CHALLENGES FACED BY FAMILIES OF CHILDREN LIVING WITH DISABILITY IN KASARANI CONSTITUENCY, NAIROBI COUNTY.

BY

MONICAH MUTHONI NGIGI

A PROJECT PAPER SUBMITTED TO THE INSTITUTE OF ANTHROPOLOGY, GENDER AND AFRICAN STUDIES IN PARTIAL FULFILMENT OF THE REQUIREMENT FOR THE DEGREE OF MASTER OF ARTS IN GENDER AND DEVELOPMENT STUDIES OF THE UNIVERSITY OF NAIROBI.



OCTOBER 2013

DECLARATION

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

Sign. Date 25/11/2013

Monicah Muthoni Ngigi

N69/69212/2011

This work has been submitted for examination with my approval as the university supervisor.

Sign. William Date 25 11 2013:

Dr Wilfred K. Subbo

DEDICATION

I dedicate this project to my dear father Robert Ngigi Muchendu whose moral and financial support has been overwhelming and without whom the realization of this degree would have been a dream in the pipeline. Thank you and May God bless you abundantly.

ACKNOLEDGEMENT

My immeasurable gratitude is to my supervisor Dr Wilfred K. Subbo for his invaluable guidance and, positive criticism throughout the research study. I also extend my heart most appreciation to all families of children living with disability in Kasarani Constituency and the Kasarani Children's Department who took part in this research by offering their invaluable information.

Special thanks to the University of Nairobi through the institute of Anthropology, Gender and African Studies for giving me a chance to study M.A in Gender and Development. I am really grateful to all lecturers in the department for equipping me with the knowledge and capacity required to undertake the research. May God bless you abundantly.

My indefinite thanks is to my father Robert Ngigi Muchendu and my two siblings Esther Njeri and Paul Kamau whose support has been incredible. I acknowledge and appreciate the encouragement accorded to me by my classmates and friends. They really gave me the moral support I needed to accomplish my studies, may God bless you all.

Above all, I am grateful to God for his protection throughout my studies at the University of Nairobi. Last but not least, I salute all women and men from all walks of life whose efforts has been immense in ensuring that persons with disability are recognized and treated as equal beings.

LIST OF ACRONYMS AND ABREVIATIONS

UPE- Universal Primary Education

MDGs-Millennium Development Goals

IQ- Intelligence quotient

EFA-FTI- The Education for All- Fast Track Initiative

GOK- Government of Kenya

UNICEF-United Nation Children's Fund

NHIS-National Health Interview Survey

WHO-World Health Organization

LIST OF TABLES

Table 4.1: Duaration Lived in Constituency	
Table 4.2: Gender	24
Table 4.3: Education of Disabled Child	25
Table 4.4: Needs Special Care	27
Table 4.5: Costly Needs	28
Table 4.6: Inability to Save	30
Table 4.7: May Cause Poverty	31
Table 4.8: Mistreating Disabled Children	33
Table 4.9: Abandonment by Friends and Relatives	34
Table 4.10: Confinement to Home care	35
Table 4.11: Feeling insecure to introduce Disabled Child	36
Table 4.12: Embarrassment in case of Mental Disability	37

LIST OF FIGURES

Figure 4.1: Age of the Disabled Child	23
Figure 4.2: Source of Disability	24
Figure 4.4: Needs Special Equipment	26
Figure 4.5: Special Diet	27
Figure 4.6: Drains Family Resources	29
Figure 4.7: Eats into Prior Investments	31
Figure 4.8: III Treatment	32
Figure 4.9: Discrimination	34
Figure 4.10: Humiliation	36
Figure 4.11: Healthcare Challenges	38

TABLE OF CONTENTS

DECLARATIONii	
DEDICATIONiii	
ACKNOLEDGEMENTiv	
LIST OF ACRONYMS AND ABREVIATIONSv	
LIST OF TABLESvi	
LIST OF FIGURESvii	
TABLE OF CONTENTSviii	
ABSTRACTxii	
CHAPTER ONE:1	
INTRODUCTION1	
1.1 Background of the Study	
1.3 Research Questions	
1.4 Research Objectives	
1.4.1 Broad Objective	
1.4.2 Specific Objectives	
1.5 Justification of the Study	
1.6 Significance of the study	,
1.7 Scope of the Study	
1.8 Limitations to the study	,
1.9 Definition of Terms	,
CHAPTER TWO:	3
LITERATURE REVIEW	3
2.1 Introduction	3
2.2 Overview of Disability	3
2.2.1 Forms and Causes of Child Disability	,

	2.2.2	Effect of Child Disability on Families	11
	2.3	Challenges of Families with Disabled Children	14
	2.4	Theoretical Framework	15
	2.5	Assumptions	17
C	HAP'	TER THREE	18
R	ESEA	ARCH METHODOLOGY	18
	3.1	Introduction	18
	3.2	Research Site	18
	3.2.1	Location	19
	3.3	Research Design	19
	3.4	Study Population	19
	3.5	Sample size and Sampling Procedure	19
	3.6	Methods of data collection	20
		Survey Method	
	3.6.2	Key informant interviews	20
	3.7	Data Processing and Analysis	20
	3.8	Ethical Considerations	21
C	HAPT	TER FOUR:	22
D.	ATA.	ANALYSIS AND INTERPRETATION	22
	4.1	Introduction	22
	4.2	Background information	22
	4.2.1	Duration Lived in Constituency	22
		Age of the Disabled Child	
	4.2.3	Gender	24
	4.2.4	Source of Disability	24
	4.2.5	Education of Disabled Child	25

4.3	Financial Implications of Disability on Family	26
4.3	3.1 Needs Special Equipment Costing a lot of Money	26
	3.2 Needs Special Care	
4.3	3.3 Special Diet	27
	3.4 Costly Needs	
4.3	.4 Drains Family Resources	29
4.3	.5 Inability to Save	30
4.3	6.6 Eats into Prior Investments	31
4.3	.7 May Cause Poverty	31
4.4	Social Challenges faced by Families of Disabled Children	32
4.4	.1 Ill treatment from other people	32
4.4	.2 Mistreating Disabled Children	33
4.4	.3 Discrimination from other people	34
4.4	.4 Abandonment by Friends and Relatives	34
4.4	.5 Confinement to Home care	35
4.4	.6 Humiliation	36
4.4	.7 Feeling insecure to introduce Disabled Child	36
	.8 Embarrassment in case of Mental Disability	
4.5	Healthcare Challenges	37
НА	PTER FIVE	39
	MARY, CONCLUSIONS AND RECOMMENDATIONS	
5.1	Introduction	39
5.2	Summary of Findings	39
5.3	Conclusions	41
5.4	Recommendations	41
5.5	Suggestions for Further Research	42

References	4	1
References		
Appendices	4	1
Appendix 1 : Consent Form	4	1
Appendix 11: Survey Questionnaire	4	ľ

ABSTRACT

The number of children born with disability has been progressively increasing over time since the year 1960. Children with chronic disability may require medical or psychological attention that may last for their entire lifetime. This attention requires enormous resources either from the caregivers or other sources to ensure they get the appropriate care. The purpose of this study was to establish the challenges faced by families of disabled children in Kasarani Constituency in Nairobi County. The study had three objectives: to examine the financial implications of raising disabled children on families in Kasarani Constituency; to establish the social challenges faced by families of disabled children in Kasarani Constituency and to investigate the healthcare challenges faced by families of disabled children. The study adopted a survey research design and data was collected through questionnaires and key informant interviews. The findings from the study revealed that some of the challenges facing families with disabled children include: expensive medication; depletion of family financial resources; rejection and abuse from society as well as long term healthcare challenges.

CHAPTER ONE

INTRODUCTION

1.1 Background of the Study

Providing care to people with disability is a daunting and challenging task to the caregivers. According to National Health Interview Survey (1998) the number of children born with disability has been progressively increasing over time since the year 1960. Children with chronic disability may require medical or psychological attention that may last for their entire lifetime. This attention requires enormous resources either from the caregivers or other sources to ensure they get the appropriate care. Stabile and Allin (2012) assert that the resources employed into the care of children with disability amount to long term economic costs that have far reaching financial implications on both family and society. The direct costs of families with disability are even more enormous thus causing financial challenges.

Rupp & Ressler (2009) caring for children with disability is quite demanding and may require the caregiver to be around most of the time to perform functions such as feeding and others. Families find it difficult to coordinate other things if they have to stay around and assist a child with disability. According to Earle and Heymann (2002) the effects of children with disability on families largely depends on the type and magnitude of the disability.

People in modern societies achieve their survival and wellbeing through families, the market, and the state. They receive care and support from family members, work at jobs to earn income, and draw benefits of various kinds from the state. Each of these may be thought of as an institutional arena or a set of relationships governed by informal and formal rules and each of these arenas is subject to a set of state policies that are closely interconnected (Fuwa & Cohen 2006). Families with disabled children are disadvantaged with regard to two of these arenas. In

the family, they shoulder greater care work obligations in the upbringing of their children. They also face obstacles to their success in the labor market, where their earning potential is limited by care work burdens. Thus, although the married couple is the model for the story of work and family in modern life, it is families with disabled children more than any other group who confront the dilemmas and contradictions of the work-family collision (Robinson & Godbey 1999).

Living with a disabled child can have profound effects on both the immediate and extended family members such as parents, siblings and relatives. It is a unique shared experience for families and can affect all aspects of family functioning. It may have both positive and negative repercussions depending on how the issue or condition is handled by the family concerned. The positive effects of living with a disabled child may include broadening horizons, increasing family members' awareness of their inner strength, enhancing family cohesion, and encouraging connections to community groups or religious institutions. However, there are also negative effects of child disability on the family such as the time and financial costs, physical and emotional demands, and logistical complexities associated with raising a disabled child can have far-reaching effects as described below. The positive or negative effects will largely depend on the type of condition and severity, as well as the physical, emotional, and financial means of the family and the resources that are available (Noonan et al., 2008).

A number of studies have been conducted on child disability. For instance Lee et al. (2004) carried out a study on the impact of child disability on mothers' work participation. The study established that child disability has a significant impact on mothers' work participation, but not to a great extent as the mother's own disability. The impact of child disability also varies by

children's age between single and married mothers. Older healthy children have a positive influence on maternal work only among married mothers, while older children with a disability increase families' partial work activities. Rupp and Ressler (2009) also carried out a study on family care giving and employment among parents of children with disabilities. The study findings indicate that there is an association between the child's disabilities and parental employment. Overall, while there is some substitution between parental employment and care giving there appears to be a substantial net burden on the family arising from the child's needs for care giving. Dobson, Middleton and Beardsworth (2001) also conducted a study on the impact of childhood disability on family life. The study findings revealed that the financial costs to parents of bringing up a disabled child are significant.

It is evident from the studies that have been reviewed that most of the studies have not focused on families of children with disability in African Nations. This leaves a wide research gap since there are several families in most African countries living with disabled children due to poor healthcare and poverty. Most of the African countries are also riddled with traditions and beliefs on disability and this makes it more difficult for families to live with disabled children. This study will therefore examine the challenges that families in Kasarani Constituency face as they provide care to their children with disability.

1.3 Research Questions

- i. What are the financial implications of raising disabled children on families in Kasarani Constituency?
- ii. What are the social challenges faced by families of disabled children in Kasarani Constituency?

iii. Which Healthcare challenges do families of disabled children in Kasarani Constituency face?

1.4 Research Objectives

1.4.1 Broad Objective

To examine the challenges faced by families of children living with disability in Kasarani Constituency.

1.4.2 Specific Objectives

- To examine the financial implications of raising disabled children on families in Kasarani
 Constituency
- ii. To establish the social challenges faced by families of disabled children in Kasarani Constituency
- iii. To investigate the healthcare challenges faced by families of disabled children in Kasarani Constituency

1.5 Justification of the Study

Families have got a huge responsibility of caring for children until they attain an age when they can be able to support themselves. When a family has a child living with disability, it faces a myriad of challenges that make it difficult to discharge other duties to the other children. Having a disabled child in a family may force one of the parents to quit active employment in order to provide the necessary care and support for the child. There is currently little empirical research on the challenges faced by families of children living with disability especially in most developing countries such as Kenya.

There is a possibility that having a disabled child in the family may also be a recipe for family disintegration or cohesion depending on how the situation is handled. Traditions and beliefs in

most African countries also play some role on how people view disability. It is therefore important to carry out a study and establish the challenges that families with disabled children face so that more light can be shed on this subject that seems to have limited research activity.

If it's challenging for parents to take care of an average child then, it is even more daunting and traumatizing for parents to take care of a disabled child.

1.6 Significance of the study

Upon completion, the findings of this study will hopefully be beneficial to several groups of people. Those in the academic fraternity may be able to get information on an area that is inadequately researched at the moment. It will therefore be a significant contribution to the body of knowledge on families and child disability.

The findings of this study may help the government in formulating policies as well as rules and regulations that can assist in addressing the needs of families of children living with disability in the country.

The findings of this study may also assist those non-governmental organizations engaged in assisting disabled people. They may be able to get a glimpse of what families with disabled children go through. This will enable them refocus and channel their support to the activities that can improve the lives of children living with disability and their families.

1.7 Scope of the Study

The study was limited to Kasarani Constituency in the County of Nairobi. The study involved only families of children with disability hence data was collected from this specific group of people.

1.8 Limitations to the study

In most cases, children with disability are often hid from the general public because of the psychological trauma disability causes on the immediate relatives. It was challenging to find families members who admitted to having disabled children. The researcher therefore used snowballing technique to identify and approach these families.

Some families did not accept to be interviewed. They accepted the fact that they had disabled children but refused to be interviewed. This limitation was overcomed by assuring them that the main purpose of this study was purely academic and not for any other perceived reason.

Kasarani Constituency is a densely populated area with an estimated half a million residents. Therefore, it took time to look for these respondents because they are a minority. This required a lot of time and money to achieve. In order to alleviate this challenge, the researcher conducted in-depth interviews with the respondents who were identified in order to ensure that everything was exhaustively handled. Key informants also played a significant role in identifying the respondents.

1.9 Definition of Terms

This section provides the meaning of those technical terms that have been used in this study

Association- In this study, it is used to refer to the existence of a relationship between some variables.

Condition- Is used in this study to refer to a state in which someone finds himself or herself due to impairment either mentally, physically, visual, hearing, learning or other impairment.

Disability-This is the physical, sensory, mental, or other impairment including any visual, hearing, learning or physical incapacity which impacts adversely on social, economic or environmental participation.

Family-This is the natural and fundamental group unit of society which is entitled to protection by society and the state.

Health- In the context of this study, the term refers to those who do not suffer from any disability.

Trauma- This is used to refer to the disturbance that caregivers of disabled children go through as they undertake this responsibility.

Hyperactivity- This is a condition whereby an individual is always abnormally active.

Gender mainstreaming- It is a globally accepted strategy for promoting gender equality.

Universal Primary Education (UPE) - This is one of the United Nations Millennium Development goals.

Millennium Development Goals (MDGs) - These are the eight international development goals that were officially established following the Millennium Summit of the United Nations in the year 2000, following the adoption of the United Nations Millennium Declaration.

Intelligence quotient (IQ)-This is a score derived from one of the several standardized tests designed to assess intelligence.

Malnutrition-This is the condition that result from eating a diet in which certain nutrients are lacking, in excess (too high an intake), or in the wrong proportions.

Vulnerability-This refers to the inability to withstand the effect of a hostile environment.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter outlines the relevant literature that has been reviewed by the researcher. It focuses on a review of what has been done by other researchers in the area of child disability and families of children with disability. The literature that was reviewed concerns three main areas: An overview of disability in children was done and it addresses the main causes and nature of disability; challenges faced by families of children with disability as well as theoretical framework upon which the study is based. The chapter also presents the research gap that needs to be filled by this study.

2.2 Overview of Disability

According to Karoline et al. (2008) more than 600 million people live with disability around the globe. The World Health Organization projects that this number will continue to increase in the years to come due to increase in the number of chronic ailments capable of causing disability; injuries from violence related incidents; increase in the number of vehicle related accidents across the globe as well as workplace related accidents. Karoline further states that most of those living with disability are found in developing countries which are dominated with poor healthcare and poverty.

Disability among children can be a very demanding and stressful task to families who live with and support children born with disabilities. Such kinds of families spend enormous resources to provide care and support for the disabled children. The care provided to disabled children may at times proceed even after the parent or caregiver is long gone since some severe cases of disability may not allow the children to be independent at any one particular time. The type of

healthcare required for disabled children may also be complicated and expensive in nature and may take many years or the entire lifetime of the child who is born with that disability. In cases of chronic disability, some adjustments may be needed on the existing residential facilities in order to accommodate the child living with disability (Reichman & Coman, 2007).

2.2.1 Forms and Causes of Child Disability

According to research carried out by the United Nations organization on disability in the Caribbean, it was established that there are different types of disability. Disability may take the form of visual or hearing impairment; it may also take the form of speech impairment; disability may also involve physical aspects such losing the lower or upper limb as well as disorders related to behavior. Most young children are faced with visual impairment which seems to be higher among girls than in boys (Karoline et al., 2008). It was also clear that handicap type of disability involving loss of limbs are common among young boys due to their hyperactivity nature that predisposes them to the causes of this type of impairment.

There are several causes of disability among children even though the rate at which each of them leads to disability differs from one country to another. Some of the causes of disability among children seem to be universal in nature whereas others are only prevalent in some regions or countries. For instance, The Government of Zimbabwe (1996) in its survey on children and adolescents with disability in Zimbabwe established that there are six main causes of child disability in the country. The major cause of disability among Zimbabwean children was found to be disease which contributed more than 60% of the disability in children. Accidents take the second position among the leading causes of disability in children and it attributes to 23% of the cases on children disability. There are other causes of disability even though they do not account

for a greater percentage of disability. These include abnormal birth, malnutrition, heredity and war related activities.

Karoline et al (2008) confirmed that in the Caribbean, there are three main causes of disability in children. These causes are similar to those determined in Zimbabwe thus making them appear to be universal causes of disability among children. Ailments or diseases were found to be the leading cause of disability and more than 51% of the disabilities can be attributed to diseases in the Caribbean. Birth related complications cause a significant number of disabilities, accidents are also among the leading causes of disability in children. Karoline further asserts that there are other causes of disability such as lifestyle related diseases like diabetes, hypertension and arthritis that can cause serious disability in someone's later life.

According to UNICEF (1999) among the deaths reported in children across the world, approximately half of them are believed to be attributed to lack of proper feeding or nutritional deficiency in children. As much as nutritional deficiency is not an infectious disease, millions of children who go through it and survive are faced with aftermath challenges such as physical impairment, psychological disturbance, vulnerability to chronic forms of illnesses as well as intellectual shortcomings. It more surprising that even with these shocking statistics, the crisis caused by nutritional deficiency has not received adequate attention across the entire globe. Improving child nutrition can have significant effects on not only the children themselves but also on the entire population of a country. Nutritional deficiency is not a preserve of developing nations but rather a universal problem that seems to afflict both developed and developing countries.

Deficiency of some important elements in child nutrition has profound effects on the physical, mental and intellectual development of the child. For instance, if a child lacks enough iron during the early stages of its development, the Intelligence Quotient of the child may be affected due to delayed psychomotor development and impaired cognitive development. In most cases, the IQ may be far much lower compared to children who had enough supply of iron during their early stages of development. It has been confirmed too that children who experience nutritional deficiencies in their early years not only have lifetime disabilities and weakened immune systems, but they also lack the capacity for learning that their well-nourished peers have (UNICEF, 1999).

2.2.2 Effect of Child Disability on Families

For parents, having a disabled child may increase stress, take a toll on mental and physical health, make it difficult to find appropriate and affordable child care, and affect decisions about work, education/training, having additional children, and relying on public support. It may be associated with guilt, blame, or reduced self-esteem. It may divert attention from other aspects of family functioning (Noonan et al, 2008). The out-of-pocket costs of medical care and other services may be enormous. All of these potential effects could have repercussions for the quality of the relationship between the parents, their living arrangements, and future relationships and family structure. Having a disabled child may also affect parents' allocation of time and financial resources to their healthy and unhealthy children, their parenting practices, their expectations of healthy siblings in terms of achievement, responsibility, and short- and long-term contributions to the household, and the siblings' health and development. Finally, having a disabled child in the family may affect the contributions of time and financial resources on the part of the child's grandparents or other extended family members, the relationships of those individuals to the core

family, and the financial, physical, and emotional well-being of those family members. All of these potential effects on families have implications for the health and well-being of disabled children (Noonan et al, 2008).

Raising children in a family in which there is a child with a disability adds another dimension to the complexity and challenges of parenting. The age of the child at diagnosis, the specific disability, and the culture of the family are variables that may affect family functioning. Some children are diagnosed at birth, others when they are one or two years old, and occasionally, when the child is older. Some disabilities require intense medical intervention and support; others require adaptive equipment and/or accommodations, while still others need intensive behavioral interventions (Lessenberry & Rehfeldt, 2004). Cultural views of disabilities may also add to stress. Whatever the disability, the impact on the family occurs on a daily basis with differing degrees of intensity. It is important to be aware of the implications, not only how the disability affects development and learning, but also the potential limitations in life style and options for these families.

According to Meyers et al. (2000), there are various costs involved in caring for disabled children. These costs are in form of private and public costs. The private costs that families incur when taking care of a disabled child include extra specialized costs spent on the provision of specialized healthcare for the disabled; purchase of special clothes that can fit the disabled child, provision of unique diet that can meet the nutrition requirements of the disabled as well as transportation arrangements since the disabled child may not be able to travel using normal or ordinary public transport. Those charged with the responsibility of taking care of the disabled may also have to forgo some work related activities in order to be available to serve the disabled child. Meyers et al. (2000) further argue that these costs are likely to cause material shortages in

the family thus leading to poverty since families with disabled children are more likely to be poorer than those without.

Because of the perception and costs of caring for children with disability, most of them are left out from accessing quality education. Mattingly & McInerney (2010) asserts that with many developing countries currently making strong progress to the achievement of the Millennium Development Goals (MDGs) of universal primary education (UPE), the largest number of those children who remain left out of school, a substantial proportion will be children with some disability. They will also be amongst the poorest children since disability includes long-term physical, mental, intellectual or sensory impairments.

According to EFA (2008) EFA FTI (2008) report on Equity and inclusion in education reaching the marginalized, children with disabilities remain one of the main groups being widely excluded from quality education. Disability is recognized as one of the least visible yet most potent factors in educational marginalization. Whereas this is happening in most regions and countries around the globe, families of children with disability need to understand that children with disability have a right to education. This right is contained in the United Nations Human Rights declaration of 1948 which has seen many countries enact laws to support education for children with disability.

According to World Bank (2005) study, disability is associated with long-run poverty in the sense that children with disabilities are less likely to acquire the human capital that will allow them to earn higher incomes. The report further gives reprieve to this statement by indicating that educating children with disability is very important in reversing this trend. Educating disabled children reduces current dependence and frees other household members from caring

responsibilities, allowing them to increase employment or other productive activities. It also increases children's potential productivity and wealth creation which will in turn help to alleviate poverty. Education, particularly inclusive education, is able to reduce discrimination through enabling children with and without disabilities to grow up together. Education gives children with disabilities skills to allow them to become positive role models and join the employment market, thereby helping to prevent poverty.

2.3 Challenges of Families with Disabled Children

There are many challenges families of children with disability have to address. For instance, many parents of disabled children become used to being stared at in public or the topic of other people's or professionals' conversations. Many people do not regard families with disabled children as an ordinary family but rather one with some abnormality. This makes the family invisible since they are considered as people without the same aspirations and rights as families who do not have a disabled child. This physical exclusion is in most cases hard to deal with and largely requires change in attitudes by society, including professionals. Families with disabled children are considered unable to evoke positive feelings hence can only be pitied. This strips the families of their family status and denies them the same emotional and social worth as other families (Doson et al., 2001).

Parents of disabled children often have two roles: parent and career. Many parents cannot differentiate between their role as parents and the tasks they perform to care for their child with disability. Parents of children with disability always have to do whatever they can to look after their child and the only difference is that a child has specialized health needs. However, parents describe how often their parental or caring roles are denied. In some instances, the specialized knowledge that parents have acquired about their child's condition is ignored thus devastating

them. In some cases their role as parents is overlooked as professionals discuss their child with them in cold clinical terms (Noonan et al., 2001).

2.4 Theoretical Framework

The study was guided by positive perceptions theory as its theoretical framework. This model suggests that positive emotions serve functional role in the context of stressful events (Lazarus, Kanner, and Folkman (1980). The theory borrows a lot from the repression sensitization construct by Byrne (1964) and Eriksen 1966. These are constructs that propose methods of coping with stressful situations such as having a disabled child. They hypothesized that under stressful conditions, when negative emotions are predominant, positive emotions may provide a psychological break or respite, support continued coping efforts, and replenish resources that have been depleted by the stress. Positive perceptions could be viewed as a factor ameliorating the impact of a child's disability on family members. Essentially, positive perceptions are different outcomes to stress and other negative experiences but they occur in concert with the negative or stressful experiences. Positive affect might help to bolster psychological and physical resources during stress, act as a buffer against the adverse physiological consequences of stress and help to protect against clinical depression (Folkman and Mosokowitz, 2000).

Existing individual and family focused theories also suggest that positive perceptions play a central role in the coping process. It proposes that positive perceptions may assist people to cope better with the traumatic and stressful events (Taylor, 1983). Cognitive adaptation model of responses to threatening events posits that people attempt to adapt to threatening events by searching for meaning, trying to gain mastery, and enhancing the self. A key mechanism by which this adaptation is achieved is termed as cognitive illusions. When these illusions are

challenged, different perceptions will be generated in order to maintain meaning, mastery, and/or the self-system. Setting achievable goals and engaging in problem-focused coping in order to achieve them, leads to feeling of control and mastery (Taylor, 1983).

Problem-focused coping refers to efforts directed at solving or managing the problem that is causing distress. It includes strategies for gathering information, making decisions, planning, and resolving conflicts. It also includes efforts directed at acquiring resources such as skills, tools and knowledge essential in dealing with an underlying problem, and instrumental, situation-specific, task oriented actions. In a stressful situation, it is possible to identify goals and experience efficacy, mastery, and control even in situations that appear uncontrollable and even worsening. However, this often requires relinquishing previous goals that are no longer tenable and turning to new, realistic goals (Carver and Scheier, 1998).

According to Lazarus (1999) under stressful conditions, individuals may bring about, note or remember ordinary events and in fact often infuse ordinary events with positive meaning. It may be that when a negative event occurs, the individual creates a positive event or interprets an otherwise ordinary event as positive as a way of offsetting the unpleasant affective consequences of the negative event. People are often keyed to respond to the adverse sequel of loss by turning their attention to their resources and looking for positive aspects of their lives. Coping basically involves creating, reinstating, or reinforcing meaning in the midst of stress. This aspect has long been implicated in the appraisal of stress where it helps determine the personal significance of a stressful situation in relation to the individual's beliefs, goals, values, or commitments. This appraised or situational meaning shapes the emotions that the person experiences in the stressful

encounter. This is in contrast with the global meaning which refers to a more abstract, generalized meaning related to people's fundamental assumptions, beliefs, and expectations about the world and the self in the world (Lazarus, 1999).

Relevance of the Theory

The relevance of this theory to families with disabled children is built on the fact that having a child living with disability can be a source of stress to the family. The financial implications of caring for a disabled child are likely to cause stress to the family. The family can equally be stressed because of social exclusion by other people who view families with disabled children from a different perspective. The outcome of having a child living with disability will depend on the perception of the family involved. A positive perception will enable the family to accept the condition and seek for information. This will definitely provide the family with a chance to reduce the consequences of child disability. It also allows the family to easily adapt to a situation of living with a child who is disabled. Due to positive perception, the challenges are likely to become lighter on a family that has a disabled child since positive perception encourages the family to look for resources and information on how to handle the disability.

2.5 Assumptions

Families raising disabled children face financial challenges.

Families of children living with disability face social challenges.

Families of children living with disability have difficulties accessing appropriate healthcare services.

CHAPTER THREE

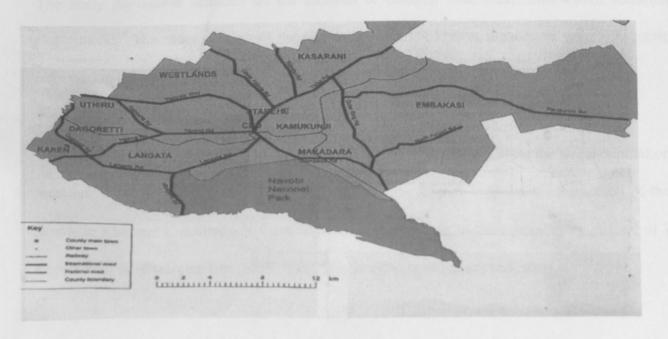
RESEARCH METHODOLOGY

3.1 Introduction

This section discusses the methodology that was adopted in conducting the study. Among the items discussed herein include the research site, research design, the target population, the sample size that was selected for the purpose of data collection, the procedures the researcher adopted in selecting the sample size, The tools the researcher employed in collecting data, the techniques the researcher used to process and analyze the data that was collected as well as the ethical issues that were observed during this study.

3.2 Research Site

The research was conducted in Kasarani Constituency in Nairobi County. The government of Kenya population census statistics indicated that Kasarani had a total population of 525,624 by the year 2009 (GOK, 2009).



Source: http://www.flickr.com/photos/albertkenyaniinima/4729795674/

3.2.1 Location

Kasarani is one among the eight constituencies that form Nairobi County. The constituency lies approximately 18 Kilometers North of Nairobi. The constituency is accessed through the Thika superhighway. Kasarani constituency is bordered by Starehe, Kamukunji and Embakasi constituencies (GOK, 2010).

3.3 Research Design

The study employed a cross-sectional research design. This is a basic type of research method in which a large cross-section of the population is studied at one specific time and the differences between individual groups within the population compared. It is commonly used by sport scientists to evaluate and compare a given physiological variables or fitness components in individual already belonging to different groups. A cross-sectional design was appropriate since the researcher interviewed families of children with disability across Kasarani Constituency.

3.4 Study Population

The study population included all the families of children with disabilities within Kasarani Constituency. The exact number of the population was not known since there was no accurate information on the number of families who have children with disability.

3.5 Sample size and Sampling Procedure

The sample population consisted of 42 respondents who were selected from the target population mentioned above. The study adopted stratified sampling to pick respondents from each of the Wards in Kasarani Constituency. Currently, there are 6 Wards in the constituency. A total of 7 respondents were selected from each of the Wards using snowballing technique.

3.6 Methods of data collection

3.6.1 Survey Method

The study adopted survey method of data collection. The data was obtained through a standardized questionnaire which was carefully prepared to ensure that the respondents are able to understand. The questionnaire contained both structured and open ended questions. It had four sections: Section A contained questions on background information of the respondent; Section B solicited data on the financial implications of raising disabled children on families in Kasarani Constituency; Section C sought data on the social challenges faced by families of disabled children within Kasarani Constituency while Section D contained questions on the healthcare challenges faced by families of children with disability. The structured questions were in form of five point Likert scale.

3.6.2 Key informant interviews

Key informants interviews are qualitative in-depth interviews with people who are knowledgeable of the issues that are of interest to the researcher. The researcher used both unstructured and semi-structured interviews. The researcher interviewed 10 key informants who included one District Children's Officer, two Deputy Children's Officers, two police officers from Child Protection Unit and five Volunteer Children's Officers. The researcher used key informants so as to ensure that everything was exhaustively handled. Key informants also played a significant role in identifying the respondents.

3.7 Data Processing and Analysis

The data analysis is the whole process which starts immediately after data collection is completed and ends at the point of interpretation and processing of the results (Kothari, 2007). Data may not be of any value merely as data, it has to be analyzed in order to give meaning that provided answers to the research problem. The data collected was sorted in order to ensure that it was complete and could be used for data analysis. Since the type of data collected was qualitative and quantitative in nature, the researcher employed both qualitative and quantitative techniques of data analysis in order to be able to draw conclusions from the data collected. In this case, the researcher used content analysis to analyze the qualitative data and the quantitative data was subjected to Statistical Packages for Social Sciences for analysis. Frequencies and percentages were used to explain the various challenges faced by families of children with disability. The findings were presented in tables and graphs.

3.8 Ethical Considerations

The researcher ensured that all the required research ethics are observed during this study. The researcher sought informed consent from the respondents before going ahead to collect data from them. All information collected from the respondents was treated with the degree of confidentiality required to avoid any leakage. The researcher also observed the guiding principles of research such as acknowledgement of sources of published information to avoid plagiarism (Kothari, 2004). A permit to enable the researcher to collect data from the respondents was obtained from the National Council for Science and Technology.

CHAPTER FOUR

DATA ANALYSIS AND INTERPRETATION

4.1 Introduction

The purpose of this study was to establish the challenges faced by families of children living with disability in Kasarani constituency in Nairobi County. The study sought to achieve three objectives: to examine the financial implications of raising disabled children on families in Kasarani Constituency; to establish the social challenges faced by families of disabled children in Kasarani Constituency and to investigate the healthcare challenges faced by families of disabled children in Kasarani Constituency. Data was successfully collected from 42 respondents through questionnaires. Some data was also collected from key informants in form of interviews. This implies that the study managed to attain 100% response rate. The findings from the study are discussed below.

4.2 Background information

The study sought some information from the respondents to assist in understanding the issues surrounding child disability and families. The respondents were therefore required to respond to a total of six questions and the findings are discussed below.

4.2.1 Duration Lived in Constituency

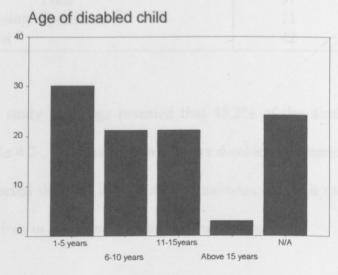
Table 4.1: Duration Lived in Constituency
How long have you lived in this constituency

While's especially are same when	Frequency	Percent
Valid 1-5 years Over 5 years Total	15	35.7
	27	64.3
	42	100.0

It is evident from Table 4.1 above that 64.3% of the respondents have lived in Kasarani constituency for over five years. The study also revealed that all the respondents were from the constituency where the study was being carried out.

4.2.2 Age of the Disabled Child

Figure 4.1: Age of the Disabled Child



Age of disabled child

The study sought to establish the age of the disabled child in each of the families. The findings as illustrated in Figure 4.1 above confirms that 30% of the disabled children are between the age of 1-5 years old; 20% are between 6-10 years old and another 20% are between the age of 11-15 years. Only 4% of the respondents have children who are above 15 years old. This is an indication that most of the children with disability may probably not survive beyond their 15th birthday especially in cases where the disability is severe.

4.2.3 Gender

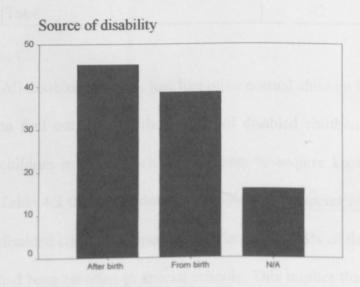
Table 4.2: Gender Gender

respo	ndents indicased that	Frequency	Percent
Valid	Male	19	45.2
Female N/A	Female	8	19.0
	N/A	4	9.5
	Total	31	73.8
Missing	System	11	26.2
Total		42	100.0

The study findnings revealed that 45.2% of the disabled children are males. As indicated in Table 4.2, female children who are disabled are represented by 19%. These findings reflect the expected situation in the entire constituency since it can be generalized that majority of disabled children in Kasarani constituency are males.

4.2.4 Source of Disability

Figure 4.2: Source of Disability



Was the disability right from birth or after

The researcher was interested in understanding the time the disability was manifested in the child who is currently disabled. It is clear from the results in Figure 4.2 above that 45% of the respondents indicated that the children acquired the disability after birth while 38% of the respondents indicated that disability of their children began right from birth. The findings indicate that the 45% of the disability cases may be due to illnesses that affected the children after birth and could easily be contained.

4.2.5 Education of Disabled Child

Table 4.3: Education of Disabled Child

Is the child enrolled in a special school

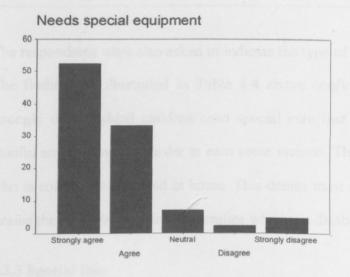
		Frequency	Percent
Valid	Yes	10	23.8
	No	17	40.5
	N/A	4	9.5
	Total	31	73.8
Missing	System	11	26.2
Total		42	100.0

All disabled children, just like other normal children have a right to education. The study sought to find out whether the parents of disabled children had made efforts to enroll their disabled children in special schools for them to acquire knowledge. It is evident from the findings in Table 4.3 that approximately 40.5% of the respondents indicated that they had not enrolled their disabled children in special schools. Only 23.8% of the respondents confirmed that their children had been enrolled in special schools. This implies that most parents who have disabled children do not seem to be making efforts to ensure that the children get enrolled in special schools.

4.3 Financial Implications of Disability on Family

This is the first objective of the study. The study sought to establish how the disability of children affects the financial position of the respective families. The respondents answered several questions on the financial implications that have been brought by the disability of their children. Each of these implications is discussed below.

4.3.1 Needs Special Equipment Costing a lot of Money Figure 4.4: Needs Special Equipment



The researcher wanted to establish whether disabled children require special equipment that cost a lot of money. The findings in the figure above confirm that 52% of the respondents indicated that disabled children actually require some specialised equipment that cost a lot of money. The purchase of such equipment is likely to drain the family of its financial resources thus affecting the financial stability of the family. Accessing such amout of money to purchase the equipment is also a challenge as was indicated by some of the respondents who participated in the study.

4.3.2 Needs Special Care

Table 4.4: Needs Special Care

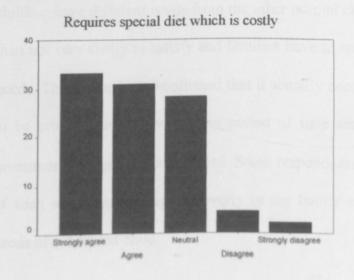
Needs special care that denies one opportunity

		Frequency	Percent
Valid	Strongly agree	15	35.7
	Agree	9	21.4
	Neutral	6	14.3
	Disagree	7	16.7
	Strongly disagree	5	11.9
	Total	42	100.0

The respondents were also asked to indicate the type of care that is required by disabled children. The findings as illustrated in Table 4.4 above confirm that 35.7% of the respondents agree strongly that disabled children need special care that denies one an opportunity to engage in gainful employement in order to earn some income. This care can only be provided by someone who is constantly stationed at home. This denies most caregivers the opportunity to work and it strains the financial position of families who have disabled children.

4.3.3 Special Diet

Figure 4.5: Special Diet



The researcher also sought to find out from the respondents the type of diet that is required by the disabled children. The findings from the study confirm that 33.3% of the respondents strongly agreed that disabled children require special diet that is usually costly; 31% also agreed that indeed the diet that disabled children normally require is special in nature and does cost a lot of money. It was also clear from the study that if such a special diet has to last the entire lifetime of the disabled child, then it is a very expensive undertaking that is likely to lead to financial strain on the family resources.

4.3.4 Costly Needs

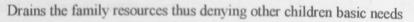
Table 4.5: Costly Needs

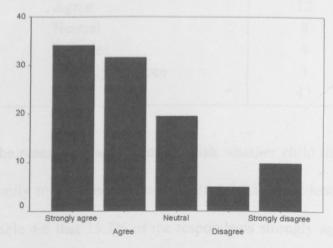
	Frequency	Percent
Valid Strongly agree	21	50.0
Agree	9	21.4
Neutral	6	14.3
Disagree	4	9.5
Strongly disagree	2	4.8
Total	42	100.0

It was also important to investigate on the general needs that are required by disabled children and their implications on the financial resources of the family. The study reveals that disabled children have different needs from the other normal children. These special needs are more often than not very costly to satisfy and families have to spend huge amounts of money to meet these needs. The respondents confirmed that it actually becomes a huge burden when such needs have to be provided over a very long period of time since they are likely to eat into the family investments in order to be satisfied. Some respondents further indicated that there is a possibility of such scenarios leading to poverty in the family as efforts are made to maintain the costly needs of a disabled child.

4.3.4 Drains Family Resources

Figure 4.6: Drains Family Resources





Drains the family resources thus denying other children basic needs

The study findings confirmed that disability of a child is a condition that has adverse effects on the family's financial resources. According to the results illustrated in Figure 4.6 above, 33% of the respondents indicated that child disability has the potential of draining a family's resources thus denying other children in the family some basic needs. This implies that as the family concentrates on providing special care and treatment to a disabled child, the resources that would otherwise be channeled towards providing basic needs such as education to other children are diverted.

4.3.5 Inability to Save

Table 4.6: Inability to Save

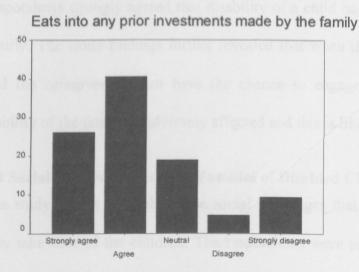
Family can not be able to save money for any reasonable investment

			Frequency	Percent
Valid	Strongly agree	AMALE TO	15	35.7
	Agree		12	28.6
	Neutral		8	19.0
	Disagree		4	9.5
	Strongly disagree		3	7.1
	Total	-	42	100.0

The researcher sought to establish whether child disability has any impact on the ability of the family to save money for investments. It is evident from the results that are tabulated above in Table 4.6 that 35.7% of the respondents strongly agree that the disability of a child does reduce the ability of the family to make any meaningful savings that can be utilized in making reasonable investments. The respondents further confirmed that the family becomes strained financially to an extent that nothing is channeled towards savings.

4.3.6 Eats into Prior Investments

Figure 4.7: Eats into Prior Investments



Eats into any prior investments made by the family

The study also established that disability of a child has the potential of eating into prior investments that have been made by the family. Approximately 40% of the respondents confirmed that providing for the costly needs of the disabled child can easily devour previous investments that the family had made. The respondents further indicated that if the disability and its special costly needs last for a short duration then it may not have a huge impact on the family investments. However, when the disability is more of a permanent condition that can last a lifetime, the family may end up consuming all prior investments to maintain the disabled child.

4.3.7 May Cause Poverty

Table 4.7: May Cause Poverty

May easily cause poverty in the family

	Frequency	Percent
Valid Strongly agree	22	52.4
Agree	5	11.9
Neutral	4	9.5
Disagree	5	11.9
Strongly disagree	6	14.3
Total	42	100.0

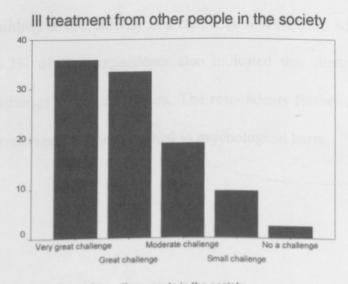
The researcher was also interested in investigating the relationship between child disability and poverty in the family. The respondents were required to indicate whether disability of a child can cause poverty in the family. It is clear from the findings in Table 4.7 above that 52.4% of the respondents strongly agreed that disability of a child has the potential of causing poverty in the family. The study findings further revealed that when the family eats into its prior investments and the caregivers cannot have the chance to engage in gainful employment, the financial stability of the family is adversely affected and this is likely to lead to poverty.

4.4 Social Challenges faced by Families of Disabled Children

The study sought to establish the social challenges that families with disabled children face as they take care of the children. The respondents were provided with a number of questions on social challenges and were required to indicate the extent to which they think each one of them affects families with disabled children. The findings from their responses are discussed below.

4.4.1 Ill treatment from other people

Figure 4.8: Ill Treatment



Ill treatment from other people in the society

The study sought to establish whether ill treatment to families and children living with disability from other people in the society is a challenge to affected families. The findings reveal that most of the respondents confirmed that ill treatment from other people in the society is such a great social challenge they have to deal with. It was also clear from the study that this treatment makes parents with disabled children have a difficult time or fear of introducing their disabled children to other people.

4.4.2 Mistreating Disabled Children

Table 4.8: Mistreating Disabled Children

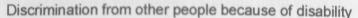
Mistreatment of disabled children by other people in society

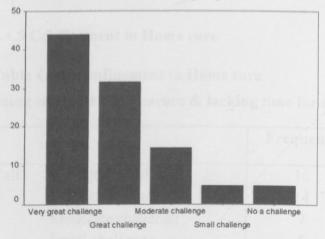
		Frequency	Percent
Valid	Very great challenge	11	26.2
	Great challenge	16	38,1
	Moderate challenge	8	19.0
	Small challenge	3	7.1
	No a challenge	4	9.5
	Total	42	100.0

It was established from the study that 38.1% of the respondents indicated that mistreating children with disability is a challenge that families with disabled children have to grapple with. 26.2% of the respondents also indicated that mistreating disabled children is such a great challenge to most families. The respondents further indicated that mistreating may take many forms ranging from physical to psychological harm.

4.4.3 Discrimination from other people

Figure 4.9: Discrimination





Discrimination from other people because of disability

It was also evident from the findings that discrimination of children with disability is also a very great challenge to parents of children with disability. The respondents further indicated that most of the people in the society do not want to be associated with disabled children due to a number of reasons that range from beliefs and superstitions.

4.4.4 Abandonment by Friends and Relatives

Table 4.9: Abandonment by Friends and Relatives

Being abandoned by friends and relatives

		Frequency	Percent
Valid	Very great challenge	21	50.0
	Great challenge	9	21.4
	Moderate challenge	5	11.9
	Small challenge	3	7.1
	No a challenge	4	9.5
	Total	42	100.0

The findings from the study indicate that 50% of the respondents confirmed that friends and relatives abandoned them once they leant that they had a disabled child. The respondents indicated that this becomes a psychological problem to them since they feel rejected by close friends and relatives who should be giving them support.

4.4.5 Confinement to Home care

Table 4.10: Confinement to Home care

Being confined to homecare & lacking time for other social activities

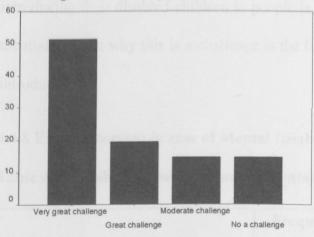
		Frequency	Percent
Valid	Very great challenge	16	38.1
	Great challenge	14	33.3
	Moderate challenge	7	16.7
	Small challenge	5	11.9
	Total	42	100.0

The researcher sought to establish whether providing care to the disabled children in one way or another confines the caregivers to the home environment thus denying them the opportunity to participate in other social activities. It is evident that 38.1% of the respondents and 33.3% of other respondents indicated that this is a very great and great challenge respectively. This implies that it is a fact that providing care to disabled children confines one to homecare and it hurts their social life.

4.4.6 Humiliation

Figure 4.10: Humiliation





Feeling humiliated in public for severe cases of disability

The study findings also indicate that most of the families that have disabled children actually feel so much humiliated in public especially when they have children with severe cases of disability. The respondents indicated that the humiliation comes as a result of the negative perception of the people in the society and the treatment they receive from other people.

4.4.7 Feeling insecure to introduce Disabled Child

Table 4.11: Feeling insecure to introduce a Disabled Child Feeling insecure to introduce the child to people

		Frequency	Percent
		16	38.1
Valid	Very great challenge		
	Great challenge	11	26.2
	Moderate challenge	7	16.7
	Small challenge	3	7.1
	No a challenge	5	11.9
	Total	42	100.0

It was also critical for the researcher to establish whether introducing a disabled child to the public is a challenge to families with disabled children. The findings in Table 4.11 above indicate that 38.1% of the respondents feel insecure to introduce their disabled children hence to them this is a very great challenge. It is also clear that 26.2% of other respondents feel that introducing their disabled children to people is such a great challenge. The study confirmed that the main reason why this is a challenge is the fear of people's perceptions and reactions after the introduction.

4.4.8 Embarrassment in case of Mental Disability

Table 4.12: Embarrassment in case of Mental Disability

		Frequency	Percent
Valid	Very great challenge	17	40.5
	Great challenge	9	21.4
	Moderate challenge	5	11.9
	Small challenge	4	9.5
	No a challenge	7	16.7
	Total	42	100.0

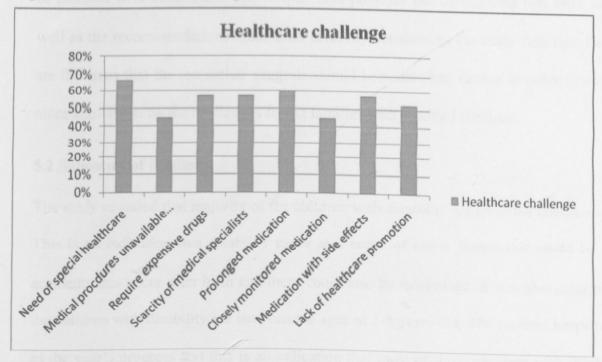
It is evident from the findings as illustrated in the above table that 40.5% of the respondents agree that in cases of mental disability, they feel so much embarrassed. The respondents confirmed that the embarrassment usually emanates from the behavior of mentally challenged children who may cause problems any time.

4.5 Healthcare Challenges

The study considered a number of likely healthcare challenges that are likely to be faced by families with disabled children. The respondents were required to respond to each one of them.

In the following bar chart, the highest percentage that was received for each of the challenges was selected and compared with the others.

Figure 4.11: Healthcare Challenges



It is evident from the findings as illustrated in the bar chart above that the healthcare challenges that were considered to be a very great challenge by the respondents are: the need for special healthcare which received 67% support from the respondents; prolonged medication of the disabled child and this was supported by 60% of the respondents; use of expensive drugs and medication with side effects had 57% respectively of the respondents indicating that they are very great challenges.

CHAPTER FIVE

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

This chapter provides a summary of the findings of a study on the challenges faced by families of children with disabilities. The chapter also provides the conclusions that were arrived at as well as the recommendations made after carefully considering the study findings. Provided also are the areas that the researcher suggests should be researched further in order to come up with more knowledge on the challenges facing families with disabled children.

5.2 Summary of Findings

The study revealed that majority of the children with disability acquired the condition after birth. This is an indication that disability came as a result of either illness that could be avoided or accidents that occur after birth and these could also be minimized. It was also clear that most of the children with disability are between the ages of 1-5 years old. The number keeps on reducing as the year's progress and this is an indication that most of those children with disability either do not live beyond their 15th birthday or some of them overcome the condition and lead normal lives. It was also established that most of the children with disability are males in most of the families that were surveyed.

The other aspect that also came out clearly from the findings is that disability of a child has adverse financial effects on the family. Some of the financial related challenges that families go through in the face of disability include: spending enormous amounts of money to purchase specialized equipment for disabled children. This money is sometimes not available and the family is forced to dispose off some of its investments and also spend any savings that may be available in order to meet the cost. The study confirmed that the other challenge that comes

along with disability is the possibility of a family exhausting all its financial resources and thus ending up in poverty. It was also evident that families with disabled children may not have the ability to save money for any meaningful investments since it gets eroded by the costly needs of a disabled child.

The findings from the study also revealed that disability of a child has negative social implications on a family with a disabled child. Some of the social challenges the families go through include rejection from close relatives and friends because of disability; the discrimination of their children who are disabled by other members of the society; physical and psychological abuse to both the families and their disabled children. Some families also indicated that it becomes difficult for them to introduce their disabled children for fear of public reactions and perceptions. It is also evident that most people with mentally challenged children go through a lot of embarrassment due to the behavior and actions of such children. The findings also confirmed that care giving to disabled children confines the caregiver and deny him/her the opportunity to participate in other social activities.

The most common healthcare challenges revealed by the study include lack of some medical expertise locally to handle some of the disability conditions; the need for special healthcare which is usually expensive; prolonged medication which may last an entire lifetime as well as medication that at times has side effects to the disabled child. It was also clear that the fact that some of the drugs required by disabled children are very expensive is a very great challenge that families with disabled children have to grapple with either for very many years or even for an entire lifetime.

5.3 Conclusions

Families with disabled children face a number of challenges. These challenges include: purchasing of expensive drugs and specialized healthcare that drains financial resources; exhaustion of family investments as they strive to maintain a disabled child; the risk of poverty in the family since disability may devour the family investments and erosion of the ability to save for any meaningful investments. The other social challenges include rejection and discrimination from friends and relatives; physical and mental abuse of both the family and disabled child as well as severe healthcare challenges such as prolonged expensive medication and medication with side effects.

5.4 Recommendations

- 1. The study has revealed that some of the medication for disabled children is usually expensive and it drains the families of their financial resources. It will be important for the government to find out ways of subsidizing the cost of these drugs so that the families can get some relief.
- 2. It is also clear that families with disabled children face physical and mental abuse from the society. The disabled also go through this same challenge. The government needs to come up with stringent laws that can protect these people.
- 3. There is evidence from the study that a variety of healthcare challenges befall the families that have disabled children. The government should devise ways of enhancing healthcare for the disabled across the country.

5.5 Suggestions for Further Research

There seems to be scarce research on families with disabled children in the country. It will be significant for this study to be carried out in form of a survey that covers all the other constituencies. This will assist in generalizing the findings on the entire country.

It will also be important to do a comparative study with other countries to establish how they handle issues on child disability and families that have disabled children. This can assist in formulating appropriate policies that can assist the families of children with disability in Kenya.

References

- Bennett, Lynn. 2002. Using Empowerment and Social Inclusion for Pro-poor Growth: A Theory
- Carver CS, Scheier MF. (1998) On the Self-Regulation of Behaviour. New York: Cambridge University Press, 1998.
- Dobson, B. Middleton, S. and Beardsworth, A. (2001) The impact of childhood disability on family life. Joseph Rowntree Foundation, York Publishing Services Ltd.
- Durst, D. (2006) Urban Aboriginal Families of Children With Disabilities: Social inclusion or Exclusion? National Association of Friendship centres, Canada.
- Earle A and Heymann SJ. (2002). What Causes Job Loss Among Former Welfare Recipients? The Role of Family Health Problems. JAMWA. 57, 5-10.
- EFA FTI (2008). Equity and inclusion in education: tools to support education sector planning and evaluation. www.educationfasttrack.org/media/library/Equity%20&%20Inclusion204-08.pdf. Accessed on 23/04/2013.
- Folkman S, Mosokowitz JT. (2000) Positive Affect and the Other Side of Coping. American Psychologist; 55: 647-654.
- Fuwa, M. and Philip N. C. (2006) "Housework and Social Policy." Social Science Research in Press.
- Government of Zimbabwe (1996) A Study on Children and Adolescents with Disabilities in Zimbabwe. Government Printer, Harare
- Karoline, et al. (2008) Disability in the Caribbean. A study of four countries: a sociodemographic analysis of the disabled. Studies and Perspectives, United Nations Publications.
- Lazarus RS, Kanner AD, Follkman S. (1980) Emotions: A Cognitive-Phenomenological Analysis. In Plutchik R, Kellerman H, eds. Theories of Emotion. New York, Academic Press, 189-217.
- Lee et al. (2004) The Impact of Disabilities on Mothers' Work Participation: Examining Differences between Single and Married Mothers. Institute for Women's Policy Research, Washington.

- Lessenberry B.M, & Rehfeldt, R.A. (2004). Evaluating stress levels of parents of children with disabilities, Exceptional children, 70(2), 231-244.
- Lessenberry B.M, & Rehfeldt, R.A. (2004). Evaluating stress levels of parents of children with disabilities, Exceptional children, 70 (2), 231-244.
- Mattingly, J. and McInerney, L. (2010) Education for children with disabilities improving access and quality. Department For International Development Practice Paper.
- Meyers et al. (2000) Expensive Children in Poor Families: The Intersection of Childhood Disabilities and Welfare. Public Policy Institute of California.
- National Health Interview Survey (1998) Health Statistics. National Center for Health Statistics (NCHS), United States of America.
- NGO CRC (2001) Supplementary Report. Kenya's First Country Report on Implementation of the UN Convention on the Rights of the Child
- Noonan Walsh, P., Emerson, E., Lobb, C., Hatton, C., Bradley, V., Schalock, R., Moseley, C. (2008). Supported accommodation services for people with intellectual disabilities: A review of models and instruments used to measure quality of life in various settings. Dublin: National Disability Authority of Social Change. Working Draft of Background Paper for the Social Development Strategy Paper. W Washington, DC: World Bank.
- Powers, Elizabeth T. 1999. "Child Disability and Maternal Labor Force Participation: Evidence from the 1992 School Enrollment Supplement to the Current Population Survey." Working Paper. Institute of Government and Public Affairs, University of Illinois at Urbana-Champaign.
- Reichman, E. and Coman, H. (2007) Impact of Child Disability on the Family. *Maternity Child Health Journal*.
- Rupp and Ressler, S. (2009) Family caregiving and employment among parents of children with disabilities on SSI. *Journal of Vocational Rehabilitation 30 (2009) 153–175*.
- Simmerman S, Blacher J, Baker B. (2001)Fathers' and mothers' perceptions of father involvement in families with young children with a disability. Journal of Intellectual & Developmental Disability.;26:325–338.
- Sophie. C. and Lissete, C. (2007) The women empowerment approach: A methodological guide. Commission on Women and Development, Brussels.

- Stabile, M. and Allin, S. (2012)-The Economic Costs of Childhood Disability. *The Future of Children, Vol.22, No1.*
- Taylor SE. (1983)Adjustment to Threatening Events: A Theory of Cognitive Adaptation. American Psychologist; 38: 1161-1173.
- UNICEF (1999) Major Causes and Consequences of Childhood Disability. UNICEF, Volume 2, Issue 4
- Wolfe, Barbara L. and Steven C. Hill. 1995. "The Effect of Health on the Work Effort of Families." Journal of Human Resources 30(1): 41-62.
- World Bank (2005). Inclusive Education: an EFA Strategy for All Children http://siteresources.worldbank.org/EDUCATION/Resources/278209907987726/InclusiveEdu_efa_strategy_for_children.pdf. Accessed on 23/04/2013.

Appendices

Appendix 1: Consent Form

Hallo, my name is Monicah Muthoni Ngigi an M.A student in Gender and Development Studies at the University of Nairobi. I am conducting research on challenges faced by families of children living with disability. You have been conveniently chosen to participate in the study as residents of Kasarani constituency. I want to assure you that all your answers will be kept strictly in secret. To this extent, i will not keep a record of your name or address or any leading identification. You have the right to stop the interview at any time, or to skip any question that you do not want to answer. There is no right or wrong answer in this research. Your participation is completely voluntary but your participation could be very useful in helping families of children living with disability to understand how to approach and address the various challenges that come with such a responsibility. They will also be able to learn how others have managed this situation. The interview takes approximately 45 minutes to complete. Do you agree to be interviewed?

Please sign here as indication of your c	onsent	
Signature	Date	
Thank you for your cooperation		

Appendix I1: Survey Questionnaire

Section A: Background Information

1.	Name of your constituency
2.	For How long have you lived in this constituency
3.	How old is your disabled child
4.	What is the gender of the child with disability
5.	Was the disability right from birth or after
6.	Is the child enrolled in a special school.

Section B: financial implications of disabled children on families

Kindly indicate the extent to which you agree with the following statements concerning the financial implications of raising a child with disability.

Use the scale of 1=strongly agree 2= Agree 3= Neutral 4= Disagree 5= strongly disagree

No	Statement	1	2	3	4	5
1	Needs special equipment that cost a lot of money					
2	Needs special care that denies one opportunity to work and earn money					
3	Requires special diet which is costly					
4	The needs are costly and may last a lifetime					
5	Drains the family resources thus denying other children a basic needs					
6	Family can not be able to save money for any reasonable investment					
7	Eats into any prior investments made by the family					
8	May easily cause poverty in the family					

Section C: Social challenges faced by families of children with disability

Please indicate the level to which you consider the following as social challenges faced by families of disabled children.

Use the scale of 1= Very great challenge 2= Great challenge 3= Moderate challenge 4 small challenge 5 = Not a challenge

No	Social challenge	1	2	3	4	5
1	Ill treatment from other people in the society					
2	Mistreatment of disabled children by other people in society					
3	Discrimination from other people because of disability					
4	Being abandoned by friends and relatives					
5	Being confined to homecare and lacking time for other social activities					
6	Feeling humiliated in public for severe cases of disability					
7	Feeling insecure to introduce the child to people					
8	Embarrassment that may be caused by a mentally disabled child					

Section D: Healthcare challenges

Please indicate the level to which you consider the following as healthcare challenges faced by families of disabled children.

Use the scale of 1= Very great challenge 2= Great challenge 3= Moderate challenge 4 small challenge 5 = Not a challenge

No	Healthcare challenge	1	2	3	4	5
1	Need specialized healthcare which is costly and unaffordable					
2	Some necessary medical procedures can't be done locally	+-				
3	Require expensive drugs that cost so much money					
4	There is lack of medical specialists locally who understand some of the conditions that come with disability					
5	Prolonged medication that may last for the entire life of the child			-		
6	Medication requires close administration hence someone must be close all the time					
7	Medication with side effects that cause further problems			-	-	
8	lack of health care promotion program for persons with disability		+	-		

RESEARCH AUTHORISATION



NATIONAL COMMISSION FOR SCIENCE, TECHNOLOGY AND INNOVATION

9th Floor Utalii House

Uhuru Highway P.O. Box 30623-00100

NAIROBI-KENYA

Date:

24th September, 2013

Telephone: +254-20-2241349, 20-267 3550,

0713 788 787, 0735 404 245 Fax: +254-20-2213215

Email: secretary@nacosti.go.ke Website: www.nacosti.go.ke

When replying please quote

Our Ref: NCST/RCD/14/013/1625

Monicah Muthoni Ngigi University of Nairobi P.O.Box 30197-00100 Nairobi.

RE: RESEARCH AUTHORIZATION

Following your application dated 2nd September, 2013 for authority to carry out research on "Challenges faced by families of children living with disability in Kasarani Constituency, Nairobi County" I am pleased to inform you that you have been authorized to undertake research in Nairobi County for a period ending 31st December, 2013.

You are advised to report to the County Commissioner and the County Director of Education, Nairobi County before embarking on the research project.

On completion of the research, you are expected to submit two hard copies and one soft copy in pdf of the research report/thesis to our office.

DR. M. K. RUGUPT, PhD, HSC.

DEPUTY COMMISSION SECRETARY

NATIONAL COMMISSION FOR SCIENCE, TECHNOLOGY & INNOVATION

Copy to:

The County Commissioner
The County Director of Education
Nairobi County.

RESEARCH PERMIT

PAGE 2

THIS IS TO CERTIFY THAT:
Prof./Dr./Mrs./Miss/Institution
Monicah Muthoni Ngigi
of (Address) University of Nairobi
P.O.Box 30197-00100, Nairobi,
has been permitted to conduct research in

Nairobi

Location District County

On the topic: Challenges faced by families of children living with disability in Kasarani Constituency, Nairobi County.

for a period ending: 31st December, 2013.

PAGE 3

Research Permit No. NCST/RCD/14/013/1625
Date of issue 24th September, 2013
Fee received KSH, 1000

received KSH. 1000

Applicant's Signature N

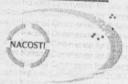
For: Secretary
National Commission for Science
Technology & Innovation

CONDITIONS

- You must report to the County Commissioner and the County Education Officer of the area before embarking on your research. Failure to do that may lead to the cancellation of your permit
- 2. Government Officers will not be interviewed without prior appointment.
- 3. No questionnaire will be used unless it has been approved.
- 4. Excavation, filming and collection of biological specimens are subject to further permission from the relevant Government Ministries.
- You are required to submit at least two(2) hard copies and one(1) soft copy of your final report.
- 6. The Government of Kenya reserves the right to modify the conditions of this permit including its cancellation without notice



REPUBLIC OF KENYA



National Commission for Science, Technology and Innovation

RESEARCH CLEARANCE PERMIT

Scrial No. An DO 9

CONDITIONS: see back page