

**Coping strategies of families with low socio-economic status raising children
with physical disabilities in Mafeteng, Lesotho**

By:

Makhau I. Pelea

**A mini-dissertation submitted in partial fulfilment of the requirements for the
degree:**

**Master of Social Work in Health Care
(MSW Health Care)**

At the

**Faculty of humanities
Department of Social Work and Criminology
University of Pretoria**

Supervisor: Mrs. N.J. Bila

August, 2016

Acknowledgements

I wish to express my gratitude to the following Individuals and Organizations that made this study possible:


- My sponsor, Careerwise Ltd South Africa, in particular, Mr Tshabalala, the Kellogg Foundation Scholarship Manager, and his assistant, Ms Sehume, who have been very supportive and understanding throughout my studies.
- Families that participated in this study and the family representatives who spared their time for the interviews.
- Mrs N.J. Bila, my supervisor, for her ongoing patience, support and guidance throughout the study.
- The Department of Social Development, in particular the Mafeteng District Office, for granting me access to its clients who served as participants in the study.
- Mr 'Mota, the Senior Librarian at the Mafeteng district Library, who selflessly assisted me with the resources needed to facilitate my study, and dedicated his time to review some of my work.
- My friend, Tori Raymond, who has been very encouraging from the beginning of my studies, and dedicated her time to review my work at each level of the study.
- My colleagues at the Anti Drug Abuse Association of Lesotho; Mrs Mofokeng, Mr Penane, Ms Foso, Ms Christeen, Mr Thulo and Ms Stephanie, each of whom spared an effort to facilitate my study, and collectively provided ongoing support throughout my studies.
- A lot of thanks to my husband, Mr Maine Mahlaka, for providing the undying support and encouragement throughout my studies, and for taking care of our family while I was away.

Dedication

This work is dedicated to all mothers who experienced the diagnosis of their children's disabilities, and were strong enough to accept it in their hearts.

Declaration

I hereby declare that, “*Coping strategies of families with low socio-economic status raising children with physical disabilities in Mafeteng, Lesotho*” is my own work, that all the sources used or quoted have been indicated and acknowledged by means of complete references, and that this dissertation was not previously submitted by me for a degree at another University.

Signature: 

Date: 29/08/2016

ABSTRACT

Coping strategies of families with low socio-economic status raising children with physical disabilities in Mafeteng, Lesotho

BY: Makhau I. Pelea

SUPERVISOR: Mrs. N.J. Bila

Department of Social Work and Criminology, Faculty of Humanities, University of Pretoria

Raising children is a highly demanding job for any family; the demands are even higher when the child has a disability. The cost of raising a child with a disability is said to be three times higher than that of raising a non-disabled child. Unfortunately, children with disabilities could be born into any family, including the poorest of the poor, who, due to their low socio-economic status, already have less than what is necessary to meet the needs of the non-disabled members.

There is limited research into the coping strategies of families raising the children with disabilities in Lesotho, for this reason, the researcher decided to undertake this particular study to feed the curiosity on how families with low socio-economic status managed to raise the children with physical disabilities in this poverty stricken country.

Following the Qualitative methodology, the researcher utilised both the purposive and the simple random sampling techniques to select participants from a list provided by the Department of Social Development. A total of ten (10) interviews were conducted with representatives of low socio-economic status families raising children with physical disabilities in the Makaota E12 community council of the Mafeteng district.

The study revealed that the majority of families were coping well and that they were generally happy despite the presence of a child with a disability in their homes. The study further revealed a number of factors that played a role in determining the

coping ability of each family; these include availability of the support structures and the severity of the child's disability.

Finally, the study raised a need for post diagnosis counselling and educational campaigns intended to equip the families of children with physical disabilities with relevant skills and information they require to assist the children to develop to their full potential. The study further raised a need for broader research into the lives of children living with disabilities and their families, for better understanding of the area and for improved service delivery.

Key Concepts

Children

Poverty

Families with low socio-economic status

Childhood disabilities

Coping strategies

Table of Contents

CHAPTER ONE	1
GENERAL BACKGROUND TO THE STUDY	1
1.1. INTRODUCTION	1
1.2. DEFINITION OF THE KEY CONCEPTS.....	2
1.2.1. Children	2
1.2.2. Poverty.....	2
1.2.3. Families with low socio-economic status	3
1.2.4. Childhood Disabilities	4
1.2.5. Coping strategies.....	4
1.3. THEORETICAL FRAMEWORK	5
1.3.1. Family systems theory	5
1.3.2. The ecological systems perspective	6
1.4. RATIONALE AND PROBLEM STATEMENT	8
1.4.1. Justification	9
1.5. STUDY GOAL AND OBJECTIVES	9
1.5.1. The Goal of the study	10
1.5.2. Objectives.....	10
1.6. RESEARCH DESIGN AND METHODOLOGY.....	10
1.7. LIMITATIONS OF THE STUDY	11
1.7.1. Researcher-Participants relationship.....	11
1.7.2. Lack of understanding from the participants	11
1.7.3. Duration of the study.....	12
1.7.4. Changes in sampling techniques	12
1.8. CONTENTS OF THE RESEARCH REPORT	12
1.8.1. Chapter One	12
1.8.2. Chapter two	13

1.8.3. Chapter three.....	13
1.8.4. Chapter four.....	13
CHAPTER 2.....	14
Coping strategies of families with low socio-economic status raising children with physical disabilities.....	14
2.1. INTRODUCTION	14
2.2. THE SOCIO-ECONOMIC STATUS	14
2.3. CHILDHOOD DISABILITIES.....	15
2.3.1. Prevalence of childhood disabilities	16
2.3.2. Common causes of disabilities in childhood	16
2.3.3. The costs of raising the child with a disability	21
2.3.4. Childhood disabilities in families with low socio-economic status	21
2.3.5. Coping with the challenges of raising a child with a disability	23
2.4. PHYSICAL DISABILITIES.....	24
2.4.1. Causes of physical disabilities	24
2.4.2. Classification of physical disabilities	25
2.5. THE SITUATION OF CHILDREN WITH DISABILITIES IN LESOTHO	26
2.6. DISABILITY LEGISLATION, POLICIES AND PROGRAMMES IN LESOTHO	26
2.7. SOCIAL WORK INTERVENTION IN FAMILIES WITH LOW SOCIO-ECONOMIC STATUS THAT ARE RAISING THE CHILDREN WITH PHYSICAL DISABILITIES	28
2.8. SUMMARY.....	30
CHAPTER 3.....	31
Research methodology and empirical findings of the study	31
3.1. INTRODUCTION	31
3.2. RESEARCH METHODOLOGY	31
3.2.1. Research approach.....	31

3.2.2.	Research question of the study	32
3.2.3.	Type of research	32
3.2.4.	Research design and methods.....	33
3.2.5.	Data collection method.....	35
3.2.6.	Data analysis.....	36
3.2.7.	Trustworthiness of qualitative data	37
3.2.8	Pilot study	39
3.3.	ETHICAL CONSIDERATIONS.....	39
3.3.1.	Informed Consent	40
3.3.2.	Avoiding deception of participants	40
3.3.3.	Debriefing of Participants.....	40
3.3.4.	Privacy, anonymity and confidentiality	41
3.3.5.	Publication of the study findings	41
3.3.6.	Competence of the researcher	41
3.4.	EMPIRICAL FINDINGS.....	42
3.4.1.	Empirical Findings: Part 1	42
3.4.2.	Empirical Findings: Part 2	49
3.5.	SUMMARY.....	103
CHAPTER 4	105
THE KEY FINDINGS, CONCLUSIONS AND RECOMMENDATIONS	105
4.1.	INTRODUCTION	105
4.1.1.	The Study Goal and Objectives	105
4.2.	SUMMARY OF THE KEY FINDINGS	106
4.3.	CONCLUSIONS.....	109
4.4.	RECOMMENDATIONS.....	111
4.5.	CHALLENGES ENCOUNTERED DURING THE STUDY	113
4.6.	SUMMARY.....	113

REFERENCES.....	115
APPENDICES	125

Terms and definitions

Basotho: The people of Lesotho

The mountain Kingdom: A nickname given to Lesotho because of its mountaineous terrain and the monarchy rule

List of Acronyms

ADHD:	Attention Deficit Hyperactivity Disorder
APA:	American Psychological Association
BOS:	Bureau of Statistics
CNS:	Central Nervous System
COPE:	Can Overcome Problems Effectively
FASD:	Fetal Alcohol Spectrum Disorders
GOL:	Government of Lesotho
HIV:	Human Immunodeficiency Virus
ID:	Intellectual Disabilities
IDAL:	Intellectual Disability Association of Lesotho
IFSW:	International Federation of Social Workers
IQ:	Intelligence Quotient
LNFOD:	Lesotho National Federation of the Disabled
MDGs:	Millennium Development Goals
MoSD:	Ministry of Social Development
NDRP:	National Disability and Rehabilitation Policy
NGOs:	Non-Governmental Organizations
OVCs:	Orphaned and Vulnerable Children
PLWD:	People Living With Disabilities
PRS:	Poverty Reduction Strategy
UN:	United Nations

UNCRC: United Nations Convention on the Rights of the Child
 UNCRPD: United Nations Convention on the Rights of Persons with Disabilities
 UNICEF: United Nations Children’s Fund
 WHO: World Health Organization

List of Tables

Table 1: Risk factors for disability among children in Africa 17
 Table 2: Participants' position and relationship to the Child 44
 Table 3: Positions of the Participants in their families 45
 Table 4: Number of children with disabilities in participating families 46
 Table 5: The types and severity of disabilities among children in participating families
 49
 Table 6: Themes and Sub-themes extracted from the data 50

List of figures

Figure 1: Gender of the participants 43
 Figure 2: Ages of Participants and their children 43
 Figure 3: Marital status of the Participants 44
 Figure 4: Participants' level of education 45
 Figure 5: Sizes of participating families 46
 Figure 6: Average monthly income in the participating families and the amount
 allocated to the children’s special needs 47
 Figure 7: Average education in the participating families 48
 Figure 8: Causes of the children's disabilities 48

List of Appendices

1. Ethical Clearance 126
 2. Letter of Permission from Social Development 127
 3. Letter of Introduction to Participants 128
 4. Participants’ Informed Consent Letter 129
 5. Interview Schedule 133

CHAPTER ONE

GENERAL BACKGROUND TO THE STUDY

1.1. INTRODUCTION

The cost of raising a child can be overwhelming for any family. For families with children with disabilities, the expense is even higher (Meyers, Henry, Brady & Seto, 2000:07). Children with disabilities require additional time and financial means due to their wide ranging special needs. Meyers et al. (2000:07) suggest that families that raise the children with special needs spend at least three times the cost of raising a non-disabled child. The presence of a child with a disability in the home therefore presents a significant challenge to the family's economic self-sufficiency.

The causes of childhood disabilities vary greatly. While some children become disabled due to environmental and developmental conditions that deteriorate their health, some children are born with disabilities as a result of complications during pregnancy and birth (Anderson, Dumont & Azzaria, 2007:06). Unfortunately, children with disabilities could be born into any family, including the poorest of the poor. In fact, some authors (Meyers et al., 2000:09; Newacheck & Kim, 2005:11) argue that there is a higher possibility of children with disabilities being born into families that have low socio-economic status, than into more affluent families. "This elevated risk stems, in part, from exposure to living conditions and health care practices that increase the probability and the severity of illnesses and other potentially disabling conditions among people with low socio-economic status" (Meyers et al., 2000:09).

This study was undertaken to explore the coping strategies employed by families with low socio-economic status raising the children with physical disabilities. The study was conducted in Mafeteng, Lesotho. Lesotho is a mountainous country entirely surrounded by South Africa. The country covers 30.355 square kilometres and has a population of approximately 1.8 million people in ten districts (BOS, 2006:sa). Mafeteng is one of the developing districts in Lesotho, located in the southern region of the country. The district comprises of both lowland and mountainous area.

Due to a lack of services and the low levels of development in the district, the quality of life for people in Mafeteng is generally poor (Thabane, 2008:i). It was for this reason, and also because there was no previous research done into the coping mechanisms of families of children with disabilities, that the researcher developed an interest and undertook this study.

1.2. DEFINITION OF THE KEY CONCEPTS

The following key concepts are defined in this study:

1.2.1. Children

The Lesotho National Children's Protection Act No. 6 of 1980 defines a child as "any unmarried person aged below 18 years" (National Children's Protection Act No. 6 of 1980, Section 2). The words child and children as used in this study are based on this definition. Throughout this report, the researcher occasionally refers to the children with physical disabilities as "the child", or "the children".

1.2.2. Poverty

In this study, the researcher refers to poverty in relation to material and economic hardships, drawing from Lauer and Lauer (2011:159) 's definition which categorises poverty as "a state in which income is not sufficient to provide for basic necessities such as food, medical care and clothing". The Oxford Dictionary of Social Work (2008:1573) distinguishes between relative and absolute poverty. Absolute poverty is defined by the dictionary as severe, life threatening deprivation of basic human needs (Oxford, 2008:1573). Additionally, the International Federation of Social Workers (2012:sa) asserts that people who live in absolute poverty may frequently be hungry, lack safe drinking water and may lack (proper) shelter and adequate clothing. Relative poverty, on the other hand, refers to a situation in which people can afford their basic needs even as they fail to keep up with the living standards of those around them (Oxford, 2008:1573).

The families that were targeted by this study were those that lived on or below the poverty line and who had one or more children living with a physical disability. For sensitivity purposes, the researcher decided to use the phrase ‘families with low socio-economic status’ instead of ‘poor families’ to refer to the target population.

1.2.3. Families with low socio-economic status

The researcher encountered a variety of definitions formulated to describe the concept “family”. From a socialist perspective, the family is regarded as a social group, differentiated from other groups by the permanent, involuntary membership that is established by the biological connectedness between members (Doherty, Boss, LaRossa, Schumm, & Steinmetz, 1993:13). On the other hand, the systems theory construes the family as a system of interconnected and interdependent parts (members), who exist to complement one another in order to survive (Hurst, 2009:73). From the structural-functionalism perspective, the family is regarded as a social institution, whose existence is mainly to meet the needs of its members so as to enable the society to survive (White, Klein & Martin, 2014:164). The structural functionalists further propose two major structures in which the family can be presented. Firstly, the family can be presented in the form of an extended family, one that consists of the entire kinship. Secondly, the family can present in the more typical structure of a nuclear family, one that consists of a husband, wife and children (White et al., 2014:165).

The definition of the concept “family” as used in this study was drawn from these three perspectives. The researcher uses “family” to refer to a group of permanently interdependent and interconnected members, related biologically or otherwise, each of whom has a role to play in the development and survival of others. The main functions of the family are support, regulation, nurturing and socialisation of its members (Allen, 2007:133).

On the other hand, the socio-economic status as described by Ncho and Wright (2013:sa) is an economic and sociologically combined measure of an individual or family’s economic and social position relative to others based on income, education and occupation. For purposes of the study, the researcher decided to use the phrase

'families with low socio-economic status' to refer to those families living on or below the acceptable standard of living, which in Lesotho is measured at 14 Maloti (\$1) per day.

1.2.4. Childhood Disabilities

A disability is defined by Andrews (2008:13) as "the inability to engage in any substantial activity by reason of a medically determinable physical or mental impairment". Activities that are mainly affected by the presence of a disability include: caring for oneself in hygiene and homemaking; having intact senses; communicating with others; learning and working; using mental processes such as thinking, concentrating and problem solving; interacting with others and developing and maintaining relationships (Midgley & Conley, 2010:sa).

Childhood disabilities is a phrase used to define the "chronic physical, mental and emotional conditions that limit activities, learning and healthy development of children" (Meyers et al., 2000:11). Of importance to the study were the children with 'physical disabilities', which are defined as "any impairment which limits the physical function of one or more limbs or fine or gross ability" (Midgley & Conley, 2010:sa).

1.2.5. Coping strategies

Taylor (2008:98) refers to coping strategies as "specific efforts, both behavioural and psychological, that people employ to master, tolerate, reduce or minimize stressful events". Based on this definition, and for purposes of the study, 'coping strategies' is used herein to refer to any measures employed by the families raising the children with physical disabilities to survive the stress brought on by taking care of their children.

Taylor (2008:98) states that there are two classes of coping strategies: problem-solving strategies and emotion-focussed strategies. Problem-solving strategies are efforts used to alleviate or eliminate stressful circumstances; while emotion-focussed strategies are efforts used to reduce or manage the emotional distress associated with the situation (Taylor, 2008:98-99). A similar distinction is made by Holahan and

Moss (2007:948) who established the categories active and avoidant coping strategies. Active coping strategies are said to be those efforts designed to change the nature or presence of the stressful event, while avoidant coping strategies refer to those activities people engage in to keep away from the reality of having to deal with their stressful situations (Holahan & Moss, 2007:948).

1.3. THEORETICAL FRAMEWORK

As rightfully noted by Lysaght (2011:572), a researcher's choice of framework reflects important personal beliefs and understanding about the nature of knowledge, how it exists in relation to the observer, the possible roles to be adopted, and the tools to be employed by the researcher in his or her work. Therefore, the researcher found it imperative to approach this study from a combination of the family systems theory and the ecological systems perspective in order to understand the coping strategies employed by the low socio-economic status families who are raising the children with physical disabilities.

1.3.1. Family systems theory

The family systems theory was introduced by Dr Murray Bowen who derived it from the general systems theory (Hurst, 2009:73). The family systems theory suggests that individuals cannot be understood in isolation but rather as a part of their families. In lieu of this theory, a family is defined as "a system of interconnected and interdependent individuals in which each member has a role to play" (Hurst, 2009:73).

Each family has unique properties that are known only by observing the relationships and interactions among its members. The unique characteristics of the family members, the family's resources, cultural beliefs and ideological styles determine the family's support for one another and the degree of adaptability to challenging conditions (Allen, 2007:133).

Following the family systems perspective, Feher-Prout (1996:158) points out that "a disability in one family member affects the entire system ...". However, it is the

unique properties of the family unit that determines the manner in which members react to the presence of a special needs child. The personal characteristics of family members, the family's resources, cultural beliefs and ideological styles influence the family's efforts to integrate the disabled child. For instance, cultural beliefs can influence if and how family members seek help, as well as the extent to which individual members shift from their normal roles and positions to accommodate the needs of the child.

By considering the interconnectedness and interdependence among family members as components of the system, together with the distinctiveness of each family and the influence that the community and the external environment as the supra-system can have over the operation of family units, the researcher aimed to uncover a wide range of stressors associated with raising the child with a disability, as well as the varying coping strategies across families.

1.3.2. The ecological systems perspective

The study further adopted an ecological systems perspective of Urie Bronfenbrenner, which explains the importance of the environment on stress and coping. The ecological systems perspective (also known as the eco-systems perspective) describes that human development can only be understood from considering the five socially organized sub-systems that support and guide human growth (Bronfenbrenner, 1994:39). These sub-systems are defined as levels in which humans interact with their environment, they are explained as thus:

The *microsystem*, refers to the setting where an individual interacts at personal, face to face level with particular social, physical and symbolic features which invite, permit or inhibit engagement in sustained, progressive interaction with the immediate environment (Bronfenbrenner, 1994:39). The *mesosystem* comprises of linkages and processes taking place between two or more settings containing the developing person, for example, the relation between home and church. The *exosystem* refers to linkages between two or more microsystems, one of which does not include the individual but has implications for the individual, for instance, the child's parent's workplace. The *macrosystem* refers to a culture or sub-culture in which other

systems are nested, for instance policies, whereas the *chronosystem* encompasses a change or consistency over time of the individual's characteristics and the environment in which the individual lives (Bronfenbrenner, 1994:39).

The ecosystem perspective was introduced to social work by Carol Meyer in 1970 (Dorfman, 2013:15). Similarly to Bronfenbrenner, Meyer emphasizes that human beings do not exist in isolation, but rather as a part of their environment (Dorfman, 2013:15). To understand the situation of an individual person therefore, Meyer developed an eco-map which locates the person within their social context. The eco-map clearly demonstrates that humans are only a part of a more complex social environment, consisting of various other entities such as the family, community, relationships and culture, which are all also interrelated (Dorfman, 2013:15).

The implication of eco-systems perspective for social work research is that an individual reacts to his /her environment and that various aspects of the individual's environment are interconnected (Washington, 2007:49). Based on this perspective, Munhali and Fitzsimons (2001:51) argue that not all families experience the environment in the same way: an environment that places one family at risk may give another family a developmental advantage.

Together the family systems theory and the eco-systems perspective explain how and why a disability in a child can affect other members of the family and the functioning of the family as a whole. Based on the family systems theory, it makes sense to assume that as a result of a disability in one or more children in the family, other members will experience both economic and psychological pressures. On the other hand, the ecological systems theory emphasises the influence that the external environment has on individual families, which results in different families employing different coping strategies to deal with the pressures of raising the child with a disability. These theories were found to be the most appropriate for the study. They have informed the investigation of the research problem, they have further guided the researcher during data collection and also in the interpretation of the findings.

1.4. RATIONALE AND PROBLEM STATEMENT

As noted earlier, raising children is a highly demanding job for all families; the demands are even higher when a child has a disability because the needs of a child with a disability are three times higher than the needs of a non-disabled child (Meyers, et al., 2000:07). When childhood disabilities occur in families with low socio-economic status, raising children becomes even more difficult for the families as they already have less than what they require to meet the needs of the other members (Sharma & Dowling, 2004:37).

“Lesotho has a very limited coordinated disability database to provide statistics of people with disabilities” (Chitereka, 2010:17). Nevertheless, based on available data, it becomes clear that the number of *Basotho* children living with disabilities increased significantly between 2001 and 2011. Data collected by the BOS in 2001 indicate that about 18.7% of persons aged zero to twenty four years was living with various forms of disabilities (BOS, 2001:298). Ten years later, Kamaleri and Eide (2011:42) estimated that the prevalence of disabilities was 23.8% among the Basotho people aged between zero and twenty years. This figure is corresponded by the 2011 Lesotho demographic survey report (BOS, 2011:277), which depicts that the overall number of persons aged zero to nineteen years, who were living with disabilities at the time summed up to 23.8% among the population of the same age.

The increase in childhood disability parallels the persistent rise in poverty among citizens of the *Mountain Kingdom* over the last two decades. As stated by the Lesotho’s poverty reduction strategy paper of 2004/2006, Lesotho is currently one of the poorest countries in the world (GOL, 2005:03). In the 2011 country situational report, the United Nations Children’s Fund described the situation of Lesotho’s children as dreadful. “Out of 1.8 million residents, more than 900 000 were found to be living below \$1.25 a day without proper shelter, and 500 000 of these were children” (UNICEF, 2011:1-2). More than half (52%) of the citizens of Lesotho are aged below 18 years (BOS, 2006:sa). With all these figures, poverty is among the biggest threats to the survival, care, protection and development of children in the country (Kimane, 2005:sa). Poverty inflicts even greater hardships on those families

whose children are living with disabilities as it makes it difficult for the families to meet their children's special needs.

1.4.1. Justification

There is limited data on the situation of the children living with disabilities in Lesotho. The ministry of social development indicates that there is no comparative report, in the public reports, of the particular risks faced by the children with disabilities and their families as opposed to their non-disabled peers (GOL, 2014:sa). Owing to this, programmes initiated by the government for the benefit of such children are greatly influenced by the outcries from organisations that support the people living with disabilities, and most of these are delivered as subsets of the programmes intended to meet the needs of the general population. For example, Lesotho does not have a specific grant for the people living with disabilities, rather the children with disabilities are enclosed within the larger group of orphaned and vulnerable children entitled to the child grant of 360 Maloti (ZAR 360.00) per child received once a month. Disabled adults who are financially underprivileged receive the public assistance grant of 250 Maloti (ZAR R250.00) per month along with other poor citizens (Makakole, 2014:sa). The cost of child care is already too high for many families with low socio-economic status in Lesotho. For this reason, the researcher developed the quest to know how families with the children with disabilities managed.

The study was not only undertaken to feed the researcher's curiosity, but also to raise awareness on the situation of children with disabilities and their families in Mafeteng, and to influence policy implementation and decentralisation of services throughout the country.

The main research question for the study is: *“What are the coping strategies of families with low socio-economic status raising children with physical disabilities in Mafeteng, Lesotho?”*

1.5. STUDY GOAL AND OBJECTIVES

The goal and objectives of the study are listed hereafter.

1.5.1. The Goal of the study

To explore and describe the coping strategies of families with low socio-economic status raising children with physical disabilities in Mafeteng, Lesotho.

1.5.2. Objectives

- To conceptualise childhood disabilities within families with low socio-economic status
- To explore the challenges experienced by families with low socio-economic status in raising the children with physical disabilities
- To explore the coping strategies of these families when dealing with the challenges of raising the children with disabilities
- To suggest strategies to the Department of Social Development about the social work services that are needed by the families with low socio-economic status that are raising the children with physical disabilities

1.6. RESEARCH DESIGN AND METHODOLOGY

The following discussion is a brief overview of the research methodology utilised for the study. It is worthy to note, however, that a detailed description of the research methodology, including the research approach, type of research, research design, methodology, and the measures that were taken to ensure the trustworthiness of the data, as well as the ethical considerations of the study, are presented in chapter three of this report.

The study assumed a qualitative nature, it was undertaken from an explorative research approach. The explorative approach was chosen because it is compatible with studies that intend to explore and describe phenomena for which knowledge is limited (Punch, 2005:14).

The study was designed in the form of a collective case study, which enabled the researcher to gather exhaustive data by coordinating and aggregating evidence from a number of individual case studies (Johnson & Christensen, 2008:408). Data was

collected through open-ended, semi-structured, face-to-face interviews from a sample of ten families.

Because of the interpretive nature of the information collected, data was analysed thematically following these steps of qualitative data analysis as suggested by Creswell (2009:173-189): transcription, familiarization, generation of codes and themes and finally interpretation of collected data.

A detailed discussion of the methodology is provided in chapter three of this report.

1.7. LIMITATIONS OF THE STUDY

Even as the study was successfully undertaken, there were minor issues which could to a certain extent influence the quality of collected information, these are:

1.7.1. Researcher-Participants relationship

The study was conducted in the researcher's home town, where some of the participants happened to be aware of the researcher's previous work with vulnerable children. For this reason, there is a possibility that some of the participants could give responses hoping for a remedial action, even as it had been clearly stipulated that the study was purely for academic purpose and that participation did not guarantee any direct benefit.

1.7.2. Lack of understanding from the participants

The researcher further noted that some participants believed the information they provided would somehow influence the services they were entitled to at the Department of Social Development (referred to herein as "the Department"), and were for most part of their interviews bringing in their woes and concerns about the services offered by the Department rather than the system in general.

1.7.3. Duration of the study

This study was intended to last for twelve months (from January to December 2015), however, due to inevitable delays, the researcher could not complete the study within the proposed time period. Data was collected in March 2016 as opposed to the initial plan, nonetheless, researcher believes the time difference between research proposal and data collection was not so significant as to have impacted on the relevance of the information collected.

1.7.4. Changes in sampling techniques

Some details of the participants as provided by the Department were outdated. Some families' contact details were no longer in use while other families were no longer residing in the addresses provided. In one other case, the researcher only learned upon contacting the family that the child had passed on in about four months back. These affected the sampling procedure as the researcher had to get back to the list to replace this family and those that could not be contacted with those that had been left out during the random selection.

1.8. CONTENTS OF THE RESEARCH REPORT

The contents of the present report are described below:

1.8.1. Chapter One

This chapter introduces the report and then provides the background of the study through the theoretical framework. The chapter further discusses significance of the study through statement of the problem and the study rationale, it outlines the study goals and objectives, research design and methodology as well as the limitations of the study.

1.8.2. Chapter two

The second chapter presents in-depth details of the study background that are particular to the literature review on raising the children with physical disabilities as well as the eco-systems perspective and family systems theory that provided a framework for the study.

1.8.3. Chapter three

Through this chapter researcher discusses the research methodology and summarises the study findings, with detailed descriptions of the research approach; research type; research design; research methods; population and sampling; data collection; data analysis; the pilot study; and the ethical considerations.

1.8.4. Chapter four

The last chapter marks the conclusion of the report. Entailed within the chapter is a summary of the study findings, empirical results, the researcher's recommendations and the concluding remarks.

The next chapter presents a detailed discussion on the coping strategies of families with low socio-economic status in raising the children with physical disabilities.

CHAPTER 2

Coping strategies of families with low socio-economic status raising children with physical disabilities

2.1. INTRODUCTION

The research into families' experiences of raising a child with a disability is varied, with recurring themes of stress and burden being reported, and only modest of the positive experiences. This chapter focuses on common themes and reviews fundamental debates on the cost of caring for the children with disabilities. The researcher's goal in conducting the literature review was to identify the overarching discussions and theory emerging in the field of childhood disabilities especially in the context of poverty.

The researcher collected review material from publications on childhood disabilities, poverty and childhood disabilities, childhood disabilities in Lesotho, child poverty in Lesotho and childhood disabilities in low income families. Even as there were not many publications focussing solely on the children of Lesotho, the researcher discovered a wide variety of relevant publications, the majority of which were scholarly articles in social sciences, education and the medical sciences.

2.2. THE SOCIO-ECONOMIC STATUS

A number of indicators have been attached to the definition of socio-economic status, such as income, education and occupation. For example, the American Psychological Association (APA) dictionary of psychology (VanderBos, 2007:871) defines socio-economic status as "the position of an individual or group on the socio-economic scale, which is informed by a combination or interaction of social and economic factors, such as income, amount and type of education, kind of prestige and occupation, place of residence and in some societies, even the ethnic origin and the religious background". These factors separate high socio-economic status groups from low socio-economic status groups, thus provide the basis for definition and identification of the "families with low socio-economic status".

In many cases, the socio-economic status is used interchangeably with the “standard of living”, the “social class” and by some authors, the “quality of life”, perhaps because of the similar indicators used to define all these concepts. For instance, the human development index, which is used to measure the standard of living, takes into account the following indicators; life expectancy, level of education and the gross domestic product (Ramey & Ramey, 2004:684). Moreover, social class is defined by Gilbert (2008:11) as “groups of families more or less equal in rank and differentiated from other families above or below them with regard to characteristics such as occupation, income, wealth and prestige” whilst the quality of life is defined using “social and economic resources such as intimate relationships, work and neighbourhood” (Gilbert, 2008:11).

Based on the nature of the problem under investigation, researchers contextualise the socio-economic status differently even as they use the same indicators. For instance, a study done in South Africa on the influence of socio-economic status on educational achievement used indicators like whether the house had a television or radio, type of dwelling, the father’s educational level, number of people sharing a bedroom, cooking mode used, and the household income (Themane, Koppes, Monyeki, Twisk & Kemper, 2006:300). The justification for using these indicators was that they formed the home environment that was conducive to a child’s learning.

In the context of this study, socio-economic status is used to refer to the assessment of the people’s standard of living as compared to those around them (Ncho & Wright, 2013:sa). The standard of living customary to Lesotho is measured at the rate of 14 Maluti (\$1.25) per day. Families with higher socio-economic status are those whose daily expenditure is above the standard of living, whereas the families with low socio-economic status are those whose overall daily expenses cost less than 14 Maloti.

2.3. CHILDHOOD DISABILITIES

Childhood disabilities is a phrase used to define the “chronic physical, mental and emotional conditions that limit activities, learning and healthy development of children” (Meyers et al., 2000:11). Millions of the world’s children live with a disability that makes them more likely to be marginalized (UNICEF, 2013:86). Initially, such

children were cared for in specific institutions, however, with the emphasis on de-institutionalisation and home based care, majority of the children with disabilities are lately being cared for at home (Parish & Cloud, 2006:224).

2.3.1. Prevalence of childhood disabilities

UNICEF (2013:47) highlights the difficulty to gather precise data on the children with disabilities, especially in developing countries. In 2005, the same organization gave an estimate that across the world; at least 150 million children under age 18 were living with disabilities (UNICEF, 2005:192). Five years later, Chitereka (2010:xi) asserted that there were at least 180 million children with disabilities worldwide, and that 400 million of those were living in developing countries while 80 million lived in Africa. Looking at these figures, it becomes apparent that the number of children with disabilities is on the rise. Parish and Cloud (2006:223-224) attribute this rise to the advances in medical technology which have improved the chances for premature babies and children with complex health conditions to survive into adolescence and adulthood.

2.3.2. Common causes of disabilities in childhood

There is consensus among various authors on the causes and detection of childhood disabilities. Causal factors general to all forms of childhood disabilities include genetic, pregnancy and birth related predisposition, environmental hazards, illness and developmental vulnerability (Anderson et al., 2007:06). Diagnosing a child's disability can be either sudden or gradual. Hunt and Marshal (2013:213) say most families recognise the signs of disability at a later stage in life, rather than at birth. Nevertheless, parents are often the first to suspect, even as they postpone acknowledgement of their child's problem (Hunt & Marshal, 2013:213).

Specific risk factors have been associated with disabilities among children in Africa. UNICEF (2012:sa) summarised the risk factors as follows:

Table 1: Risk factors for disability among children in Africa

Risk factor	Predisposing factors	Resultant health conditions	Impairment/Disability
<i>1. Risk factors before birth (during pregnancy, antenatal, prenatal)</i>			
Genetic and congenital disorders	Genes/Hereditary	Congenital heart disease, cataract & deafness; down syndrome; neural tube defects & hydrocephalus	mobility, cognitive, sight & hearing
Environmental (nutritional, infections, toxic & traumatic)	Viral Infections/ Mother's alcohol & drugs intake	Congenital rubella/syphilis; Attention deficit disorder & FASD	mobility, cognitive, sight & hearing
<i>2. Risk factors at birth (neonatal)</i>			
Prematurity/ Birth complications	Low birth weight, Birth asphyxia, hypothyroidism, jaundice & meningitis	Developmental delay, Epilepsy, Intellectual disability & retinopathy of prematurity	Physical, intellectual, visual
Infections	HIV mother-to-child transmission	HIV encephalopathy; cerebral palsy	Neurodevelopmental disability; cognitive, visual, spatial & motor deficits; neurological impairment & mobility impairment
<i>3. Risk factors after birth (perinatal)</i>			
Infections; injuries	CNS infections, accidents	Cerebral palsy, epilepsy, HIV, ID & rheumatic heart disease	Cognitive, mobility



<i>4. Risk factors during infancy (under 1 year old)</i>				
Infections	High fevers, dehydration, febrile convulsions	Encephalitis, Bacterial meningitis	cognitive, hearing, visual	
<i>5. Risk factors during early childhood (1-5 years old)</i>				
<u>Infections</u>	Lack of vitamin A, unhygienic conditions, upper respiratory tract infections, neglected ear care, mosquitos and lack of nets	Measles and resultant corneal scarring, polio, otitis media, cerebral malaria, encephalitis & malaria	Mobility, sight & hearing	cognitive,
<u>Parasites</u>				
Injection of eggs of the pork tapeworm	Parasitic disease of CNS-neurocycercosis	Acquired epilepsy	Intellectual, cognitive, motor deficits	
Intestinal worms	Unhygienic habits & conditions around the house	Anaemia	Intellectual, cognitive	
Bilharzia	Using water from contaminated rivers			
<u>Child Injuries</u>				
Non intentional (accidental)	Falls, burns & thermal injuries due to neglect, environmental hazards, poor safety standards, unattended appliances/poisons	Head injury, traumatic brain injury, spinal cord injury, limb amputation, burns	Mobility, psychological, cognitive, aggressive behaviour	
Intentional (non-accidental)	Trauma, violence, Child abuse (physical, emotional, sexual, child neglect)	Anxiety, depression, post traumatic stress disorder, physical injury, malnutrition	Psychological, mobility	



<u>Malnutrition</u>				
Child undernutrition	Protein energy malnutrition	Underweight for age, stunting (sign of chronic malnutrition), wasting (sign of acute malnutrition), lack of essential nutrients, strong predictor of mortality	Developmental delays, psychological, Impaired cognitive function	mobility, Mild cognitive disabilities
Micronutrient deficiencies	Mineral deficiencies (i,e iron, iodine, foliate), vitamin deficiencies (i,e vit A), Iron deficiency (linked to insufficient iron intake, worm infestations)	Delayed physical and mental growth, decreased resistance to infections, Iron deficiency anaemia, ADHD	Mobility, cognitive deficits, Intellectual disability, Learning disabilities, behavioural disabilities (aggression), psychiatric disabilities	
<u>Environmental</u>				
Unclean water, lack of sanitation	Compromised immunity to infections linked to malnutrition	Diarrhoeal diseases, Intestinal worms, Eye ailments, Skin ailments (eczema, impetigo)	Visual, (learning)	cognitive
Air pollution	Smoke	Lower respiratory tract infections, asthma, respiratory diseases e.g pneumonia, chronic cough, Eye problems, cancer	Mobility, cognitive	visual,

Lead	High levels of lead in the blood	Long term, potentially irreversible health problems, Anaemia & abnormal growth of almost all organs, permanent muscle paralysis, brain damage (lowered IQ) hyperactivity and difficulty concentrating, reading and learning, difficulties in school	Mobility, cognitive	visual,
------	----------------------------------	---	---------------------	---------

Source: UNICEF (2012:sa)

While disability is a primary condition with its own underlying cause(s), it has been established that with time further complications can occur as a consequence or sequel of the original disability (Simeonson, 2002:349). Simeonson (2002:349) carved these secondary conditions up into the following criteria:

- They are either direct or indirect consequences of an underlying primary condition,
- They reflect the effect of a person-in-environment interaction for which the primary condition was a risk factor,
- The nature and extend of the expressed secondary condition is related to factors such as age or developmental stage of the individual and
- The mediating role of the individual's personal traits and characteristics play a role in the development of a secondary condition.

Examples of secondary conditions are obesity, pressure sores and urinary tract infections (Simeonson, 2002:349).

2.3.3. The costs of raising the child with a disability

Raising the child with a disability is obviously very costly. As noted by Parish and Cloud (2006:09), the strain is not only financial but it is also psycho-social. In light of this, some authors began using the term “expensive children” to refer to children with disabilities (Newacheck & Kim, 2005:18; Parish & Cloud, 2006:09; Meyers et al., 2000:21). Meyers et al. (2000:21), identified two faces in the financial cost of raising the child with a disability; firstly there is the indirect financial costs from the work reductions and forgone earnings as a result of care for a special needs child and secondly, families incur direct financial costs through the out of pocket expenses incurred to cover the child’s needs.

On the other hand, the psycho-social costs of raising the child with a disability encompass “a wide variety of deteriorations in the quality of life resulting from the child’s disability” (Hodgson & Meiners, 1982:435). Care-giving tasks such as daily therapy, concern about the child’s future, and the financial costs of the child’s disability can all lead to emotional stress, disruptions in family relationships, and other psychosocial costs (Neely-Barnes & Marcenko, 2004:287; Newacheck & Kim, 2005:27).

Due to low levels of development, Lesotho is currently not in a position to provide specialized services for the people living with disabilities. However, in more advanced countries such as the United States, Canada and the United Kingdom, a portion of the public resources is devoted to assist the families of children with disabilities to care for such children (Woolley, 2004:42; Meyers et al., 2000:xi). Whilst this can be interpreted as a relief measure to those directly affected by the child’s disability, some complain that the private dilemma of caring for a child with a disability goes on to yield public implications (Meyers et al., 2000:21).

2.3.4. Childhood disabilities in families with low socio-economic status

A relationship between low socio-economic status and childhood disabilities is well established. For instance, a number of authors contend that children from low-income families are at a 40 percent higher risk of being disabled than children from

more affluent families (Newacheck & Kim, 2005:28; Reitemeir, 2011:02). This discrepancy is attributed to the psychosocial environment provided by the low income families, which is believed to be friendly to infections, illnesses and other potentially disabling conditions (Newacheck & Kim, 2005:28).

It has further been established that life is particularly dismal in families where childhood disabilities overlap with low socio-economic status. Sharma & Dowling (2004:37) noted that raising special needs children becomes even tougher because the families with low socio-economic status already have less than what is required to meet the needs of the rest of the members. Additionally, due to the high cost of special services, the children with disabilities in low socio-economic status families miss on the much needed services and the basic entitlements required for improved quality of life; including education, health care, shelter, hygiene and feeding (Reitemeir, 2011:02).

On a different note, some authors believe that childhood disabilities trigger poverty because of the financial costs associated with care of a child with a disability, family break-up that can follow birth or diagnosis of the child and the loss of earnings resulting from increased care giving responsibilities (Woolley, 2004:58; Anderson et al., 2007:11). “While poverty is already an impediment to development of children in all families, for families of children with disabilities, the impact of poverty can be particularly severe as these families are faced with substantial additional costs, such as larger heating bills, higher travel costs, and a higher need for medical care” (Woolley, 2004:58). Families with more than one child with a disability are, therefore, living under an even further strain, with a much higher risk of living in poverty. A study undertaken by Sharma and Dowling (2004:37) estimated that ten per cent of families raising the children with disabilities in the United Kingdom care for more than one such child.

As a consequence of additional costs and limited income, families of children with disabilities are more likely to be poorer than others. Woolley (2004:67) indicated that families with only healthy, non-disabled children who happen to fall below the standard of living are able to get back to their feet within the first year of financial

struggle, whereas for families of children with a disability or chronic illness, poverty, if introduced, will most likely become permanent.

2.3.5. Coping with the challenges of raising a child with a disability

Even as parents of children with disabilities experience periodic sadness and stress, many are able to cope successfully. Pritzlaff (2001:28) mentioned that parents of the children with disabilities have a greater appreciation for the smaller and simple things in life and that many of them have grown stronger (and not weaker) as a result of raising the special needs child, such that they can survive situations which are dreaded by others. Consequently, Pritzlaff (2001:28) suggests that “we should not automatically assume that a family is experiencing debilitating stress when they have a child with a disability”.

Nevertheless, Washington (2007:23) noted that characteristics and behaviour of individual children and the family’s resources are factors which determine the level of stress experienced by the families of children with disabilities. Since the children with disabilities exhibit different types of behaviour and the capacities of families are varied, it is reasonable to suggest that coping strategies of families will differ (Washington, 2007:23).

In countries such as the United States, Canada and the United Kingdom; public programs are said to be the most common ray of hope to addressing the burden experienced by low income families raising the children with disabilities (Meyers et al, 2000:75; Woolley, 2004: 21). Nevertheless, Woolley (2004:42) argues that these programmes, whose intention is to supplement the income of families so as to make it easier for them to cover the children’s special needs, converts into the only source of livelihood for the entire family. Researcher understands that it was this observation which influenced the introduction of institutionalisation in a number of countries. “Unlike the children’s needy families, institutions seemed to provide better, specialised response to the children’s needs” (Parish & Cloud, 2006:224). However, due to psychosocial purposes institutionalisation is at present giving way to home based care, thus a huge portion of the care-giving responsibility for the children goes back to lying with their needy families (Meyers et al, 2000:59).

Pritzlaff (2001:25) cited several studies in which coping strategies of families with children with disabilities were compared to the coping strategies of families without disabled children. In the first study, parents of the children with disabilities reported significantly higher avoidance coping, emphasized less on family interrelations, and reported few opportunities in the family for personal growth and lower coherence than parents of children without disabilities (Pritzlaff, 2001:25). The second study revealed that parents of children with disabilities experience more personal stress than those who do not have special needs children, with mothers subjected to higher amounts of stress. In this study, mothers of children with disabilities reported more daily care-giving demands, less time for themselves and they felt less competent as mothers. Furthermore, friendship networks for parents of children with disabilities were smaller (Pritzlaff, 2001:25). Based on these examples, the researcher is convinced that the presence of the child with a disability affects the family's functioning and will in one way or another bind the family to adopt specific strategies to cope with the challenges brought about by the child's condition.

2.4. PHYSICAL DISABILITIES

There are several types of disabilities; however, due to the vast amount of data available for all the different types of disabilities, the researcher decided to narrow the focus of this study to the children with physical disabilities only. Physical disabilities are defined as “any impairment which limits the physical function of one or more limbs or fine or gross ability” (Wolf-Branigin, 2013:sa). The physical disabilities are not only the most common but they also hold a number of implications for the children's families as they require changes within the environment structures, assistance with care such as hygiene and movement, and health care (Wolf-Branigin, 2013:sa).

2.4.1. Causes of physical disabilities

Physical disabilities range from congenital to acquired, meaning one is either born with the disability or one develops it at a later stage in life (Wolf-Branigin, 2013:sa). Mizrahi and Davis (2008:50) identified the following common causes of physical

disabilities among children: genetic or chromosomal disorders, which may be due to heredity or factors that interfere with foetal development; environmental events or exposures such as physical accidents; physical trauma before, during or after birth as well as the physical impact of disease or illness. Physical disability may be a temporary state for some, especially if it occurs after birth, but in many cases, physical disability becomes a lifetime condition (Mizrahi & Davis, 2008:51).

2.4.2. Classification of physical disabilities

Hunt and Marshall (2013:452-460) identified the following classes of physical disabilities; neurological disabilities, muskoskeletal disabilities and traumatic injuries.

2.4.2.1. Neurological Conditions

These are those disabilities that affect the nervous system (brain, nerves and spinal cord). Hunt and Marshal (2013:452) say in this type of disabilities, “the muscles and the bones are healthy, but the neurological messages send to them are faulty or interrupted”. This category of physical disabilities is said to occur from a defect in the formation of the neural tube during pregnancy, it occurs in an average of two among one thousand live children in Southern Africa (Kibel & Wagstaff, 1997:343). Neurological disabilities include cerebral palsy; spine bifida and seizure disorders. They affect the child’s posture and ability to move (Hunt & Marshall, 2013:452-456).

2.4.2.2. Muskoskeletal Conditions

The muskoskeletal disabilities affect directly the muscles and the bones. Physical disabilities of this type can show at any stage in life. Once present, the muskoskeletal disabilities debilitate the muscles, bones or joints, causing limitations in their functioning (Hunt & Marshall, 2013:456). They are mostly hereditary but can also occur as a result of the damage inflicted upon a child during pregnancy (Kibel & Wagstaff, 1997:345). Examples of muskoskeletal disabilities are muscular dystrophy; juvenile rheumatoid arthritis and congenital malformations (Hunt & Marshall, 2013:456-458; Kibel & Wagstaff, 1997:345-346).

2.4.2.3. *Traumatic Injuries*

These are described as the damage inflicted to the brain or the body after birth, mainly as a result of child abuse and accidents. Examples of traumatic injuries are spinal cord and traumatic brain injuries (Hunt & Marshall, 2013:458).

Physical disabilities place demands both on the children and their families. Children with physical disabilities may be inclined to use wheelchairs, canes, crutches, specialized chairs, desks and tables (Mizrahi & Davis, 2008:51).

2.5. THE SITUATION OF CHILDREN WITH DISABILITIES IN LESOTHO

The Lesotho Bureau of Statistics population census of 2006 revealed that 3.7% of Lesotho's population, which is about 68, 926 were living with disabilities in 2006. On the other hand, the Ministry of Social Development (GOL, 2014:sa) reported that around 8% of all Basotho children have a disability. The prevalent types of disabilities among the children in Lesotho are visual disabilities (blindness), communication disabilities (deafness and speech impairment), intellectual disabilities (mental illness/retardation) and physical disabilities (amputation of limb and lameness/paralyzed limb) (Makakole, 2014:sa).

In Lesotho, the common causes of childhood disabilities are poor maternal health, poor nutrition, poor medical access, home based deliveries, the childhood accidents and the complex medical conditions among infants and young children (Makakole, 2014:sa). In a country where more than half of the population is living in poverty, the children with disabilities are said to be among the most vulnerable in all societies (GOL, 2014:sa).

2.6. DISABILITY CONVENTIONS, LEGISLATION, POLICIES AND PROGRAMMES IN LESOTHO

In April, 2014 the Ministry of Social Development adopted a policy for persons with disabilities known as the Lesotho National Disability and Rehabilitation Policy (NDRP). This policy "seeks to ensure full enjoyment of the fundamental rights of the

people with disabilities as enshrined within the national constitution” (GOL, 2011: 03).

Development of the NDRP was informed by the various international and regional conventions ratified locally, for instance, the United Nations Convention on the rights of Persons with disabilities (UNCRPD) and the United Nations Convention on the Rights of the Child (UNCRC). Article 4 of the UNCRPD calls for member countries to engage in the development and implementation of policies, laws and administrative measures aimed at securing the rights of people with disabilities and to abolish laws, regulations, customs and practices that constitute discrimination towards the people with disabilities (Matlho, 2016:25). Furthermore, article 23(3) of the UNCRC spells out the rights of disabled children to special care, education and training (United Nations, 1990:07).

The national disability and rehabilitation policy was further informed by the strategic plan number “k” of the Poverty Reduction Strategy (PRS), which propels the government of Lesotho to “improve facilities to enable people with disabilities to access basic services” (GOL, 2005:16); the section 2.3.1 of the National Vision 2020, which states that “people with disabilities will be equal before the law; and will be accorded equal opportunities in all aspects of life” and the strategic action number thirteen of the vision which enhances the promotion of special education programmes for people living with disabilities (GOL, 2004:05).

The legal provisions that further contributed to the NDRP include the Education Act of 2010, The Buildings Control Act of 1995, the Sexual Offenses Act of 2003 and the National Health and Social Welfare Policy of 2003 (Makakole, 2014:sa; Dube, 2008:sa). One of the purposes of Lesotho’s 2010 Education Act is to “ensure, as soon as circumstances permit, that a learner who is physically, mentally or otherwise handicapped is given the special treatment, education and care required by his or her condition” (Education Act No.3 of 2010, section 2(b)). The Buildings Control Act also advocates for the inclusion of PLWD through section 19(2), which states that “Subject to sub-section (1), the Minister may by notice published in the gazette, order that any plan, specification, document or information in relation to a proposed building, shall provide for the physical access to the proposed building to persons of

different categories of disabilities” (Buildings Control Act No.8 of 1995, section 19(2)). The Lesotho National Health and Social Welfare Policy compelled the then ministry of health and social welfare to support, design, coordinate and provides services that are intended to improve the health and welfare of people living with disabilities (GOL, 2008:24-25). Lastly, the Sexual offences act, through section 15(2) states that “a person who commits any act with the intent to invite or persuade a disabled person to allow or to commit a sexual act in relation to that disabled person commits an offence” (Sexual offences act No.3 of 2003, section 15(2)).

However, the policy implementation continues to be a problem in the country, thus the presence of these frameworks tends to have little or no impact on the lives of children with disabilities and their families (Kimane, 2005:sa).

2.7. SOCIAL WORK INTERVENTION IN FAMILIES WITH LOW SOCIO-ECONOMIC STATUS THAT ARE RAISING THE CHILDREN WITH PHYSICAL DISABILITIES

Childhood disabilities challenge the resources of the children, families and communities with multidimensional and developmental stage-sensitive needs. Successfully addressing such needs requires a coherent plan or vision that can be achieved in consultation with social workers and other professionals for children with disabilities (Bricout, Porterfield, Tracey & Howard, 2011:56).

Literature reveals that social workers have been involved in disability services for many years. Initially they worked in residential facilities or medical settings and have provided counseling and case management services, responsible for financial aid, prosthetics and many other services. However, with the shift from residential to community care the contribution of social work in disabilities has changed from merely providing services to passive recipients to working together with PLWD and their families as collaborators, allies and advocates (Bricout et al, 2011:56).

Social workers support and facilitate independent, community living for children with disabilities and their families. They assist the children with disabilities and their families to access community resources by brokering the much needed services. They further provide counseling and advise to the children and their families, they

protect the children against exploitation and abuse, they ensure full participation of the children and their families in decisions that affect their lives and thus empower the children and their families to lead the best possible socio-economic lives despite the presence of a disability (Midgley & Conley, 2010:sa).

Social workers in Lesotho are also engaged in assisting the people with disabilities to develop to their best capacity in the country. Data from the ministry of social development indicates that there is a qualified social worker serving in the position of a rehabilitation officer in each of the ten districts, and these work together with the families and communities to empower the people living with disabilities by providing preventive, curative and rehabilitative services (GOL, 2011:sa).

In addition to the government, there is a number of organizations that work with PLWD in Lesotho, these include; the Lesotho Federation of the Disabled (LNFOD) which mothers a number of community based organizations, the training and rehabilitation institutions such as St. Angela's home and a number of special schools, which offer the rehabilitation services for children with disabilities (Chitereka, 2010:11).

Nevertheless, as noted earlier, services for the people with disabilities are still very limited in Lesotho. Such that the services referred to above are limited to specific areas and thus not accessible at ground root level where they are needed most (Chitereka, 2010:16). Mafeteng is no exemption to this disparity, the people residing in remote parts of the district are unable to benefit from essential services due to lack of transport, centralization of services to towns and the inaccessibility of their villages due to lack of infrastructure.

Sustainability is also a challenge to the development projects intended to meet the needs of vulnerable societies in the country. Due to low levels of development, operating in the rural areas becomes a problem such that services only survive when they are conducted from towns. For example, the Intellectual Disability Association of Lesotho (IDAL) is one of the organizations known to the researcher that made attempts to decentralize the disabilities services to the rural areas of Mafeteng, setting up its first rural post in Boleka, Ha Tanka in joint efforts with the community.

Nevertheless, this idea did not last long as the organization had to close office in 2015 due to operating challenges, whilst its urban offices continue to operate.

2.8. SUMMARY

From the above literature review, it is evident that Lesotho still has a long way to go in terms of responding to the needs of children with disabilities in the country, and assisting their families to cope with the strain of meeting the children's special needs. Lack of research in this area has been identified by the researcher as the main obstacle towards service provision for families of special needs children, along with poor implementation of the existing policies and the generally low levels of development especially among the rural population, which is exacerbated by centralization of essential services.

The researcher conducted this study not only to raise awareness on the situation of children with disabilities and their families in Mafeteng, but to also influence policy implementation and decentralization of services throughout the country. Since institutionalization is no longer a preferred option to caring for the children with disabilities, low income families have to be empowered to cope through the frustrations brought about by raising their "expensive" children.

With primary focus on how families with low socio-economic status cope through the challenges of raising the children with disabilities, the researcher is looking forward to yielding information that will effectively contribute to the literature on childhood disabilities in Lesotho and to also lure research interest towards children's families as secondary victims. The researcher hopes to influence even more systematic investigations studying the cost of childhood disabilities on the families with low socio-economic status. It is the belief of the researcher that these investigations will influence policy development and development of effective social work strategies aimed at empowering the families of children with disabilities to provide the best possible care for such children within the comfort of their homes.

The research methodology, ethical aspects, empirical findings and the summary will be presented in the next chapter.

CHAPTER 3

Research methodology and empirical findings of the study

3.1. INTRODUCTION

In this chapter, research methodology and empirical findings from the study will be discussed. The study particularly sought to establish the coping strategies of families that raise children with physical disabilities in conditions of poverty. The study question was influenced by the assumption that raising children is a challenging process on the families with low socio-economic status and that raising the children with disabilities is even more strenuous due to the special needs that the family faces as a result of the children's condition.

The first section of this chapter provides a detailed description of the procedure followed in conducting the study while the last section presents the empirical study findings.

3.2. RESEARCH METHODOLOGY

Following the applied research concept, the study was intended to benefit social work service delivery and provide recommendations on how best to address the challenges faced by families that raise the children with physical disabilities. This study has achieved the aforementioned goal by investigating, describing and therefore providing an in-depth understanding of specific efforts that families of children with physical disabilities adopt to cope with the stresses and challenges they experience as a result of raising these children.

3.2.1. Research approach

The study followed a qualitative approach which enabled the researcher to obtain a detailed description of the participants' perspectives and lived experiences from the participants themselves (Yount, 2006:43). The researcher understands that human beings are diverse and have different, though equally valid reactions towards the same stimuli, a qualitative approach alone would enable the researcher to

accommodate each participant's account through induction of themes and categories from which conclusions will be drawn (Braun & Clarke, 2006:79).

The study further adopted an explorative research approach. The explorative research approach was chosen because it is compatible with studies that intend to explore and describe phenomena for which knowledge is limited (Punch, 2005:14).

The researcher has observed how families with low socio-economic status struggle to meet the needs of their children, she has further learned that raising a child with a disability requires three times the efforts employed in raising a child without a disability, the researcher thus developed the curiosity to know how a family of low socio-economic status would manage to raise the child with a disability. The explorative approach therefore enabled the researcher to feed the curiosity by obtaining an in-depth understanding of the coping strategies of these families as described by the participants themselves (Mitchel & Jolley, 2012:261).

3.2.2. Research question of the study

The question behind this study is, *“What are the coping strategies of families with low socio-economic status raising children with physical disabilities in Mafeteng, Lesotho?”*

This question gave shape and direction to the study throughout all the stages. It also determined the degree to which the researcher was able to clarify the interview questions as well as to interpret the information gathered during the study (Flick, 2006:105).

3.2.3. Type of research

This study is of the applied research type. De Vos and Strydom (2011:475) explain that the goal of applied research is to develop resolution strategies for problems and how to apply those in practice. Through this study, the coping strategies of families with low socio-economic status that are raising the children with physical disabilities were explored, even as the primary goal was to improve the present knowledge and understanding, but a number of service provision gaps were identified and

recommendations made accordingly. These recommendations can be utilised by relevant service providers to improve their services.

3.2.4. Research design and methods

This sub-section presents the design and methodology followed in the study.

3.2.4.1. Research design

A research design is defined as a blueprint of the research process (Babbie & Mouton, 2010:38). This study followed a case study design. A case study is an empirical inquiry that “explores a real-life, contemporary bounded system (a case) or multiple bounded systems (cases) over time, through detailed, in-depth data collection involving multiple sources of information and reports of case description and case themes” (Creswell, 2009:197).

The researcher was interested in exploring collectively the coping strategies utilised across all families. Therefore, a collective case study was used. The collective case study enabled the researcher to gather exhaustive data by coordinating and aggregating information from a number of individual families and using this to support the generalised claims, to make them more convincing (Johnson & Christensen, 2008:408).

3.2.4.2. Research methods

Research methods encompass a detailed description of the study population, sample and sampling procedures followed when undertaking the study.

3.2.4.2.1. Population

The researcher’s interest was to explore the coping strategies of “low socio-economic status families raising children with physical disabilities in Mafeteng, Lesotho”. Ideally, each and every family in the Mafeteng district which was raising a child /children with physical disabilities fitted into the target population. Nevertheless,

boundaries had to be drawn to break the population into a manageable portion to which the researcher had reasonable access (Yount, 2006:73). In this light, the population was limited to the families with low socio-economic status that were raising the children with physical disabilities and were residing in one of the twelve community councils of Mafeteng; the Makaota E12.

3.2.4.2.2. Sampling and sampling method

A sample is defined by Creswell (2009:203) as “a set of units selected from the population to be studied so that results may be fairly generalized to the population from which they were chosen”. There is a number of factors that would not allow the researcher to gather information from the entire population, for instance limited time and resources (Creswell, 2009:203). For this reason, a sample was drawn.

The sampling method utilised in this study is two-fold, it combined the purposive and simple random sampling, which are correspondingly classified under non-probability and probability sampling. A combination of these two methods gave the researcher an advantage to be in control of choosing the most relevant participants from a divergent population (Rubin & Babbie, 2013:355).

Firstly, the researcher included only those families which were registered with the Department of Social Development (purposive sampling). Upon request, a list of fourteen eligible families and their contact details was provided by the Mafeteng rehabilitation office of the Department of Social Development, alongside a letter which introduced the researcher to the participants. From the list, the researcher randomly selected ten (10) families that were to participate in the study; by writing the names of the children on pieces of paper, placing the pieces in a bowl and then picking out ten names. Unfortunately, as the sampling process progressed, the researcher could not reach some of the families through the contacts provided, for this reason, researcher had to revisit the list to pick replacements for the families that could not be contacted.

The criteria for participating in the study were that families should:

- have a child/ children, aged below 18 years, who were living with a physical disability
- be living on or below the standard of living, which is 14 Maloti per day (as is typical among low socio-economic status families)
- be receiving welfare/rehabilitation services from the rehabilitation office of the Mafeteng Department of Social Development.
- be residing within the Makaota E12 community council at the time of study

Selected families were contacted through the phone to set an appointment, upon arrival at the participant's homes, the researcher presented a letter of introduction given by the Department of Social Development, and also discussed the consent form with those that were to represent the families in the interviews.

3.2.5. Data collection method

Data was collected through open-ended, semi-structured, face-to-face interviews. The semi-structured interviews were adopted because of their flexibility which allows the interviewer to adjust questions and change direction as the interview is taking place and also because the researcher aspired to conduct interviews in an informal atmosphere which would encourage participants to be open and honest (Mitchell & Jolley, 2012:302).

The semi-structured interviews enabled the researcher to obtain as much information as possible while at the same time maintaining boundaries to keep the interview discussions aligned to the study objectives (Punch, 2005:106). Interviews were conducted from the participants' homesteads, and as mentioned earlier, only ten families participated. Due to high levels of flexibility, the semi-structured interviews are known to be time consuming both in terms of data collection and analysis (Punch, 2005:118). The researcher therefore found it imperative to limit the number of interviews to a relatively small sample which comprised of only those families most likely to provide the most relevant information (Mitchell & Jolley, 2012:302). Conducting the interviews in the comfort of their homes allowed the participants to

relax, be involved and enthusiastic about the interview (Bryman, 2015:507), thus they were better able to express themselves. Each interview lasted for an average of one hour.

A digital audio recorder was used to capture the interview discussions to ensure that all information is stored accurately and in its original form. The researcher also kept a note book in which some of the observations and critical points that arose during the discussions were written.

3.2.6. Data analysis

Data analysis began in the field. As the researcher was collecting data, she was already identifying themes and recording those in the memo book. Because of the interpretive nature of the data collected, thematic analysis was used throughout the process of data analysis. Thematic analysis is “a method of identifying, analysing and reporting patterns within data (Braun & Clarke, 2006:79)”. Analysis went through each one of the following steps of qualitative data analysis as suggested by Creswell (2009:173-189):

- *Transcription:* Practically, transcription began on the first day of data collection. Transcription refers to the process of interpreting the audible interview recordings by presenting them as visual text (Bryman, 2015:586). Researcher transcribed each one of the discussions immediately after the interview.
- *Familiarisation:* Following the transcription of each interview, researcher read over the transcripts, comparing them with the field notes in order to gain a general sense of the overall meaning of the information (Creswell, 2009:181). The transcripts were then complemented with important points which had been noted during the discussions, especially the observations and non-verbal communication.
- *Generating codes and themes:* Upon completion of all interviews, researcher began to read the transcripts collectively, in order to identify important

themes. While some themes were recurring across all transcripts, there were those themes that were exclusive to only one or few interviews. To better manage the information, transcribed data was classified into segments (themes) which were then labelled (coded) with one word or short phrase that described the data on different levels of abstraction (Braun & Clarke, 2006:79). As researcher was coding the themes, sub-themes were also identified. For example, across all interviews, participants had narrated some experiences which were identified by the researcher as challenges, the theme “challenges” was then created, under which different challenges were consigned as sub-themes.

- *Interpreting data:* As noted by Creswell (2009:177) “qualitative research is interpretative research”. Having segmented the interview data, researcher started to interpret the meanings of the coded data against the backdrop of “her own view point as well as information gleaned from the literature and theories” (Creswell 2009:189). For example, a number of participants had reacted in a similar pattern when asked about their competence in providing care to the child; some took a long pause while others sighed. Nonetheless, majority of these participants said they were fulfilled in their roles as care-givers. Comparing these participants’ reactions with their verbal response, researcher concluded that the participants were actually not happy as care-givers, but they felt like they would portray themselves as weaklings or as if they had not accepted their children if they admitted that they were sometimes frustrated in their role as care-givers.

Interpretation of data will be presented in a written format, and will form the basis of the next chapter. In effort to ensure validity of the study findings, researcher employed the following trustworthiness measures to test the reliability of the extracted themes and sub-themes.

3.2.7. Trustworthiness of qualitative data

Trustworthiness is established when the study findings reflect, as closely as possible, the meanings described by the participants. It is a measure intended to

guarantee credibility, dependability, transferability and conformability of qualitative data (Lietz, Langer & Furman, 2006:444). Conformability of the study findings was of priority to the researcher as the findings are intended to influence the most relevant policies and intervention strategies targeting families of children with physical disabilities. To ensure conformability of the study findings, the following trustworthiness measures were employed:

3.2.7.1. Avoiding bias during interviews

When testing trustworthiness, the aim of the researcher was to ensure that the findings represent, with greatest accuracy, the situation of the participants as opposed to the beliefs or biases of the researcher. The researcher avoided any conduct that would influence the information provided by the participants, and ensured at all cost that the questions asked of the participants are clear, not leading, not double-barrelled and not passing on any prejudicial attitude (Rakotsoane & Rakotsoane, 2007:21).

3.2.7.2. Peer debriefing

The researcher further engaged what is known as reflexivity, which is an active acknowledgement that own socio-cultural background, experiences, perspectives and orientation could inevitably influence conduct and judgements during the study (Horsburgh, 2003:308). To minimize the effects of reactivity and bias, researcher held a one day discussion with a social work colleague, who has worked on disability projects before, and holds a Master of Social Work degree. This particular colleague was chosen because she is from a different cultural and religious background, thus she most likely holds different values and attitudes. Researcher and the colleague held a lengthily debate over the transcripts, this exercise led to identification of new themes and restructuring of some of the initial themes.

3.2.7.3. Member checking

At the end of each interview, the researcher provided a recapitulation of the conversation and gave participants a chance to confirm if the information as

captured by the researcher represented their situation, where rectifications were suggested, researcher noted in a memo book and later included those in the transcripts (Lietz et al, 2006:444). Where appropriate, participants were also asked to explain particular patterns observed by the researcher (Creswell, 2009:191). For example, as the interview was going on in one of the households, researcher noticed that the child was feeding on crushed “pap” (under normal circumstances the pap is eaten in its solid form), having heard about children who only ate soft food in previous interviews, researcher then assumed the child was one of those, but was corrected by the participant during the recapitulation, who said that the child could take solid foods, and that she had only crushed the pap because she wanted him to eat quickly.

Having employed these measures, the researcher is confident that the findings of this study reflects as closely as possible the thoughts, feelings and experiences of the participants, such that even if someone else was to objectively conduct the same study he or she would yield highly similar results.

3.2.8 Pilot study

The pilot study helps to determine the effectiveness of the actual study and to identify which elements of the prototype may need to be revised (De Vos & Strydom, 2011:483). Prior to the study, a pilot test was conducted with one of the fourteen families provided by the Department of Social Development. Having completed the pilot study, a few amendments were made to the interview schedule to accommodate the emerging themes in the actual study; the rest of the methodology was utilized as per the initial plan. After the pilot study; this family was removed from the list as they no longer qualified to participate in the actual research.

3.3. ETHICAL CONSIDERATIONS

Ethics is a set of moral principles which is suggested by an individual or group, is subsequently widely accepted, and which offers rules and behavioral expectations about the most correct conduct towards experimental subjects and respondents, employers, sponsors, other researchers, assistants and students (Strydom,

2011:114). The researcher understands the necessity to undertake precautions that anticipate and addresses potential ethical dilemmas. In this subsection, the researcher outlines the ethical guidelines that were adhered to in effort to mitigate the harm that could occur to anyone affected by this research during the course of the study.

3.3.1. Informed Consent

Families selected to participate in the study were not coerced into doing so. It must be noted that participants were adults, in competent mental and social state; they were granted the freedom to decide whether or not to take part in the study and they were informed of their right to withdraw at anytime if they no longer felt comfortable (Strydom, 2011:116).

The permission to use the digital audio recorder was sought from participants through a consent form, which also stated that data is going to be kept at the University of Pretoria for a period of 15 years after the study.

3.3.2. Avoiding deception of participants

The researcher furnished the participants with a detailed explanation of the study objectives, both orally and in writing. This explanation omitted any form of deceitful promises or misleading information. It is thus the understanding of the researcher that those who participated in the study had a complete understanding of the study purpose, the methods used in the study, the risks involved, and the demands placed upon them as participants (Punch, 2005:277).

3.3.3. Debriefing of Participants

When the researcher was about to leave each of the homesteads, a summary of the interview was made and participants given a chance to validate the information. An arrangement had been made with the rehabilitation social worker to assist any of the participants who might need a restorative intervention as a result of the study proceedings. Thanks to this arrangement, researcher was able to refer one of the

distressed participants whose child had been sick for some days and not able to consult a Doctor due to lack of funds, researcher later followed up on this family and learned that the Department was able to assist the family with a clearance certificate which enabled the child to access health services for free from the district hospital.

3.3.4. Privacy, anonymity and confidentiality

In preparation for data collection, the researcher made a phone call to each of the families to arrange an appointment; this was done so as to avoid invasion of the families' privacy that might have occurred if the researcher arrived unannounced. Interviews were conducted in a discreet setting at the participants' homes, and the researcher maintained anonymity and confidentiality of the participants' information by not disclosing any features through which their responses could be traced back to them. Apart from the researcher and the research peer who conducted the debriefing, the University of Pretoria alone is to be granted access to the research material, which is going to be kept in a safe storage by the Department of Social Work and Criminology for a period of 15 years after the study.

3.3.5. Publication of the study findings

Study findings are to be availed to the public in the form of a written report, which does not single out individual respondents. The researcher was careful not to fabricate or misinterpret any data. Could the researcher discover any significant errors in the published data, reasonable steps will be undertaken to correct such errors in a correction, retraction, erratum or other appropriate publication means (Strydom, 2011:115-126). All individuals and organizations that contributed to the study will be acknowledged in the published report.

3.3.6. Competence of the researcher

The researcher is human, and that alone subjected her to bias. For this reason, the study was conducted under close supervision of a qualified professional. Furthermore, prior to the commencement of the study, the researcher compiled a research proposal with detailed description of the procedure which would be followed

in conducting the study; this was reviewed by the supervisor, the departmental review panel and ultimately submitted to the Research Ethics Committee of the University of Pretoria's Faculty of Humanities for approval.

After extensive scrutiny of the proposed methodology, the researcher was awarded an ethical clearance certificate by the Research Ethics Committee of the University of Pretoria's Faculty of Humanities. This letter has been attached in the appendices. Throughout the study, the researcher also employed ongoing efforts to maintain professionalism by adhering to the standard research ethics.

3.4. EMPIRICAL FINDINGS

This section presents a discussion of the study findings. The section is divided into two; part 1 details biographic details of the participating families, whereas part 2 outlines the researcher's interpretation of data by providing an illustration of the identified themes and sub-themes.

3.4.1. Empirical Findings: Part 1

The research information was obtained from a sample of ten participants representing the low socio-economic status families that are raising the children with physical disabilities in the Makaota E12 community council in Mafeteng, Lesotho. In all families, Sesotho was the first language; therefore the language was used across all interviews.

The researcher collected biographic details of both participants and their families. The details of participants include their age, gender, marital status, highest level of education, occupation, position in the family and the participant's relationship with the child. The details are illustrated in the tables and graphics below.

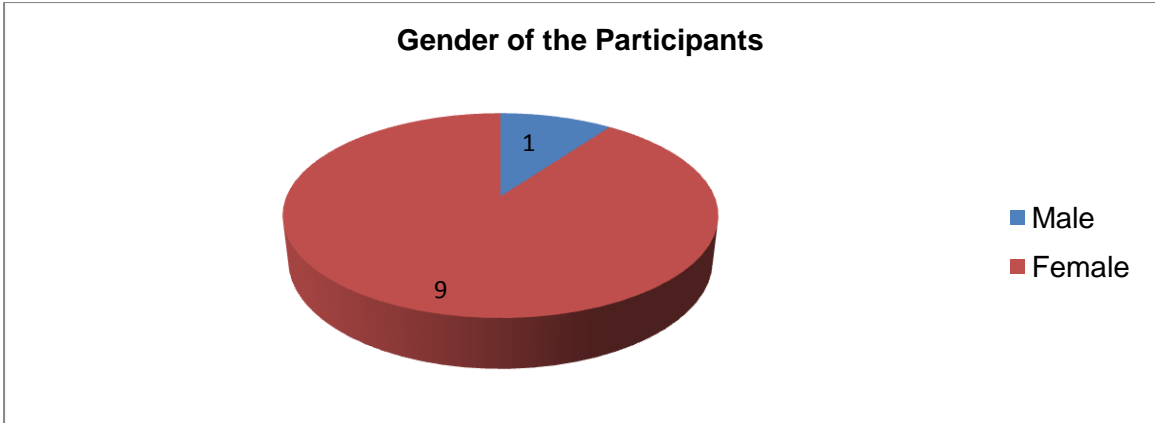


Figure 1: Gender of the participants

It can be observed, as illustrated by the figure above, that there were nine females and only one male who participated in this study as the family representatives. Ages of the participants are demonstrated against those of their children in the next figure:

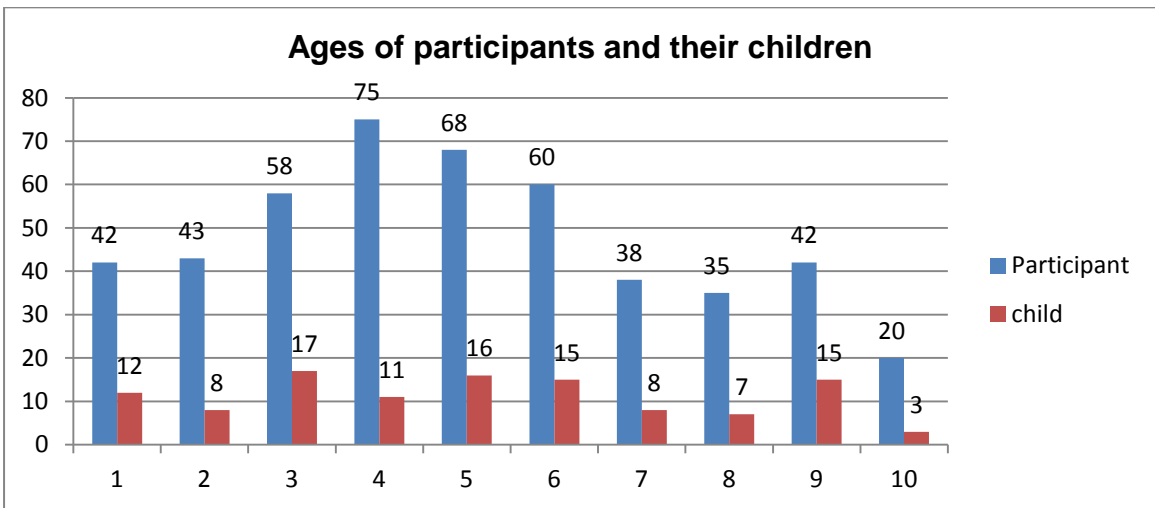


Figure 2: Ages of Participants and their children

The figure above illustrates on the ages of participants, as well as the children at the centre of the study. In summary, the average age of participants was 49,6 years while the average age of the children was 11,2 years. Two of the participants were in their late years, with ages 58 and 60; five others were in their middle age, with ages ranging from 35 to 43; two of the participants were at an elderly age of 68 to 75, whereas one participant was 20 years old. With regard to the children, four were in their late teenage years ranging from 15 to 17; two were pre-teens aged 11 and 12 years, three others were aged between 7 and 8 years and one was 3 years old.

One of the family representatives who participated in the study was widowed, one was single, four were divorced/ separated and the other four were married. This information is presented below:

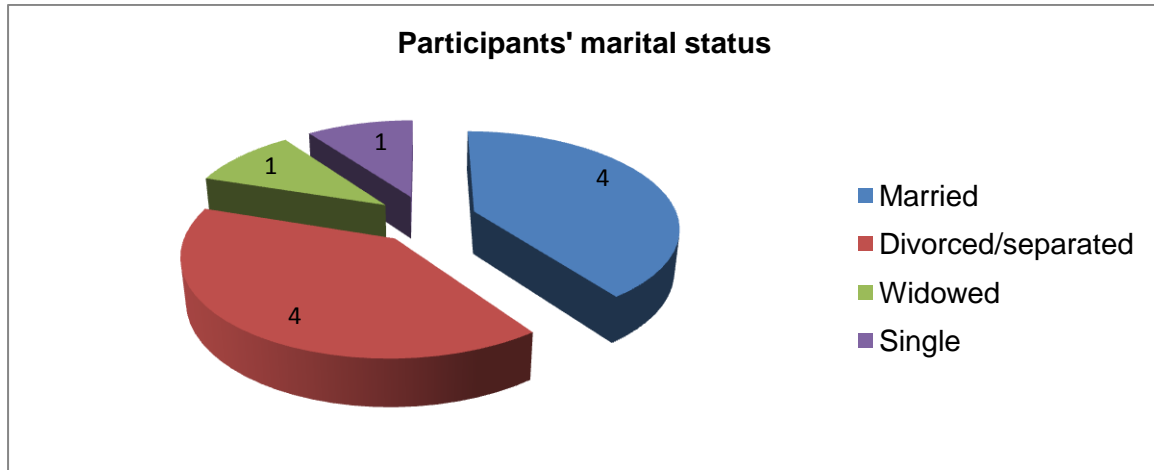


Figure 3: Marital status of the Participants

All nine female participants were primary care-givers; six of these participants were the children's mothers whereas the one male participant was the child's father and secondary care-giver. Two participants were the children's maternal grandmothers and one was the child's babysitter. The following table provides an illustration of the participants' position and relationship to the children under focus:

Table 2: Participants' position and relationship to the Child

Participant	Occupation	Relationship to child
1	Housewife	Mother and Primary Care-giver
2	Housewife	Mother and Primary Care-giver
3	Childminder	Nanny and Primary Care-giver
4	Pensioner	Maternal Grandmother and Primary Care-giver
5	Housewife	Maternal Grandmother and Primary Care-giver
6	Shopkeeper	Mother and Primary Care-giver
7	Housewife	Mother and Primary Care-giver
8	Delivery Man	Father and Secondary Care-giver
9	Housewife	Mother and Primary Care-giver
10	Student	Mother and Primary Care-giver

Most of the participants have had access to the secondary school education, even as five of them could not complete secondary school. Only one participant completed high school, three did not get beyond primary school level and one did not go to school at all. The education level of participants is illustrated below:

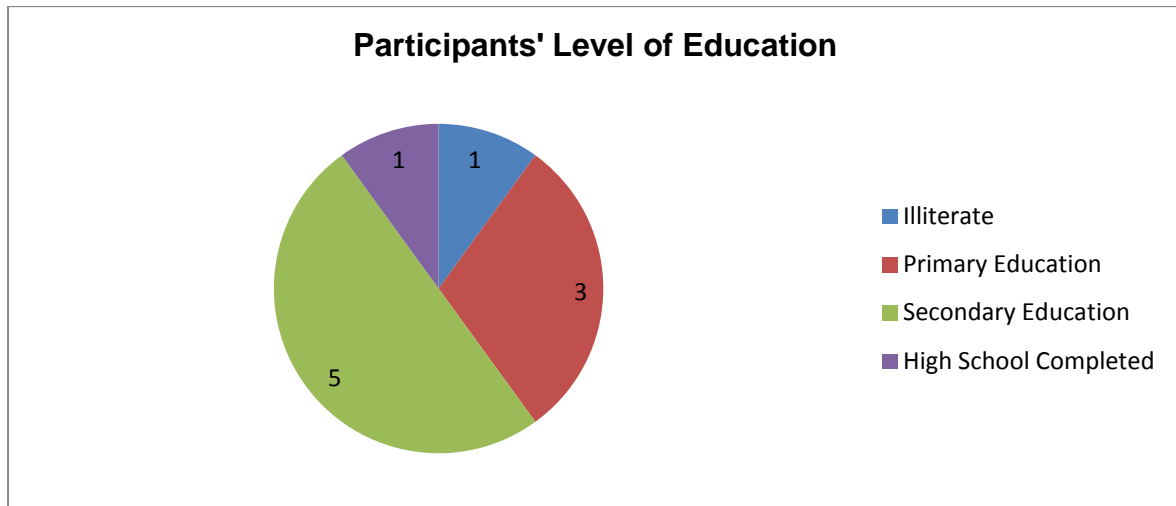


Figure 4: Participants' level of education

Some of the participants who were primary care-givers were also breadwinners and heads of their families. Positions of the participants in their families are summarized below:

Table 3: Positions of the Participants in their families

Participant	Position in the family
1	Mother, wife and care-giver to the child and 4 sisters
2	Mother, breadwinner and Household head
3	Family friend and baby sitter
4	Breadwinner and Household head
5	Household head and care-giver to child and child's sister
6	Mother, Breadwinner and Household head
7	Mother, wife, breadwinner and care-giver to child and four brothers
8	Breadwinner and Household head
9	Mother, breadwinner and care-giver to child and three older siblings
10	Mother and Wife

On the other hand, the researcher gathered some properties of the participating families in order to understand the families' social and economic capacity. The properties taken into consideration were; the family size, income, housing conditions, education, the number of children with disabilities and the family assets.

The biggest of the participating families had eight members; six children and their two parents. The smallest of the families was made up of the child and the caretaker alone. The following figure provides a summary of the sizes of participating families:

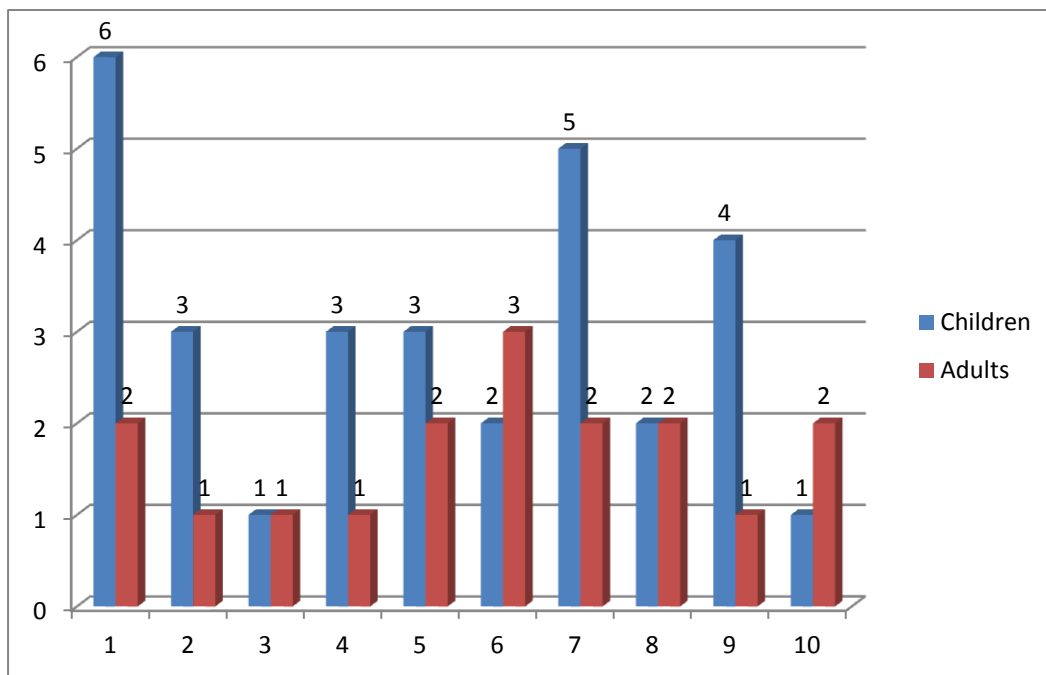


Figure 5: Sizes of participating families

In one of the families, there were two children with disabilities while the rest of the families were raising just one disabled child. The following table illustrates the number of children with disabilities in each family:

Table 4: Number of children with disabilities in participating families

Family Number	Number of Children with disabilities
1	1
2	2
3	1
4	1
5	1

6	1
7	1
8	1
9	1
10	1

The income level of participating families was widely varied, ranging between R500.00 and R 5000.00 per month. The figure below illustrates the average income across all participating families against the portion of income that the family uses to meet the needs of the special needs child.

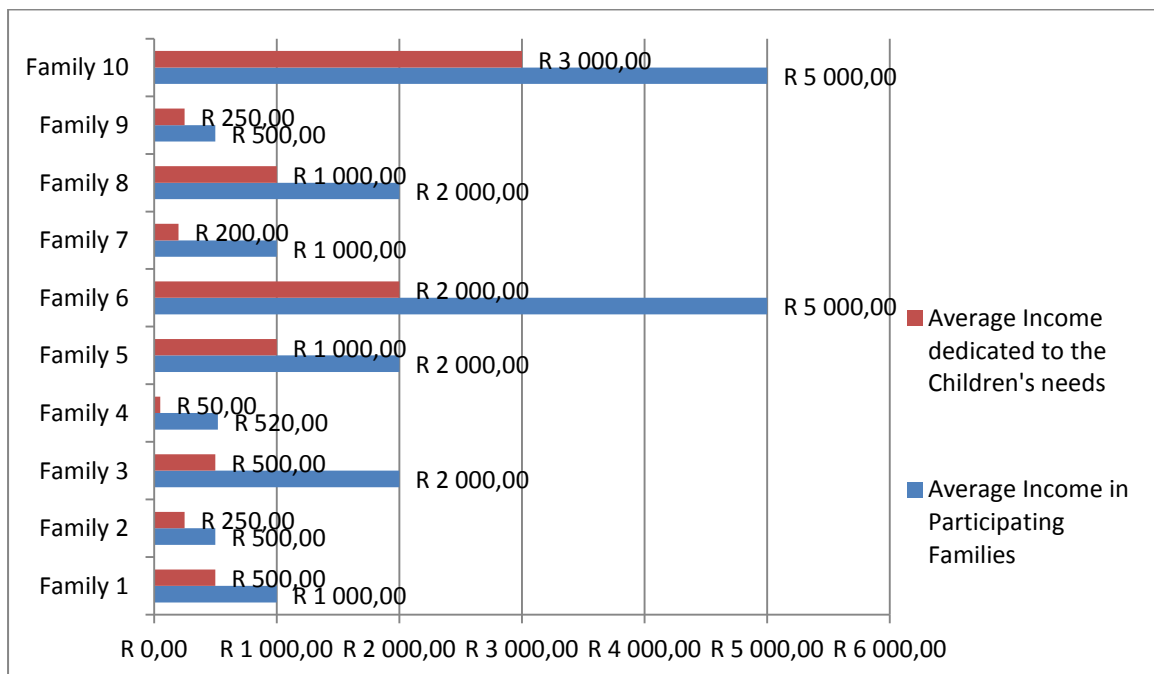


Figure 6: Average monthly income in the participating families and the amount allocated to the children's special needs

The average education in each of the participating families was also captured. The average education was determined by studying the level of education reached by the majority of the members in the family. Most families had an average of secondary education, while only a few had an average of primary school education. This information is illustrated in the figure below:

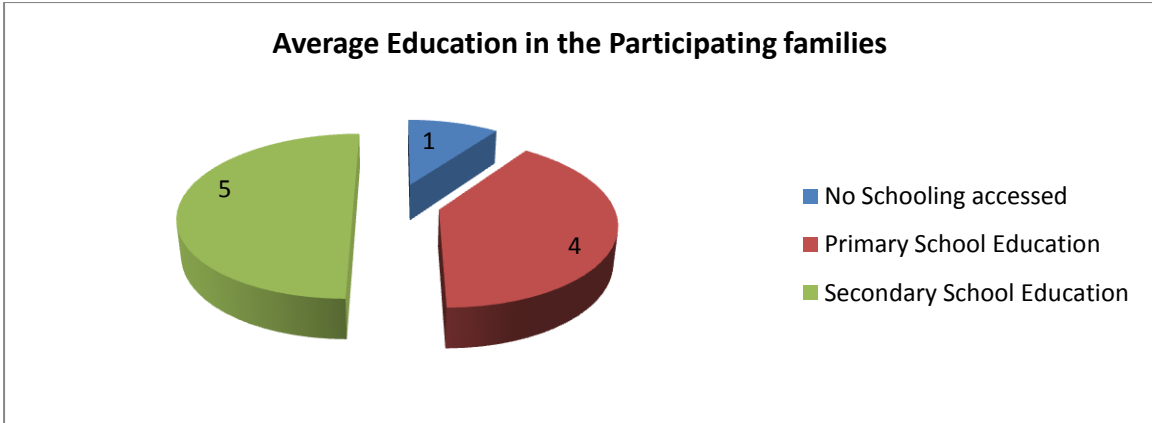


Figure 7: Average education in the participating families

Information gathered during the study confirms that while some children were born with the disabilities, others became disabled at a later stage in life. Meningitis and preterm labour were cited among the known causes of the children’s disabilities; a case of head injury in infancy was also mentioned. Some other families did not know why or how their children developed a disability, while others attributed their children’s condition to witchcraft and wrath from the ancestors. Causes of the children’s disabilities in the participating families are summarized below:

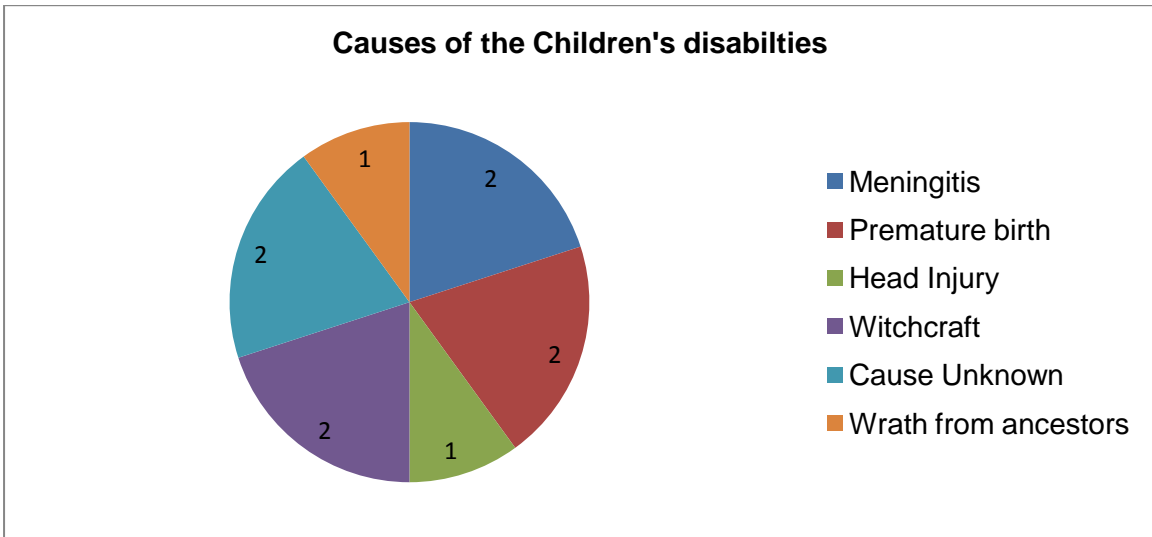


Figure 8: Causes of the children's disabilities

The children in all participating families were living with a physical disability, nevertheless, the severity of their disabilities differed. In most families, the child’s physical disability was accompanied by speech impairment, and in a few cases, hearing and vision problems were also present. The table below illustrates the types and severity of disabilities among children in participating families.

Table 5: The types and severity of disabilities among children in participating families

Family Number	Type and severity of the child's disability
1	Immobility, inability to speak nor conduct any other physical activities; can hear and communicate with signs and sounds.
2	Immobility, able to speak and hear, can perform all other activities that do not require movement from one place to another.
3	Immobility, blurred speech, can perform all other activities that do not require movement from one place to another.
4	Immobility; Blindness; Inability to neither speak nor to conduct any other physical activities; can hear and communicate with signs and sounds.
5	Deformed posture (uses hands and knees to crawl from one place to another). Can speak, hear, see and do most other physical activities.
6	Immobility, can speak, hear, see and do most other physical activities.
7	Immobility, blindness, lack of speech and hearing, inability to conduct any other physical activities; communicates with sounds.
8	Immobility, inability to speak nor conduct any other physical activities; can hear and communicate with signs and sounds.
9	Immobility, blurred speech, inability to conduct most physical activities.
10	Immobility, inability to speak nor conduct any other physical activities; can hear and communicate with signs and sounds.

3.4.2. Empirical Findings: Part 2

In this section, the researcher presents the themes that were identified during analysis of the gathered information. Some of the themes identified were new to the researcher, but others merely confirmed what was discovered by previous studies. In the following presentation, the themes are substantiated by the participants' words, and where relevant, literature from previous research. The table on the next page outlines the extracted themes along with the sub-themes that emanated from under each theme:

Table 6: Themes and Sub-themes extracted from the data

Themes	Sub-themes
Theme 1: The family's ability to satisfy the needs of the child and of other family members	1.1: Food 1.2: Housing 1.3: Children's education 1.4: Health care 1.5: The child's special needs
Theme 2: The role played by the participant in the support of the child	2.1: Tasks carried out in care-giving 2.2: Time allocated to care-giving 2.3: Competence (Ability to provide effective care) 2.4: Role played by other family members to support the child and care-giver
Theme 3: Positive aspects of care-giving	3.1: Acquisition of new skills 3.2: Development of a strong character 3.3: Maturity 3.4: Opportunity to meet new people 3.5: No positive aspects to care-giving
Theme 4: Challenges encountered by the family with regard to raising the child	4.1: Challenges encountered socially 4.2: Financial challenges 4.3: Psychological challenges 4.4: Challenges related to service delivery
Theme 5: Factors that influence the family's adaptation	5.1: Spirituality 5.2: Financial Security 5.3: Personal Relationships 5.4: Community Support 5.5: Religious Services
Theme 6: How families managed	6.1: Turning to spirituality 6.2: Developing and maintaining family cohesion

<p>the pressures of raising the child with a physical disability</p>	<p>6.3: Utilizing personal and family resources 6.4: Accepting the child in his/her condition 6.5: Living with hope that one day the child will get healed 6.6: Disengaging from the child 6.7: Seeking external aid 6.8: Adopting alternative means to generate income</p>
--	---

3.4.2.1. Theme 1: The family's ability to satisfy the needs of the child and of other family members

Two participants mentioned that in their families, life only became difficult following the child's diagnosis. In such families the capacity to provide even for the other members was lost due to the demands of the child's special needs. Responses from these participants are quoted below:

- *"... ho bua nnete re ne re ntse re sa sokole hakana hobane le nna ke ne ke sebetsa femeng, ho qalile ho ba boima hore ke tlohele mosebetsi ke tlo shebana le eena"*

("Honestly we were not struggling this much, I used to work at the garment factory, things only got bad after I quit my job to look after him.")

- *"Ua e bona pompo eo? E qetetse ho tsoa metsi ka 2009... ba re ke lokela ho patala one point mang mang kannete ka e tlohela...(Ngoana) o ne a ena le lilemo tse peli ka nako eno ene a qalella ho nts'okolisa ka bokulo, ho ile ha eba thata 'M'e."*

("You see that water tap? We last used it in 2009... they said my water bill amounted to one thousand and something so I gave up on it... (Child) was two years old at the time and starting to show poor health, life became difficult.")

Nevertheless, some other participants mentioned that their families were already struggling to survive by the time the child was diagnosed, and this made their livelihoods even more challenging. These participants are quoted below:

- *“Ke ne ke khathetse matla feela, ke ipotsa naa ha ke se ntse ke sokola ka baa ba phetseng hantle ebe ea nang le bokooa ke tlo mo etsa joang!”*

(“I was out of strength, considering that I was already struggling with these other children I was wondering how I would manage with the disabled one”.)

- *“Jonna! Ho ile ha ba boima. Joaloka motho eo eleng hore ke ne ke se ntse ke iphelela ke le mong, bophelo bo ne bo se bo ntse bo se bobebe ka bana ba bang feela.”*

(“Hey! It once was difficult. As a single parent, I was already struggling with the others alone”)

The sub-themes that emanated from theme 1 are discussed below:

3.4.2.1.1. Sub-theme 1: Food

Five participants reported that in their families, meeting specifically the food needs for both the child and other family members was a problem due to limited income. Below are their responses:

- *“... o tla be a hloka lijo tse itseng nako e ‘ngoe (joale) ebe ha re na chelete”*

(“... he needs specific food (which) we do not afford at times”)

- *“Empa hee ntho e kholo ke lijo le liaparo, joalokaha u ‘mona a khasa tjee, borikhoe bono ha bo qete khoeli re tla be re se re tlameha ho bo lapa hobane joale le eena o utloa bohloko.”*

(“But his main needs are food and clothing, just as he moves on hands and knees, his pants do not last long so we have to replace them time and again because he hurts his knees when they are torn.”)

- *“Hantle ntle tlhoko e kholo ke tsona lijo ‘M’e, hobane che liaparo tsona nkhono oa hae oa mo rekela, ehlile ka motho ea mo ratang, liphahlo tsona oa mo rekela hantle ntle bothata thata ke lijo.”*

(“Actually our main problem is food, as for things like clothes her grandmother buys for her, she loves her, the clothes she buys so the main problem is food.”)

- *“... oa utloa chelete ea pension ke 520? Ha e khone le ho reka lijo tse itseng chaa, joale u se u ntse u utloa hore (litlhoko) tsa hae li tla tla morao.”*

(“... my pension allowance is only R520. It does not even buy us proper food, so her needs are definitely the last of our priorities.”)

- *“Lijo ‘M’e. Lijo! Ke ee ke bone ele sono ka ngoana enoa ha re se na lijo mona hobane nako e ‘ngoe akere ‘m’ae ho ka etsahala ebe le eena haa na letho koa?”*

(“Food madam, Food! There are times when his mother is not able to send money and it breaks my heart to see him go without food.”)

Only one participant mentioned that her family was able to satisfy the food need at home due to the child grant from Social Development. Below is a quote from the participant’s response:

- *“... kea kholoa challenge ke eona taba ea hore naa o tla ea sekolong kae feela hobane lijo re ntse re khona ho li reka le sesepanyana ka chelete eno eo a e kholang Social Welfare”*

(“I think the only challenge is the question of where we can take him to study, as for things like food and soap we are able to buy with the grant he earns from Social Welfare”)

With regard to the families quoted above, it is clear that food security can be negatively affected when there is a child with a disability in a family, thus the social security grant brings about the much needed help. Meyers et al (2000:400) concluded that receipt of a means-tested cash assistance has a modest anti-poverty effect for families of children with disabilities, reducing the prevalence of poverty and extreme poverty for families even after the additional direct costs of caring for these children are considered (Meyers et al, 2000:400). The family systems theory posits that when one member of a family goes through a difficult situation, all the other members suffer the consequences. The implication for the family systems theory in this regard is that due to the urge to meet the child’s special needs, the family that raises the child with a disability are compelled to sacrifice even their own food needs.

3.4.2.1.2. Sub-theme 2: Housing

Three of the families lived in rented houses, whereas the other three had borrowed the houses they lived in. Asked if they could afford to rent or built own house if the owners were to claim the houses borrowed by the three families, the following responses were obtained:

- *“Aoo ekaba mathata feela hle, keha re inkela thoto ea rona re lo batla leqhofa nqé nngoe.”*

(“That would be a problem, we will be left with no choice but to pack our stuff and find another house to borrow”.)

- *“... re tla mo fa bohahae kannete, joalokaha re ile ra nna ra lula mona re tloha moo re neng re ntse re hirile, ... ntate ke motho ea ntseng a ena le ho etsa li piece job joale akere nako e nngoe li piece job lia fela! Joale ebe re lutse re le babeli...”*

(“... we will have to give her house back, just as we were renting a flat before, but then the problem is that my husband does temporary jobs sometimes and those are not reliable...many a times we are both not working”)

- *“ke ntse ke hloka le ho rulela ntlo eaka... Ntlo ea motho e mong ha e na boroko.”*

(“I still need to repair my house... you cannot live freely in someone else’s house.”)

Nevertheless, participants from those families that had rented a house did not mention a problem related to their bill. Based on their level of income, the families rented houses that they could afford. Below are responses from two such Participants:

- *“Rente eona ha e boima hakaalo, re patala 350 ka khoeli.”*

(“Rent is not much of a problem, we only pay M350 in a month”)

- *“Ache kannete nka se re (‘M’e oa ngoana) a mpatale a sokola hakaana! Haa rometse chelete re patala rente ebe re reka le lijo... ekaba bomalimabe ha nka re a mpatale”*

(“No I cannot expect (the child’s mother) to pay me, she is struggling. With the money she sends I pay her rent and buy (the child’s) food”)

Meyers, Lukemeyer and Smeeding (2000:400) noted that, “Families caring for disabled and ill children were more likely than other families to live in subsidized housing”. Among families that participated in this study, only four owned the houses they lived in, and of these, two inherited the homes from their deceased relatives. This situation is explained by the eco-systems perspective as the *mesosystem* level, the condition in which the personal needs of the child connect to other entities such as the needs of other members of the family and the family’s resources. This sub-

theme suggests that the families had to deal with their need for housing on top of the child's special needs and together these factors left the families overwhelmed.

3.4.2.1.3: Sub-theme 3: Children's Education

In six of the participating families, schooling costs for all children, including the child were reported to be a challenge. In their own words, participants said:

- *"...haele hantle takatso ea rona e ne e ntse ele hore enoa moená hae ebe o sa qalile ho ea sekolong, motho ea lilemo li 'ne o moholo. Empa joale ka pokothong ho khoehlile 'M'e li ngata lintho tseo re sa khoneng ho li fihlela."*

(... actually our wish was for her younger brother to have started school by now, at four years he is old enough. But we are in short of money; we are not able to achieve a lot of things.)

- *"...ea mo hlahlamang ke ngoanana... eena one a kena sekolo (lebitso la sekolo) feela o lutse hae hona joale ka baka la eona chelete."*

(...the one that comes after him is a girl, she used to go to (*name of school*) high school but now she is staying at home here due to lack of funds.)

- *"... ntho'e boima ke school fees... ua utloa ke school fees saka, le rangoane oa hae o hloka lintho tsa sekolo, re reka lithoko tsa ka tlung ntate oa hae oa palama... ha re khone kannete."*

(...the challenge is in schooling fees... we pay my school fees, her uncle's educational requirements, and the family's bills and her father's transport, honestly we do not manage.)

- *"Na bana bana ba bang ke ne ke ntse ke ikenyetsa bona sekolo, feela hona joale ha ke khone"*

("I was paying for these other children's school fees, but now I can't.")

- *“... taba tabelo eaka e ne e ntse ele hore a ee sekolong motho enoa, empa joale ha ke na matla.”*

(“My wish is for him to go to school, but then I cannot afford.”)

- *“Hona joale ke hloka mosebetsi ke tiile hore ke tlo patalla ngoana enoa oa ngoan’aka ea lahlehetsoeng ke scholarship. Sheba ngoana e mokaana haa se a lutse hae!”*

(“Right now I am in dire need of a job to send my grandson back to school after he lost the scholarship, can you imagine a child of his age having to idle at home!”)

As noted by (Strohm, 2014:36), many siblings’ own social needs are often compromised when their brother or sister has a disability. Families find it difficult to accommodate the needs of other members as all decisions revolve around the child’s condition. Similar to the preceding sub-theme, this condition only reflects what is described by the eco-systems perspective as the *mesosystem* level, the condition in which the personal needs of the child connect to the needs of other members of the family and the family’s resources. At this level, the families are forced to compromise the needs of the other children and prioritise the child’s special needs.

3.4.2.1.4. Sub-theme 4: Health Care

Accessing health care, especially to attend the monthly physiotherapy sessions, was said to be a challenge by three participants as a result of the children’s immobility, which made it both difficult and expensive for the children to travel to the health care centres. These participants described their situation as quoted below:

- *“Akere re tsamaea physiotherapy Maseru, transport le eona ea tura”*

(We go to Maseru for physiotherapy, transport is expensive.)

- *“... lits’ebeletso tsa bophelo kea kholoa ke taba ea physiotherapy eo ke neng ke ee ke bone ba ikitlaelitse ka eona kannete, feela joale ka baka la hobane ho hole, ha re ee hangata. Ke hle ke re kea kholoa re qetetse 2012 koana, hoba joale transport ea re imela.”*

(“The support that was provided selflessly by the health services providers is the physiotherapy, but the hospital is far, so we rarely attend the sessions. In fact we last went there in 2012 because the transport cost is too much for us.”)

- *“Re ne re ntse re e tsamaea eona (physiotherapy) empa... bana bana ba palama habohloko likolong mona”*

(“We used to (attend physiotherapy sessions) but... travelling with these children on public transport is cumbersome.”)

Yantzi, Rosenberg and McKeever (2007:11) mentioned that the children with disabilities and their care-givers are house-bound because of the many challenges they encounter when leaving the home, for example; work and planning required to move the child’s equipment and supplies (Yantzi, Rosenberg & McKeever, 2007:11). This explains why the frequent visits to the health centres were so frustrating to some of the families that they quit the physiotherapy sessions. Situations like this are defined by the eco-systems perspective as the *exosystem* level of interaction between humans and their environment. At this level, the theory identifies social structures that hold implications over the child’s condition, for example the neighbourhood, church, the hospital and social services providers. Accessibility of the required services and the level of support towards the family highly influenced the stress levels and coping. For the families referred to above, accessing the health services is frustrating so much that the families would rather give the services up.

3.4.2.1.5. Sub-theme 5: The Child’s special needs

Seven participants reported that their families, some of which have constant income, were not able to fulfil the special needs of their children. Across all participating

families, identified special needs ranged from food, to special milk, clothing, diapers, soap, mobility aids (in all cases, the wheelchair), and the babysitter . These were their responses:

- *“Nakong e nngoe u ka fumana hore ho feta nako e telele hampe re sa khone ho mo rekela le lona lebese feela”*

(“Sometimes we go for a very long time unable to buy her the milk alone”)

- *“Na bana baka ba phela ka ho ikamohela... ba rata ba sa rate... ha ke ba khone.”*

(“My children have learned to be content with what I offer, whether they like it or not... I cannot afford”)

- *“Ho tsoa hore naa ke life, ho ea ngakeng teng rea mo isa haeba ele ntho e potlakileng le chelete nka e kalima, tsena tse kang bo li pampers tsona kannete ha re li reke kamehla.”*

(“It depends on what the needs are. When there’s a critical health matter I rush her to the Doctor, even if I’m forced to borrow the money for that. But things like diapers are not urgent”)

- *“... hona joale haa na wheelchair akere ua bona eo e felile joang, ha ke khone ho mo rekela e nngoe.”*

(“... he needs a wheelchair now, you see how this one is worn out, I cannot afford to buy him a new one”)

- *“Ha ho bobebe. Ka nako e ‘ngoe u tla fumana hore kannete ha re na letho... ene u fumane hore o tla b’a ja ka sono ua utloa!”*

(“It is not easy. Sometimes you find that we have nothing at all... and then she goes without suitable food you understand!”)

- *“Ache e seng ka mokhoa oo re neng re ka rata... Batho bana ba turu bana.”*

(“Not as much as we would want... These people (children with disabilities) are expensive.”)

- *“Mm. Ua utloa ke school fees saka, le rangoane oa hae o hloka lintho tsa sekolo, re reka litlhoko tsa ka tlung ntate oa hae oa palama... ha re khone kannete.”*

(“No. We pay my school fees, her uncle’s educational requirements, and the family’s bills and her father’s transport, we do not manage.”)

On the other hand, there were two participants who mentioned that their families were able to meet the children’s special needs, these participants are quoted below:

- *“Akere ‘m’ae o ntse a re romella chelete, haa rometse rea khona ho li finyeletsa.”*

(“His mother sends us the money, when she does, we meet all his needs”)

- *“Eea kannete. Rea leka ho li finyeletsa”*

(“Yes. We try our best to meet all his needs”.)

A number of authors noted that sustaining livelihood is a challenge to low socio-economic status families that raise the children with disabilities. Sharma and Dowling (2004:37) argued that life becomes harder in such families because they already have less than what is required to meet the needs of the rest of the members. On the other hand, Woolley (2004:58) and Reitemeir (2011:02) attributed the struggle in these families to the burden brought forth by the high cost of the child’s special needs.

Information collected during the study confirmed both theories. It should be noted that all the families were registered with the Department of Social Development because of their low socio-economic status (and not because of the children’s

disabilities) as there is no programme for the people with disabilities in the country but one for the needy.

With regard to the above sub-themes, it is evident that the ability to meet the needs of the children and of other family members varies across families as a result of the environmental and attitudinal variances. The eco-systems perspectives explains that an individual reacts to his /her environment (Washington, 2007:49), and that an environment that places one family at risk may give another family a developmental advantage (Munhali & Fitzsimons, 2001:51). This not only justifies the disparity among families with regard to their ability to provide for their members, but it also corroborates the family systems perspective, which denotes that each family has unique properties that are known only by observing the relationships and interactions among its members. In the family systems perspective, the unique characteristics of the family members, the family's resources, cultural beliefs and ideological styles determine the family's support for one another and the degree of adaptability to challenging conditions.

The second most recurring theme is discussed hereafter.

3.4.2. Theme 2: The role played by the participant in support of the child

It came to the attention of the researcher that the roles played by care-givers across all participating families are the same roles as would be played by a parent to any child in the first years of life, just that the children living with disability never outgrow the need for such assistance. Sub-themes that emerged under this theme are: the tasks carried out in care-giving; time allocated to care-giving; ability to provide effective care and the role played by other family members in support of the child and care-giver.

3.4.2.2.1. Sub-theme 1: Tasks carried out in care-giving

Participants mentioned that the kind of assistance provided for their children revolved around the basic daily living activities such as feeding, bathing, hygiene,

and assisting the child to move about. Below are quotes from some participants on the tasks carried out in providing care to their children:

- *“O hloka ntho e ‘ngoe le e ‘ngoe hobane haa khone ho etsa letho, o hloka ho jeso a hlapisoe a apesoe, le lintho kaofela.”*

(“She needs everything as she cannot do anything for herself, she needs assistance with feeding, bathing, clothing and all the other things.”)

- *“Ntho e nngoe le e nngoe, kea mo jesa, kea mo hlapisa, ke hore ntho e nngoe le e nngoe.”*

(“Everything! I feed her, I bathe her, I help her with everything”)

- *“Ae, eena ke mo thusa ho hlapa feela, ntho tse ling oa iketsetsa.”*

(“I only assist him to bathe, the rest he does by himself.”)

- *“Kea kholoa ke ho mo thusa ka ho hlapa ho ea ntloaneng joalo joalo... oa itjese, le ho ikhanna o na le ho ikhanna feela ha a ntse tjeka tjeka haufi mona.”*

(“I assist him to bathe and to get to the toilet, such things... He feeds himself, he is also able to move around in a wheelchair for a short distance.”)

From the above quotes, it can be observed that the children required varying levels of assistance based on their individual strengths. This observation corroborates a comment made by Washington (2007:23), who noted that concern over the child is determined by characteristics and behaviour of individual children.

3.4.2.2.2. Sub-theme 2: Time allocated to care-giving

In six of the ten participating families, care-givers had committed all their time to looking after the child. Below are responses given by the said participants:

- *“Leha a sala le ausi oaka hakaalo feela ke ne ke sa khotsofala, keha ke tla tlohella mosebetsi hore ke tlo itlhokomella eena”*

(“I wasn’t happy with the care he received from my sister, so I decided to quit my job and take care of him myself”.)

- *“Ntate ke eena motho ea ntseng a batla ka matla matla. ‘Na ke ne ke ntse ke sebetsa femeng, ka tlameha ho tlohela hobane joale ke ne ke hloka motho ea serious ea ka nts’allang le eena...”*

(“My husband is the one that’s looking for a job. I used to work at the Garment factory but I had to quit as I could not find a dedicated babysitter...”)

- *“... mosebetsi eo nka e etsang ke e ntumellang hore ke lule ke na le eena... eena (ausi) le nkho oa bona tlaase mono kea khona ho mo sia le bona, empa ele hore nka se its’epise hore ke tla mo sia le bona ke ee mosebetsing, ho hlokahala ha ke mo sia ke phetha mabakanyana a makhuts’oane ke khutla.”*

(“I can only do jobs that will enable me to be with her... her sister and grandmother are able to help me, but I cannot always leave her, I only do it when I have to run short errands”)

- *“Ee (ke lula le eena bosiu le mots’eare). O robala mona hobane habo ha ho na motho, re ea feela re lo bula ha ho na le ntho eo re e hlokanang.”*

(“Yes (I’m with him day and night). He sleeps here because there is no one at his home; we only go there to fetch his staff when he needs something.”)

- *“Ha ke na ‘M’e, ngoan’eso kapa ntate ea ka nthusang leha e ka ba ka ho sala le eena feela hore ke khutlele mosebetsing. Ha ke kule, feela ke lutse hae mona, kea mo hlokomela.”*

(“I do not have a mother, sibling or father to help look after her so I could get back to work. I am not sick, but here I am stuck at home, taking care of her.”)

- *“Ee, ke tla etsa joang! Hoseng re theohela le eena re chaise mantsiboea.”*

(“Yes. What can I do! We come to work together in the morning and knock off together in the evening.”)

Similar to what was revealed by previous research (Meyers et al. 2000:21), the responses provided by these participants portray the effect of care-giving responsibilities on the care-givers’ ability to generate income. Some of those who were previously employed had to quit their jobs to take care of the children; others can only engage in jobs that will allow them to watch over the child as they work while others have decided to exit the labour market altogether. This setting is summarized by the family systems theory, which defines a family as “a system of interconnected and interdependent individuals” (Hurst, 2009:73), in which “an injury to one is an injury to all” (Feher-Prout, 1996:158). The disabilities not only affect the lives of children, but of everyone else around them.

3.4.2.2.3. Sub-theme 3: Competence (Ability to provide effective care)

Four participants who were providing care to their own children reported that they were able to undertake the care-giving tasks without any strain. Below are their responses:

- *“Hantle haholo kannete. Ua tseba ngoana ea tjee oa tloaeleha, ‘na ke ee ke utloe ho se na phapang pakeng tsa hae le enoa e monyane, re se re mo tloaetse.”*

(“Very well! You get used to this kind of a child, I no longer find her different from this younger one, we are used to her now”)

- *“Eena re ntse re mo hlokomela hantle hobane leha ho ka ba ha thoe ke na le lebaka le ntsamaisang, re ke ke ra tsamaea re le babeli le ntate akere! Ho*

tloha mono haeba re tsamaea le ntate oa hae, bo abuti oa hae baa tseba hore naa ba ts'oaetse hore ba mo hlokomele joang."

("We are able to provide good care, because even if I have to go somewhere, her father takes over, if not, her brothers look after her when they are not in school, they know what to do.")

- *"Kea leka ua tseba, haholo lilemong tse na tsa morao hobane bana ba bo ba se ba khona ho nthusu."*

("I try my best, especially these years because his siblings are able to help me.")

- *"Ee. Ua tseba esale ke itlhokomella eena tjee ke ee ke bone ho se na mathata."*

("Yes. Ever since I started taking care of him by myself there are no problems.")

From the above quotes, it is evident that some families are happy and fulfilled despite the presence of the child with a disability in the home. Thus, as Pritzlaff (2001:28) suggests, it would be wrong to automatically assume that a family is overwhelmed from raising a child with a disability. Conversely, three other participants, also primary care-givers, reported that they were not able to provide effective care. Below are their responses:

- *"Hohang ha ke khone. Ua utloa hore le baa ba bang ba shebile 'na? Kannete kea imeloa."*

("I do not manage at all! You understand that I'm also raising other children? It is too much for me.")

- *“Kea leka ‘M’e. Leha ho le boima hobane joale akere ha se eena feela ngoana, ho na le ba bang bao ke ntseng ke lokela ho ba fa nako eaka le bona.”*

(“I try my best. But it is not easy because I have other children who also need my care.”)

- *“Mm. Ua utloa ke kena sekolo, ha ke khone ho mo fa tlhokomelo eno... bo ka nako e ‘ngoe ho tla be ho ngoloa li test, kea bala, kea pheha, kea hlatsoa, u fumane hore ha ke be le nako e ntle ea hae.”*

(“No. You understand that I am studying, so I am not able to provide that much care... at times you find that we are writing exams, I have to read, I have to cook, I do the laundry and then I do not get to give her good attention.”)

Some of the above responses match what was written by Neely-Barnes and Marcenko (2004:287) as well as Newacheck and Kim (2005:27) who associated the care-giving tasks to emotional stress and other psycho-social consequences in families that raise the children with disabilities. The family systems theory attributes this to the natural setting of interconnectedness and interdependence among family members, owing to which a dysfunction in one member will affect the functioning of all other members.

3.4.2.2.4. Sub-theme 4: Role played by other family members in support of the child and care-giver

Six participants reported that the children’s siblings and fathers were the most trusted to assist with care-giving tasks such as babysitting, feeding and moving the child around. In most families, the role played by care-givers was said to be complemented by efforts from other family members, especially the child’s father and siblings. Below are their responses:

- *“Ke ee ke bone e le eena feela ea khonang ho kena lieteng tsaka haa lebane le bona, ke se ke ee its’epise eena hobane ha ho na motho ea khonang ho ba hlokomela joaloka eena”*

(“He (the child’s second brother) is the only one that understands them (the child and the oldest brother who is mentally retarded) as much as I do, and I trust him to provide better care than anyone else”)

- *“Ee. Ha ke sa ea mosebetsing tjena ‘M’e oa bona oa ‘ne a khone hore a phethe mabaka ebe ke sala ke ba bona.”*

(“Yes. When I am not working I am able to look after them to give their mother a chance to run some errands”.)

- *“...Kea phomola ha ho khoneha. Bo li weekend ha ntate oa hae a sa theohela,... ke eena ea mo hlokomelang.”*

(... I make time to rest. On weekends when her father is not at work... he takes care of her.)

- *“Ha ke imeloe hakaalo kannete hoba re thusana le ntate oa hae, bo haeba ke na le lebaka le ntlamang ho tsamaea ke mo sia le eena kapa le bo abuti’ae haeba ese letsatsi la sekolo.”*

(“Honestly, I am not that burdened because her father and I take turns, whenever there is need for me to leave the house her father or her brothers take over.”)

- *“Ba ntse ba le teng bona, eena (ausi’ae) le nkono oa bona tlaase mono kea khona ho mo sia le bona, empa ele hore nka se its’epise hore ke tla mo sia le bona ke ee mosebetsing...”*

(“There are people who help me; (Child’s sister) and their grandmother down there. But I just cannot always leave her...”)

- *“Motho ea nthusang ke eena (ausi) haa le teng, chee le bo ausi oa hae ha likolo li koetsoe.”*

(“The person that helps me is (sister) when she is here, her sisters also help when they are not in school.”)

In addition, three participants mentioned that the other family members provided financial support to the care-givers to facilitate upbringing of the children with disabilities. These participants are quoted below:

- *“Re phelisoa ke eona shopo ena, chee le ausi oa hae o nthusa haholo.”*

(“We live on this shop, his sister also helps me a lot.”)

- *“...re se re ts’epile abuti’ae le malom’ae hore ke bona ba tla re thusa ka ntho tse ling... malom’ae eena o ee a re romelle kannete mafelo a khoeli.”*

(“... we wait on his uncle and his brother’s wages to meet the other needs... his uncle sends us money at the end of every month.”)

- *“... ha ntle-ntle motho ea seng a ntse a re thusa ke ‘M’e Matsale oaka. Eena o sebetsa makichining, Khauteng.”*

(“... actually my mother in law is the one that helps us. She works as a maid in Gauteng.”)

This theme illustrates the influence that commitment, support and the level of assistance required by each child hold over the care-givers’ quality of life and the families’ ability to provide quality care to the children living with disabilities. Based on the nature of care required by their children and the income generating opportunities availed to them, some care-givers were able to balance their care-giving responsibilities with their engagement in income generating activities (Allen, 2007:133). With regard to situations like this, the family systems theory explains that

the interconnectedness and interdependence among members of each family as well as the influence that the community and the external environment have over the operation of family units are the reasons why two families will have a different experience of the similar situation.

The positive aspects of caregiving were also noted from the responses provided by the participants, a detailed discussion of this theme is provided hereafter.

3.4.2.3. Theme 3: Positive aspects of care-giving

In light of all the hard work put into providing care for the children with disabilities, some participants pointed out a number of blessings that came along with raising the child with a physical disability. Sub-themes that emanated from this theme are the acquisition of new skills, development of a strong character, maturity both socially and spiritually, the opportunity to meet new people and no positive aspects to care-giving; they are discussed below.

3.4.2.3.1. Sub-theme 1: Acquisition of new skills

Asked if there was a positive side to raising the child with a physical disability, one of the participants noted the skills that she acquired from the support group of the parents of children with disabilities. Below is her response:

- *“ka lebaka feela la boemo ba ngoan’enoa, hee ke li tsamaile lithupelo hle, re ne re qete beke kaofela re rutoa ka leruo la liphoofofo, ke se ke tsoa bo lithupelong tsa moroko le tsa lieta... ha kea nts’a leha e le sheleng”*

(“Thanks to my child’s disability, I am always invited to trainings on income generating skills, I’ve acquired skills on animal keeping, shoe making and dress making without pay”.)

Brue and Wilmshurst (2016:112) mentioned that as much as parents experience intense feelings upon learning that their child has a disability, but later on in life,

many begin to appreciate the related personal growth which they also find astonishing. The family systems theory explains that perceptions of individual family members, among other things, shapes the way families react to a specific situation, such that a situation which poses threat to one family may put another at a developmental advantage. This particular family had a more positive outlook towards life as compared to the others. Thus, even as care-givers from three other participating families had also been in the same trainings, only this participant felt like attending the trainings was a merit that accompanied her child's disability.

3.4.2.3.2. Sub-theme 2: Development of a strong character

Two other participants mentioned that raising a special needs child had made them stronger and more resilient to life challenges. Below are their responses:

- *“ke fetohile motho e mocha ‘M’e kamor’a hore ke be le ngoana oa mofuta ona, ha ke khone ho iphpanyetsa batho ba nang le mathata, ha ke khona ke thusetsa ka sohle seo ke nang le sona.”*

(“Having a child of this kind has brought the best out of me; I am so empathetic and always willing to help others, especially the vulnerable people”.)

- *“Ke u joetse eena o nthutile bophelo. ‘Na ke ee ke re motho ea so hlaheloeng ke bothata, haa tsebe bophelo. ‘Na pelo ena eaka e thata hampe hona joale.”*

(“I learnt a lot about life. I always say before one encounters a problem, they know nothing about life. My heart is very strong right now.”)

The view of these participants is corroborated by Pritzlaff (2001:28) who observed that some parents of children with disabilities have grown stronger (and not weaker) as a result of raising a special needs child. With regard to this perspective, the family systems theory explains that a change in one family member prompts a corresponding change in the others. Therefore, it only makes sense that when a child in the family is diagnosed with a disability, the rest of the members will

automatically adopt the new status and character which will enable them to best nurture the special needs child.

3.4.2.3.3. Sub-theme 3: Maturity

Participants from two families noted that raising a special needs child had influenced both spiritual and social maturity among care-givers in the two families. Their responses are quoted below:

- *“ke ee ke shebe ke bone bana ba bang ba lekanang le rona tjena ba ntse ba tletse papali feela ka hloohong ka mona ke re “ao, esale bana bana ha ba tsebe letho”. Le ntate oa hae o ne a rata monate hampe khale koana hona joale haa sa li kena, haa tloha mosebetsing o toba lapeng, li weekend re qeta lets’ehare kaofela le eena mona, u fumane leha bakhotsi ba hae ba feta mono a ntse a ba sheba feela.”*

(“Most youth at our age are not serious, when I see them I think, “Well, these ones know nothing about life”. Her father also used to go partying a lot but now he has lost interest in such things, from work he comes straight home, on weekends we all spend the day together here, even when his friends pass by he does not go with them.”)

- *“... tumelong teng re holile haholo.”*

(“... our faith has grown a lot.”)

The family systems theory brings forth the importance of the external environment on resilience of each family against challenging situations. The wider the eco-system, the more options families have to align with healthier networks (Mattaini & Meyer, 2002:84). In the two families cited above, parents chose to align with the church, family and workplace, which are better networks in their external environment as opposed to friends and beerhuts. In return, the networks influenced a rather positive outlook from the parents with regard to their children’s conditions.

3.4.2.3.4. Sub-theme 4: Opportunity to meet new people

One participant further mentioned that raising the child with a disability provided his family with an opportunity to meet new people. The participant is quoted below:

- *“Ke hore re khonne le ho iphumanela metsoalle, bo hona ka sepetlele ka mane, motseng mona rea chakelana le malapa a mang a nang le bana ba mofuta oona.”*

(“We also got to make friends, for instance in the hospital, we have also grown close with other families in our area that have similar children.”)

Upon discovering that their child has a disability, some families are forced to withdraw from their previous networks in order to focus on the child, whilst others begin to reach out to the world in effort to acquire the resources, information and support they need to nurture their child.

The Eco-systems perspective explains that as part of their self-organizing process, systems create their own boundaries, which determines the level at which they interact with their environment. With regard to this, Mattaini and Meyer (2002:81-82) bring up the concepts of “open systems” and “closed systems”. Open systems engage positively with their environments, which enables them to grow and develop. On the other hand, closed systems are self-contained; for this reason they fail to thrive and ultimately they lose their ability to function (Mattaini & Meyer, 2002:81-82). The former action applies to the family referred to above. It can be constructed from the response of this participant that the family not only looked out for support related to their child’s condition but they also seized the opportunity to connect with the people that they would have otherwise not been able to reach. This interaction enhances the family’s ability to provide effective care to the child while also giving them an opportunity to develop in other spheres of life.

3.4.2.3.5. Sub-theme 5: No positive aspects to care-giving

Nevertheless, three participants said nothing positive came out of caring for the child with a disability. Asked if there was anything positive they learnt or acquired from raising the special needs children, the participants responded as thus:

- *“Ae kannete.”*
(“Not at all”)

- *“Ha hona letho kannete, u ka fumana molemo ofe ka ho hlokomela ngoana ea tjee!”*
(There is nothing. What benefit can you get from taking care of the child of this nature?)

- *“Ha ho na letho kannete.”*
(“Honestly, there is nothing.”)

In summary, this theme merely consents to the person-in-environment perspective of the eco-systems theory. According to this perspective, Individuals react differently to the same stimuli as a result of the pressures of environmental structures which affect each person differently. Thus, as depicted by this theme, the opportunities accessible to each family, spirituality, attitude and resources determine the opinions of each family with regard to the responsibility of providing care to the children with disabilities.

The next theme covers the opinions of the participants on the challenges that families encounter in the journey of bringing up the children with disabilities.

3.4.2.4. Theme 4: Challenges encountered by the family with regard to raising the child

Across all the interviews, participants mentioned an array of challenges that their families encountered as a result of raising the children with disabilities. Challenges

derived during data analysis were related to the families' social, financial and psychological lives, whereas others were specific to service delivery for the children with physical disabilities. These challenges are discussed below as sub-themes.

3.4.2.4.1. Sub-theme 1: Challenges encountered socially

With regard to social challenges, two of the participants mentioned that they suffered blame from other people, one with regard to the child's condition and another with regard to the quality of care she provides to the child. One other participant brought to light the challenge of stigmatization while three others said they lacked social support in raising their children. The following quotes capture the expressions of these participants:

- *“Akere batho ba tla bua ntho ena le ntho eane ha ba bona u na le mathata, haholo ha u se u sa lule le monna joaloka ‘na ha ke ne ke ba le (ngoana). Empa hee ke ee ke bone eka ba se ba bile ba tloetse hona joale hore o teng o teng.”*

(“You know people will always say this and that when you have problems, especially when you are separated from your husband as I was when I begot (the child). But I think they have grown used to his presence now.”)

- *“... joale le nakong e nngoe ke ee ke bone Ntate oa hae a nkhathatsa matla eka o utloa ke sa mo hlokomele hantle.”*

(“... sometimes her father demotivates me, he thinks I am not doing well enough [as a care-giver]”)

- *“... o lilemo li tharo feela u tla utloa batho ba bang ba mo buisa joalokaha eka ke lese... potso ke hore naa le ba bona ba ba buisa joalo ha ba le li lemo li tharo?”*

(“She is three years old and yet some people still baby talk when they speak to her, do they also baby talk to their three year old children?”)

- *“Malom’ae o nts’a le teng ka Taung ka mona, feela u ke ke ua bona a fihla mona a botsa naa ngoana o ntse a etsa joang.”*

(“His uncle is alive, he lives right there at Taung, but he never comes to inquire about the child.”)

- *“M’ae o nts’a solla hohle mona, o re oa sebetsa feela kee ke bone eka ke leqheka la hore a tlohe pel’a ngoan’enoa. Hobane haa ne a sebetsa akere re ne re tla bona a tlisa chelete?”*

(“Her mother is out there going up and down, she claims she’s working but I think it is just an excuse she makes to get away from this child. If she was working she would be sending us money, isn’t it?”)

- *“... ‘na ke ee ke bone batho bao re reng ke bona bao re ikarabellang ho bona ba sa ikamahanye hohang, feela baa tseba hore ke kena sekolo le ntate oa hae oa sebetsa, empa u ke ke ua utloa ba botsa le hore naa ngoana o sala le mang”*

(“... the people that we consider as our next of kins do not care, they know that I go to school and her father goes to work, yet they never bother to ask as to who looks after the child.”)

Talley and Crews (2012:38) indicated that care-givers required support to effectively undertake their caregiving tasks, and also to find quality of life and balance in their own lives (Talley & Crews, 2012:38). However, as noted by Gray (2002:sa), the parents of children with disabilities, especially mothers, were subjected to what is named a “courtesy stigma”, which is the stigma of affiliation that applies to people who associate with stigmatized groups rather than through any quality of their own (Gray, 2002:sa). The first quote only substantiates this claim. At face value, the stigma may appear as a response to the supposed moral failure of the participant, who gave birth out of the wedlock. Nevertheless, in the participant’s society, it is generally acceptable for single women to bear children and raise those on their own,

thus the stigma that appears in this instance is only encouraged by the child's disability.

On the other hand, as depicted by the second quote, Woolley (2004:58) and Anderson et al., (2007:11) highlighted the possibility for conflict among couples that parent the children with disabilities, which is attributed to the personal frustrations over the child's condition.

In light of the family systems theory, "an injury to one is an injury to all" when it comes to handling problems within the family unit, thus families can only function effectively when members balance the responsibilities among themselves other than when it is carried by a certain member/members alone. The role of the external environment as emphasized by the eco-systems perspective also comes to light in the families quoted above; how the community and extended family approaches the families is important in determining their effectiveness in providing care to the children.

3.4.2.4.2. Sub-theme 2: Financial challenges

Three participants mentioned that as a result of raising the children with disabilities, they found it difficult to find and keep jobs. Below are their responses:

- *"... u tla fumana hore neng-neng kea imeloa, ke be ke mo batlele motho ke tsamaee, empa ke boele ke khutle kamor'a nakonyana hape ka baka la hae"*

("... at times it gets so difficult that I find a babysitter and go (to work), only to return after a short while because of him.")

- *"Ntate ke eena motho ea ntseng a batla (mosebetsi). 'Na ke ne ke ntse ke sebetsa femeng ka tlameha ho tlohella hobane joale ke ne ke hloka motho ea serious ea ka nts'allang le eena..."*

("My husband is (looking for a job). I used to work at the Garment factory but I had to quit because I could not find a dedicated nanny.")

- *“Ha ke kule, feela ke lutse hae mona, kea mo hlokomela. Ke tlamehile hobane ha nka mo sia e ka ba mathata.”*

(“I am not sick, but here I am stuck at home, taking care care of her. I have no choice, if I leave her then it will only result in misery.”)

As noted by Meyers et al. (2000:21), families that raise a child with a disability incur indirect financial costs from the work reductions and forgone earnings. It is for this reason that many such families find it difficult to fulfil the needs of both the children and other family members. Researcher classifies this state as the *microsystem* level of the eco-system perspective. At this point the families interact with the children as individuals and are stressed by the children’s demand for special care, the decisions that families take at this level will determine their coping in subsequent levels. In those families where care-givers decide to give up on work altogether, the gap will always be felt each time the need for money arises, but also those families in which care-givers decide to prioritize the economic activities over care-giving, the child’s needs will always prevail, and as explained by the family systems theory, when the child’s needs are not being fulfilled all other members will continue to lack peace.

3.4.2.4.3. Sub-theme 3: Psychological challenges

Two of the participants mentioned that they were strained from providing care to their special needs children, whereas four others said that they were constantly worried about their children’s future. Their responses are quoted below:

- *“Ho thata ‘M’e ho holisa ngoana ea tjee, nakong e nngoe ke ee ke utloe eka Molimo a ka mo nka.”*

(“Raising this kind of a child is not easy, sometimes I wish she could just die.”)

- *“[Ngoana] o ntlamme ke le mong tjena... ke khathetse kapa ke sa khathala ha hona moo nka reng ke sa ea kae kae, ka lo pholisa hlooho... ke ee be ke nts’etse khalefo ho eena.”*

("[Child] is my responsibility, strained or not I have nowhere to hide... sometimes I find myself taking my frustrations out on her.")

- *"Ke rapela feela hore kutloelo bohloko eo ke nang le eona Ntate Molimo a tle a e kenye lipelong tsa basali batla nyaloa ke bana bana... Kea tseba hore nke ke ka phelela [ngoana] ho fihlela, ka le leng Molimo o tla nkhopola..."*

("I just pray that the women that my sons marry will have the same compassion that I have (towards her), I know that I will not always be there for [child], one day God will call me unto him.")

- *"Ke ntho eo ke lulang ke ipotsa eona. Hobane ha ho na motho e mong eo nka reng a ka mo hlokomela!"*

("That worries me all the time because no one else is willing to care for him.")

- *"Boemo ba ngoana enoa bo nkutloisa bohloko haholo ausi oaka... e nts'eisa letsoalo ntho ea hore naa ngoana eo ebe pheletso ea hae e tlo ba efe?"*

("This child's condition hurts my sister... I become scared when I think about her future.)

- *"Re ee re bue ka taba eno le molekane hore qetellong ea qetello, re tlo qetelletse Molimo a re hopola, ha Molimo a se a re hopotse, bo abuti'ae batlo nyala, ha ba se ba nyetse rea ipotsa hore naa eba o tlo phela joang (face saddens). Ebe bophelo ba hae e tlo ba bofeng!"*

("We sometimes think about it, that eventually God will take us, and then her brothers will marry, when they do marry what will happen to her... [Face saddens] What is to become with her life!")

Neely-Barnes and Marcenko (2004:287) noted that in families of children with disabilities, care-giving tasks, concern about the child's future, and the financial costs

of the child's disability place care-givers at risk of emotional stress. This can be observed in the responses quoted above. Within the first two responses there is an element of burnout and the ache to break away from the care-giving responsibilities. The other quotes demonstrate the continuous worry that families are faced with when thinking about the future of their children. Due to advanced medical technology, the children born with disabilities live longer and this means care-givers will be attending to the children for only a portion of their lives (Mac Donald & Callery, 2007:sa; Talley & Crews, 2012:33); therefore, it is only rational that parents worry about their children's future especially if they (parents) may not be a part of it.

In lieu of the eco-systems perspectives, the possibility for consistency or change in the children's condition plays a significant role in determining the emotions that care-givers experience. As they interact with their environment, families will time and again examine the odds for improvement in their children's condition, a setting referred to as the *chronosystem* level. However, families with low socio-economic status live in an environment that does not offer any hope for improvement in their situation and that of their children. Due to lack of resources and support, these families and their children have limited opportunities for development, a circumstance that renders them helpless and distressed.

3.4.2.4.4. Sub-theme 4: Challenges related to service delivery

With regard to service delivery, four participants mentioned that their children were not able to access the special education, seven participants said their families were not on any of the social security programmes, while one participant reported that her family's attempts to get help from the Government with regard to repairing her house has been fruitless, this despite the fact that the Government has repaired other houses in the area which were affected by the same storm that blew away her home. These participants expressed their situations as quoted below:

- *“Na taba-tabelo eaka e ne e ntse ele hore a ee sekolong motho enoa, empa joale ha ke na matla.”*

(“My wish is for him to go to school, but then I cannot afford.”)

- *“Ea sekolo eona ‘m’ae o mathile o bile o hlotsoe; o se a bile a tsoa le Maseru koana, o hlotsoe.”*

(“With regard to his education his mother knocked so many doors to no avail; she has even been to Maseru with the same issue, she failed.”)

- *“Na baa ‘makatsa batho bano (Social Development) hobane le maqalo a selemo mona ha ba batla bana bao ba ba isang sekolong ba ile ba re bitsa, ra ba ra ts’epa empa ele neng ra utloa ho thoe ba bang ba se ba ile.”*

(“Those people (Social Development) surprise me, earlier this year they were looking for children to send to school, they called us as well, that raised our hopes but not long after that we heard that they have send some children to school already.”)

- *“Ua tseba [Ngoana] o ne a khethuoe har’a bana baa ba eang Leribe, eaba ‘na kannete ke bona a hlora... Hoja re ne re ka etsetsoa sekolo mona Mafeteng, moo re tla nne re ba isa hoseng re ba lata mantsiboea...”*

(“[Child] was among the children who were sent to a school in Leribe, but he was not happy there... at least if the school could be established in the district to which our children would commute every day...”)

- *“Re mathile ebile re khathetse. ‘Na ke bona eka ke mokhethoa ea sa batleng hobane ha u ka sheba leha ho ntse ho thoe ho haheloa batho ba se nang bolulo pele, empa ho qaluoe ka ba party ea hae ka mor’a mono eaba re se re bona ho sisintha.”*

(“We pursued until we gave up. I think our Member of Parliament is not interested. Even as they claimed to prioritize those that were homeless but he actually prioritized members of his party, after that the project began to show redundancy.”)

- *“Na ausi ea sebetsang Social Welfare (eo eseng ele Social Development) mono o n’a ntjoetse straight hore ngoan’aka a ke ke a fumana letho hobane ke mocha ebile kea sebetsa”*

(“I was told by the Social Welfare (now social development) Officer that I am young and employed thus my child is not entitled to any of their grants”.)

- *“Social Development esale ke ea kea kholoa ka 2013... ba re batla mpitsa kannete ke ntse ke lebeletse.”*

(“I applied to Social Development in 2013... they promised to call me, I am still expecting.”)

- *“Social Development esale ke ea ke ba kopa wheelchair, ebe hee ha ke ba hlaloseka ka boemo ba ngoana ke ha ba re ba tla mpha le maleiri, eaba baa tla mona empa hee esale ba re ba tla re bolella ha kopo ea rona e amohetsoe.”*

(“I went to Social Development asking for a wheelchair, but then when I explained the child’s condition they said they would also provide the disposable nappies, they later came here and said they will let us know once our application has been approved.”)

- *“Ache teng (Social Development) esale ke ngolisa feela, eaba ba re ba re ba tla ntetsetsa.”*

(I’ve only been there (Social Development) to register, they promised to call.)

- *“Ua tseba bona (Social Development) ba kile ba tla moo! Ba fihla ba sheba-sheba ba botsa lipotso, eaba ba re ba tla tla.”*

(“They (Social Development) once came here, you know. They checked the place and asked some questions, and then they promised to return.”)

It is important to note that there are no specific social security services for children with disabilities in the country. Such children can only get the OVCs grant or the social security grant along with all other needy families. Meyers et al. (2000:399) wrote down that due to the fact that parents of children with disabilities have both care-giving and economic responsibilities for their children, families of children with disabilities are highly dependent on public assistance to fulfil the needs of their children and those of the other members. From the eco-systems perspective, these families are merely reacting to their environment (the need to provide for their families that runs concurrently with the need to provide care for the child with a disability), however, the coping abilities of these families are restricted by lack of programmes specific to disability, a state defined by the theory as the *macrosystem* level.

In summary, the proposition for this theme (*Challenges encountered by the family with regard to raising the child*) is that the journey of care-giving has differing implications for each family. The family systems theory explains that the unique properties of the family unit determines the manner in which members react to their problems, which, in the case of this study, is the presence of a disabled child. These unique properties include the personal characteristics of family members, the family's resources, cultural beliefs and ideological styles (Allen, 2007:133). Based on this theory, it is only reasonable that some families are so overwhelmed by the presence of children with disabilities even as others were said to have adapted without a problem. Based on their unique properties, some families are in a better state than others to adapt to the children's conditions.

The factors that influenced adaptation level among participating families are discussed in the following sub-section.

3.4.2.5. Theme 5: Factors that influence the family's adaptation level

The adaptation level among participating families differed. Factors underlying this disparity were identified as spirituality, financial security and available support

structures such as personal relationships, community support and religious services. These factors are discussed below as sub-themes.

3.4.2.5.1. Sub-theme 1: Spirituality

Four of the participants indicated that their families resorted to God to find justification for their children's conditions, and this assisted them to find peace of mind. Below are quotes from their interviews:

- *“Ke ile ka itjoetsa hore Molimo o re re lebohe linthong tsohle, mme le hona mona ke ntse ke re ho lokile ho lokile.”*

(“I just told myself that the Lord would love for us to give thanks in all situations, and I will continue to say it is well.”)

- *“...feela hee ntate oa hae o il'a ntlhabolla kannete, haholo! A re ha ho na moo ke entseng phoso, empa feela Molimo a ila bona hore ke 'na ea ka khonang ho jara moroalo ona.”*

(“... my husband is basically the one that counselled me, he assured me that I did nothing wrong and that the Lord found me strong enough to handle this burden... ”)

- *“Ke ngoan'aka enoa, ke mpho eo ke e fuoeng ke Molimo.”*

(“This is my child, my gift from God.”)

- *“Kea tseba hore Molimo o teng ebile o ntse a mpona ebile ha ke khutsana kapele ho sefahleho sa hae.”*

(I know that God exists and that He is watching over me and that with Him I am no Orphan.)

The Christian belief has made it easier for families to find their feet amid the challenges brought about by raising the children with disabilities. Christianity itself has been associated with an afterlife reward for those that commit their lives to doing good (Galatians 6:9 New International Version), and this encourages perseverance among care-givers who follow this religion. In the eco-systems perspective, the beliefs are among those complex aspects of the environment enshrined within the *macrosystem* level, which controls the family's adaptability. Spirituality encourages the positive beliefs, which create a favourable environment for adjustment of the families.

3.4.2.5.2. Sub-theme 2: Financial Security

Families with stable income were better adapted to the presence of the children with disabilities than those families that had no reliable means to generate income. Four participants mentioned that due to lack of reliable income, raising the children with disabilities was highly challenging for their families. These participants are quoted below:

- *“Re phela ka li piece-job...Hee ke imetsoe ‘M’e. Hona joale ke hloka mosebetsi ke tiile...”*

(We live on part-time jobs... life is difficult for me! Right now I am in dire need of a job...)

- *“O itsébeletsa likonterakeng feela ua tseba... ha hona le letho baa mo bitsa ha mosebetsi o fela o tla be a ntse a lutse feela... Ho thata ‘M’e, nakong e ‘nngoe u ka fumana hore ho feta nako e telele hampe re sa khone ho mo rekela le lona lebese feela...”*

(He does part-time contract jobs, they call him when there's work but when there's no work he stays at home... It is not easy, sometimes we are not able to buy even the milk alone...)

- *“(Re phela) ka tsona li piece job tseno tseo eleng hore abuti’ae o tla tsoa a lo rekisa ka stopong, kapa eena ntate enoa eo re lulang le eena haa ts’oarisitse matsoho... ea mo hlahlamang o ne a kena sekolo o lutse hae hona joale ka baka la eona chelete”*

(We live on part time jobs by his brother who vends in town, or my partner... his little sister used to go to school but she stays at home now due to lack of funds)

- *“Re ntse re na le eena (Ntate) hae mona hobane haa sebetse le ‘na ha ke sebetse... hantle-ntle motho ea seng a ntse a re thusa ke ‘M’e matsale oaka... o ntse a li fihlela (lithoko) but ka thata hobane o mong akere ua utloa?”*

(We are both unemployed and staying at home... actually we are depending on my mother in law for financial assistance... she helps us meet some of our needs although not effectively because she is the only provider you understand?)

On the contrary, four other participants said that having a steady income made it less wearisome to live with their special needs children. They are also quoted below:

- *“(Mae) O sebetsa makichineng... O amohela two thousand... Haa rometse rea khona ho finyeletsa lithoko tsa hae”*

([His mother] works as a maid... She earns two thousand... When she sends us the money, we meet all his needs)

- *“(Re phela) Ka eona sentenyana ena eo ke e fumanang, le ‘M’e ke motho ea its’ebetsang joale ha re ntse re kopanya matsoho joalo bophelonyana bo ntse bo eba teng”*

([We live] On the little that I earn. My wife is also self-employed and as we join hands we are able to sustain livelihood)

- *“Re fumana ena ea (Ngoana)... ehlile re e sebelisetsa eena... re ka kena ho eona haeba litlhoko tsa hae li ile ka ‘moho... lijo re khona ho li reka le sesepanyana”*

(We get [Child]’s grant... all of it is spend to meet his needs we only get to use the change if any... as for things such as food and soap we are able to buy)

- *“Ua tseba ha e n’e ba ntate oa hae haa sebetse, ha ke tsebe naa re ne re tlo mo etsa joang”*

(I cannot imagine how we would cope if my husband did not have this job)

Families of children with disabilities are faced with substantial additional costs, such as special education, larger heating bills, higher travel costs, costly foods or drug supplements and a higher need for medical care” (Woolley, 2004:58). For families with low socio-economic status, it is almost impossible to meet these needs. Despite the social security efforts provided by most governments, most of the additional costs remain uncovered (Sheinin, 2006) and this makes it difficult for the families to adapt to life with a special needs child. The ecosystems perspective explains that humans are only a part of a more complex social environment, consisting of various other entities such as the family, community, relationships and culture, which are all also interrelated (Dorfman, 2013:15), a balance is needed across all these entities if the person is to enjoy a fulfilled lifetime. However, in the case where a family is struggling to make ends meet, it becomes difficult to adapt to the life that the family is faced with.

3.4.2.5.3. Sub-theme 3: Personal relationships

Participants from four families mentioned that the primary care-givers received support from their partners, which placed them in a position to better handle the weight of care-giving responsibilities. These participants are quoted below:

- *“Na le bana beso ha bana taba le ‘na, ngoan’enoa esale ke ikh’olisetsa eena ke le mong empa kaha Molimo haa lahle motho, o ile a nkopanya le monna enoa, ha ke tsebe hore nka be ke ntse ke etsa joang hoja ese ka eena”*

(“My own family deserted me, but when no one else was there to help me with my grandchild the Lord send this man into my life, I don’t know how I would manage without him”.)

- *“Acheke ha nke ke utloe ke khathetse kannete, haholo ha ke ea ke lebane le eena, ha nke ke khathale, haholo hobane ha se boikarabelo ba ka ke le mong ntate le eena o kenya letsoho...”*

(“No. I never get tired, not from taking care of her, especially because I am not the only one responsible, her father contributes...”)

- *“Ha ke sa ea mosebetsing tjena ‘M’e oa bona oa ‘ne a khone hore a phethe mabaka ebe ke sala ke ba bona.”*

(“When I am not working I am able to look after them to give their mother a chance to run errands.”)

- *“Ah ehlile kea phomola ha ho khoneha, bo li weekend ha ntate oa hae a sa theohela; ke iphapanya hampe ke eena ea mo hlokomelang.”*

(“I make time to rest when possible, especially on weekends when her father is not at work. I just keep busy with other things so he takes care of her.”)

Craft-Rosenberg and Pehler (2011:901) noted that care-givers of children with special needs also have their own special needs, most outstanding of which is the need to frequently take a break from care-giving responsibilities. Care-givers who fail to create this time are placed at a higher risk of suffering from burnout, which will render their care-giving efforts much less effective. It is therefore important that other members of the family avail themselves to award care-givers some time off the care-giving role. In view of the family systems theory, the responsibility of raising the child

lies not only with a specific individual, but with all members of the child's family. The interview lines quoted above affirm this perspective, with alliance from members of the children's family; the weight of care-giving is dispersed among members and care-givers are able to lead balanced lives.

3.4.2.5.4. Sub-theme 4: Community Support

Participants from three families said they had a back up from their communities, whereas participants from four other families reported that their communities were not supportive. These participants are quoted below:

- *“Kea khona ho mo sia le bahaisane ua tseba, ha e s’e ba (ausi) a le sieo kapa eena nkho oa bona tlaase moo, kea khona ho kopa motho e mong feela hore a mo shebe...”*

“I can leave her with any of the neighbours, at times when (child's sister) and grandmother are not available; I ask any of the neighbours to watch over her...”

- *“Ua tseba ‘na ke ee ke bone ke le mothonyana ea ratoang ke batho, le eo ho ka thoeng enoa o khopo bona boo ‘na haa tla a lebane le ‘na o ba bonolo-nolo. (ngoana) batho ba re tsebang kaofela baa mo utloisisa.”*

“I happen to be an appreciated person; even those very impossible characters get along fine with me. (child) is liked by all the people around us.”

- *“Ba kang bo (moahisane) bona baa nthusa kannete ke ‘na feela ea eeng a tsoafe ho ba khathatsa.”*

“The likes of (neighbour) are willing to help; I just never want to bother them.”

- *“Bahaisane bona ha nke ke rate le ho bua le bona hobane ke batho batlo u hobosa feela ha u ba joetsa mathata a ngoan’a hau... ba tlo u ts’eha ka oona.”*

(“I never open up to my neighbours because all they do is harass you when they hear about your child’s problems... and laugh at you”)

- *“Ache ‘na ngoan’enoa ke ee ke bone batho ba mona ba sa rate ho mo ts’ehetsa, hobane ka nako e ‘ngoe u ka tloha ua utloa feela ho se ho thoe ho no bitsitsoe likooa ka mane ka moreneng empa eena ho sa thoe letho ho eena.”*

(“I think the people in this neighbourhood do not like to support this child, because sometimes we only hear as they talk that disabled people had a meeting at the chief’s place, and yet nobody would have said anything to him.”)

- *“Akere batho ba tla bua ntho ena le ntho eane ha ba bona u na le mathata, haholo ha u se u sa lule le monna joaloka ‘na ha ke ne ke ba le ngoana enoa.”*

(“You know people will always say this and that when you have problems, especially when you are separated from your husband as I was when I begot this child.”)

- *“... baa tseba hore ke na le ngoana ea phelang le bokooa akere, feela ha hona... hore ba ka re ka letsatsi le leng feela “Ak’u re re ke re ee ho (lebitso) mane re ke re eo qoqa re mo hlabolle re mo joetse 1,2,3,..”... le hore ba ke ba botse feela hore o ntse a hola hantle ngoana.”*

(“... they know that I have a child with disabilities,yet they never bother, even for one day, to pay me a visit so we can talk and have a good time... or even just to ask how the child is doing.”)

Those care-givers who felt connected were less prone to anxiety and depression, whereas a low sense of connectedness perpetuated a low self-esteem and psychological distress (Munsell, Kilmer, Cook & Reeve, 2013:sa). Elements of

distress and isolation are notable from the quotations of four participants who reported that their communities were not supportive. With regard to this matter, the family systems theory brings to light the influence of the supra-system, within which the community is classified, over the operation of family units. Families that live within the affectionate communities are better able to tackle their problems as opposed to those that live among indifferent societies.

3.4.2.5.5. Sub-theme 5: Religious Services

All participants were Christians. Five of these participants mentioned that their families were regular church goers and that the church provided a hospitable atmosphere for them and their special needs children. They are quoted below:

- *“Batho bao ke kenang kereke le bona kaofela rea utloana. Le bana ba bona ba ipapalla le eena ha monate ho se na mathata a letho. Joale ua bona ke ‘na ea tsamaisang ma Sunday school, ae ke ikela le eena kerekeng ebe hoa bapaloa ho monate.”*

(“I am in good terms with all the people in my church. I am also in charge of the Sunday school service so I usually take her along, the other children interact well with her and they all like to play together.”)

- *“... ha hona le bo li conference, (ngoana) u tla fumana eka ha se ngoan’aka ba kapisana ka eena ebe le ‘na ke khona ho rapela hantle ke ntse ke sa re ke hlokomela ngoana.”*

(“... when there is a church conference, they take turns to baby sit (child) so I enjoy the event, not worrying about the child.”)

- *“Ache ‘na ha ke le motho oa likereke hakaalo, empa molemong oa hae lits’ebeletso tsona kea li tsamaea kannete motho enoa o rata kereke hampe ‘M’e ha u ka mo bona a bina ka mono a opa liatla!”*

(“Well I am not a believer per se but for his sake I do go to church, he loves church very much, you should see him singing and clapping his hands in there!”)

- *“Batho ba kang bo (lebitso) ke kopane le bona hona kerekeng, ha re se re ntse re qoqa mathata a rona ra fumana hore rea ts’oana.”*

(“I met the likes of (name) in church, as we began opening up about our problems we discovered that we were faced with the same challenge.”)

- *“Kerekeng ‘M’e ha ho ts’oane le motseng mona, mono kea rapela ke lle ha hona motho ea tle re “jooe le mo utloile”. Leha ke imetsoe ke ipuela feela hore ba nrapelise.”*

(“Unlike anywhere else, in church I can freely express my pain and no one will judge me. Even when I have problems I just open up and ask them to pray with me”.)

From the above quotes, it is evident that the families enjoy vast support from the religious groups. Religion encourages selfless support for one another. Religious groups, in particular the church, have been complemented for facilitating integration of children with disabilities and their care-givers and also for organizing the charity events and projects intended to assist families to meet the children’s special needs which they could not afford (Poston & Turnbull, 2004:101; Meyers et al, 2000:75). The eco-systems perspective raises the relation between processes that take place in one or more settings containing the developing person. The implication of the eco-systems perspective in this scenario is that religion incites a sense of altruism within believers, which is extended to the care-givers of children with disabilities and goes on to reign at home. With this kind of support, families are exposed to a variety of strategies that help them to cope successfully with the demands of raising the children with disabilities.

Strategies that emanated from this study are discussed hereafter.

3.4.2.6. Theme 6: How families managed the pressures of raising the child with a physical disability

Participating families were coping differently with the demands of raising the children with physical disabilities. Eight major coping strategies were identified that assisted participating families to manage the daily challenges brought about by raising a disabled child, and these are; turning to spirituality, developing and maintaining family cohesion, utilizing personal and family resources, accepting the child with his/her condition, disengaging from the child, living with hope that the child will get healed, seeking external aid and adopting alternative means to generate income. These strategies are discussed below as sub-themes.

3.4.2.6.1. Sub-theme 1: Turning to Spirituality

Three participants indicated that when the challenges of raising the children with disabilities emanated, their faith kept them afloat. These participants are quoted below:

- *“... ke ngoan’a Molimo nna mathata haa nketse letho”*

(“... I am a child of God and I am not shaken by the problems.”)

- *“Ua tseba kea rapela, ke kena ka tlung ka mona ke ikoalle ebe kea rapela. Ha ke qeta mono ke tsoe eka ha hoa etsahala letho.”*

(“I pray. I lock myself in the room and pray and then come out as if nothing happened.”)

- *“... ngoan’enoa esale ke ikh’olisetsa eena ke le mong empa kaha Molimo haa lahle motho, o ile a nkopanya le monna enoa, ha ke tsebe hore nka be ke ntse ke etsa joang hoja ese ka eena”*

(“... when no one else was there to help me with my grandchild the Lord send this man into my life, I don’t know how I would manage without him”.)

Lane (1992:53) asserts that spirituality enables one to “live with” rather than to “suffer from” the effects of disability. With Spirituality, families are relieved of the psychological pressures by acquiring faith and beliefs that give comfort (Meyers et al, 2000:75). The eco-systems perspective explains that as individuals attempt to organize themselves in order to adapt to their environment, they are guided by an array of cultures and beliefs which determine how they should interact with their environment. Spirituality is one of the philosophies that encourage optimism among believers, which assists the families to adapt successfully.

3.4.2.6.2. Sub-theme 2: Developing and maintaining family cohesion

Four other participants reported that in their families, the parents and siblings of the children with disabilities shared the responsibility of meeting the child’s needs and of generating income for the family. They are quoted saying:

- *“Ha ke imeloe hakaalo kannete hoba re thusana le ntate oa hae, bo haeba ke na le lebaka le ntlamang ho tsamaea ke mo sia le eena kapa le bo abuti’ae haeba ese letsatsi la sekolo”*

(“Honestly, I am not burdened because her father and I take turns, whenever there is need for me to leave the house her father or her brothers take over”.)

- *“Ua mmona ngoan’eo oaka ‘M’e, nka tsamaea ka qeta matsatsi ke le sieo hae mona, ha feela lijo le sesepa li le teng ka tlung ka mona ke fumana ngoan’enoa oa ka a hlokomelehile u keke ua re o setse le moshanyana”*

(“Do you see that boy? I am able to spend days away from home, so long as there is food and soap I always find my child in good condition, you can bet it was not a boy taking care of her”.)

- *“Ha ke batle ho lula hae mona ke shebile ntate oa hae, hobane le eena oa imeloa ene ke ee ke bone hore taba ea ngoana ea mo stressa, ke batla ho sebetsa ke mo thuse.”*

“I cannot just stay at home looking up to her father to provide everything, the child’s issue is too much for him, I want to find a job and help him.”)

- *“Ke ne ke ntse ke sebetsa ho tloha khale empa kamor’a hore ‘M’e enoa a qale ho roka, ke hona ke bonang tema ua tseba ke u joetse!”*

“I was working all along but since my wife started sewing, there has been significant progress.”)

Cooperation among family members made it easier for the families to put up with the demands of raising a special needs child. When members share the responsibility families are able to provide better care and with less effort than if the responsibility was carried by the care-giver alone (Craft-Rosenberg & Pehler, 2011:901). The family systems theory emphasizes the importance of joint effort in addressing problems within families. In the perspective of this theory, a problem that occurs to one of the members of a family shall in one way or another affect the rest of the members, thus a collective effort to tackle this problem liberates not only the direct victim but the entire family as well. Tackling the problem as a team promotes effectiveness and also mitigates the harm that the challenge would have posed if wrestled by a specific member alone.

3.4.2.6.3. Sub-theme 3: Utilizing personal and family resources

Five participants said that the personal and family’s resources, especially financial and social means such as employment, skills and education, made it easier for their families to manage with the pressures of raising the children with disabilities. Below are the quotes from their interviews:

- *“... empa hee ntate oa bona oa leka ho ba khotsofatsa hobane leha eba ho thoe haa fumana mosebetsi ke motho ea khonang ho iketsetsa bo li piece job ebe haa bokellelitse o tla hae.”*

(“... but then their father tries his best to meet their needs, he engages in some temporary jobs and when he has collected some money he comes home.”)

- *“Akere ‘m’ae o nts’a re romella chelete, haa rometse rea khona ho li finyeletsa.”*

(“His mother sends us the money, when she does, we meet all his needs.”)

- *“(Re phela) ka hona ho ts’oarisa matsoho, re ntse re lema le merohonyana re rekisa.”*

(“We survive on manual work, we produce some crops for sale.”)

- *“Ua tseba ha en’e ba ntate oa hae haa sebetse, ha ke tsebe naa re ne re tlo mo etsa joang!”*

(“I cannot imagine how we would cope if my husband didn’t have this job”.)

- *“Ho na le ‘M’e eo nke keng ka mo lebala bophelong... ‘M’e eo o ile a re kopanya re le batsoali ba bana ba nang le bokooa a re rupela ho roka lieta tse na tseo ke phelisang bana baka ka tsona.”*

(“There is this particular Lady who volunteered to train us (parents of children with disabilities) on shoe making, to date I raise my children on the income generated from selling the shoes I made myself, I will forever be grateful to her”.)

Allen (2007:131) believes families can easily manage their problems if they are assisted to identify and utilize strengths that already exist within themselves and among their circles of support. From the eco-systems perspective, a person’s environment can build or destroy that particular person. Solutions to problems are found within the same environment that subjected a family to the challenges; the role

of the family is to discover their strengths and seize opportunities that the environment brings their way.

3.4.2.6.4. Sub-theme 4: Accepting the child and his/her condition

Four participants mentioned that they had learnt to accept their children and the children's conditions; this placed them in a better position to manage the demands of raising the children with disabilities. The participants are quoted below:

- *“Ke ne ke ote hore ke be tjena ha ke qala ho hlokomela hore [ngoana] o na le bothata, ke ne ke sa rate leha batho ba mo bona... Hona joale ke ikamohetse ke u joetse, haeba ke se ke tseba ho bua tjee ka [ngoana]!”*

(“When I first realized that [child] is living with this condition I lost so much weight! I did not even want people to see her... Right now I have accepted the situation, that I am able to discuss her condition so freely is proof.”)

- *“Ua tseba ngoana ea tjee oa tloaeleha, ‘na ke ee ke utloe ho se na phapang pakeng tsa hae le enoa e monyane, re se re mo tloaetse.”*

(“You get used to a child of this kind, I no longer find her different from this younger one, we are used to her now.”)

- *“Kannete ke qeteletse ke se ke ikamohela, ke re ache ke mpho eo ke e fuoeng ke morena Molimo... le ntate a cho a re “mosali oaka ke mpho eo re e fuoeng ke Morena Molimo ke hore re e amohele”...”*

(“Ultimately I decided to accept the situation, I just told myself that she was my gift from God... my husband also said, “my wife, this is our gift from God, all we can do is to accept her”...”)

- *“Ho na le nako eo ke neng ke ikahlola, ke sa its'oarele hohang ka ntho ena e hlahetseng ngoana enoa. Empa ha nako e ntse e ea ke ile ka itjoetsa hore*

Molimo o re re lebohe linthong tsohle, 'me le hona mona ke ntse ke re ho lokile ho lokile."

("There was a time when I blamed myself so much, I couldn't forgive myself because of what happened to this child. But as time passed I just told myself that the Lord would love for us to give thanks in all situations, and I will continue to say it is well.")

Accepting the children merely changed the attitudes of family members towards the children's condition, thus improving their level of functioning. As indicated by some of the participants quoted above, Neely-Barnes and Marcenko (2004:288) mentioned that accepting the child's disability is a long-term process, which may be achieved over the years. However once the families reach the level of acceptance, it means they have completed the process of grief and are in a position to lead a normal life. The eco-system perspective indicates that humans are self organizing subjects within their environment, always striving to adapt. When a change occurs in their environment, human beings are prompted to revolutionize so as to adapt to the changes in their environment. Therefore, it is only a matter of time before each family adjusts to the presence of the child with a disability in the home; nevertheless, owing to the unique properties of each family, the duration of this adjustment varies across families.

3.4.2.6.5. Sub-theme 5: Living with hope that one day the child will get healed

Two participants portrayed a certain degree of hope that it was only a matter of time before their children got healed of the disabilities. These participants expressed themselves as quoted below:

- *"...ba ile ba re re mo etsetse meetlo chee ntse re mo fa le lebese la hae le li boostara, mohla a folileng ke sure re tla ke re utloe le litsebeng,"*

("...they (elderly relatives) said we should perform certain rituals and we did, we also make sure that she does not run out of the special milk and food supplements, I cannot wait to see her well".)

- *“Ua tseba ngoan’eo oaka haa tsoaloa a le tjee! Kea lumela hore o nts’a tla fola ha re ka tiisetsa thapelong... Kerekeng mona ho se ho thusitsoe batho ba bangata hampe, ke lumela le eena la hae le tla chaba.”*

(“My child was not born with this condition; I believe that as long as we continue to pray, she will get well... I have seen a lot of people getting help from my church and I believe her day will come.”)

Holahan and Moss (2007:945) appraise hope as an important element of adaptation for the many people that are going through difficulties in life. Hope and faith usually complement one another, and in the two responses quoted above, the first is dominated by hope and the latter by faith. Either ways, an element of denial is eminent in both responses, and, as noted by Kubler-Ross (2009:8), denial is only just another step of grief, which the unconscious mind projects to temporarily protect individuals against the pain of a complex reality. With time and experience, individuals that are in denial will begin to consider the possibility that their ideal situation is far from reality, this introspection is important as it facilitates acceptance of the painful reality (Kubler-Ross, 2009:8).

The family systems theory explains that based on their unique features, families react differently to a similar stimulus. The outstanding features identified from statements quoted above are beliefs and the level of knowledge in families of the participants. The belief in healing power of the rituals in the first family, and of prayer in the second family has sponsored the families’ hope. Additionally, the eco-systems perspective explains that individuals are social beings, shaped by the environment they live in. The environment surrounding these two families has also contributed to their perceptions. The extended family has assured the first family that rituals will heal their child, whereas the second family has witnessed as other members of its church were healed through prayer, and they have been socialized to believe that the same will happen with their child.

3.4.2.6.6. Sub-theme 6: Seeking external aid

In effort to counter the challenges of raising the children with disabilities, some families went out to seek assistance from social service providers. Five of the participants said their children's wheelchairs were donated to them. They are quoted below:

- *“Wheelchair ena ua tseba ha re tla e fumana, keha motho e mong a feta mona a mpotsa naa ke utloile hore Mohato o teng ka mane ka Makeneng kerekeng ebile o tlile le limpho bakeng sa batho ba phelang le bokooa, eba ke se ke mo pepa re palama.”*

(“The day we got this wheelchair, a random passerby asked if I was aware that the King is at the Makeneng church, issuing gifts to the people living with disabilities, I quickly took her child there.”)

- *“Ke e fuoe (sepetlele) ha ke lo etsa lengolo la bokooa ba ka.”*

(“I got it [from the hospital] when I was going to get a document for my disability.”)

- *“(Wheelchair) O e fuoe hona ka mono... Ba mo file eona haufinyane tjena”*

(“[He got his wheelchair] from the hospital... he only got it recently”)

- *“O e fuoe kerekeng khaale koana. Ene kannete e felile le mabili ua a bona a pelekane.”*

(“He got it from the church a long time ago. It is worn out, even the wheels are no longer in position.”)

- *“Wheelchair ena re e fuoe ke ‘M’e eo ho thoeng ke ‘M’e Lihlong Education mola...”*

“This wheelchair was donated to us by a lady called Lihlong from the (special) education office...”

In the majority of participating families, financial and material support from individuals and institutions of good will assisted most families to better manage the challenges they encountered as a result of their children’s disability. Apart from the wheelchairs, some other participants highlighted that their children received aid in the form of disposable diapers, livelihood grants and educational bursaries provided by the Department and other service providers. This sub-theme corroborates the views of Meyers et al (2000:75) and Woolley (2004:42), who identified public programs as the most common ray of hope for low income families raising the children with disabilities. Woolley (2004:42) went on to say that these programmes, whose intention is to supplement the income of families so as to make it easier for them to cover the children’s special needs, usually converts into the only source of livelihood for the entire family. A similar observation was made by the researcher in one of the interviews where a participant mentioned that the child grant received by her special needs child from the Department of Social Development (R250.00per month) is the only reliable income for the entire family. In her own words, the participant said:

- *“Chelete ena ea [ngoana] re e tonetse mahlo kaofela ka tlung ka mona, kaha ke eona feela eo re nang le eona rea sebelisa.”*

“We are all depending on [child]’s grant... it is all we have so we use it”

In the view of the eco-systems theory, individuals require support from their environment to fully adapt to the same environment. As individuals attempt to organize themselves at the microsystem level, they get to interact with certain features which invite, permit or inhibit engagement in sustained, progressive interaction with the immediate environment. With regard to the families referred to above, the low socio-economic status, coupled with the demands of raising a special needs child have restricted the families’ opportunities to embark fully into the economic activities. For this reason, the families had no choice but to resort to the environment around them for support that would enable them to cope in the mist of the challenges.

3.4.2.6.7. Sub-theme 7: Disengaging from the child

In one of the interviews, the participant mentioned that the child's mother uses work as an excuse to escape the pressures of bringing up a child with a disability and that she (participant) is also seeking a job so that she won't have to look after the child anymore. She is quoted below:

- *“M’ae o nts’a solla hohle mona, o re oa sebetsa feela ke ee ke bone eka ke leqheka la hore a tlohe pel’a ngoan’enoa... Hona joale ke tsoile lets’olo ke batla mosebetsi, hang ha ke o fumane ‘M’ae o tla lokela ho tla hae mona a tlo ikh’olisetsa eena.”*

(“Her mother is out there going up and down, she claims she’s working but I think it is just an excuse she makes to get away from this child... I’m actively seeking employment myself, when I get an offer, her mother will have to come home and take care of her.”)

The statements quoted above affirm what was mentioned by Woodman and Houser-Cram (2012:13-15), who noted that disengagement moderates the impact of the child’s problems on care-givers (Woodman & Houser-Cram, 2012:13). However, disengagement itself results in negative consequences for parents of children with disabilities, including decreased parental efficacy and a set of depressive symptoms (Woodman & Houser-Cram, 2012:14-15). The eco-systems perspective denotes that human beings can only accomplish fulfilment in life if they adapt to their environment. Following this explanation, it becomes clear that the family referred to in the quotes lacks peace not because of the child’s disability, but because of their resistance to fate that is presented by their environment.

3.4.2.6.8. Sub-theme 8: Adopting alternative means to generate income

As shown in subsection 3.4.2.4.2., some families lost their financial security when care-givers quit their jobs to provide care to the children with disabilities. In such cases, engaging in jobs that would enable the care-givers to mind the children as

they generated income was the best response utilized by some of the families. Participants from five families mentioned that their children's care-givers engaged in income generating activities that allowed them to work while also providing care to the child. In their own words, these participants said:

- *"... keha ke tla tlohella mosebetsi hore ke tlo itlhokomella eena...(re se re phela) ka hona ho ts'oarisa matsoho re ntse re lema merohonyana re rekisa"*

(I decided to stop working so I could take care of him myself... [we now live] on small scale commercial farming)

- *"M'e ke motho ea its'ebetsang... o roka lieta, o na le mochine hape o roka liphahlo..."*

(My wife is self-employed... she produces hand-made shoes, she also has a sewing machine and she tailors clothes...)

- *"Hoseng re theohela le eena re chaise mantsiboea"*

(We come to work together in the morning and knock off in the afternoon)

- *"Ua tseba ha hona mosebetsi oo nka khonang hoo etsa kantle ho lieta, kea li loha ebe ke rekisetsa batho"*

(There is no job that I am able to do other than the shoes, I make shoes and sell to people)

- *"Ke butse likonyana holimo mane...mesebetsi eo nka e etsang ke e ntumellang hore ke lule ken a le eena hobane ho hiroa ua utloa ho tlo ntlama hore ke mo sie"*

(I run a day care centre up there... the only jobs I can engage in are those that enable me to be with her as I work because seeking employment will require me to leave her)

In summary, this theme brings to light the answer to the study question. The theme presents the coping strategies identified among low socio-economic status families that are raising the children with physical disabilities in Mafeteng, Lesotho. The COPE model of Carver, Scheier and Weintraub as discussed by Feher-Prout (1996:156) categorises between active and avoidant coping strategies. Active coping strategies are said to be those efforts designed to change the nature or presence of the stressful event, while avoidant coping strategies refer to those activities people engage in to keep away from the reality of having to deal with the stressful situations (Holahan & Moss, 2007:948).

Following the COPE model, researcher identified the following as active coping strategies: turning to spirituality, developing and maintaining family cohesion, utilizing personal and family resources, accepting the child with his/her condition, seeking external aid as well as adopting alternative means to generate income. These strategies assisted the families to live positively despite the pressures of raising the child with a physical disability. On the other hand, disengaging from the child and hoping the child will get well were classified as the avoidant coping strategies. Hope held an element of denial in it, since what the parents were hoping for (the child getting healed) is technically impossible. Furthermore, disengagement only delayed adaptation of the families, and will forever hold the families back from being able to manage the challenges brought about by their children's conditions.

3.5. SUMMARY

Data collected in this study confirms that families with low socio-economic status, who are also raising children with physical disabilities, encounter a lot of challenges specifically related to their children's conditions. To live with these challenges, families adopt an array of coping strategies, both positive and negative. The identified coping strategies among participating families were turning to spirituality, developing and maintaining family cohesion, utilizing personal and family resources, accepting the child with his/her condition, disengaging from the child, hoping that the child will get well, seeking external aid and adopting alternative means to generate income. Some of these strategies, for instance, turning to spirituality and utilizing the

public programmes had already been identified by previous researchers (Meyers et al, 2000:75).

The next chapter provides a generic discussion of the findings from the researcher's perspective, as well as the conclusions and recommendations.

CHAPTER 4

KEY FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

4.1. INTRODUCTION

This chapter presents a discussion of the key findings from the study, from which the answer to the research question is derived. The latter part of the chapter outlines the conclusions and recommendations developed by the researcher during data analysis.

4.1.1. The Study Goal and Objectives

As noted by Babbie and Mouton (2010:16), the purpose of social science research is to provide answers to the many questions we have about human behaviour in social settings. At this point, researcher goes back to consider the aims of the study and to examine if (and how) these were met.

The main purpose of the study was, *“to explore and describe the coping strategies of families with low socio-economic status raising children with physical disabilities in Mafeteng, Lesotho”*.

To achieve this purpose, researcher designed and pursued the following objectives:

4.1.1.1. To conceptualise childhood disabilities within families with low socio-economic status

Conceptualisation of the key terms was important in order to assist other people to understand the study from the researcher’s view point. Review of the literature particularly informed the researcher’s contextualisation of the terms and phrases central to this study, and this is presented in section 1.2 and section 2.3.4 of this report.

4.1.1.2. To explore the challenges experienced by families with low socio-economic status in raising the children with physical disabilities

In order to understand how the families cope through the challenges of raising the children with physical disabilities, it was important to first understand such challenges. An array of the challenges was identified both during the review of the existing literature and during data collection. A comprehension of these challenges is provided section 2.3.3 and section 3.4.2.4.

4.1.1.3. To explore the coping strategies of low socio-economic status families when dealing with the challenges of raising the children with physical disabilities

Analyses of the collected data confirmed and revealed a number of coping strategies, both positive (active) and negative (avoidant). While the researcher acknowledges that the coping strategies identified by this study may not necessarily apply to all families raising the children with physical disabilities, the researcher is confident that the study yielded coping strategies exhaustive to all the families that participated. These are outlined in sub-section 3.4.2.6 of this report.

4.1.1.4 To suggest strategies to the Department of Social Development about the social work services needed by families with low socio-economic status that are raising children with physical disabilities

The study would leave no significant mark if it did not raise suggestions on how best to fill the service provision gaps as identified during data analysis. Section 4.4 was specifically designed to meet this particular objective.

4.2. SUMMARY OF THE KEY FINDINGS

In this sub-section researcher provides an outline of the study findings, from which conclusions were drawn about the low socio-economic status families raising the children with physical disabilities.

- Firstly, the study found out that primary care-givers in all participating families were women, mostly mothers of the children. However, given the deeply rooted patriarchal ideology in Lesotho, this setting was to be anticipated.
- The study further discovered an astonishing sense of unity among members in some of the participating families. In these families, care-takers were working hand in hand with the father and/or siblings to take care of the child, and the family united more in taking care of the child than in conducting other tasks.
- The study also established that most care-givers have had to retire early in order to commit a hundred percent of their time to taking care of the children with disabilities. Some of these found alternative ways of generating income whilst also providing care to the child, for example, commercial crop farming, child-minding and handicraft work.
- The study also discovered that the low socio-economic status families could not afford to attend to the needs of the child and those of the other members all together. Due to limited resources and opportunities, the families were forced to choose whether to prioritise the child's special needs or the needs of the other members.
- It was further observed that mothers of the children living with physical disabilities preferred to take care of their children themselves and were in most cases comfortable leaving the child with no one else but the child's father and siblings. Other children who were not cared for by their mothers were cared for by their maternal grandmothers.
- The study further revealed that most families lacked the crucial knowledge regarding their children's disabilities. The participants did not know much about their children's conditions other than what they learned from the experience of caring for such children. As such, families were not guided as to how best to take care of their children, and the majority of them were only relying on their instincts and advices from the ordinary people.

- The study also found out that even as they continued to follow the western medicine perspective, some families also consulted lay men and traditional health practitioners to seek traditional and spiritual answers for their children's conditions, and they better agreed to the primitive accounts of their children's conditions than the western views.
- Additionally, the study discovered that even as the diagnosis of their children's disabilities was given by the hospital, most families only heard about Social Development services from friends and acquaintances who knew someone with the similar condition or who were living with the condition themselves, and were receiving services from the Department of Social Development. In most cases families contacted the Department months or even years after the diagnosis.
- The study further discovered that most of the families were generally happy in life even as they were raising the children with disabilities. Only a few participants said their families were overwhelmed by raising children with physical disabilities, most of the participants stated that they had learnt to accept their children and that raising the child with a physical disability has since been like raising "any other child".
- The study also found out that families of children with physical disabilities adopted an array of coping strategies in order to manage the challenges they encountered as a result of their children's conditions. The study discovered the following coping strategies: turning to spirituality, developing and maintaining family cohesion, utilizing personal and family resources, accepting the child in his/her condition, living with hope that one day the child will get healed, seeking external aid, adopting alternative means to generate income and disengaging from the child.

In summary, it is evident that diagnosis of a child with a physical disability brings about agony into families with low socio-economic status. With time, some families begin to adjust and find ways to cope in this challenging environment, even as their

lives never get to be as stable as they may have been before. Nevertheless, some families take longer to adapt. A lot of families lack the crucial modern knowledge concerning their children's disabilities. For this reason, families are generally of the view that modern medicine is restricted when it comes to explaining and treating their children's disabilities, and they resort to traditional health practitioners and the wise men for profound explanations, which they hold dearly.

4.3. CONCLUSIONS

From the literature review and the key findings discussed above, the researcher reached the following conclusions,

- In families of the children with disabilities, mothers bear the burden of the child's needs more than all the other members.
- The presence of a child with a disability intensifies unity among members in some families. Having gone through a traumatic experience together, family members develop a mutual sense of compassion towards one another and towards the child.
- The study also led to a conclusion that due to the demands of care-giving, the presence of a child with a disability affects the adults' ability to provide for the families.
- Based on previous literature and the study findings, researcher concluded that the families of children with disabilities cannot cope without external aid if they are to meet both the child's special needs and the needs of the other family members.
- Researcher further concluded that the parents of children with disabilities believe only them and close family have the compassion needed to provide good care to their children. For this reason, parents do not trust outsiders with their children.

- The need to educate families of children with disabilities on the children's conditions; more especially the treatment options, the services required and the services available, has been overlooked by the local service providers.
- The researcher further reached a conclusion that some families of children with disabilities believe their children's conditions are beyond the means of western medicine, and can only be explained by those with the supernatural powers.
- The study also led to a conclusion that there is not enough coordination between the Department of Health and the Department of Social Development with regard to providing services for the children with disabilities in the district.
- Having a child with a physical disability does not necessarily make the family miserable, but the negative attitude towards the child's condition does.
- Lastly, it can be concluded that the families of children with physical disabilities adopt mostly the positive over the negative coping strategies.

The family systems and the ecological systems theories together provided a perspective from which researcher looked into the research problem. According to the family systems theory, the main functions of the family are support, regulation, nurturing and socialization of its members (Allen, 2007:133). In lieu of this perspective, researcher decided to examine the coping strategies of the "family" as a unit rather than of specific members of the children's families. Conducting the study in this perspective verified the importance of collective action among family members in raising the children with physical disabilities. Those families whose members lacked cohesion were living in despair over the child's condition, whereas those whose members raised the child jointly were better adapted and living happily despite the child's disability.

On the other hand, the Ecological systems perspective provided a better understanding of the role of the environmental structures on the stress of raising the

child with a disability, as well as the coping strategies sought by different families (Washington, 2007:48). Based on this theory, the researcher reached a conclusion that the choices, plans and actions of humans are all activated by the state of affairs in their environment, and are also conceived on the basis of what the environment presents to these people.

4.4. RECOMMENDATIONS

Based on the key findings and conclusions discussed above, the following recommendations have been developed:

- Alternative means of earning livelihood

There is need for alternative income generating activities for adult members of the families raising the children with physical disabilities. This is because of the prevalent practice of early retirement as observed during the study. Social service professionals should aim more towards assisting the parents to acquire new skills which will enable them to work from home while also taking care of the children, as such, the financial impact of raising special needs children will be curbed and ultimately there won't be much need for handouts.

- Awareness campaigns

There is dire need for sensitization campaigns intended to equip families of children with physical disabilities and the general public with relevant knowledge on the subject. The information gap that was observed holds a number of implications for both the children and their families; firstly, care provided to the children by their families has no formal foundation, which restricts the possibility that children will develop to their full potential. For example, most of the families have stopped taking the children to the physiotherapy sessions due to limited information on the importance of the exercise; as such the children are missing out on the opportunity to acquire self reliance.

Secondly, families themselves are struggling to adapt due to a lack of essential information that would make it easy for them to raise their children. For example, many of the families are not aware of the resources available for children with disabilities and their families, such as community support groups, and they miss out on the support that they would otherwise be receiving from these set ups.

- Establishment of the district based special school

The need for a government run special school has also been established. The only district based special school in Motsekuoa is run by the Roman Catholic Church and it does not accommodate children with severe disabilities. Owing to this, majority of the families only have an option to take their children to the private school in Leribe, which is not only expensive but also very far from Mafeteng. A public school established within the district would operate at lower cost and also allow parents to see their children often.

- Post diagnosis counselling

It is further recommended that the health sector should design a continuous post diagnosis counselling programme for patients and their families. With this arrangement in place, families of children diagnosed with disabilities will better understand their children's conditions, and rely on valid information in providing care to their children as opposed to the myths and speculations.

- Coordination between the Department of Health and the Department of Social Development

The researcher further recommends that there should be a representative of the Department of Social Development based at the hospital premises, and that patients diagnosed with disabilities and other relevant cases be referred to this particular representative right away for the required services.

- Recommendations for further research

This study was only limited to families raising children with physical disabilities, which were registered with the Department of Social Development, and resided in the Makaota E12 community council. For this reason, the findings from this study cannot be used to define families of children with other forms of disabilities and those that reside in other parts of the country. Future research is therefore required on additional and larger disability populations for a more diverse sample.

4.5. CHALLENGES ENCOUNTERED DURING THE STUDY

- Delayed response from the Department of Social Development

Due to the structural red tape within the ministry, there was considerable delay of response from the Department of Social Development. Researcher filed a request at the ministry's headquarters in the first week of November 2015, and only received a response in February 2016 from the Mafeteng district Office. As such, data collection had to be postponed from November 2015, to March 2016.

4.6. SUMMARY

Findings from this study confirm that services for the people with disabilities are still very limited in the country (Chitereka, 2010:16). The gap manifests at all levels of the families' experiences, from diagnosis of the child's disability through post diagnosis counseling, to referral and support of the families in raising children with physical disabilities. The families are left to fend for themselves at each stage, and with the prevalent lack of information, adaptation is not easy.

The study further revealed and confirmed an array of coping strategies, utilized both deliberately and unconsciously by the families of children with physical disabilities to survive the challenges they face as a result of their children's conditions. As predicted, some of the strategies were healthy and sustainable in the long term, whereas others were only temporary measures through which families escaped the reality of living with their children's conditions. Lack of formal education and

counselling were identified as the major determinants for the coping strategies assumed by individual families. Factors such as availability of the support structures and the severity of the child's disability were also outstanding. Nevertheless, majority of the families have adapted fairly well and this can be attributed to the general feeling of acceptance among parents of the children with physical disabilities.

It is the sincere hope of the researcher that this report will prompt concerned individuals and the relevant service providers to undertake further investigations into the lives of children living with disabilities and their families, for better understanding and for improved service delivery.

REFERENCES

- Allen, J. 2007. *Understanding families*. New York: Guilford
- Anderson, D., Dumont, S. & Azzaria, L. 2007. The Personal Costs of caring for a Child with a Disability: A Review of the Literature. *Public Health Rep.* 122(1):3-16
- Andrews, M. 2008. Material Hardship in U.S. Families Raising Children with Disabilities. *WakeMed Rehab.* 75(1): 71-92. Available: [http:// iafor.org/ace2011](http://iafor.org/ace2011) (Accessed 18/02/2015)
- Babbie, E. & Mouton, J. 2010. *The practice of Social Research*. 10th Ed. Cape Town: Oxford University Press
- Braun, V. & Clarke, V. 2006. Using Thematic Analysis in Psychology. *Qualitative Research in Psychology.* 3(1): 77-101
- Bricout, J.C., Porterfield, S.L., Tracey, C.M. & Howard, M.O. 2011. *Linking Models of Disability for Children with Developmental Disabilities*. Glasgow: University of Glasgow
- Bronfenbrenner, U. 1994. Ecological Models of Human Development. *International Encyclopaedia of Education.* 3(2): 37-43
- Brue, A.W. & Wilmshurst, L. 2016. *Essentials of Intellectual Disability Assessment and Identification*. Columbia: John Wiley & Sons
- Bryman, A. 2015. *Social Research Methods*. 5th Edition. United Kingdom: Oxford University Press
- Buildings Control Act No.8 of 1995 (Published in the Lesotho Government Gazette (No.5) Maseru: Government Printers)

Children's Protection Act No. 6 of 1980 (Published in the Lesotho Government Gazette (No.1) Maseru: Ministry of Health and Social Welfare)

Chitereka, C. 2010. *People with Disabilities and the Role of Social Workers in Lesotho*. Available: www.socwork.net (Accessed 18/02/2015)

Craft-Rosenberg, M. & Pehler, S.R. (Eds) 2011. Changing views of marriage, home responsibilities and caregiving. *Encyclopedia of Family Health*. 1(1): 154-155

Creswell, J. W. 2009. *Research design: Qualitative, quantitative, and mixed methods approaches*. Thousand Oaks, CA: Sage

De Vos, A.S. & Strydom, H. 2011. Intervention Research. In De Vos, A.S., Strydom, H., Fouche, C.B. & Delport, C.S.L. 2011. *Research at Grass Roots: For the social sciences and human service professions*. Pretoria: Van Schaik Publishers

Doherty, W.J., Boss, P.G., LaRossa, R., Schumm, W.R., & Steinmetz, S.K. (1993). Family theories and methods: A contextual approach. In P. G. Boss, W. J. Doherty, R. LaRossa, W. R., Schumm, & S. K. Steinmetz (Eds.), *Sourcebook of family theories and methods: A contextual approach*. New York: Springer

Dorfman, R.A. (Ed.) 2013. *Paradigms of Clinical Social Work*. New York: Brunner/Mazel

Dube, A. 2008. *The Law and Legal Research in Lesotho*. Harare: University of Zimbabwe

Education Act No.3 of 2010 (Published in the Lesotho Government Gazette (No. 20) Maseru: Government Printers)

Feher-Prout, T. 1996. *Stress and Coping in Families with Deaf Children: Theoretical Review of Articles*. Available: <http://jdsde.oxfordjournals.org/> (Accessed 18/02/2015)

Flick, U. 2006. *An Introduction to Qualitative Research*. Thousand Oaks, CA: Sage

Gilbert, N. 2008. *Researching Social Life*. (3rd Ed) UK: Sage Publications

Government of Lesotho (GOL). 2004. *Lesotho vision 2020: Empowerment for Prosperity*. Maseru: Ministry of Finance and Development Planning

Government of Lesotho (GOL). 2005. *Poverty Reduction Strategy 2004/2006 2006/2007*. Maseru: Ministry of Finance and Development Planning

Government of Lesotho (GOL). 2008. *National Health and Social Welfare Research Policy (NHSWRP), Lesotho*. Maseru: Ministry of Health and Social Welfare. Available:<https://healthresearchweb.org/?action...file...Lesotho%20Nov%202008final01>. (Accessed 30/11/16)

Government of Lesotho (GOL). 2011. *National Disability and Rehabilitation Policy: Mainstreaming persons with disabilities into society (NDRP)*. Maseru: Ministry of Health and Social Welfare

Government of Lesotho (GOL). 2014. *Summary of findings from the mapping and assessment of Lesotho's child protection systems 2013/2014*. Maseru: Ministry of Social Development

Gray, D.E. 2002. Everybody just freezes. Everybody is just embarrassed: felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health and Illness*. 24(6): 734-739

Hodgson, T.A., & Meiners, M.R. 1982. In Meyers, M.K., Henry, E., Brady, E. & Seto, Y. 2000. *Expensive children in poor families: the intersection of childhood disabilities and welfare*. San Francisco: Public Policy Institute of California

Holahan, C. & Moss, R. 2007. Personal and Contextual Determinants of Coping Strategies. *Journal of Personality and Social Psychology*. 52(1): 946-955

Horsburgh, D. 2003. Evaluation of Qualitative Research. *Journal of Clinical Nursing* 12(2): 307–312

Hunt, N. & Marshal, K. 2013. *Exceptional Children and Youth*. New York: Cengage Learning

Hurst, M. 2009. *Family Systems Theory*. New York: Wiley and Sons

International Federation of Social Workers. 2012. *Poverty Eradication and the Role of Social Workers*. Available: ifsw.org/assets/ifsw_83315-6.pdf (Accessed 18/04/2014)

Johnson, B. & Christensen, L.B. 2008. *Educational Research: Quantitative and Qualitative Approaches*. South Alabama: University of South Alabama

Kamaleri, Y. & Eide, E.A. 2011. *Living Conditions among People with Disabilities in Lesotho: A National Representative Study*. Norway: SINTEF

Kibel, M.A. & Wagstaff, L.A. (Eds) 1997. *Child Health for All: A Manual for Southern Africa*. Cape Town: Oxford University Press

Kimane, I. 2005. *Protecting Orphaned Children through legislation: The case of Lesotho*. A paper presented at the 4th World Congress on Family Law and Children's rights. 20-23 March 2005, Cape Town, South Africa

Kubler-Ross, E. 2009. *On Death and Dying: What the Dying Have to Teach Doctors, Nurses, Clergy and Their Own Families*. 40th Anniversary Ed. London: Routledge

Lane, N.J. 1992. A spirituality of being: Women with disabilities. *Journal of Applied Rehabilitation Counseling*. 23(4): 53-58

Lauer, R.H. & Lauer, J.C. 2011. *Social Problems and the Quality of Life*. 11th Ed. USA: McGraw Hill

Lesotho Bureau of Statistics (BOS). 2001. *Lesotho Demographic Survey, 2001*. Maseru: Bureau of Statistics

Lesotho Bureau of Statistics (BOS). 2006. *Lesotho census of population and housing: preliminary results report*. Maseru: Bureau of Statistics

Lesotho Bureau of Statistics (BOS). 2011. *Lesotho Demographic Survey, 2011*. Maseru: Bureau of Statistics

Lietz, C.A., Langer, C.L. & Furman, R. 2006. Establishing Trustworthiness in Qualitative Research in Social Work: Implications from a Study Regarding Spirituality. *Qualitative Social Work*. 5(1): 441-458. Available: <http://qsw.sagepub.com/content/5/4/441> (Accessed 04/06/2015)

Lysaght, Z. 2011. *Epistemological and paradigmatic ecumenism in Pasteur's Quadrant: Tales from doctoral research*. Official Conference Proceedings of the Third Asian Conference on Education in Osaka, Japan

Mac Donald, H. & Callery, P. 2007. Parenting children requiring complex care: A journey through time. *Blackwell Publishing Ltd*. 34(2), 207–213

Makakole, B.M. 2014. *Reaching out to Children with Disabilities*. Paper presented at the Lesotho National Conference on Vulnerable Children. 8-11 December, Maseru, Lesotho

Matlho, L. 2016. *Review of existing laws and policies in Lesotho to determine harmony with the United Nations Convention on the rights of persons with disabilities*. Maseru: LNFOD

Mattaini, M.A. & Meyer, C.H. 2002. The eco-systems perspective. In Mattaini, M.A. & Lowery, C.T. (Eds.), *The foundations of social work practice: A graduate text*. 3rd Ed. Washington, DC: NASW Press

Meyers, M.K., Henry, E., Brady, E. & Seto, Y. 2000. *Expensive children in poor families: the intersection of childhood disabilities and welfare*. San Francisco: Public Policy Institute of California

Meyers, M.K., Lukemeyer, A. & Smeeding, T. 2000. Expensive Children in Poor Families: Out-of-Pocket Expenditures for the Care of Disabled and Chronically Ill Children in Welfare Families. *Journal of Family and Marriage*. 62(2): 399-415

Midgley, J. & Conley, A. (Eds) 2010. *Social Work and Social Development: Theories and Skills for Developmental Social Work*. New York: Oxford University Press

Mitchel, M. & Jolley, J. 2012. *Research Design Explained*. London: Cengage Learning

Mizrahi, T. & Davis, L. 2008. Children with Disabilities and Health Impairments. *Encyclopaedia of Social Work*. 4(20): Chapter 13

Munhali, P.L. & Fitzsimons, V.M. 2001. *The Emergence of Family into the 21st Century*. Massachusetts: Jones & Bartlett Learning

Munsell, E.P., Kilmer, R.P., Cook, J.R. & Reeve, C.L. 2013. The Effects of Care-giver Social Connections on Caregiver, Child and Family Well-Being. *Journal of Orthopsychiatry*. 82(1): 137-145

Ncho, C., & Wright, S. 2013. Health maintenance and low socio-economic status: A family perspective. *Curationis*. 36(1):1-7

Neely-Barnes, S. & Marcenko, M. 2004. Predicting the impact of childhood disability on families: Results from the 1995 National Health Interview Survey Disability Supplement. *Mental Retardation*. 42(1): 284–293

Newacheck, P.W. & Kim, S.E. 2005. A national profile of health care utilization and expenditures for children with special health care needs. *Archives of Pediatrics and Adolescent Medicine*. 159(1): 10–18

Oxford dictionary of Social Work. 2008. 17th Ed. New York: Oxford University Press

Parish, S.L. & Cloud, J.M. 2006. Financial wellbeing of young children with disabilities. *Social Work*. 51(1): 223–232

Poston, D.J. & Turnbull, A.P. 2004. Role of Spirituality and Religion in Family Quality of Life for Families of Children with Disabilities. *Education and Training in Developmental Disabilities*. 39(2): 95-108

Pritzalff, A. L. 2001. *Examining the Coping Strategies of parents who have children with disabilities*. Available:

www2.uwstout.edu/content/lib/thesis/2001//2001pritzlaffa.pdf. (Accessed 16/10/2015)

Punch, K.F. 2005. *Introduction to Social Research: Quantitative and Qualitative Approaches*. 2nd Ed. London: Sage Publications Ltd

Rakotsoane, F.C.L. & Rakotsoane, M.A. 2007. *The ABC of Research Project, Dissertation and Thesis Proposal Writing*. Revised Edition. Lesotho: Morija Printing Works

Ramey, C.T. & Ramey, S.L. 2004. *Early Learning and School Readiness: Can Early Intervention Make a Difference?* Available: <http://www.psy.cmu.edu/~sieglar/423-ramey04.pdf> (Accessed 22/11/2015)

Reitemeir, B. 2011. *4 in every 10 Disabled children living in poverty*. Available: www.childrenssociety.org.uk (Accessed 18/02/2015)

Rubin, A. & Babbie, E. 2013. *Essential Research Methods for Social Work*. 3rd Ed. Belmont, CA: Cengage Learning

Sexual Offences Act No.3 of 2003 (Published in the Lesotho Government Gazette (No.29) Maseru: Government Printers)

Sharma, N. & Dowling, R. 2004. *Postcards from Home: The Experience of Disabled Children in the School Holidays*. Essex: Barnardo

Sheinin, A.G. 2006. *The high cost of autism*. Available: <http://web.lexis-nexis.com/universe> (Accessed 18/12/16)

Simeonson, R.J. 2002. Secondary conditions in children with disabilities: Spina-bifida as a case example. *Ment Retard Dev Disabil Res Rev*. 8(3): 198-205

Strohm, K. 2014. *Siblings: Brothers and Sisters of Children with Special Needs*. Australia: Wakefield Press

Strydom, H. 2011. Ethical aspects of Research in the Social Sciences and Human Service Professions. In De Vos, A.S., Strydom, H., Fouche, C.B. & Delpont, C.S.L. 2011. *Research at Grass Roots: For the social sciences and human service professions*. Pretoria: Van Schaik Publishers

Talley, R.C. & Crews, J.E. (Eds) 2012. *Multiple Dimensions of Caregiving and Disability: Research, Practice, Policy*. New York: Springer

Taylor, S. 2008. Effects of Optimism and coping on stressor-related mood and immune changes. *Journal of Personality and Social Psychology*. 96(3): 90-104

Thabane, N. 2008. Community Profile: Makaota E12. In Government of Lesotho: Department of Planning, Ministry of Local Government and chieftainship. 2008. *Mafeteng District Council Information Handbook*. Maseru: Global Print

Themane, M. J., Koppes L. L. J., Monyeki, K. D., Twisk, J. W. R., & Kemper, H. C.G. 2006. Relationship between socio-economic status and educational achievements of Ellisras rural primary school children, South Africa. In *African Journal for Physical, Health Education Recreation and Dance*. 12(1): 298-309

United Nations Children's Fund (UNICEF). 2005. *The state of the world's children: excluded and invisible*. New York: UNICEF

United Nations Children's Fund (UNICEF). 2011. *Lesotho 2011 Country Situational Report*. Maseru: UNICEF

United Nations Children's Fund (UNICEF). 2012. *Children with Disabilities in South Africa: A situation Analysis 2001-2011*. Available: www.unicef.org/southafrica/SAF_resources-sitandisability.pdf (Accessed 16/11/2015)

United Nations Children's Fund (UNICEF). 2013. *State of the World's Children: Children with Disabilities*. New York, UNICEF

United Nations. 1990. *Convention on the Rights of the Child*, 20 November 1989 Treaty Series. 1577 (3). Available: <http://www.refworld.org/docid/3ae6b38f0.html> (accessed 22 December 2016)

VanderBos, G.R. (Ed) 2007. *APA Dictionary of Psychology*. Washington DC: APA

Washington, F.L. 2007. *A phenomenological Exploration of Caregivers of Children with Disabilities: Challenges and Adaptation*. A Dissertation submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy in the Graduate School of Texas Women's University. College of Health Sciences. Denton: Texas University

White, J.M., Klein, D.M. & Martin, T.F. 2014. *Family Theories: An Introduction*. 4th Ed. Thousand Oaks, CA: Sage

Wolf-Branigin, M. 2013. *Physical Disabilities*. Columbia: Oxford University Press

Woodman, A. & Houser-Cram, P. 2012. The Role of Coping Strategies in Predicting Change in Parenting Efficacy and Depressive Symptoms among Mothers of

Adolescents with Developmental Disabilities. *Journal of Intellectual Disability Research*. 10(1):1365-2788

Woolley, M. 2004. *How do they manage? Income and Expenditure of Families with a Severely Disabled Child*. NewYork: Family Fund

Yantzi, N.M., Rosenberg, M.W., & McKeever, P. 2007. Getting out of the house: the challenges mothers face when their children have long-term care needs. *Health Soc Care Community*. 15(1):45-55

Yount, R. 2006. Populations and Sampling: Research Design and Statistical Analysis for Christian Ministry. *Research Fundamentals*. 4th Ed. Columbus: Merrill Publishing Company

APPENDICES



1: Ethical Clearance



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Research Ethics Committee

29 February 2016

Dear Prof Lombard

Project: Coping strategies of families with low socio-economic status raising children with physical disabilities in Mafeteng, Lesotho
Researcher: M Pelea
Supervisor: Ms N Bila
Department: Social Work and Criminology
Reference numbers: 14267676 (GW20151119HS)

Thank you for your response to the Committee's correspondence of 27 November 2015.

The **Research Ethics Committee** notes that the outstanding permission from the *Lesotho Ministry of Social Development* was submitted as requested and has therefore given **final approval** for the above application at an *ad hoc* meeting on 29 February 2016. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should the actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

The Committee requests you to convey this approval to the researcher.

We wish you success with the project.

Sincerely

Prof Karen Harris
Acting Chair: Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: Karen.harris@up.ac.za

Research Ethics Committee Members: Prof KL Harris (Acting Chair); Dr L Blokland; Dr JEH Grobler; Ms H Klopper; Dr C Panebianco-Warrens; Dr C Puttergill; Prof GM Spies; Dr Y Spies; Prof E Taljard; Ms KT Andrew (Committee Admin); Mr V Sithole (Committee Admin)



2: Permission Letter from the Department of Social Development



22/02/2016

Ms 'MakhauPelea
P.O. Box 150
Mafeteng 900

RE:REQUEST FOR PERMISSION TO CONDUCT RESEARCH INTERVIEWS WITH FAMILIES OF CHILDREN LIVING WITH PHYSICAL DISABILITIES IN MAFETENG

This correspondence serves to confirm that your request has been approved.

For the purpose of your research, the Ministry of Social Development shall furnish you with the list of participants and a letter of introduction. Kindly note that the information provided to you and your encounter with our clients in this regard can only be used for your study and no other purpose.

Our Rehabilitation Officer/ Community Rehabilitation Officer will be specifically assisting you with the logistics of your research. For further details do not hesitate to contact the Mafeteng district office.

Regards,

'MatebelloMarite (Mrs)

Senior Child Welfare Officer
Ministry of Social Development
Mafeteng District Office





3: Introduction Letter from Social Development



LESOTHO

Ministry of Social Development
Mafeteng

22/02/2016

Monghali/ Mofumahali

RE: LIPHUPHUTSO (RESEARCH) KA BANA BA PHELANG LE BOKOOA BA
MASAPO SETEREKENG SA MAFETENG

Ke hlahisa kapele ho uena 'Makhau Pelea, eo e leng moithuti Universithing ea Pretoria. Moithuti enoa ea etsang liphuputso ka bophelo ba bana ba nang le bokooa ba masapo seterekeng sa Mafeteng, ke mo kopela tséhetso eohle eo a ka e hlokang hotsoa ho uena ele ho ntsétsapele mosebetsi oa hae.

Kaboikokobetso,

'MatebelloMarite (Mof)

Senior Child Welfare Officer
Ministry of Social Development
Mafeteng District Office



4: Informed Consent Letter

27/10/2015

Madam/ Sir,

RE: Invitation to participate in a research study

As one of the caretakers/ breadwinners in the family of a child with a physical disability in Mafeteng, and which, due to low income status is receiving assistance from the Department of Social Development, you are kindly invited to participate in a research study about the coping strategies of families with low socio-economic status in raising the children with physical disabilities. The study is undertaken to identify challenges experienced by families with low socio-economic status in raising the children with disabilities, to explore the coping strategies of these families and to recommend services which respond to the needs of the families as identified.

Title of the study: Coping strategies of families with low socio-economic status raising children with physical disabilities in Mafeteng, Lesotho

Researcher: 'Makhau Pelea (Student: Master of Social Work in Health Care, University of Pretoria)

A. RESEARCH PROCEDURE

Shall you agree to participate in this study, researcher will visit your home at the time agreed by both you and the researcher, to have a discussion of approximately one hour with regard to your experiences in raising a child with a physical disability in a low income family, challenges your family encounters in raising the child as well as how you cope through the challenges. The discussion will be audio taped and thereafter transcribed by the researcher. Information you share is going to be analysed together with the information from other participants and produced in the

form of a report. Please note that your name or the name of your child shall not be used in the study, nor any personal information through which you may be identified as one of the participants. Further note that for protection of the participants, the study is guided by the research ethics endorsed by the ethics committee of the University of Pretoria's faculty of humanities.

Risks and benefits

This study does not involve any type of physical risk. Nevertheless, an arrangement has been made with the Social Worker at the Department of Social Development to assist with therapeutic service if need arise during the study proceedings. Although this study is not designed to help you personally, the information you contribute will help us to better understand the prospects for adaptation for low income families in raising the children with disabilities and help reveal the gaps that need to be filled by service providers. The results of the study are going to be shared with the Department of Social Development and other child welfare services providers with the intention of assisting them to improve their services to children with disabilities and their families.

Confidentiality and Anonymity

The information you provide will be kept strictly confidential. To protect your privacy, your responses to the interview questions will only be identified with a code number. The researcher cannot disclose any features that relate you or your child to the information you provide and will further not violate your family's privacy. Please note that the University of Pretoria alone will keep the research material for fifteen years after the study has ended and data shall be stored for access by other researchers, who will be bound by the same ethical principles, for further research. Anyone else who has interest in the research can only access the processed report which does not single out an individual person's response.

Right to participate voluntarily or to withdraw

Please note that you have a right to decline my request and that if you choose to participate, you'll be granted freedom to withdraw at any point during the study if you are no longer willing to participate. Your decision will not result in any loss of benefits to which you are otherwise entitled at the Department of Social Development.

Shall you have any queries pertaining the research, please do not hesitate to contact the Department of Social Development or call the researcher at +266 58607261.

If you are willing to participate, please sign on the section below as proof that you understand the purpose and conditions of the study, and that you give consent to take part.

Your cooperation will be highly appreciated.

Sincerely,

Date

.....

.....

Makhau Pelea
(+266 58607261)

B. DECLARATION BY PARTICIPANT

By signing this form I certify that I..... (Full names), understand the purpose of this study as has been explained to me by the researcher, therefore I accept, at my own liberty, the researcher's request for me to participate in the study. I am aware that I have the right to refuse to participate and that I can withdraw at any time during the study proceedings if I no longer wish to participate.

.....
Participant's Signature Date

.....
Researcher's Signature Date

5: Interview Schedule

TITLE OF THE STUDY: Coping strategies of families with low socio-economic status raising children with physical disabilities in Mafeteng, Lesotho

RESEARCHER: 'Makhau Pelea (Student: Master of Social Work in Health Care, University of Pretoria)

1. Biographic Information

- Age
- Gender
- Marital Status
- Relationship with the physically disabled child
- Highest level of education
- Occupation
- Position in the family

2. The family's socio-economic status

- Number and ages of people living in the household
- Average education in the family
- Housing conditions
- Sources of income
- Family assets
- Average income
- Average spend on the child's needs
- Average spend on the needs of the other members
- Ability to satisfy the needs of the child and of other members

3. The child's condition

- Description
- Diagnosis

- Needs
- Abilities
- External aid

4. Role played by participant in support of the child

- Tasks carried out in support of the child
- Hours per day and week engaged conducting the tasks
- Competence (ability to play the role effectively)
- Feelings about the participant's role
- Role played by other members
- Views and feelings of the participant about the child's condition
- View about the future of the child and family with regard to support of the child
- Positive aspects of care-giving (Lessons learnt)

5. Challenges

- Encountered by the family as a result of raising the child with a physical disability
- Encountered by participant in his/her role in supporting the child

6. Social support network and impact on participant's role in support of the child

- Personal relationships
- Family
- Community
- Health services
- Social Work Services
- Religious Service

7. Coping Strategies