toll on a parent, leading to exhaustion. The American Academy of Family Physicians relates that these issues can cause significant caregiver stress (Dunn, Burbine, Bowers & Tantleff 2001).

In addition, parents may be forced to play additional roles as parents of a child with intellectual disability. Heward (2000) for instance says that, in addition to their natural role, parents may become obliged to provide their children with intensive care, counseling and education, support their behaviors, become their specialists and act as financial providers.

The parental challenges have been found to have a strong relationship with their income and the ability to meet their family's expenses. The presence of a child in the family with intellectual disability requires several supportive services that cost a lot of money, including medical, educational, psychological, and occupational services. Van Der Veek, Kraaij, & Gamefski, (2009) observe that caring for an intellectually disabled child calls for a higher financial ability as compared to expenditure on children without intellectual disabilities.

What happens, however, to the mother who is raising a child with a significant disability, particularly an intellectual one? Indeed, more often than not, a dependent child becomes a dependent adult, short-term care giving becomes a lifelong responsibility (often hindering the mother's ability to find employment), and the child does not learn from the mother's better education or health status. Regarding those with significant physical and/or sensory disabilities, in the developed world it is recognized that with the right supports, these children have a better chance to eventually live fairly independent lives and may contribute economically and socially to society. In many developing countries such as Zambia, however, this is not the case. This group along with the intellectually disabled are often denied the right to basic education and health care; therefore, they lose the chance to become

independent (Zinkin & McConachie, 1995). Even if their mothers could access health care, the necessary treatments would be much more costly than interventions needed for children with minor disabilities. However, a few African studies about disability in general, such as Chirwa (2011), noted that it is not uncommon for a family to be banished to the outskirts of a village once it is known that they have a child with a disability (particularly if it is thought to be a contagious disability, like epilepsy is believed to be).

In Africa, for example in Uganda, the investigators noted that negative societal attitudes manifested primarily as rejection of the child (by teachers and schools refusing admittance, by family members and by friends), and resulted in loneliness for the child and mother (Hartley, Ojwang, Baguwemu, Ddamulira and Chavuta, 2005). Several informants mentioned that some members of the community still believe that children with disabilities are “objects of shame,” and thus should be hidden. As for the disability’s cause, many parents attributed it to God’s will, witchcraft or angry ancestral spirits. In a study out of Nigeria, a full 35% of mothers attributed the cause of disability to evil spirits or witchcraft, while only 10.4% believed in natural causes (Abasiubong, Obeme, and Ekpo, 2008)

In Zambia, the majority of people with disabilities are found in the rural areas of the country. Furthermore, rural areas in Zambia are characterized by limited basic services (health and education facilities). People with disabilities are mainly involved in agriculture activities- accounting for 80% of the common occupation among persons with disabilities (Mubita, 2009). Hence, the majority of people with disabilities are impoverished since agriculture in a country like Zambia does not offer high returns. Besides that, a significant number of persons with disabilities have low literacy levels, and a considerable number of them are involved in street begging as a survival strategy, especially in the major cities (ibid).

This study focused on parents of Lusaka district and mainly those whose children go to Special Schools in Lusaka district specifically University Teaching Hospital Special School and Bauleni Special School. Records obtained from Special Schools in Lusaka district indicated that, parents of these children encountered problems as cited by schools management in some parents' inability to pay for their children. The questions which could be raised concerning the plight of the parents in Zambia would include how they manage the perceived complex situation in Zambia to have a child with intellectual disability? Are societies and professionals concerned about this problem? And what could be the challenges in Zambia to have a child with intellectual disability?

Due to an availability of many published studies in this area in Zambia underscored the importance of this study to contribute towards better understanding of challenges faced by parents in Zambia when caring for children with intellectual challenges. It is therefore against such background that I wished to conduct a study and ascertain the challenges that parents undergo in raising children with intellectual challenges in the Zambian context.

1.2 Statement of the problem

Studies show that parents with children with intellectual disabilities face numerous challenges in their effort to raise these children (Dyson, 1997). While these studies have been conducted mainly in western countries, little is known about the challenges that parents of children with intellectual disabilities go through in the Zambian context, hence the need to do a study in Zambia.

1.3 Purpose of the study

To investigate the challenges faced by parents and guardians who have children with intellectual challenges in Lusaka District.

1.4 Objectives

The study was guided by the following objectives:

- i. To ascertain the socio-economic challenges of raising a child with intellectual disability.
- ii. To determine how parents of children with intellectual disabilities cope with these challenges.
- iii. To establish the views of parents with children with intellectual disabilities on how society perceives them.

1.5 Study Questions

The study was guided by the following research questions:

- i. What is socio-economic challenges of raising a child with intellectual disability?
- ii. How do parents of children with intellectual disabilities cope with these challenges?
- iii. What are the views of parents with children with intellectual disabilities on how society perceives them?

1.6 Significance of the study

The study may be of great importance to parents of children with intellectual disabilities as it may generate information which might equip parents with the strategies of raising a child with intellectual disabilities. It is further hoped that, the study may contribute to the body of knowledge on challenges of parenting a child with intellectual disabilities. The study may also have a positive bearing in the formulation of policies towards intellectually challenged children and also help in formulation of curriculum framework

1.7 Limitation of the study

There was limited literature on the topic in Zambia for reference purposes and some participants were reluctant to be interviewed hence little information was collected from them. Therefore, due to reluctance by some parents and guardians, findings may not represent the feelings of the target population.

1.8 Delimitation of the study

The study covered parents with children with intellectual disabilities from selected Special Education Schools in Lusaka District and for the purpose of convenience to the researcher; the population was restricted only to parents in Lusaka District.

1.9 Definitions of terms

Experience: an event or activity that has an effect on you.

Parents: According to the Longman Dictionary of Contemporary English (1987), the word parent refers to a biological or foster mother and father, a person or animal. In this study, it will include a category of all adults who might carry the primary responsibility of a child's health, development and education. It includes both biological and foster mother and father, siblings and members of the extended family.

Parenting: to care for the young until fully grown.

Attitude: is the way of thinking towards something.

Intellectually challenged: intellectual challenge means having a cognitive disability that manifests in a person through a reduced cognitive (intellectual) ability, limited adaptive behavior and the need for support to participate fully in the community. Grossman, (1983)

defines Intellectual Challenge as functioning existing concurrently with Deficit in adaptive behavior and is manifested during the developmental period.

Social Skills: are described as those activities that are done on a daily basis such as personal hygiene.

Children: means any male or female persons not more than twelve years of age.

1.10 Summary

This chapter has covered the introduction to the study. The background to this study emanating from the need to determine the challenges of parenting a child with intellectual challenges. In addition, the chapter covered the research problem under investigation, Purpose of the study, objectives and research questions. The chapter also presented the significance of the study, study limitations and definitions of terms used and the organization of the study.

CHAPTER TWO LITERATURE REVIEW

2.0 Overview

In this chapter, the study explores existing literature on the challenges which parents of learners with intellectual disability face. The chapter presents review of relevant literature relating to challenges that parents of intellectually challenged children face when raising their children. It ends with a summary.

2.1 WHAT IS INTELLECTUAL DISABILITY?

Intellectual disability is defined by Papalia and Sally (1998) as significantly subnormal general intellectual functioning existing concurrently with deficits in adaptive behavior manifested during the development period. It is indicated by an Intelligence Quotient of about 70 or less, coupled with a deficiency in age appropriate adaptive behavior such as communication, social skills, and self-care. Ministry of Education (MOE, 2005) indicates that children with intellectual disability are children who have a cognitive (intellectual) disability, limited adaptive behavior and the need for support to participate fully in the activities of the country. Therefore, intellectual disability is a disability characterized by limitations in intellectual functioning and resulting in the need for extraordinary support for the person to participate in activities involved with typical human functioning.

Dyson (1991) states that experts divide the types of cognitive impairment into four categories: mild intellectual disability, moderate intellectual disability, severe intellectual disability, and profound intellectual disability. The degree of impairment from an intellectual disability varies widely. DSM-V places less emphasis on the degree of impairment that is Intelligence Quotient scores and more on the amount and type of intervention needed. Mild intellectual disability is characterized by slower than typical in all developmental areas and

has no unusual physical characteristics. Individuals with mild intellectual disability are able to learn practical life skills and can attain reading and math skills up to grade levels 3 to 6. They are also able to blend in socially in daily life. Gray (2002) states that about 85% of people with intellectual disabilities fall into the mild category and many even achieve academic success. A person who can read, but has difficulty comprehending what he or she reads represents one example of someone with mild intellectual disability.

Another category is moderate intellectual disability with an Intelligence Quotient of 35 to 49. Judge (1998) explains that this category is characterized with noticeable developmental delays such as speech and motor skills. Individuals with moderate intellectual disability may have physical signs of impairment such as a thick tongue. However such individuals can communicate in basic, simple ways and learn basic health and safety skills. Such individuals can complete self-care activities and travel alone to nearby, familiar places.

Lam and Mackenzie (2002) found that people with moderate intellectual disability have fair communication skills, but cannot typically communicate on complex levels. They may have difficulty in social situations and problems with social cues and judgment. These people can care for themselves, but might need more instruction and support than the typical person. Many can live in independent situations, but some still need the support of a group home. About 10% of those with intellectual disabilities fall into the moderate category.

A further category is severe intellectual disability with an Intelligence Quotient of about 20 to 34. Kraft and Kraft (1998) explain that individuals with severe intellectual disability have considerable delays in development. They understand speech, but have little ability to communicate and are able to learn daily routines. These individuals may learn very simple self-care, but to a larger extent needs direct supervision in social situations. Thompson (2000) found that only about 3 or 4% of those diagnosed with intellectual disability fall into the

severe category. These people can only communicate on the most basic levels. They cannot perform all self-care activities independently and need daily supervision and support. Most people in this category cannot successfully live an independent life and will need to live in a group home setting.

The final category is profound intellectual disability with an Intelligence Quotient of less than 20. Wood and Hewitt (1989) state that children with profound intellectual disability have significant developmental delays in all areas. They have obvious physical and congenital abnormalities and require close supervision, for example, attendant to help in self-care activities. They may respond to physical and social activities but certainly not capable of independent living.

Newman (2007) found that people with profound intellectual disability require round-the-clock support and care. They depend on others for all aspects of day-to-day life and have extremely limited communication ability. Frequently, people in this category have other physical limitations as well. About 1 to 2% of people with intellectual disabilities fall into this category.

2.2 SOCIAL-ECONOMIC CHALLENGES OF RAISING A CHILD WITH INTELLECTUALDISABILITY

The dream of each parent is to see that a child who is born grows up to be 'normal', productive and uses all his or her potential in life. Giving birth to a child with a disability maybe the beginning of another type of life in terms of child nurturing. Studies show that parents of intellectually disabled children miss a lot of opportunities which were to satisfy their personal needs such as enough sleep, leisure time and job opportunities (Heward, 2006)

Kraft and Kraft (1998) observes that parents of intellectually disabled children experience additional challenges as compared to parents of normal children in looking after these children. However, it is still unclear on whether the situation is the same in countries like Zambia. Dyson (1991) indicates only minimal differences in terms of challenges between parents of intellectually disabled children and those that do not have. Other studies done showed that challenges that parents of a child with intellectual disability and those without a child with intellectual disability cannot be so minimal because intellectual disability is a disorder which is qualitative in nature (it deals with emotions that are covert and not overt in nature). Hence, it leaves doubt to qualify challenges as minimal without any consideration to environmental, cultural, economic status and religious belief variations (Engle & Black, 2008). This shows that parents from rich economic status homes have higher chances of managing their children's challenges as compared to parents from low economic homes.

Makasa (1998) found that challenges faced by parents of children with intellectual disabilities in Zambia showed that generally parents lived a perfectly normal life and were responding positively to the presence of a disability (meaning that though parents were disappointed with the child's disability, they achieved satisfactory adjustment to their emotional and psychological well-being). The study included cultural variations, onset of the problem, and the degree of severity as some of the causal factors to perfect normal life on parents with disabled children. People with intellectual disabilities are frequently given low priority in government planning and policy development (Gombosi, 1998). Governments may fail to provide essential services to people with intellectual disabilities and their families in such areas as education and employment thereby perpetuating the devaluation of persons with intellectual disabilities, as well as the stigma, exclusion, and shame associated with the disability (World Bank, 2011). Less than 50% of low or middle income countries report

providing any support to families of children with intellectual and/or developmental disability in such areas as respite care, in-home support or advocacy.

Literature attests that intellectual disability has a great socio economic impact on the parents and the family. Dunn, Burbine and Bowers (2001) state that levels of parenting stress are highly pronounced in parents of children with intellectual disabilities as compared to parents of children with other disabilities like physical disabilities or health problem. Gordon (1993) intellectual disability has been known to be a major problem and very expensive. This cost comes in many forms such as emotional, social, finances towards transport, medications, and education.

According to Mac Dowell, Adams, and Word (1982) argue that both socially and physically, parents have failed to accept the handicapped child. This is so because a parent expects a normal child all the time and if such a misfortune befalls the family, it is a shock and instead parents waste much time finding out the cause. Due to this they hide their child from others denying him or her early intervention procedures. Parents will finally reject the child and concentrate on other siblings. This in itself is a problem created by unaccepting parents. Most parents find it a problem to adjust to the high demands of the child.

Chanzan and Laring (1982) further explained that this will create self-identification and the child will ask himself or herself a lot of questions which will remain unanswered. This will disturb the child's emotional power and if parents practice perfectionism which is love of the child without facing the reality of the handicap this may compound the problem even more. Parents should not ignore the handicap and exert undue pressure and expect high achievements from the child. These children are not expected to perform like able-bodied children.

Chanzan and Laring (1982) also wrote about social isolation by most parents with intellectually challenged children. Social isolation was not entirely due to rejection of the family by friends and neighbors, but was as a result of the parent's own attitudes. Negative attitudes by the community tend to compound the problem of the parents in managing intellectually challenged children. This lack of community support implies that, parents will fail to ask for assistance from the community and they will eventually lose self-confidence (Ganz, 2007). Community attitude therefore, matters a lot in as parenting an intellectually challenged child is concerned.

Wing (1971) also argues that ignorance and illiteracy also increase the number of problems due to the fact that education is important in the management of the intellectually challenged children. This implies that parents will be powerless to help the child because they lack skills and systematic methods of management of the condition. Due to illiteracy, it can be difficult for parents to secure competent professional help. The family usually has little or no knowledge of the condition of the intellectually challenged child. As such parents are unable to identify the needs of the intellectually challenged child.

Finne (1990) found out that lack of resources such as finances and materials help retard the progress of the management of the intellectually challenged children. Management of the intellectually challenged child requires a nice room of his own, fenced yard not too much in doors, no multi family dwelling and no overcrowding, but with lack of resources, it cannot be attained. Most families live far from hospitals or units where they can get advice on the management procedures of the intellectually challenged children.

Wing (1971) indicates that hospitals can diagnose and assess the intellectually challenged children so that schools can be provided for these children. However, distance deprives these children of hospital treatment and vocational units. Other problems include single parents

who usually are unsupported mothers. They happen to be found in a situation of low income and are overburdened with tasks of survival that they have neither the energy, nor, material resources necessary to participate in an intervention programme.

Dobson and Middleton, (1998) revealed challenges experienced by parents in different dimensions and estimated that the costs of parenting a disabled child are four times higher than those of parenting a child without any disability. Treatment is expensive, indirect costs are high also (Ganz, 2007). A study done in the United States of America postulated that for a child born in 2000, parents would spend an estimated average life time cost of \$3.66 million (over 14 million kwacha at the rate of K400 per US dollar on one person (Heiman, 2002). Sharpe (2007) further noted that, parents would spend about 10% for medical care, 30% extra on education and other care responsibilities and 60% lost economic productivity. Another related study by Finne (1990) found that intellectual disability is associated with higher probability that child care problems would greatly affect parental employment. Funjiura et al. (1994) also state that cost measurement analysis of intellectual disability on parents' services discovered that almost all the care for children with disabilities was provided by the parents and the family. Jarbrink, (2003) points out that this cost did not include materials like books, toys, computer games and other necessities. The researcher in this respect sought to explore the challenges that parents with intellectually disabled children in Zambia face and particularly found out how they cope with these economic challenges.

Other challenges which parents of children with intellectual disabilities may face are loss of social life and fun. Leisure activities such as participation in sports, clubs, weddings, picnics and attending family gatherings like funerals are affected. Parents are overburdened by the child's behavior such that parents have been reported to have committed suicide or have had depression leading to psychopathology. United Kingdom and Canada has seen such an increase in the number of these cases (Robert, 2002). Zambia may face the same stories,

though few of such stories reach media attention mainly in rural areas where superstitions and traditional beliefs are strong.

Bellington, McNally and McNally (2000) observe that there is adequate literature attributed to child costs, materials and social aspects of the children with intellectual disabilities and little or nothing at all is mentioned about how these parents cope with these socio economic challenges. It is against this background that the study sought to establish the challenges that parents of learners with intellectual disabilities face in the Zambian context and further ascertain how these parents cope with the socio economic burden of caring for these learners.

Parents may need both emotional and financial help to manage such problems. For example, in South Africa, a family and community motivator programme was put in place whose basic premises were to help the family to work with the community in early childhood development programmes. Most developed countries have financial benefits available to assist such families (Newman, 2007).

Literature indicates that when a child is diagnosed with intellectual disability, parents experience a range of emotional feelings, feelings of sadness, worry, denial, anger, embarrassment, fear, confusion, guilt, concern, resentment, and shock usually occur before a sense of acceptance enters their mind (Bellington, Fisman et al. 1989; McNally & McNally, 2000).

These states of affair make parents feel like they have lost the dream of their child. However, it is natural to go through the phase. Gombosi (1998) and Woods and Hewitt (1989) suggest that parents of children with intellectual disabilities face a unique set of challenges that impact on their psychological adjustment. Their lives are never the same. If married, then their marriage will never be the same; it will encounter more challenges and stress.

The birth of a child in a society normally brings joy to couples and the extended family and the community at large. Any strange happening in the family cause uncertainty in the family, mainly if it had to do with a disability. Superstition, finger pointing, witchcraft, blaming God, spouse, or past life activities come in. All such dominate parents' mind. During this period parents need to also adapt and adjust to daily routine as the child's disability take more of their time as compared to the normal child (Cosser, 2005). If this is not well handled; the child's disability can split the family.

When the child is diagnosed with intellectual disabilities, parents face another challenge of life-adjustment. At this stage anxiety maybe high and parents may feel shocked by the diagnosis. They may accuse themselves, members of the community, professionals and the Supreme God as the cause of the child's problem. They may start bargaining that the child will be fine if treatment is correct (Boushey, 2001). Parents' enthusiasm about the child's future slowly comes to be viewed with apprehensions as their thinking is now more about the past and the present than the future of the child; that he or she still has the potential of surviving. Such a feeling becomes worse if that is the only child in the family. A sense of immortality encloses parents and they may deny that the child has intellectual disability.

Literature indicates that when there is a child with a disability there is a degree of marital conflicts which comes aboard. (Blair, 1996; Osborne & Reeds, 2008). However, Blair (1996) and Fisman et al. (1989) suggest that parents with a disabled child had their marriage strengthened. Considering variations in literature on marital relationship between couples, it is important to carry out a study to find out if there are any challenges that couples go through or not. However, it could be speculated that their cultural and religious belief play a major role.

Donovan (1988) indicated that parents of children with intellectual challenges experience greater stress. For example, a child with intellectual challenge may not be able to express his or her basic wants or needs. The child's frustration can lead to aggressive or self-injurious behaviors that threaten their safety and the safety of other family members (e.g., siblings) since children with intellectual challenges have deficits in social skills, such as lack of appropriate playing habits. These act as sources of stressful events for families. Mothers may struggle on daily basis to get the children sleep, stop crying and running about in the house or eat a wider variety of foods. All of these deficits and behaviors are physically exhausting to parents and they emotionally drain them.

Literature further indicates that children with intellectual disability face a big challenge with communication skills; many children repeat the words and speech in form of an atonal voice (Rosenberg, Westling & Mcleskey, 2011). Due to poor communication skills, this leads children to also get isolated, discriminated against and to throw tantrums as a means of getting what they want in life. It is the duty of parents to teach children different ways of communication such as use of picture exchange, sign language and many other meaningful ways of communicating (Mash & Wolfe, 2003).

Boushey (2001) some professions may reinforce the denial and retard recovery by setting unrealistic goals and assurances. Osborne, McHugh, Saunders, and Reed, (2008) cited in Osborne (2009) explained that one obvious source of initial stress for parents of children with intellectual disability is the experience of seeking, and obtaining a diagnosis for their child with intellectual disability, and their contact and communication with professionals involved in this diagnostic process.

2.3 STRATEGIES THAT PARENTS OF INTELLECTUALLY DISABLED CHILDREN USE TO COPE WITH THE SITUATION

Families with a child who has special health care needs experience life differently than other families. Mothers appear to carry the larger burden of care and may feel a need to be with their child at all times and experience stress related to coping with the heavy load of care giving (Engle and Black, 2008).

For most parents, the birth of their child is a joyous time. Gray (2003) also wrote that nearly 4% of parents receive distressing news about their children's health. In fact, about every 3.5 minutes a parent is told that his or her child has a serious chronic medical illness, health defect, disability, sensory impairment, or intellectual disability. For these parents, the time of their child's birth may become a mixture of stress and despair (Barnett, D. et al. (2003). Parenting is a highly stressful job, and becoming a parent of a child with disability is one of the most stressful life events that can occur. Dyson (1991) stated that families with a child who has special health care needs to experience life differently than other families. Mothers are usually the primary caregivers of these children because most of them remain in the family environment during their treatment and they appear to carry the larger burden of care and they may feel a need to be with their child at all times so they experience stress related to coping with the heavy load of care giving (Thompson, 2000, James & Ashwill, 2007, Peters & Jackson, 2009).

Mothers may have to face immediate decisions about their child's medical care and treatment (Case-Smith, 2004). Moreover, mothers of children with disabilities cope with the same responsibilities and pressures that other mothers face. However, these mothers reported higher amounts of stress and they experience greater demands caring for a child with special needs. This sense of stress may be associated with a child's characteristics, greater financial

and care-giving demands, feelings of being unprepared for the tasks of parenting, and a sense of loneliness and isolation (Bolyai, Sullivan, Sadler & Knafl, 2003, Oruche & et al, 2012).

Coping involves psychological resources and coping strategies that help to eliminate, modify, or manage a stressful event or crisis situation. Having a child with intellectual disability creates a crisis event, how mothers respond to the stresses of raising their child with intellectual disability depends on a wide variety of factors influencing their ability to cope, such as their interpretation of the crisis event, the family's sources of support, community resources, and family structure. The personality characteristics of the family members, their financial status, educational level, problem-solving skills, and spirituality all influence a family's ability to cope. Strong marital relationship and social support also help determine mother adjustment (Emerson, 2003, Fazil, Wallace & Singh, 2004). The goal of coping strategies is to strengthen or maintain family resources, reduce the source of stress or negative emotions, and achieve a balance in family functioning. Strategies directly aimed at coping with the source of stress, such as problem solving and seeking information are more adaptive strategies than those efforts to deny or minimize the situation (Bailey & Smith, 2000).

More ever, the literature on the adaptation of families of children with special needs repeatedly indicates that it is important for service providers to understand family belief systems, both in a general sense and entity. Researchers document the importance of understanding families' worldviews, values and spiritual beliefs and day-to-day priorities and concerns (King et al, 2009). Because each family system is unique, each family may have different coping strategies. So professionals need to know what coping strategies are helping each family. One should not assume that any one specific strategy works well for all families. Professionals should identify family sources of support and promote the utilization of both formal and informal support systems. Furthermore, nurses who work with mothers who have

children with intellectual disability must understand how to assist the mothers in coping with their stressors. In order to accomplish this, nurses can help mothers realize their abilities and strengths, identify problems, develop problem-solving strategies, and identify new coping strategies (Hockenberry & Wilson, 2007, Woodgate, Aleah & Seccol, 2008).

The professional-parent relationship is also very important. While professionals may suggest ways to help a child with disabilities and offer information regarding the child's disability, mothers are the real experts on their child's like or dislikes and how they communicate. Mothers and professionals need to work together concerning their child's level of care, as well as individual and family needs. Professionals should also direct their attention towards what is helping the mothers cope with the added stressors of raising a child with special needs (King, et al, 2009, Sivberg, 2002).

2.4 VIEWS OF THE PARENTS WITH CHILDREN WITH INTELLECTUAL DISABILITIES HOW SOCIETY PERCEVES THEM.

Philosopher Martha Nussbaum (1997) has identified three capacities that are essential to the cultivation of humanity in today's world. The first is an ability to examine oneself and one's traditions critically. The second is an ability to see beyond some local region, group, or country. As Nussbaum suggested that "The world around us is inescapably international."(pp 97). To cultivate our humanity, we must try to understand the variety of ways different groups realize our common needs and aims. Finally, she suggested that the development of a "narrative imagination" or "the ability to think what it might be like to be in the shoes of a person different from oneself, to be an intelligent reader of that person's story, and to understand the emotions and wishes and desires that someone so placed might have" (pp 102) is the quintessential quality for the purposes of this discussion. It is only in recent years that

we have come to recognize that to appreciate the essence of an intellectual disability, we must try to identify with the lives as they are lived by people with an intellectual disability.

Historically, society's continued negative attitude towards persons with intellectual disability, as well as society's perception that such persons are not useful, leaves much to be desired. We move from a century that started with pride in scientific rationality and the triumph of logic over superstition to a century in which we should make all human beings part of our community of dialogue and concern, showing respect for the human. (Nussbaum, (1997). While Clegg's (1998) also argues that in looking at past events in present time, one should not simply organize a set of ideas into chronological order, it is useful to examine the way society has almost consistently demeaned the place of persons with an intellectual disability in society. There are, of course, a number of positive signs that may be a harbinger for the future emancipation of this group. However, as will be indicated, significant though these signs may be, they were still quite tenuous within the overall social, cultural, political, and economic milieu at the beginning of the twenty-first century.

Cliff Judge (1987) states that an early Australian leader in the field of intellectual disabilities, provides a useful framework in which to trace the evolution of community practices and attitudes toward this population. Judge has appropriately warned, however, that it is difficult to distinguish categorically one particular period in history from any other as a complex set of customs, social attitudes, and political imperatives. For example, infanticidal practices that were once found acceptable in an earlier period of history are still practiced in some communities today. Although we currently believe that community attitudes toward people with significant disabilities are more accommodating of diversity, religious prejudices, ethnic persecution, and discriminatory practices against minority groups are still manifested in all continents of the world. People with disabilities are more often than not a part of these minority groups. A Pre scientific Era Infanticide, a practice that dates back to antiquity,

typifies the fact that it is only in recent times that children have been seen to have a distinct place in society.

In India, Edwardraj, Mumtaj, Prasad, Kuruvilla and Jacob (2010) revealed that mothers particularly emphasized how negative societal attitudes impact their quality of life. The authors found that cultural and religious beliefs reinforced negative attitudes towards disability, with the result that mothers had little support from family, friends or society. One prevalent belief is that parents (particularly mothers) must have done something wrong in a past life, or during pregnancy to deserve having a child with disabilities. Even health workers believed that mothers must have done something wrong during pregnancy such as eating wrong foods and thus had less sympathy, believing the condition had been preventable.

In another Indian study, Peshwaria, Menon, Ganguly, Pillay and Gupta (1998) found that such self-blame and internalizing negative societal and familial comments affected mothers' coping abilities more than fathers. The investigators explained that this may be due to mothers' need to rely on others more for help in the community; thus, they feel it more personally when the child is rejected. These authors also noted that mothers found "faith in God" to be a huge facilitator in coping when other help was not forthcoming (i.e., from family or friends). The authors emphasized that negative societal attitudes can be psychologically damaging to Indian mothers, and that extended family may feel that the child's disability reflects badly on the whole family.

Peshwaria, Menon, Ganguly, Roy, Pillay and Gupta, (1998) in a study in Bangladesh revealed that although many mothers recognized the biomedical causes of disability on one level, many still attributed it to possession by ghosts, the activity of evil spirits, or a mistake during pregnancy. Many mothers held these competing beliefs simultaneously. In general though, the most common reported cause was maternal behavior, such as a sin or a fall at

some time during the pregnancy. One mother said: "... maybe I am doing something wrong, doing something to God, so he gave me this child. Then I also think that I am not doing any sin, I am being honest, but maybe in my unconscious mind I am sinning" (pp143). As for those mothers who believe in reincarnation, they were less likely to seek treatment for their child, as they saw the condition as temporary (Maloni, Despres, Habbous, Primmer, Slatten, Gibson, & Landry, 2010), confirming findings in a study by Donovan (1988). In addition, many mothers who did not believe in traditional treatments as much as biomedical ones still felt pressured to seek out traditional healers by elders in the household. They felt that they had to abide by the elders' or in-laws' wishes, incurring much cost for something the mothers themselves did not believe in. Finally, Maloni, et al. (2010) also demonstrated that negative societal attitudes can even cause Bangladeshi mothers to see their own disabled children as less human than other children, as evidenced by this mother's statement: "Every mother wants their child to be educated, grow up as human being. I also want it. I want it. I want my child to grow up as human being not as disabled" (pp 88).

In China, several researchers have found that it is not uncommon for mothers to hide children with disabilities in the house, especially during the early years, in order to "save face" (Lam & Mackenzie, 2002 as cited in Wang, Michaels, and Day, 2010). Some parents would send their children far away to rural areas, to be cared for by grandparents, to avoid stigma, and perhaps out of financial necessity (McCabe, 2007). Other mothers were fearful to send their children to school, due to fear of stigmatization (Liu, 2003 as cited in McCabe, 2007). McCabe (2007) also found that within families, there is often a feeling of shame accompanying a child with a disability, as it is seen as the result of something the parents, and often the mother (or her side of the family), have done, and thus they are blamed. The authors note that pessimism among Chinese parents (raising children with autism or other significant developmental disabilities) is greater than western levels, perhaps due to the fore

mentioned factor, Chinese society and mothers themselves have more negative attitudes towards those with severe intellectual disabilities than those with minor disabilities (Huang et al., 1998 as cited in Wang, Michaels, & Day, 2010).

In Africa, particularly Uganda which maybe a reflection of the Zambian situation, the investigators noted that negative societal attitudes manifested primarily as rejection of the child (by teachers and schools refusing admittance, by family members and by friends), and resulted in loneliness for the child and the mother (Hartley, Ojwang, Baguwemu, Ddamulira, & Chavuta, 2005). Several informants mentioned that some members of the community still believe that children with disabilities are “objects of shame,” and thus should be hidden. As for the disability’s cause, many parents attributed it to God’s will, witchcraft or angry ancestral spirits. In a study out of Nigeria, 35% of mothers attributed the cause of disability to evil spirits or witchcraft, while 10.4% believed in natural causes. (Abasiubong, Obeme, & Ekpo 2008).

It is, therefore, worthy exploring on whether similar challenges affect the parents of children with intellectual disability in Zambia.

CHAPTER THREE METHODOLOGY

3.0 Overview

The chapter represents the methodology that was employed in conducting the research in terms of research design, population, sample, sampling procedure, and instruments for data collection, data analysis and ethical consideration.

3.1. Research Design

The study used both qualitative and quantitative approaches or methods in which the case study research design was employed. A case study is a detailed analysis of a single person or group and its relationship to a phenomenon. Case studies are often done in the subject's real-world context, which gives researchers a good view of what they are really like. Documents, observations, and interviews can all be sources of information for a case study. This study however, was largely depended on qualitative method which enabled the researcher to collect in-depth information from parents and also the method was appropriate in that, people's feelings and perceptions are better captured using in-depth focus. One major reason for using both qualitative and quantitative methods is that the study has qualitative data, which involves looking in-depth at non-numerical data and also quantitative data which involves numbers.

3.2. Target Population

The target population consisted of parents with children with intellectual disabilities in Lusaka District and specifically those whose children go to University Teaching Hospital and Bauleni Special Schools.

3.3. Sample size

The sample was drawn from parents with children with intellectual disabilities in Lusaka district. The sample size consisted of sixty (60) parents with children with intellectual disabilities.

3.4. Sampling Procedure

The study used purposive sampling because the researcher considered the target population as convenient and who were likely to provide valuable information. The advantage of purposive sampling is that, it allows the researcher to concentrate on those people and generate valuable data for the research. In support of purposive sampling, Cohen and Manion (2000) argued that this strategy can benefit the research because some of these selected key informants have special knowledge and perception that can add value and richness to the research.

3.5. Instruments for data collection

The study used semi- structured interview schedule which enabled the researcher to have in-depth interviews with the participants. The interview schedule was designed to get information from fathers, mothers and guardians with open ended and closed questions.

3.6. Procedure for data collection

The researcher had an introductory letter from the University of Zambia. The researcher went ahead to interview the parents and collected valuable information relevant to the study. The interviews were conducted with the parents and guardians mainly as they were coming to pick up their children at lunch hour. A few interviews were conducted in the morning when parents and guardians were bringing their children to school. However, the morning arrangement for interviews could not work well because parents and guardians were in a

hurry to go and report for work. Others showed reluctance to be interviewed in the morning and preferred to be interviewed at midday as they came to pick up their children.

The collection of data dragged on for some time because it was a bit difficult to capture the required number of parents and guardians. This situation prompted the school administrators to propose the use of the open day. During the open day, almost all the parents and guardians were at the school and interviewing the parents and guardians was much easier and the required information was collected from the parents and guardians.

3.7. Data analysis

The qualitative data collected from the sixty (60) parents was analyzed using thematic analysis and quantitative data was analyzed using frequencies.

3.8. Ethical consideration

The researcher was sensitive to ethical issues and sought permission from the involved schools. He also sought permission from who would be involved parents to conduct the research. The researcher further avoided questions which could have caused psychological harm to the participants and assured participants of the confidentiality of the data.

3.9. Summary

This chapter presented the methodology that was used in the study. A qualitative research design was used to describe the challenges that parents face when parenting their children with intellectual challenges. Sixty (60) Parents and guardians participated in the study. They were selected through simple random and purposeful sampling procedures. The instrument for data collection was the interview schedule. Qualitative method was employed in the study and the data was analyzed thematically. Ethical issues were also taken into consideration.

4.0 Overview

The chapter presents the results of the study. The results are presented under headings derived from the objectives of the study. The objectives were to ascertain the socio-economic impact of raising a child with intellectual disability, to determine how parents of children with intellectual disabilities cope with these challenges and to establish the views of parents with children with intellectual disabilities on how society perceives them.

4.1 Social challenges of parenting a child with intellectual challenges

The study sought to find out the challenges that parents of intellectually challenged children face in their quest to raise them. This was done by interviewing the parents and guardians of intellectually challenged children who provided the valuable information. The general perspective of the findings on this aspect indicated that parents had social challenges of unacceptable behaviors of their children, worries of their future, complicated caring responsibilities, inability of the children to express their needs, high stigma associated to the disability, undue pressure exerted on the mothers from the family of the husband and parents were found to be experiencing conflicts with community members.

A number of participants when asked on the social aspect of their intellectually challenged children revealed having disturbing thoughts about living with intellectually challenged children. Out of the 60 parents and guardians interviewed 55 (91.7%) of them confirmed that they had social challenges with their children, while for those without serious social challenges were 5 (8.3%). The figure below indicates the distribution of the percentages.

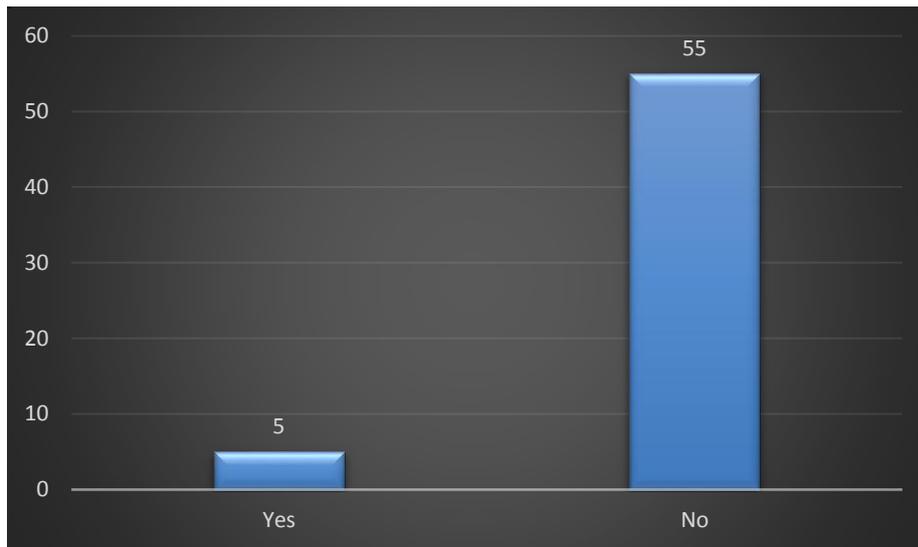


Figure 1. Social challenges of parenting a child with intellectual disabilities.

A father aged 38 of Woodlands of an intellectually disabled son aged 10 explained that:

It is very true, it's a challenge for us, there is a problem because the way he, is you can clearly see that he completely does not fit in the community. His actions are different and, of course, not accepted by other people. For example, if you look at the appearance of my own child you may think he is just okay. But his actions are so disgusting that you can't go with him anywhere; to church or so, he just has to remain at home, it's really a problem.

During the interviews, it was also revealed that parents had serious worries about the future life of the children. This was a disturbing thought that some parents experienced due to the inability of the child to accomplish personal and social needs such as self-care and education. They showed these concerns if their child could not do certain developmental tasks expected at specific ages such as feeding, toileting, bathing, and dressing, as expressed by one mother aged 26 of Kabwata flats whose son is aged 9 said:

Truly, what I am afraid of is that it will be more difficult later in life. This is what makes me fail to sleep all the days, I keep thinking only about that and my husband and i quarrel about that every day. Just imagine, now when she grows up it will become a very big task, it will really become a big task and this is a big test.

It was further revealed that parents were disturbed by the complexity of caring responsibilities that demanded a lot of work and being available most of the time to meet the daily needs of the child. The issues about how to handle the child and ensure security if the parent died was expressed by majority mothers of intellectually disabled children. The following are the quotes from mothers aged 33 and 25 respectively who expressed their feelings when asked about the social life of their children aged 11 and 8 respectively had this to say:

Until now I don't know how my child's condition will be, if let's say I die. This is because I don't have any sister, mother, or father who can take care of my child in that condition, let's say I die now; I don't think she will be in a better condition...

One mother in Bauleni Compound said;

I accept to be meek and gentle because I know it is God who has intended for the matter to be like this, but it's a big burden and challenge to me because this child is always restless. He cannot even sit down with others for a minute; he likes seeing himself wandering even in people's homes and then feel good. So in the process of wandering one would get lost, and there we are staying near the road and you know what it means to stay near the road, you have to keep vigil on the children even those that are fine. For this one, it is worse

because he moves anyhow and that places more pressure on us to ensure that there is always someone to take care of the child. Therefore as mother I don't do anything other than looking after this child all the days of his life for many years now, and we don't know what will happen in the future.

Another mother in Kamwala South.

Findings of the study also indicated that living with an intellectually challenged child was described as emotionally distressful by parents and varying degrees of emotional distress were experienced which included having feelings of sadness and inner pain or bitterness. Parents experienced these negative emotions due to disturbing behavior of the children, extra care-giving responsibilities, family and social problems caused by the child, and people's perception about families having an intellectually disabled child. A sad male guardian of Thorn Park aged 41 parenting a boy aged 10 explained:

I really somehow grieve, I just accepted it (taking care of an intellectually challenged child), but I really grieve because I suffer a lot from this child and when I look at this child with a disability and the challenges of taking care of him particularly the disparaging remarks from the community at large. Some people are too hard on an innocent sick child. This makes me grieve.

When further asked on the social aspect of the child, parents described living with or having an intellectually disabled child as a disturbing and yet unavoidable situation. They had to accept it since they had no other alternative. They viewed their caring duties for the children as very difficult and distressing. This was stated by some parents and guardians when they were explaining on the social impact of their children. One father aged 34 of a daughter aged 8 of Libala said:

Really I have accepted it because I have already been given this responsibility, but it's a big task, it's a very big task to care for a child with intellectual disability.

The interviews with parents and guardians also revealed that the inability of the children to express their needs was another source of psychological and emotional distress associated with living with intellectually challenged children. This causes parents to be unable to understand the child especially when he or she had problems, sometimes when the child goes out, he or she is mistreated by other people because of poor communication with members of the public and returns home crying and he or she will not be able to explain what happened.

One female guardian aged 48 of a girl aged 13 in NyumbaYanga emphasized that:

Yes, we have been injured, but God has already planned it for me, and I have no any other way. The challenge I face is that the child cannot express his needs. Sometimes he may be sick and you don't know, he just cries, when he has problems he just ends up crying. Now you don't know why he is crying, and sometimes when you touch him and feel that he is hot then you may guess that this could be malaria and take him to hospital. But when he has like stomach ache you can't understand, you just see him crying

The study also revealed that having a child with intellectual disabilities is usually associated with stigma. Parents were troubled by the intellectually disabled child being mistreated, discriminated against, and segregated against in the community. Sometimes the child was told words that made him or her feel bad. Parents were laughed at and told bad things about the child. The children were mistreated by people in various ways. Sometimes they were labeled and made fun of in the community, considered to be useless and even rejected by the parent because of the disability especially some fathers who did not want to support the

children and considered separation or divorce to be a solution to this problem. One mother aged 26 of daughter aged 7 of Mtendere explained:

We as parents, we are sometimes held responsible for the child's behavior. We are thought to be spoiling the child by not being strict enough when the child is behaving strangely.

Furthermore, the interviews conducted with the parents showed that they had been accused of causing the children to become intellectually disabled as a means of trying to get rich and becoming successful in life. A seemingly stressed father aged 44 of a son aged 14 of Sikanze camp explained with sadness that:

My brother, according to the prevailing situation when people see those children the majority of them say we have caused them to become sick as way of getting money and becoming successful in life which is not true because this is sickness which can come at any time to anybody.

When further asked about family life and the presence of a child with intellectual disability in the family, many mothers complained of undue pressure from the husbands and even a lot of pressure been exerted on the mothers from the family side of the husbands. A mother aged 28 of a 10 years old daughter of Ibex Hill lamented and had this to say:

This child has made my husband to divorce me. Now the burden of care is upon me. The father doesn't love her (the child) very much. Sometimes you may tell him that you have a problem with the child and he will tell you to just wait. Now that's just like totally not being involved in the care of the child.

Besides that, majority parents and guardians during the interviews conducted when asked about the social life of their children expressed high emotions and explained that, it was a very challenging task to see how the child was not showing correct behavior when socializing in the community and majority parents and guardians suffered a considerable degree of embarrassment due to inappropriate behavior exhibited by the child. Another mother aged 31 of a 9 years old son of new Kasama lamented that:

Taking a child with intellectual challenges out in public places, for instance, Shopping Malls can be a source of a big challenge to parents. People may stare, make comments or fail to understand any mishaps of behaviors that may occur. For example, a child with intellectual challenges has potential to take a stranger's food right off their plate. As a result of these potential experiences, I often feel uncomfortable taking my child to the homes of friends or relatives. This makes holidays a difficult time for me. As such may experience a sense of isolation from friends, relatives and community

Parents and guardians explained that these were their worst experiences ever because these incidences made them get affected so much that they were affected even in other daily activities because of the behavior of the child. This is what one parent had to say:

Last year I went for a Kitchen party and he was running around getting people's drinks. It was so embarrassing. Worse still some women took me aside and rebuked me that I had let him get spoilt like that. I was so devastated so much and cried. It was too bad that I don't even like talking about it. I also remember one time in an eating place. One family left because they felt offended. He loves phones and one time at Arcades Shopping Mall he rushed at someone and grabbed his phone fortunately it was someone we knew.

Otherwise with other people are helpful and have been able to help him. Then humiliation from people when you go somewhere and you find a group of people they start asking; what is wrong with this child? Some start laughing and say we have spoilt the child. It's painful.

Parents further complained of humiliation from the society due to the child's behavior and majority of them also highly complained of abuse of the sick children. Therefore, it was noted that these children were at risk of being physically and sexually abused such as being burned or raped as explained in the following comments by 26 years old mother of 8 years old son

For example, one day I left my child with the house girl. She dared to take the spoon that she was using for frying and applied it on the child's skin. When I came back I found the child with marks of wounds on the body. It is a challenge for me because it is not possible to go with the child wherever am to go. There have also been incidents of attempted rape on the child. I don't know maybe she has been abused already (shedding tears).

Libala resident

One day I woke up early and went into town leaving my child still asleep with instructions to the siblings to take care of her. When the child woke up, she strayed in the compound and nearby man was seen attempting to do a very bad thing to her. We really need to be very close to these children. The issue of being raped makes us to be with them so that they don't suffer such actions, and it makes us not to have peace almost all the time particularly when you leave the child in someone's custody.

Another mother of Chilenje

The study also revealed that many parents and guardians had each a different and touching story about taking care of a child with intellectual disability because there was so much to cushion and to withstand as a parent or guardian. One guardian aged 40 of an 8 years boy of Bauleni compound complained that:

It is worse when you visit other people's homes, when you go to church, they invite you for a wedding, or some parties then just at that moment he would behave in a way that is inappropriate and heart breaking in the eyes of many; people would turn, "What is wrong with the child, what have you done to him", "no give him what he wants" but then you don't know what he wants. So sometimes, we have to let some functions pass without going there.

The findings also revealed that parents also were found to be experiencing conflicts in the community and sometimes were even accused of negligence when the child destroyed somebody's property. Many parents and guardians complained very much on this matter. This created tension and resulted in lack of peace especially with people like neighbors. Below is a summary of what of one male parent aged 38 of 11 years old boy of Kalingalinga compound had to say:

I feel not having another child because I fear I may have another child with the same condition and create more problems for myself.

4.2 Marital challenges as a result of the presence of a child with intellectual challenge

The study sought to find out the effects of the intellectually challenged children on the married couples.

Findings indicated that the social life of parents was found to be disrupted by the presence of an intellectually challenged child in the family. Forty five (75%) of the 60 parents and guardians in this study said they were greatly affected with the presence of child with such a condition in the family. Some men had to go on separation, and others divorced their wives. Ten (16.66%) of the 60 parents and guardians said the presence of the children with such conditions strengthened and cemented their marriages and five (8.33%) of the 60 parents were single parents and could not have any marital challenges.

Below is a bar chart that shows percentages on how the presence of intellectually disabled children affected marriages.

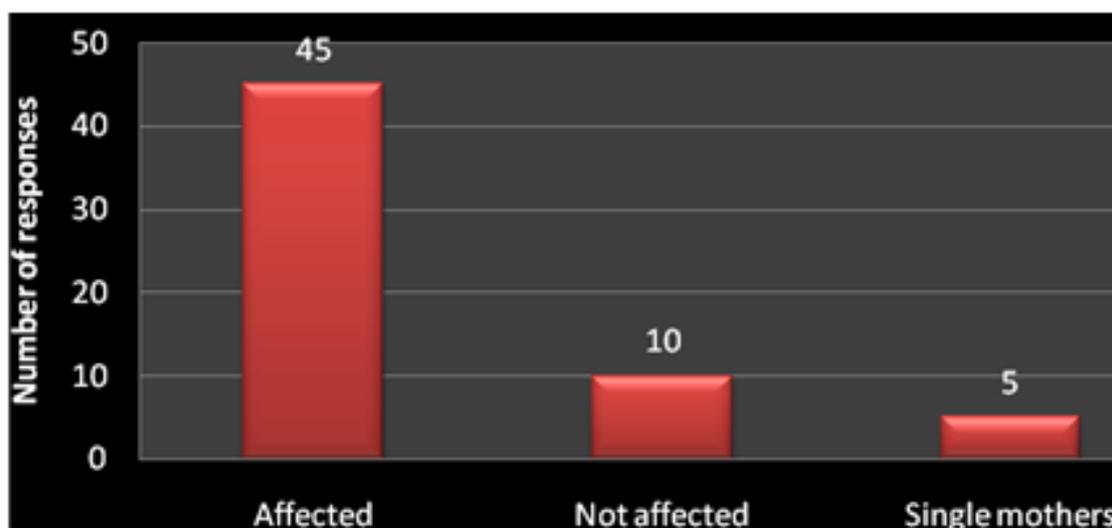


Figure 2. Marital challenges due to having a child with intellectual disabilities.

When asked about marital problems as a result of the presence of a child with intellectual disability, many parents revealed during interviews that they had problems emanating from the conditions of the children. Mothers were normally at the receiving end and suffered more.

Parents also revealed that the most common cause of conflict was related to the extreme demands on time and energy that the children with intellectual challenges made on parents.

This gave parents little or no time to spend as a couple. Participants also reported that their

partners (particularly mothers) felt the responsibility to take care of the children was not solely theirs but a shared task by both partners and spent time attending to the needs of the children with intellectual disability. Parents and guardians expressed their perceived impact on the marital relationship as follows:

i. Most fathers did not want to have another child especially those that were still in a stable marriage, they were afraid of having another child with intellectual disability.

ii. Mothers wanted to give the best to the intellectually challenged child in terms of financial resources.

iii. A total of four (4) husbands, on the other hand, thought that the child's condition had to do with the wife's parents background as a result confusion ensued in their homes.

iv. Wives believed that their husbands did not fully accept the child's condition.

4.3 Effects of having an intellectually challenged child in the family on the siblings.

The study in the above theme sought to find out how intellectually challenged children impact on the siblings

In the interviews conducted, majority parents and guardians had some difficulties in child caring which also affected their family. Parents' and guardians' joy suddenly turned into fear, concern, worry, and despair on the children' condition as the children could not do other activities as anticipated by a normal child. This brought stress, negative emotions which even affected their siblings. One father aged 37 of son aged 9 residing in Chawama when asked on how the child was impacting on the family commented in this way:

I was so excited to have a baby boy whom I thought was going to be the pillar in the family, but suddenly the child's diagnosis of

intellectual disability and its eventual behavior brought some emotional reactions to the entire family.

However, some parents and guardians revealed that, despite the negative behavior shown by the child and witnessed by the siblings, there was certainty that their brother or sister will one day be fine. On the other hand, when the siblings were told about the diagnosis, all siblings reported signs of hope for their brother or sister. Few normal children showed sadness or depression towards their intellectually disabled sibling. Despite this, most children could still ask their parents soon after returning from the hospital on whether the doctor had said that their brother or sister would talk again. One male parent expressed concern on the siblings aged 16 and 14 respectively who complained of getting tired playing and looking after their brother who needed attention each minute.

One couple expressed concern about the aggressive behaviour or bullying that their child with intellectual disability demonstrated towards a much younger sibling. They narrated how it was reported to them on how the step-brother could beat their child with intellectual disability every time they were playing. In this report only one mother confessed having never asked the children on how they felt about their sister.

4.4 Economic challenges of parenting a child with intellectual challenges

The study sought to find out the economic challenges that come along when parenting intellectually challenged children

As regards to economic factors, out of the 60 parents and guardians interviewed, 50 (83.33%) of them complained of economic constraints as a result of additional demands of taking care of an intellectually challenged child. Only 10 (16.66%) parents did not express any problems as a result of financial constraints of taking care of an intellectually disabled child. Therefore,

majority of the parents and guardians complained that taking care of a child with intellectual challenges demands for more resources. Below is a column chart showing the percentages.

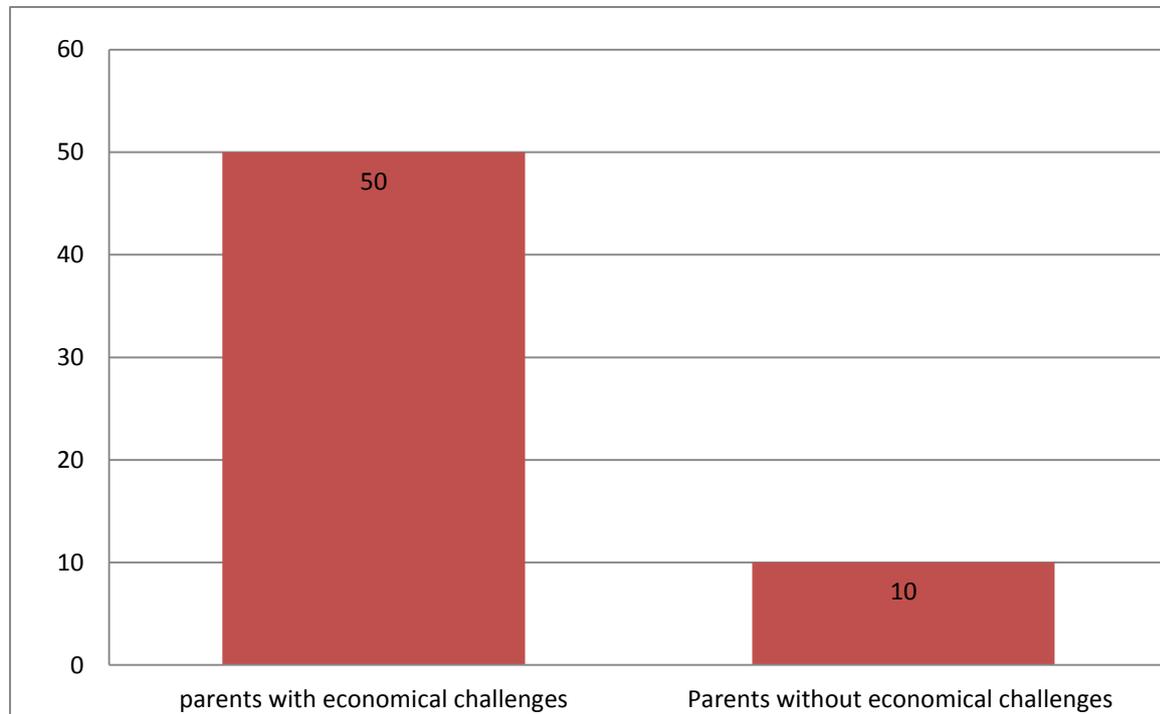


Figure 3. Whether parents have economic challenges.

One parent when asked about financial constraints of taking care of an intellectually disabled child complained of not meeting the daily needs of the child. The mother who seemed most affected narrated that:

I have to take the child to and from school, board the bus every day to ensure that the child does not just sit at home and this involves money and am not working. The little money which i make out of the sale of tomatoes is all used by one child because he has to go to school so that am also given chance to do other things when he is still at school.

The findings also showed that daily life and activities of parents in this study were very much affected by the presence of an intellectually disabled child. Much time was spent looking

after the child and as a result they were not able to do other important activities such as business activities. Income generation in families was affected and this further escalated family poverty as explained by one father aged 34 of a daughter aged 12 and a resident of State Lodge. Another mother aged 24 of son aged 8 residing in Kalingalinga when also asked on whether she had financial difficulties or not, the mother had this to say:

Care responsibilities for such children are very cumbersome; you need to stay with them for a very long time so that you watch over them from morning till evening. Your activities will be limited only to the home environment; you can't go out for activities to earn a living apart from being home. From the time the child was born and diagnosed with this sickness, my life has completely changed because I no longer have time to do businesses as I used to do before and this poses a challenge on me and the entire family.

Further, revelation by study was that Poverty was cited by parents and guardians as being responsible for their inability to meet certain important needs of the intellectually disabled children. Some mothers were completely house wives who did not have any means of earning income and depended solely on their partners; those who did not have partners expected to get help from other people, especially relatives. This was a problem if they could not get the help they needed. They (including fathers) could not manage buying drugs for their children when they did not receive drugs at the hospital. They also could not afford bus fare to go the clinic with their children on the day of their appointment. One mother aged 33 of Katungu area had this to say:

As a single mother, with one small salary, it's rough and tough going. At times you know, I feel like giving up my life but again, I fear on who will care for my children if I kill myself taking care of an

intellectually challenged child demands more than what people see. My child becomes sick regularly and when I take him to the hospital, you may find that you get only one type of drugs while you have a prescription of two or three drugs. If you go to a (private) Pharmacy you find that the drugs are very expensive beyond my reach. Now with our income in this situation; house rent, water bills, everything, transport charges, At one time, I reached a point where I once spoke with my own mouth, and may God forgive me, that instead of giving me these problems he should have taken him (the child), I reached that point. (Shedding tears)

As you can see, I am a widow who just lost my husband, a mother of two children including this one, then my job is demanding. I've to go to school, take care of him and my other daughter too, I need money for their school tuitions, transport and packed meals for their school, and then I have to think of house rentals which are ever increasing each day.

Another mother of Chilenje South

Findings further indicated that single parents had a greater challenge of caring for the child with intellectual disability as compared to married couples. This was observed during interviews and how emotional they could be when they thought of their children and challenges they faced. A single mother, who was, a worker, student, and also a widow with another sibling, reported that:

Life is rough as i have to meet financial costs of my education as a self-sponsored student, tuition fees for my grade 12 daughter daily transport (booking taxi) to take my intellectually disabled child to school, house rentals, and my demanding job as billing officer where I

need to be in the field most of the times-away from home makes it extremely hard for me to manage all these matters.

The data collected revealed that parents of children with intellectual disability suffered a lot of financial loss which were in form of transport, hospital bills, buying of toys, and food since some children were found to be selective to food stuffs. Other financial constraints came about due to destroying of items by the child for both the home and other people. One father when asked on financial matters and the child with intellectual disability had this to say:

My friend, we have spent a lot of money that unfortunately we don't count. It's not that one day we want to claim the money we have spent, but what I know is that we have spent a lot. Just to give you a picture, from the time she was born, she likes eating chicken most of the time. If you fail to provide what she wants, she becomes angry and may even throw tantrums and refuses to eat. So you can imagine how much money we spend just on her food, then there is also providing for the other children in the home. But I don't look at that; I look at the future of the girl. I would do anything for her to be independent.

During interviews conducted with parents it also came to light that a total of eight (8) parents stopped working in order to care for their children; one parent lost the job twice for taking more time caring for the child. One parent (mother) further complained that she could not find a job because no one could take care of her child and said:

I encountered challenges in keeping maids as they cannot cope with the child's behavior hence stopping working. The child's condition

has prevented me from finding formal employment and this has also restricted my hours or type of employment or work to do.

During interviews with parents, findings also showed that the burden of caring for the intellectually challenged child was found to be mainly borne by the mother. Mothers complained about the role that fathers played in everyday care of the child. They expressed that some fathers were willing to support the children financially and others did not care at all. The grandmother who was taking care of the child with intellectual disability whose mother was dead commented that:

Now the burden of care is upon me. The father doesn't love her (the child) very much. Sometimes you may tell him that you have a problem with the child and you need money, he will tell you to just wait. Now that's just like totally not being involved in the care of the child.

4.5 Views of parents with children with intellectual disabilities on how society perceives them.

The findings on the views of parents and guardians on how society perceives them varied from parent to parent. Forty (66.66%) out of 60 parents and guardians indicated having minor problems with the community. Twelve (20%) out of the 60 parents and guardians indicated that their children had caused problems in the community hence attracting some negative reactions from the members of the community. Eight (13.33%) out of the 60 parents indicated that, they had serious problems with the community and that; they were receiving and suffering disparaging remarks from the community. Below is a Bar Chart showing percentages.

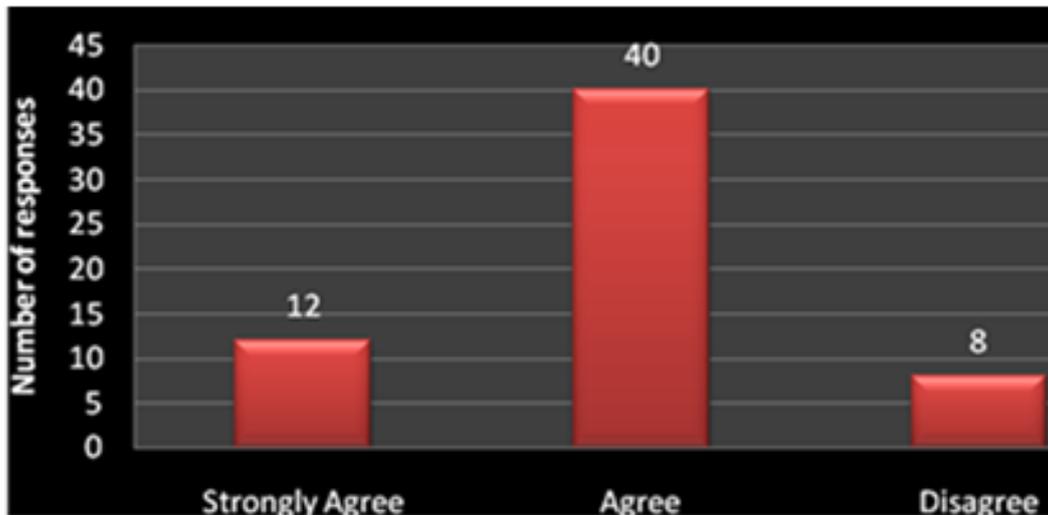


Figure 4. Whether society has poor perception towards Intellectual disabilities.

When asked on how community perceived them as parents to intellectually disabled children, one mother who seemed very much affected by the comments of members of the community had this to say:

We avoid social contact of our child with other members due to the child routine behavior which members of the community say they detest. As Parents, slowly we started counting the social benefits of letting him going out or remaining home.

Another father lamented also and said that:

My son sometimes just opens the gate and goes outside. If you don't notice quickly, he can be there as long as he wants. Each time he does that, people always mock and laugh at him. Some say parents for this child are very bad and have failed to care for the child.

On a happy note, one guardian said that the community negative perception and harassment had helped him and the child, and said:

Labeling of my child with intellectual disabilities to me has brought a relief, as am now able to look for the child's services such as education, occupation and other forms of services which can benefit the child.

A single mother when asked whether her child was able to play and socialize with other children in the community, she also bitterly complained of the society behavior towards her child and said:

Teasing from other people makes me sad more especially that people seemingly have not understood the condition of my child. Because of that, my child is not able to play with children of his age. The stigma is so rife in my case and my family has suffered considerable isolation by the community. It makes me cry sometimes because people should understand that, my child did not acquire the condition deliberately, it was something beyond our control and that they should know that such a condition can happen to anybody. It's really painful to find yourself in such a stressful situation. The father has abandoned me and the child and am all by myself to cushion all these challenges.

One guardian expressed her dismay at the way community members who tend to be rough at them as guardians of intellectually disabled children and had this to say:

There was one time when I went to intercity bus terminus with him and he was so hyper active that he went touching peoples' handbags and even attempting to open them. Then one woman came and blasted at me saying, "is this (Devil) child yours, he came from that womb" then I broke down and cried and started shouting at her. However, I appreciated one man who helped to calm down the incest

travelers and also comforted me. So you can see how members of the public can be rough and uncompromising because of the sick and innocent child. Some comments from the people suggest that, we as parents might be responsible for the condition of the child because of the love of money. What this meant I do not know?

4.6 How parents of intellectually challenged children cope with parenting their children

The study sought to find out how parents of intellectually challenged children were managing the conditions of their children.

This theme concerns ways in which parents cope with the situation of having an intellectually challenged children in the families. The term strategies in this research are defined as ways, methods and approaches which parents use to care for their children. When asked on the coping strategies, respondents explained that it was difficult to totally accept the child's condition, as each day had its own problems and challenges. The challenges were further compounded by non-availability of trained counselors to equip them on stress management and coping strategies.

During interviews conducted parents expressed various ways they used in order to address the challenges they were facing by living with children with intellectual challenges. Findings of the study revealed that a variety of coping mechanisms were employed in different situations depending on what seemed to be helpful to the parents. They sought professional and spiritual help (from religion and traditional healers).

Some parents during the interviews attributed their coping strategy to empowerment. Many mothers further said that they managed their challenges and problems by talking about the child's conditions to other members of the public. Knowledge exchange with other parents who were in a similar position greatly helped them. Both fathers and mothers said they dealt

with challenges as they came (living in the moment and taking one day at a time was their ideology). Planning for the future or planning ahead of the child greatly helped them to cope with the situation. When asked on the same matter, one parent said:

It is the hospital, it's the hospital that has helped her (the child) to be honest. If it was not for the hospital her condition would have been worse. I have done everything I could; I have not stopped going to the hospital since she began having the problem. It is 11 years now she is on medication.

The interviews also revealed that other measures parents took included training the child to do what she or he could not do such as toilet training and speaking, involving other family members such as siblings in the care of the child, and seeking information about the child's disorder from sources like the internet. Due to the nature of the disorder and the behavior displayed by some children, some parents, guardians, and caregivers tried to control the children's environment for safety reasons.

During interviews parents and guardians disclosed that comfort from friends was very helpful. Some parents found comfort through friends who now understood their challenges and the children's conditions. When asked on the coping strategies, one guardian explained and said that:

Good friends who can show empathy with you help in reducing stress. We have our childhood friends who have been encouraging us from the time the child was found with this problem and we talk about our problems. Generally friends have been there for us through out.

Interviews conducted with parents further indicated that parents derived comfort from God. They found more comfort in religious belief. This is a belief that you need to accept a gift from God regardless of the Childs' condition. Majority of the participants claimed to be Christians and have faith in God. Their strong belief is that one day their children would be fine and a solution will be found. One parent explained that:

Knowing God and believing in him has brought a lot of comfort, especially that the Bible says when God gives you something he never adds sorrows, it's a gift from God. I believe it's just time and definitely things are going to change for the better.

Parents during the interviews also indicated that they drew strength from the fact that, intellectual disability is not a killer disease but is just a condition and that there was no need to stigmatize the children who have the condition or indeed their parents. One parent made a further comment and said:

It's just a name intellectual disability so don't look at that, all you have to always look at is a boy who can do anything. Intellectual disability is just a word which is supposed to be brushed aside and look at the positive aspect of the child and how you can help him.

During interviews it was also noted that love for intellectually disabled children also played a role in helping the parents. Majority parents and guardians explained that their love for the intellectually disabled children played a major role in the parents' management of the children. When one parent was asked on how she really copes with living with an intellectually disabled child, she had this to say:

The ever present love for the child gives me strength. As a parent when you develop love for the child in spite of his or her condition, it

helps to come to terms with the unpleasant situation you are faced with.

The study revealed extra care giving as a strategy that parents use and which is employed to take care of daily activities for intellectually disabled children. Each child needs parental care from the attachment figure mainly the primary care giver. If the care is not enough, children may be affected and be insecure. Even the disorganized insecure child needs parental care to help him or her change for the better. Parents and guardians in this study indicated the use of many strategies to cope up with ways of child care. One mother explained that:

I wake up earlier than my child and prepare food for him and other children so that they eat. I bath them, which they love and take them to school. During the day, when they come back from school, my boy enjoys watching cartoons and we have provided the facility for him and the rest of the children in the house. By 20:30, they are tired and I have to sleep with them and that is when they rest. My day is programmed so I'm up by 4 a.m. to make snacks and when they are up they go to school. Only we have a bit of a problem on meal times, yes. When he's very hungry, he would sit and concentrate and eat on his own. But if he's not, you have to like guide him, force him to eat but then he would be running around, he would pick one thing, goes eats, stops eating it would take maybe an hour and a half for him to finish, and especially when he's with the father. Otherwise bathing time, he enjoys bathing very much so we never have problems with bathing. Sleeping times like I mentioned earlier, sometimes he doesn't sleep early he takes a long time, especially given the job that I do, that requires me to be reporting early becomes a challenge because I have less resting time.

Another important coping strategy revealed by the parents is that of accepting the child's condition which helps them to be sensitive to their child's welfare and understanding what is right or wrong for their child. Parents also used humor, self-appraisal, openness to the society, seeing other children who have more challenges than their child, and the belief in God. This gives parents a sense of empowerment. One parent attributed his resilience to his job as a watchman which demands to be strong as a way of coping with challenges. Other Parents also said slowly accepting societal criticism and stigmatization towards their child was helping them to cope with challenges of raising a child with intellectual disabilities.

4.7 Summary

The foregoing chapter encompassed the socio-economic challenges that parents of intellectually challenged children go through such as social stigma, worries about the future of the children, emotional distress on the parents and guardians, the inability of the children to express themselves, accusations from society that parents and guardians caused the condition and the unacceptable behavior of the children in the community as this caused conflicts with parents and the communities at large. The presence of intellectually challenged children in homes in some cases caused marital differences resulting in separations and divorces. Economically the daily life and income generating activities of the parents and guardians were adversely affected. The parents and guardians complained of teasing by the community which they deemed as negative perception and harassment. In terms of coping strategies, parents sought spiritual help, training of the children, comfort from friends and carefully planning for the children.

CHAPTER FIVE DISCUSSION OF THE FINDINGS

5.0 Overview

This chapter focuses on the discussion of the findings of the study in line with the objectives which were to; To ascertain the socio-economic impact of raising a child with intellectual disability, To determine how parents of children with intellectual disabilities cope with these challenges and to establish the views of parents with children with intellectual disabilities on how society perceives them. The order of the discussion follows the order in which the findings have been presented in the previous chapter.

The findings of this study revealed various psychological, social and economic challenges that parents experienced in living with intellectually challenged children. Some of the key themes found in the reviewed literature with respect to experiences and needs of families of individuals with intellectual challenges also emerged in this study

5.1 Social challenges of parenting a child with intellectual challenges

Caring for a child with intellectual challenges was found to be associated with many social challenges. Social services, stigma, and caring responsibilities were areas which posed major challenges and concerns for parents. Other important issues included a lack of public awareness, social support, and social life.

First and foremost, acceptance by the parents that they have a child with such a condition is a challenge for them. It is cardinal to comprehend that parents find it difficult to come to terms with the news that they have a child who is intellectually disabled and to accept the condition of the child. It was also noted that some parents may give love to this child more than any of their siblings as in over-protection and vice-versa. They may hate and reject the child altogether as in rejection as exhibited by some fathers who could not support the child and

even sought divorce with their wives. This finding is in agreement with Mac Dowell, Adam and Word (1982) who found that both socially and physically, parents have failed to accept the handicapped child. This is so because a parent expects a normal child all the time and if such a misfortune befalls the family, it is a shock and instead parents waste much time finding out the cause. Due to this they hide their child from others denying him or her intervention procedures. Parents will finally reject the child and concentrate on other siblings. This in itself is a problem created by unaccepting parents. Most parents find it a problem to adjust to the shape demands of the child.

During this study, it was revealed that most parents and guardians of intellectually disabled children develop a feeling that they are being pushed towards isolation. However, not all parents and guardians say or think that they feel isolated by virtue of having produced or keeping an intellectually disabled child citing that social isolation was not entirely due to rejection of the family by friends and neighbors, but was as a result of the parents and guardians own attitudes. Whatever reason, these parents and guardians are made by the members of the communities to feel different and they find that people in society do not or seem not to understand the difficulties they are going through. This isolation comes partly from other people's attitudes through their ignorance which leads to fear and may form a powerful barrier. This finding mirrors that of Robert (2002) who points out that parents were finding it difficult to manage their ill children because of stigma and discrimination that was practiced by the members of the public.

Additionally the family becomes stigmatized because of the presence of an intellectually challenged child in their home. Parents and guardians put in some amount of both physical and emotional energy into caring for the child during the night and the day. Whoever looks at the family, the family feels or thinks that person is talking or laughing at its child. In view of this fact, both the family and the intellectually disabled child may withdraw from public and

remain aloof. This is in agreement with Chanzan and Laring (1982) who state that negative attitudes by the community tend to compound the problem of parents and guardians in managing intellectually disabled children. This lack of community support implies that parents and guardians fail to ask for assistance from the community and they eventually lose self-confidence.

Furthermore, findings in this study indicated that some parents and guardians worry so much about the child's behavior both at home and particularly at school. With notable despair in their speeches or conversations, they wonder whether their children are unique. The parents go into revulsion which is a feeling that comes later after anger which some parents experience. Most parents of intellectually disabled children feel guilt at having produced a child with such a condition or at having been so negligent as to have allowed a child to acquire the condition. This finding is in agreement with Hewett and Forness (1984) who found that some parents with such children who may not learn to understand any instruction given to their children withdraw from public fearing how much information or explanations should be given in order to keep their intellectually challenged child alive or along with his or her peers. The problem comes mainly because some of the parents are unwilling to discuss their children with other parents and determine why their child is not able to do what other age mates to the child can do.

Inadequate social services for children with intellectual disabilities are the most challenging issues for parents. They were concerned about education for the child and to a lesser degree hospital care. This concern by the parents was consistent with Kraft and Kraft (1998) who state that the most distressing aspect was inability of the child to acquire education like any other child due to the condition. In the initial stage, parents spent a lot of time looking for schools that could accommodate the child.

The study revealed behavior problems which many parents found difficult to handle. Behavior problems like screaming, crying, inability to concentrate, aggressiveness, stubbornness which a child with intellectual disability might have. For parents, especially mothers, who have to take care of household tasks and work apart from taking care of the child, patience can wear thin and parents may get angry with him or her. Often, the child might not understand how disruptive his or her behavior is to others and why parents or guardians get angry. As rightly put by Heward (2006) who stated that parents expressed being stressed by the explicit behavior of the child that caused problems not only for the parents and guardians but also to people nearby such as neighbors. Behaviors of the children that were of particular concern to parents and as already cited were aggressiveness, destructive, restless or hyperactive, making noise, and lack of proper eating skills.

One of the main concerns of parents with intellectually disabled children is about how their children will be taken care of when they die. They feel that no one else can take care of their child with same love and care that they have and they are scared about how their child will manage to survive in the world. One parent had this to say:

Until now I don't know how my child's condition will be if, let's say I die. This is because I don't have any sister, mother, or father who can take care of my child in that condition, let's say I die now; I don't think she will be in a better condition.

The above finding was as pointed out by Boushey (2001) who found out that parents' enthusiasm about the child's future slowly comes to be viewed with apprehensions as their thinking is now more about the future of the child. Such a feeling becomes worse if that is their only child. The parents may deny that the child has intellectual disability.

Worrying about the future life of the child was a disturbing challenge for the parents and guardians that some parents experienced due to the inability of the child to accomplish personal and social needs such as self-care and education. They showed these concerns when the child could not do certain developmental tasks expected at specific ages such as feeding, toileting, bathing, and dressing.

In addition to that is the parents' loss of Social life and fun. Due to inappropriate behavior of intellectually disabled children, leisure activities such as participation in sports, clubs, weddings, picnics, and attending family gatherings like funerals were often affected. This finding is consistent with Roberts (2002) United Kingdom study which revealed that parents may really be over burdened by the child's behavior such that some parents have been reported to have had depression leading to psychopathology.

Living with an intellectually challenged child was described as emotionally distressful by parents. Varying degrees of emotional distress were experienced which included having feelings of sadness and inner pain or bitterness. This finding was consistent with Finne (1990) who found that parents experienced these negative emotions due to disturbing behavior of the children, extra care-giving responsibilities, family, and social problems caused by the child, and people's perception about families having an intellectually disabled child.

Also parents described living with or having an intellectually challenged child as a disturbing and yet unavoidable situation. Though their initial challenge was the issue of acceptance, they had to with time accept it since they had no other alternative. They viewed their caring duty for the child as very difficult and distressing. This was stated by some participants when they were responding to the question about how they generally viewed the situation of having an intellectually challenged child at home. One of these parents said;

This is very disheartening and my life has completely changed because of this child. There are lot of difficulties that I go through with this situation at hand.

The inability of the child to express his or her needs was yet another source of psychological and emotional distress associated with living with intellectually disabled children. This caused parents to be unable to understand the child especially when he or she had problems. Due to the inability of the child to communicate effectively he or she was mistreated by other people and returned home crying. When he or she was asked by the parent to explain what had happened he or she couldn't explain. This finding was similar to that of Donovan (1988) who indicated that parents of children with intellectual challenges experience greater stress. For example, a child with intellectual challenges may not be able to express his or her basic wants or needs. The child's frustration can lead to aggressive or self-injurious behaviors that threaten their safety and the safety of other family members (e.g. siblings) since children with intellectual challenges have deficits in social skills, such as lack of appropriate playing habits. Newman (2007) also found that living with intellectually disabled children was associated with stigma. Parents and guardians were troubled by the intellectually disabled child being mistreated, discriminated against, and segregated in the community. Sometimes these children were told words that made them feel bad. Parents were laughed at and told bad things about the child.

Ignorance about intellectual disability was perceived by parents, guardians or caregivers to be common in the community. This came out in form of stigma which makes many parents and guardians feel that an intellectually disabled child is something to be ashamed of and cannot be allowed out of the house. Neighbors, relatives or others might make cruel remarks about the child and parents might feel isolated and without support. This is in line with Gordon and

Browne (2004) who found that some children with intellectual disabilities and their parents suffered stigma and mistreatment out of ignorance by community members. Parents in this study expressed their concern about not receiving the needed support from neighbors and people in the community. Some people could not even give help when they found the child in an awkward situation.

Self-blame was as well noted during interviews. The parents wonder if they did something wrong during the course of the pregnancy or after birth, while taking care of the child. They wonder if God is punishing them for their sins. The children were mistreated by people in various ways. This finding is in agreement with Kirk, Anastasiow, and Coleman (2006) who found that sometimes they were labeled and made fun of in the community, considered to be useless and even sadly rejected by the parent because of the disability. Parents and guardians were sometimes held responsible for the child's behavior. They were thought to be spoiling the child by not being strict enough when the child was behaving strangely. Because of these reasons majority participants had some sort of an inner feeling of guiltiness thinking maybe they caused the sickness of the child in one way or the other.

The social life of parents was found to be disrupted by the presence of an intellectually disabled child in the family. Sometimes parents avoided going with the child to social gatherings such as church because of the child's disturbing behavior. Further parents experienced conflicts in the community and sometimes were even confronted when the child destroyed somebody's property. This created tension and resulted in lack of peace especially with people like neighbors who could not understand the condition of the child. Sometimes the love life of a mother was affected for reasons related to having an intellectually challenged child. One mother narrated her divorce ordeal and had this to say:

My husband and I divorced because of this child. The relatives to my husband also contributed to our divorce because they put all the blame on me and influenced my husband to abandon me and the innocent sick child.

The above finding is also consistent with Roberts (2002) who found that intellectually disabled children were vulnerable and suffered mistreatment from people by being beaten, pushed, and burned. These children were also reported to be at risk of being physically and sexually abused such as being burned or raped respectively as explained by one mother of a child with intellectual disability. This finding is further consistent with Newman (2007) who states that the social security of the children was not very much guaranteed as a number of attempts to abuse the children sexually and physically was reported in some quarters of the community.

Helplessness was yet another challenge for some parents and guardians that manifested in the form of ignorance on how to get help for their child once he or she has been diagnosed with intellectual disability. This finding consistent with Dyson (1997) who argues that, the sense of helplessness comes both from a lack of understanding about intellectual disability and a lack of information about the resources available for intellectually disabled individuals. It might also arise from insensitive in handling of the case by the mental health professional, who might not have enough time to talk to each family at length about their experience.

The study revealed unrealistic expectations from parents and guardians. Many times, parents of intellectually disabled children are dissatisfied with the slow progress their children make in learning new things. They push harder to force the child to learn quickly and try to be at the same level with other children. However, the child can only learn to the best of his or her ability and no more. If he or she has the mental age of 8 years old, he or she cannot be expected to undertake a vocation training which requires complicated mental processes. This

finding is line with Engle and Black (2008) who state that when parents have unrealistic expectations of what their child can achieve, it leads to disappointment not only for them, but also in the child who does not understand what he or she is doing wrong.

5.2 Marital challenges as a result of the presence of a child with intellectual challenges

The study finding indicated marital or family problems. Having a child who is intellectually disabled places greater strain on a family than otherwise. Due to the extra tasks that have to be done to take care of the child, parents feel overworked, stressed out, and unhappy. This finding of the study is consistent with Woods and Hewitt (1989), who found that the marital relationship can become strained if the parents have different approaches in dealing with the child or if one parent has to take care of the child all the time.

In this study, some mothers indicated that they were not getting enough support from their husbands in taking care of the children. Fathers on the other hand felt that the mothers are unnecessarily worried and overprotective of the children. Such a scenario has the potential to lead to marriages breaking up as evident in the study. It was also revealed during the study that other family members can complicate matters depending on how they react to the child. One mother lamented that;

This child has made my husband to divorce me. Now the burden of care is upon me. The father doesn't love her (the child) very much. Sometimes you may tell him that you have a problem with the child and he will tell you to just wait. Now that's just like totally not being involved in the care of the child.

The finding above is consistent with Cosser (2005) who states that once the family has a disabled child, parents need to also adapt and adjust to daily routine as the child's disability

takes more of their time as compared to the normal child. If this is not well handled, the child's disability can split the family.

5.3 Effects of having an intellectually challenged child in the family on the siblings.

Majority parents and guardians had some difficulties in child caring which also affected their family. Parents' and guardians' joy suddenly turned into fear, concern, worry, and despair because of the child's condition as the children could not do other activities as anticipated by a normal child. This brings stress, negative emotions to parents and guardians which even affects their siblings. One father when asked on how the child was impacting on the family commented in this way:

I was so excited to have a baby boy whom I thought was going to be the pillar in the family, but suddenly the child's diagnosis of intellectual disability and it's eventual behavior brought some emotional reactions to the entire family.

However, despite the negative behavior shown by the child and witnessed by the siblings, there was certainty that their brother or sister will one day be fine. On the other hand, when the siblings were told about the diagnosis, all siblings reported signs of hope for their brother or sister. One male parent expressed concern on the siblings who complained of getting tired of playing and looking after their brother who needed attention each minute.

One couple expressed concern about the aggressive behaviour or bullying that their child with intellectual disability demonstrated towards a much younger sibling. They narrated how it was reported to them on how the step-brother could beat their child with intellectually disability every time they were playing. In this report only one mother

confessed having never asked the children on how they felt about their sister.

The above finding was consistent with Dobson and Middleton (1998) who states that few normal children showed sadness or depression towards their intellectually disabled sibling. Despite this, most children could still ask their parents soon after returning from the hospital on whether the doctor had said that their brother or sister would talk again.

5.4 Economic challenges of parenting a child with intellectual challenges

Three major themes emerged that explained how living with an intellectually disabled child interfered with economic activities of the families. These were, existing poverty, interference with various income generating activities, and extra expenditure due to the condition of the child

Almost all parents and guardians indicated higher degree of pain, depression, anxiety, anger, and frustration at the cost of child care. Parents lost a lot of time whilst caring for the intellectually disabled child mainly in behavioral management. This cost did not include materials like books, toys, and computer games and other necessities.

The findings of the study revealed that parents and guardians had faced economic and financial challenges particularly the complexity role of caring responsibilities that demanded a lot of work and being available most of time to meet the daily needs of the child. The finding of the study is related to Bailey and Smith (2000) findings that intellectual disability is associated with higher probability of child care problems which greatly affect parental employment. Similarly Funjiura, Reccoforte, & Braddock, (1994) in Japan did a costs measurement analysis of intellectual disability on parents' services and discovered that almost all the care for people with disability is made by the parents and the family. The finding of the study was further consistent with Gray's (2002) longitudinal studies which

showed that parents found it difficult to have a career job with intellectually disabled children.

Poverty was revealed by parents as being responsible for their inability to meet certain important needs for the intellectually disabled child. Some parents were house wives who did not have any means of earning income and depended solely on their partners. Those who did not have partners expected to get help from other people, especially relatives. This was a problem if they could not get the help they needed. They (including fathers) could not manage buying drugs for their children if they did not receive them at the hospital where medication is almost free. More importantly they also could not afford bus fare to take their children to school. This finding was as pointed out by Gordon (1993) who found that intellectual disability is known to be a major problem and very expensive because it comes with many costs and these costs come in many forms such as emotional, social, finances towards transport, medication, and education.

The burden of caring for the intellectually disabled child was found to be mainly borne by the mother. Mothers complained about the role that fathers played in everyday care of the child. They expressed that some fathers rendered very little support to the child financially and others did not care at all as evidenced with one grandmother who was taking care of one child with intellectual disability whose mother was dead strongly complained that the father to the child was still alive, but did not care for the needs of the child ranging from physiological and emotion needs. The grandmother bitterly complained because that father to the child was in rewarding employment and if willing to support the child cannot at any given time fail to satisfy the needs of the child. The old woman had this to say:

The father to this child is very irresponsible and does not care about his own blood, because this is his own child, but I am struggling to

provide for the child. Money he has, but likes drinking this is very bad my son.

The above information is consistent with Finne (1990) who found out that lack of resources such as finances and materials help retard the progress of the management of intellectually challenged children. Management of intellectually challenged child requires a nice room of his own, fenced yard not too much in doors, no multi family dwelling and no overcrowding, but with lack of resources, it cannot be attained. Therefore, it was established that the mothers are the ones that were at the center of providing to the intellectually disabled children as compared to the mute fathers who pretended all was well.

The study further revealed that parents and guardians whose children were lucky and enrolled in the special schools were on the other hand facing other problems. They were finding challenges to take their children to school because they could not afford bus and taxi fares on a daily basis. This finding is very similar to Heward (2006) who found that this was further compounded by the fact that these parents and guardians or care givers had their economic activities disrupted due to the highly demanding role of taking care of the child which naturally required that they are with the children throughout the day. Therefore, daily life and activities of parents and guardians in this study were very much affected by the presence of an intellectually disabled child in the family. A lot of time was spent looking after the child and as a result they were not able to do other important activities such as business. Income generation in the family was affected and this further escalated family poverty as explained by one mother.

5.5 Views of parents with children with intellectual disabilities on how society perceives them

The findings on the views of parents and guardians on how society perceives them varied from parent to parent. Forty (66.66%) out of 60 parents and guardians indicated having minor problems with the community while twelve (20%) indicated that their children had caused problems in the community hence attracting some negative reactions from the members of the community. Eight (13.33%) out of the 60 participants indicated that they had serious problems with the community and that, they were receiving and suffering disparaging remarks from the community. When asked on how community perceived them as parents of intellectually disabled children. One mother had this to say;

We avoid social contact of our child with other members due to the child routine behavior which members of the community say they detest. As Parents, slowly we started counting the social benefits of letting him going out or remaining home.

The above finding is consistent with that of Cosser, (2005) who found that parents of children with intellectual disabilities may face loss of social life and fun. Leisure activities such as participation in sports, clubs, weddings, picnics, and attending family gatherings like funerals were affected. Parents are overburdened by the child's behaviour such that some parents have been reported to develop depression.

Another father lamented as follows;

My son sometimes just opens the gate and goes outside. If you don't notice quickly, he can be there as long as he wants. Each time he does that, people always mock and laugh at him. Some say parents for this child are very bad and have failed to care for the child.

The above finding mirrors that of Gombosi (1998) who found that the state of affair makes parents feel like they have lost the dream of their child. However, it is natural and unavoidable to go through hard times when you have a child with intellectual disabilities. Woods and Hewitt (1989) further found that parents of children with intellectual disability face a unique set of challenges that impact on their psychological adjustment. Their lives are never the same. If married, then their marriages will never be the same; it will encounter more challenges and stress.

On a good note, despite the negative remarks that the parents, guardians and caregivers were subjected to by the community one guardian said that the community negative perception and harassment that parents and guardians encounter from the community had helped him and the child and noted that:

Labeling of my child with intellectual disabilities to me has brought a relief, as am now able to look for the child's services such as education, occupation, and other forms of services which can benefit the child.

The above finding is consistent with that of Gray (2002) who suggests that anxiety reduces in parents if the child is placed in school and appropriate therapy institutions. He further argues that at this stage parents start to interact with professionals and the family may soon settle and find ways of dealing with the child's intellectual disability. Cosser (2005) found that parents may continue seeking further explanation on the cause of the disorder. Acceptance and maturity comes in, which brings with it the realization of personal insignificance. At this stage, parents may try to live a meaningful life by even socializing with others. This may be achieved with more support from the community and helping professionals.

A single mother when asked whether her child was able to play and socialize with other children in the community, bitterly complained of the societal behavior towards them as parents of intellectually challenged children where society deemed them to be irresponsible and not caring enough for the children. The complaint by majority of the parents and guardians that the community was harsh on them regularly featured in this study. One mother was unhappy of the manner in which the community aggravated their situation as parents of intellectually challenged children by even accusing them of causing the sickness of the child. Conclusively, some members of the community hold a strong view that in some cases the conditions of these children were deliberately caused by their parents for the love of money and as such the community has no kind words for these parents.

A devastated single mother lamented that:

Teasing from other people makes me sad and especially that people seemingly have not understood the condition of my child. Because of that, my child is not able to play with children of his age. The stigma is so rife in my case and my family has suffered considerable isolation by the community. It makes me cry sometimes because people should understand that my child did not acquire the condition deliberately, it was something beyond our control and that they should know that such a condition can happen to anybody. It's really painful to find yourself in such a stressful situation. The father has abandoned me and the child, and am all by myself to cushion all these challenges.

The above finding is in agreement with that of Hornby (1994) who states that early signs of parents' withdrawal from society start slowly by first avoiding social contact of the child with other members due to the child routine behaviour. Parents' social costs ranged from enduring

the behavioural disturbances by a child to comments from the society, which creates a greater sensitivity on parents with intellectually disabled children resulting into their perception about society to change. Many parents with intellectually disabled children fear comments from other people in the society who look at them as though they don't know how to take care of their children. Body (2000) found that such challenges forced parents mainly women to lead a very isolated life. This shrinking of social contact by parents represented a loss to self on the parents as a social being.

One guardian expressed her disgust at the way community members tend to be rough on guardians of intellectually disabled children. The community and some members of the public at large were quite insensitive to the plight of the parents, guardians, and caregivers. Their behavior was to a large extent demeaning to these parents and guardians in the sense that they took these parents and their children to be misfits in the community, which was not supposed to be. This parent said;

There was one time when I went to Intercity Bus Terminus with him and he was so hyperactive that he went touching peoples' handbags and even attempting to open them. Then one woman came and blasted at me saying, "Is this (Devil) child yours, he came from that womb" then I broke down and cried and started shouting at her. However, I appreciated one man who helped to calm down the annoyed travelers and also comforted me. So you can see how members of the public can be rough and uncompromising because of the sick and innocent child. Some comments from the people suggested that we as parents might be responsible for the sickness of these children.

The above finding is in agreement with that of Barlow and Durand (2007) who pointed out that stigmatizing experiences resulted in a pattern of avoidance of most social interactions in order to protect their child from the larger society's negative treatment of the children and/or the family members. Additionally the extended families and children of mothers with intellectual disabilities were often the subject of discriminatory and stigmatizing practices. Hayman (1990) also found that atypical personal characteristics and behaviours are often stigmatizing. For example, people with disabilities have been stigmatized by their disabilities and hence discriminated against by other members of society.

5.6 How parents of intellectually challenged children cope with challenges of raising a child with intellectual disabilities.

This theme concerns ways in which parents cope with the situation of having an intellectually challenged child in the family. The term strategies in this research are defined as ways, methods, and approaches which parents used to care for their children. When asked on the coping strategies, parents, and guardians explained that it was difficult to totally accept the child's condition, as each day had its own problems and challenges. The challenges were further compounded by non-availability of trained counselors to equip them on stress management and coping strategies.

Parents expressed various ways they used in order to address the challenges they were facing by living with a child with intellectual challenge. This finding in the study was consistent with Bailey and Smith (2000) who found that a variety of coping mechanisms were employed in different situations depending on what seemed to be helpful to the parents. They sought professional and spiritual help from religion and traditional healers.

Most parents attributed their coping strategy to a strong belief in God as the giver of life and the healer of all lives. Others talked about a strategy called empowerment. Many mothers said

that they managed their challenges and problems by talking about the child's conditions to other members of the public. Knowledge exchange with other parents who were in a similar position greatly helped them. Both fathers and mothers said they dealt with challenges as they came (living in the moment and taking one day at a time is their ideology). Planning for the future or planning ahead for the child greatly helped them to cope with the situation. When asked on coping strategies, one mother said:

It is the hospital, it's the hospital that has helped her (the child) to be honest. If it was not for the hospital her condition would have been worse. I have done everything I could; I have not stopped going to the hospital since she begun having the problem. It is 11 years now she is on medication.

The above finding of the study is in agreement with Hockenberry and Wilson (2007) who found that professionals identify family sources of support and promote the utilization of both formal and informal support systems. Furthermore, nurses who work with mothers of children with intellectual disabilities must understand how to assist the mothers in coping with their stressors. In order to accomplish this, nurses can help mothers realize their abilities and strengths, identify problems, develop problem-solving strategies, and identify new coping strategies. (Woodgate, Aleah, & Seccol, (2008).

Other measures parents took included training the child to do what she or he could not do such as toilet training and speaking, involving other family members such as siblings in the care of the child, and seeking information about the child's disorder from sources like the internet. This result of the study is consistent with Judge (1998) and Bailey and Smith (2000) who identified two main types of coping patterns; adaptive coping methods (e.g., information seeking and problem solving) and palliative coping strategies (e.g., efforts to deny, minimize, or escape the stressful situation). Adaptive coping strategies are directly aimed at coping with

the source of stress, whereas palliative strategies indirectly help reduce a person's awareness of the stress. Palliative strategies include a person's unconscious defense mechanisms, which are spontaneous reactions to stressful situations. Due to the nature of the disability and the behavior displayed by the child, some parents and guardians tried to control the child's environment for safety reasons.

The study also revealed that parents and guardians got comfort from friends who now understand their challenges and the children's condition and also that the children are able to go to a special school. One guardian explained;

Friends who can show empathy with you help in reducing stress. We have our childhood friends who have been encouraging us from the time the child was found with this problem and we talk about our problems. Generally friends have been there for us through out.

The above finding is similar to that of Blair (2003) who reports that mothers use support from others which becomes a very important factor helping parents to cope better. The role of men in the lives of mothers of the intellectually disabled is very important. The finding of the present study is further supported by the earlier studies by Heiman (2002) who reported social support as an important factor in coping. The study revealed that social support may be emotion-focused or it may be problem-focused depending on whether it is intended to seek emotional support from others; or it is intended to seek problem solution.

It was also revealed that comfort from God, religious belief that you need to accept a child from God as gift regardless of the Child's condition. Majority of the participants claimed to be Christians and have faith in God. Their strong belief is that one day their child will be fine and a solution will be found. This is according to the findings of the study gives parents comfort. One parent explained that:

Knowing God and believing in him has brought a lot of comfort, especially that the Bible says when God gives you something he never adds sorrows, it's a gift from God. I believe it's just time and definitely things are going to change for the better.

The above result is consistent with Hyden and Heller (1997) who reported that mothers and care givers are more likely to seek spiritual support. Mothers use more of religious coping which shows that mothers use more of religion-faith and denial-blame strategies compared to fathers. This finding is further amplified by Kim (1999) who also found that mothers who use more of religious approach to cope with the situation experienced lower burden and depression.

The study revealed also that parents drew their strength from the fact that intellectual disability is not a killer disease, but is just a condition and that there is no need to stigmatize the children who has the condition or indeed their parents. One parent commented that;

It's just a name intellectual disability so don't look at that all you have to always look at is a boy who can do anything. Intellectual disability is just a word which is supposed to be brushed aside and look at the positive aspect of the child and how you can help him.

Love for intellectually disabled children also played a role in helping the parents. Majority parents and guardians explained that their love for the intellectually disabled children played a major role in the parents' management of the children. When one parent was asked on how she copes with living with an intellectually disabled child, she had this to say:

The ever present love for the child gives me strength. As a parent when you develop love for the child in spite of his or her condition, it

helps to come to terms with the unpleasant situation you are faced with.

The above study result is consistent with Body (2000) finding that the ever present love of the parents for the children played a pivotal role in managing the stress that the parents go through and particularly becomes a major source of strength to mothers who appear to be primary caregivers to children with intellectual disabilities.

Additionally, another strategy that is employed is that of parents daily care strategies for intellectually disabled children. Each child needs parental care from the attachment figure mainly the primary care giver. If the care is not enough, children may be affected and be insecure. Even the disorganized insecure child needs parental care to help him or her change for the better. Parents and guardians in this study indicated the use of many strategies to cope up with ways of child care. One mother explained that:

I wake up earlier than my child and prepare food for him and other children so that they eat. I bath them which they love, and take them to school. During the day, when they come back from school, my boy enjoys watching cartoons and we have provided the facility for him and the rest of the children in the house. By 20:30 they are tired and I have to sleep with them and that is when they rest. My day is programmed so I'm up by 4 a.m. to make snacks and when they are up they go to school. Only we have a bit of a problem on meal times, when he's very hungry, he would sit and concentrate and eat on his own. But if he's not, you have to guide him, force him to eat, but then he would be running around, he would pick one thing, goes eats, stops eating and it would take maybe an hour or an hour and a half for him to finish, and especially when he's with the father. Otherwise

bathing time, he enjoys bathing very much so we never have problems with bathing. Sleeping times like I mentioned earlier, sometimes he doesn't sleep early he takes a long time, and taking into account the job that I do which requires me to be reporting early becomes a challenge because I sometimes report late for work.

The study finding is in agreement with that of Gordon and Browne (2004) who stated that, planning for the future or planning ahead of the child greatly helped parents and caregivers to cope with the situation. Such finding is also consistent to those of Gray (2003) who conducted a qualitative analysis of the role of gender and coping among parents of children with intellectual disabilities. His findings showed that there are similarities in terms of practical or problem-solving coping strategies, between both male and female caregivers of children with intellectual disabilities, in that they both used anticipation and planning as well as dealing with problems as they happened as their most popular practical coping strategies.

Another important coping strategy revealed by the parents is that of knowing the child's condition which helps them to be sensitive to their child's welfare and understanding what is right or wrong for their child. Parents also used humor, self-appraisal, openness to the society, seeing other children who have more challenges than their child and the belief in God. This gives parents a sense of empowerment. One parent attributed his resilience to his job as a watchman which demands to be strong as a way of coping with challenges. This finding is in agreement with that of Thompson (2000) who found that parents who slowly accepted societal criticism and stigmatization towards their child was helping them to cope with challenges of raising a child with intellectual disabilities.

5.7 Summary

This chapter has discussed the findings of the study based on the objectives. The study revealed that caring for the intellectually challenged children was found to be associated with many social challenges. Social services, stigma, and caring responsibilities were areas which posed major challenges and concerns. Acceptance by the majority parents that they have a child with such a condition is still a big challenge to them. The study results also indicated that parents and guardians of intellectually challenged children developed a feeling that they are being pushed towards isolation. Also findings of the study revealed that parents and guardians worry so much about the children's behavior both at home and particularly at school. The issue of inadequate social services for the children with intellectual challenges arose as a major challenge as the parents and guardians were concerned about education for their children and to a lesser degree hospital care.

Worrying about the future of the children was another disturbing challenge for the parents and guardians which they experienced due to the inability of the children to accomplish personal and social needs such as self-care and education. Coupled with this was the inability of the children to express their needs which became a source of psychological and emotional distress to the parents and guardians. Marital relationships were also adversely affected due to the presence of intellectually challenged children in some families. The study findings also indicated that living with intellectually challenged children interfered with economic activities of the families. The results of the study also showed that parents and guardians were receiving and suffering disparaging remarks from members of the community. Parents and guardians expressed various ways they used in order to address the challenges they were facing such as belief in God, training of the children, comfort from friends and love for the children

CHAPTER SIX CONCLUSION AND RECOMMENDATIONS

6.0 Overview

This chapter presents the conclusion and recommendations emanating from the findings and discussion of the study. The objectives of the study were to ascertain the socio-economic impact of raising a child with intellectual disability, to determine how parents of children with intellectual disabilities cope with these challenges and to establish the views of parents with children with intellectual disabilities on how society perceives them

6.1 Conclusions

Based on the findings, the study concludes that parents and guardians who were parenting intellectually challenged children had problems as regards to the social life their children which affected other members of the community. The disruptive behavior of these children attracted negative remarks from members of the community and the public at large. The children were found to be displaying inappropriate behaviors in church and other important gatherings if they were taken there by their parents, guardian and caregivers. This unacceptable behaviors caused a lot of pain, humiliation, and total embarrassment to parents, guardian, and caregivers. These behaviors by the children also led to some families being isolated on account these children were violent and needed to be avoided.

From the study, it is evident that parents, guardians, and caregivers have serious financial constraints in the management of the intellectually challenged children. The economic challenges that parents, guardians, and caregivers experienced in this study were mainly due to poverty, child care interfering with various activities such as businesses, and extra expenses associated with the illness. Child care interfering with various activities led to parents and guardians experiencing disruptions to achieving their own goals or dreams.

Ultimately parents and guardians were caught up in a web of poverty to an extent that they could not adequately provide to their children.

The study also revealed that parents and guardians had devised strategies that helped them cope with challenges of parenting intellectually challenged children. Majority of them found solace in talking to other people and particularly to other parents that had the similar situation of parenting such children. This helped them to stabilize emotionally. Also parents and guardians cited the belief in God which as well pacified them and created happiness for them. Besides that parents and guardians made use of the available medical services to try and alleviate the condition of the children.

Throughout the study some parents and guardians advanced the complaint of been accused of been responsible for the condition of the children. Parents and guardians were deemed to have made attempts to amass wealth in a wrong way of sacrificing their children in exchange for wealth. This notion held by some quarters of the community and members of the public saddened them to unprecedented levels. Furthermore, the unpalatable language that the community and members of the public used on them had far reaching consequences on the parents and guardians.

6.2 Recommendations

Based on the study findings, the following recommendations are made:

- Parents, guardians, and caregivers should be helped by planning of multi-professional support groups to reduce the burden on parents and enable them to acquire enough time for them to do their own income generating activities. This can be achieved by providing respite services and establishing day care centers for their ill children so that they do not spend so much time looking after them.

- Parents should be encouraged to closely observe their children's behavior as a source of understanding which can be helpful to the parents, guardians, and indeed caregivers in getting to know the critical aspects of the children's requirements in behavioral management.
- Parents need an intense professionals-Parents model approach, where professional counseling services and other support services like emotional, social, and finances are provided to them. This would empower parents with information and resources, and employ a collaborative parent-professional model, whereby parents would directly be involved in child treatment and recognized as experts on their children's behavior.
- There is need to build more schools for children with intellectual disability which are well-equipped with resources that may help in behavior modification and skills learning. The schools need to be staffed with specialists in speech therapy, child, and clinical psychology, occupation therapy, and behavioral management therapy.
- There is a need for nationwide assessment to find out the figures for children with intellectual disabilities. This information will benefit government to know the exact number of children with intellectual disabilities and will help in planning for their services and resources.

6.3 Suggestion for future research

The study was centered on challenges of parenting intellectually challenged children in the areas of socio-economic spheres, the way parents, guardians, and caregivers cope with the situation and indeed the perception that society has on them.

It would, therefore, be interesting in future to carry out a comparative study on parenting children with other disabilities, for example, Down syndrome. This would be a worthy while contribution to the existing knowledge on parenting children with other serious disabilities.

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APPENDIX A (i)

SEMI-STRUCTURED QUESTIONS TO BE USED FOR PARENTS WHO HAVE LEARNERS WITH INTELLECTUAL DISABILITIES

A. BACK GROUND INFORMATION OF THE CHILD

SEX.....AGE:.....

RESIDENCE: FAMILY SIZE:

1. What was your first reaction when you discovered your child had intellectual disabilities?
2. Please share your experience of having a child with intellectual disabilities.
3. What situations have greatly affected your experiences of a child with intellectual disability?
4. How would you describe a child with intellectual disability?
5. What difficulties do you encounter in relation to meals, bath time, using the toilet, bed time and fun activities?
6. What feelings come into your mind when you mention or see a child with intellectual disability?
7. Tell me about your experiences, struggles and eventual adjustment in terms of
 - 7.1. Your child's education.
 - 7.2. Effective methods of behavior control and discipline; and
 - 7.3. The impact of your child on other siblings and family members.

- 7.4. Does having a child with intellectual disability affect your family life? If so how?
8. What has been most helpful in your life with a child with intellectual disability?
9. What are the costs (financial, social, and emotional) of caring for a child with intellectual disability?
10. What has been your experience with professionals?
11. What coping strategies do you use to manage the demands on your time and energy?
12. Describe your daily programme at home for the child.
13. Is there any difference in the daily activities such as meals, bath time, using the toilet, bedtime, and fun activities? What difficulties do you encounter?
14. How do you feel about the resources and support systems available to parents with children with intellectual disabilities in Zambia?
15. Where do you run to for help? And what or who is most helpful in coping with the demands of raising a child with intellectual disabilities?
16. What is it about the child that you fail to cope with?
17. What are some of unresolved issues or problems about your child's condition which you feel still needs attention?
18. What do you still need? Suggest on how you feel the services if any available to parents with children with intellectual disabilities can be improved.
19. What have been the reactions from the community in relation to cultural beliefs about your child with intellectual disability?
20. How do the peers to your child treat your child?

21. Do you involve your child in community activities?
22. Do your neighbors allow their children to play with your child?
23. Some people say that children with intellectual disability make their isolated. What is your view?

THANK YOU

APPENDIX A (ii)

SEMI-STRUCTURED INTERVIEW GUIDE IN CHEWA

A. M'NDANDANDA WA UMOYO WATHU

DZINA LA MWANA: MWAMUNA KAPENA NDIWAMUKADZI

ZAKA:KOMWE AKHALA: KUKULA KWABANJA:

B 1. Ndi cokumana naco cothani [Dzina lamwana ya ali mulema mukukhala wakuya mumapunzilo] monga wachichepele and mwana wakhanda?

2 Ndishotani kukhala kholo kapena makholo wawo punzila ali ndi ulema mukukhala Wakhuya mumapunzilo?

3 Ndishotani zadzikhulu zimene zikhukhuzhani muzo khumana nazo mwana ali ndi Ulema mukhu khala yakhuya mumapunzilo ache?

4 Munga longosole motani zamwana amene ali ndi ulema mukukhala wakhuya mumapunzilo ache?

5 Kuhala ndi anthu otere kupezeka ndima bvuto otani monga pa thawi ya kudya, Yosamba pathupi, kugwiritsa dzimbudzi, nthawi yo gona ndi yosewera?

6. Chimakukuzani mothani mumaganizo anu pa mwana ali ndi ulema?

7. Fotokozani pazimene mupeza, zobvuta ndi zache monga:

7.1 mapunziro amwana wanu.

7.2 zinjira zili ndi zothulukamo dzenidzeni monga pa ku langiza mwana wotere.

7.3 Kodi mwana wanu ali ndi mpamvu zothani ku anazibale ake mubanja.

7.4 Kodi kukhala ndi mwana ali ndi ulema m'banja chikukhuzani motani?

8. Kodi ndi thandizo lothani yamene mupezapo kukhala ndi mwana ali ndi ulema m'banja?

9. Kodi ndizotani zofunika ku yanganira mwana wothero?

10. Kodi mwakumana ndizotani pogawirana khani ya mwana ndi akatswiri?

11. Kodi ndimundandanda wothani womwe mugwiritsa nchito kupeza nthawi mukuthandiza munthu wotero?

12. Longosolani m'ndandanda wanu momwe mukhalira ndi mwana wotero?

13. Ndi kosiyana kothani kuthandiza muntu wotere pakhani yakudya, yosamba, nthawi yogwiritsa zimbuzi kapena nthawi yamasowera?

14. Mukutipo bwanji monga pankani yothandizila makolo ali ndi ana ulemala Mudziko lathu?

15. Ndi kuti komwe mupeza thandizo pa khani yosunga ana olemala?

16. Kod indi chani chomwe chitilepelesa kusunga mwana wotele?

17. Kodi ndi mabvuto yotani omwe alephera kupeza thandizo yolereramo ana olemala?

18. Kodi ndi chani chofunikira pamwanayo? Tipaseni malingalilo ena amene angatithandizeko.

19. Kodi anthu amene mukhala nawo m'mudzi alakhulapo zotani pa ana olemala?

20. Ana amusinkhu wamwana yanu akumuthani mwana wanu sikunisiku?

21. Kodi mwana wanu mumamuikapo muzochitika komwe mukhala?

22. Kodi omwe mukukhala nawo pafupi ama vomekedza ana ao kusowera ndi mwana

Wanu alindi ulema?

23. Anthuena akuti ana otele afunika kukhala okha. Kodi mukutipo bwanji?

ZIKOMO.

