Experiences of parents of children living with disabilities at Lehlaba   Protective Workshop in Sekhukhune District of Limpopo Province

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Experiences of parents of children living with disabilities at Lehlaba Protective Workshop in Sekhukhune District of Limpopo Province

By

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DECLARATION

I, Brian Tigere do hereby declare that the dissertation hereby submitted to the University of Limpopo, for the degree of Master of Arts in Social Work has not previously been submitted by me for a degree at this or any other university; that it is my work in design and in execution, and that all material contained herein has been duly acknowledged.

Tigere M B (Mr.)   15/09/2017

Surname, Initials (title)   **Date**

DEDICATIONS

I dedicate this Research Project to all the parents of children with disabilities and all disability movements servicing the entire Limpopo Province which include the Non Governmental Organizations and the Government (Department of Social Development) for all their efforts of enabling children with disabilities. Keep up the good work.

ACKNOWLEDGEMENTS

Prof JC Makhubele my supervisor thank you for your scholarly guidance, constructive criticism and above all, your patience. Your encouragement, advice and support is truly appreciated. May the Almighty be with you always.

My employer APD Limpopo for allowing me to conduct my studies.

All the participants (parents of children with disabilities).

Thank you Everjoy Mutema for the support and editing my document.

I am eternally grateful to all.

ABSTRACT

This study investigates experiences of parents of children living with physical and intellectual disabilities in South Africa's Limpopo province. The study utilized a sample of 14 participants drawn using purposive sampling. An interview schedule with a set of questions was used to collect data. The results suggest that both positive and negative experiences are encountered by parents of children living with disabilities. Problems which children encounter on a daily basis have got also similar implications on their parents or guardians. This study has revealed that parents face many challenges ranging from personal, social, economic and financial. The study found out that it is actually more expensive, mental draining for parents of children living with disabilities to look after them. It emerged in the study that community negative attitudes on children with disabilities hinders their progress and results in social exclusion. The study also revealed that the majority of the parents believe that witchcraft had a hand in disabling their children. It also emerged that most of the parents of children living with disabilities hoped for a cure of the disabilities medically, traditionally and spiritually. However the study confirms that parents of children living with disabilities go through a cycle of denial fear, guilty, depression and acceptance after discovering that their child is disabled.

CHAPTER ONE

INTRODUCTION AND BACKGROUND OF THE STUDY

1.1 INTRODUCTION

This chapter seeks to give a general orientation and overview of the whole study. It includes the background of the study, the problem statement, aims and objectives, significance of the study, chapter outline and the conclusion of the chapter.

1.2 BACKGROUND

The challenges presented by parents of children with disabilities in different cultures of the world have raised many scholarly debates with the majority being inconclusive. Children with disabilities have been segregated in their physical, emotional, social and economic life. Traditionally, in most African societies, children with disabilities are viewed as a "curse" and this has led to them being isolated from the rest of the society either intentionally or unintentionally (Visagie, Scheffler& Schneider, 2013). Parents of children with disabilities have also faced difficulties in looking after them be it socially, economically and emotionally. Most parents develop a sense of guilt after giving birth to a child with a disability which results in the isolation of the disabled child by hiding them from the community at large (Gupta, 2011).

Disability is the consequence of an impairment that may be physical, cognitive, mental, sensory, emotional, developmental, or some combination of these and it may be present from birth, or occur during a person's lifetime (World Health Organization, 2014). As a result, disability can affect not only those who are disabled but those who are the primary caregivers. Raising a child with a disability is a challenge to most parents. In other words, primary care givers more especially those in rural settings, require assistance from all stakeholders be it governmental or from

the private sector. Primary caregivers include biological parents of the children, or legal parents who include adoption parents or foster parents.

For most parents, the birth of their first child is a major transition in life that involves the new challenge of caring for an infant, and major changes in life-style and sense of identity (Gupta, 2011). The birth of a child with a disability, or the discovery that a child has a disability, can have profound effects on the parents or the family (Brown, Goodman& Kupper, 2014). With the arrival of each new child in the family, further changes will take place. When a child is diagnosed with a disability, the experience of parenthood is affected, and expectations with regard to the child and the future may have to be revised.

Like all other children, a disabled child is born into a family and remains a lifelong family member. Among all the social institutions namely the church, the school, the community, the family is the most significant and is universally regarded as exerting the most influence on the child's development as it provides care, love, support, protection, guidance and direction to children (Monk & Wee, 2009). The way parents treat a disabled child is a reflection of attitudes they have towards disability.

South Africa has one of the best policies for children with disabilities notably being signatories to the United Nations Convention on the Rights of the Child (UNCRC) in 1995 and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2007. This has however failed to change the lives and living conditions of children with disabilities in South Africa in general and Limpopo Province in particular. In addition, significant knowledge gaps remain with regard to the situation of the parents of children living with disabilities, their families and the underlying causes of their situations**.** In general, research of children with disabilities in South Africa has been done. However, experiences of the parents of children with disabilities in rural areas especially in Limpopo has never been well documented.

It is from this background that the researcher explored the experiences of parents of children living with disabilities at Lehlaba Protective Workshop in Sekhukhune District of Limpopo Province. Lehlaba Protective Workshop is a rural community based centre which provides day care stimulation services and protected work to children and adults with different kinds of disability. Lehlaba Protective Workshop was established in the year 1999 and it is registered by the Department of Social Development as a Non-Profit Organization. The centre is located in the Makhudu - Thamaga Municipality under Sekhukhune District of Limpopo Province.

1.3 RESEARCH PROBLEM

This study was prompted by the need to explore the experiences which are faced by parents of children with disabilities at Lehlaba Protective Workshop in Sekhukhune district of Limpopo Province. Disability is a subject which is still embedded in the periphery of society. It is not widely discussed in public as well as documented in the academic circles. Disability has led to widespread misguided conclusions on the topic. South Africa's only legislation on children with disabilities is the Social Assistance Act No 13 of 2004 which only give provision to financial assistance through the Care Dependency Grant. However no any other legislation is available for children living with disabilities. This has led to widespread discrimination of children with disabilities in many spheres of their life such as the social, economic, health and educational. Without any other legislation available, the entire burden has been left to the primary caregivers of the children who are their parents (Visagie et al., 2013).

Disability has far reaching consequences on the lives of the affected children and the immediate family members mostly the parents. Children with disabilities face the full wrath of harassment and abuse from their peers, community members, care workers and disturbingly from their own families. The parents face problems ranging from financial, economic, emotional, and psychological to social isolation. The effects are cumulative and may make an already difficult situation intolerable for the family with a disabled child.

Parents of children with disabilities in rural areas are mostly affected by lack of services for their children. South Africa is a signatory to the UN Convention on the Rights of Persons with Disabilities. Little has been done to children with disabilities to improve their lives. All has been left on the shoulders of the parents. In most African societies, children with disabilities live in the most barbaric and inhumane circumstances. Some children with disabilities are locked at back rooms because they are viewed as a curse to the family and problematic to take care (Visagie et al., 2013). Children with disabilities receive a care dependence grant from Department of Social Development through the South African Social Security Agency (SASSA). As of the 1st of April 2016, the care Dependency Grant stood at R1480. This grant is aimed at assisting the children to meet their economic and physical needs such as food, clothing and assistive devices. However, the grant is too little in comparison to the costs of taking care of children with special needs. All these problems which the children face have got an effect on their parents since they are the primary care givers. In short, the parents of children with disabilities are also placed at the centre of all the problems without any assistance from the community or the government.

In light of the above implications of disabled children being at the centre, it came to the researcher's attention to conduct an investigation on experiences of parents of children living with disabilities at Lehlaba Protective Workshop in Sekhukhune District of Limpopo Province in South Africa.

1.4 ROLE OF THEORY IN THE STUDY

Theories / models which informed this study were the social and medical models on disabilities. The social model was relevant to the study since it views society as the cause of disability. In essence, children are disabled by the environment they live. Lack of support from the family and most importantly the parents plays an important role in disabling the children. Furthermore, negative attitudes (attitudinal barriers) from people of the community further disable the children.

The medical model on disabilities was also relevant to this study since it views disability as a medical condition within a person and not in the environment. Medical

professionals such as medical doctors, physio - therapists, speech therapists, occupational therapists and social workers are crucial in rehabilitating children with disabilities. In essence, the parents or guardians of the children are responsible for the ever expensive medical services of their children.

1.4.1 The Social Model

The social model of disability identifies systemic barriers, negative attitudes and exclusion by society purposely or inadvertently (Altman, 2010). That means society is the main contributory factor in disabling people. While physical, sensory, intellectual, or psychological variations may cause individual functional limitation or impairments, these do not have to lead to disability unless society fails to take account of and include people regardless of their individual differences. The social model of disability put emphasis on the family and the community as two important institutions for supporting the disabled child.

1.4.2 The Medical Model

The medical model of disability is a socio political model by which illness or disability, being the result of a physical condition intrinsic to the individual (it is part of that individual's own body), may reduce the individual's quality of life, and cause clear disadvantages to the individual (Crow, 2010). The medical model also believes that a society should invest resources in health care and related services in an attempt to cure disabilities medically, so as to improve functioning and to allow disabled persons a more normal life. Thus the parents, guardians and family of the disabled child need to invest more in health care services as a way of combating the disability.

1.5 AIM AND OBJECTIVE OF THE STUDY
1.5.1 AIM OF THE STUDY

The aim of this study was to explore the experiences of parents of children living with disabilities at Lehlaba protective workshop.

1.5.2 OBJECTIVES OF THE STUDY

The objectives of the study were ;

- To describe the experiences and life circumstances of parents of children living with disabilities at Lehlaba Protective Workshop.
- To identify the challenges experienced by parents of children living with disabilities.
- To establish the coping mechanisms for parents of children living with disabilities.
- To identify the services which are available for parents of children living with disabilities.

1.6 SIGNIFICANCE OF THE STUDY

The major aim of this study was to explore the experiences of parents of children living with disabilities at Lehlaba protective workshop. The study will be significant in that it will give clarity on the experiences the parents face in looking after their disabled children. The study will inform government departments in planning services for both children with disabilities and their parents. The results from this study can be used to make recommendations for future practice and policy development on disability issues for children. The management of Lehlaba Protective Workshop will use the study in formulating and improving their services to the children with disabilities. This will lead to employee training in areas seen lacking insight. Professionals who work with children with disabilities such as Social Workers, Care Workers, Physiotherapists, and Occupational Therapists will be informed of challenges facing the children hence they will draw out intervention plans according to their professional expertise. The study will also inform the parents about their roles in taking care of the children. There are different Non-Governmental Organizations namely Deaf South Africa, Disabled People South Africa (DPSA), Association for Persons with Disabilities (APD) and the Blind Federation who are working with persons with disabilities in the entire Limpopo Province. This study will

inform these different NGOs on the needs of children with disabilities such that they plan services for them adequately.

1.7 ETHICAL CONSIDERATION

De Vos, Strydom, Fouche and Delport (2011), define ethics as, a set of widely accepted moral principles that offer rules for, and behavioural expectations of, the most correct conduct towards experimental subjects, and respondents, employers, sponsors, other researchers, assistants and students.

1.7.1 Permission to conduct the study

Permission to conduct the study was obtained from University of Limpopo Turfloop Research and Ethics Committee. An ethical clearance letter is available as proof in this regard. Permission was also sought from the management of Lehlaba Protective Workshop. A letter is also available to support their permission

1.7.2 Confidentiality and Anonymity

Confidentiality is a basic ethical principle while anonymity is one way in which confidentiality is maintained. Anonymity means that no one including the researcher should be able to identify any subjects after wards (De Vos et al., 2011). To ensure anonymity in the study, steps were taken to protect the identity of the participants by neither giving their names when presenting research results, nor including identifying details which may reveal their identity such as work place, personal characteristics and occupation. The interview guide did not also carry actual names of the participants but rather tags in the form of numerical numbers and alphabetical letters. Confidentiality was also preserved by conducting the interviews in private rooms.

1.7.3 Informed Consent

Informed consent implies that, all possible or adequate information on the goal of the investigation, the procedures which will be followed during the investigation be

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rendered to potential subjects or their legal representatives, (Babbie & Rubin 2011). As a professional social worker, the researcher was guided by the code of ethics of the social work profession. Written consent was sought from the participants of the study. Thus a consent form was signed by every participant in the study.

1.7.4 Voluntary Participation

Voluntary participation refers to the willingness of an individual to participate in research, as no one should be forced to participate (Babbie & Rubin, 2011).Participants of this study were informed that participation in the study would completely be voluntary and that they can withdraw from the study at any stage without any consequences.

1.8 DEFINING CONCEPTS

The concepts that need to be defined include disability, parent, physical disability, intellectual disability and cerebral palsy. The aim of clarifying these concepts is to have conceptual meaning as well as operational meaning in the study.

1.8.1 Disability

The term "disability" means a physical, mental, or sensory impairment, whether permanent or temporary, that limits the capacity to perform one or more essential activities of daily life, and this can be caused or aggravated by the economic and social environment (Schulze, 2010).

1.8.2 Physical disability

Any impairment which limits the physical function of limbs, fine bones, or gross motor ability is a physical impairment, not yet a physical disability (Watermeyer, 2006).

1.8.3 Intellectual Disability

According to Crow (2010), Intellectual disability is a term used when a person has certain limitations in mental functioning and in skills such as communicating, taking

care of him or herself, and social skills. These limitations will cause a child to learn and develop more slowly than a typical child.

1.8.4 Cerebral Palsy

Cerebral Palsy is considered a neurological disorder caused by a non-progressive brain injury or malformation that occurs while the child's brain is under development (WHO, 2011). Cerebral Palsy primarily affects body movement and muscle coordination. Though Cerebral Palsy can be defined, having Cerebral Palsy does not define the person that has the condition. Cerebral Palsy is the result of a brain injury or a brain malformation. Individuals with Cerebral Palsy were most likely born with the condition, although some acquire it later.

1.8.5 Parent

A parent is the caretaker of a child. A biological parent consists of a person whose gamete resulted in a child, a male through the sperm, and a female through the ovum. Some parents may be adoptive parents, who nurture and raise an offspring, but are not actually biologically related to the child. Orphans without adoptive parents can be raised by their grandparents or other family members through foster care. For the purposes of this study, a parent is either biological, adoptive or foster who is taking care of a disabled child.

1.9 STRUCTURE OF THE DISSERTATION

Figure 1.1 illustrates the structure of the research

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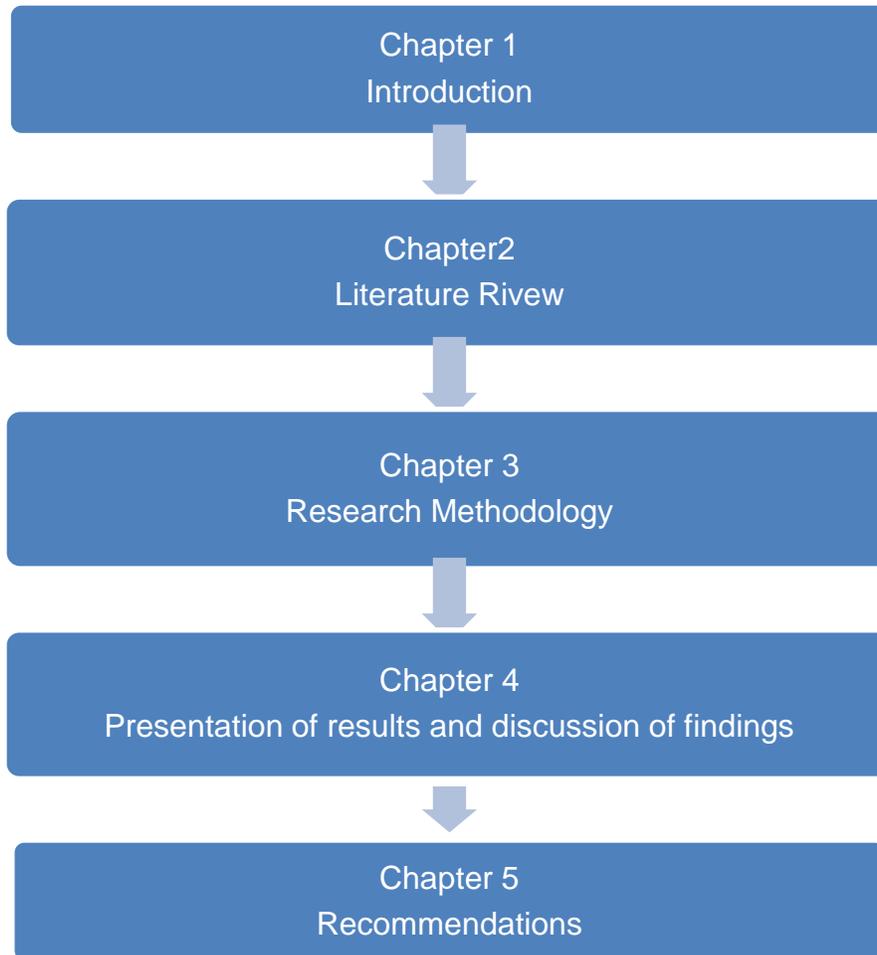
Figure 1.1 Structure of the Research

Chapter 1: Introduction

This chapter provides an overview of the term disability. It highlights the purpose of the study, providing clarification and definition of terms and outlines the significance of the study.

Chapter 2: Literature Review

This chapter explores literature available relevant to children with disabilities as well as their parents. It looks at the term disability in detail exploring aspects like the causes and theories/ models of disabilities. Chapter 2 also looks at experiences of parents with disabilities from other contexts beyond South Africa.

Chapter 3: Research Methodology

Chapter 3 covers research design, population, sampling procedures, data collection instruments, data analysis procedures and ethical issues of the research. All these aspects will be discussed in detail in this chapter.

Chapter 4: Presentation and discussion of results

This chapter presents the key findings from the data obtained and analyzed from the research. It includes data collected through the use of interviews from the parents of children living with disabilities attending Lehlaba Protective Workshop. The chapter is presented in section with the aim of answering research questions put forward in chapter one.

Chapter 5: Conclusions and Recommendations

The aim of this chapter is to present the recommendations based on the results presented in Chapter three. Recommendations will also be outlined based on the research results for future use in planning and delivering services to children with disabilities.

1.10 CONCLUSION

In this chapter introduction to the topic of the dissertation was firstly done by discussing the historical and cultural view of disability. A brief definition of disability from different models was done. The research topic, aims, objectives and significance of the study were laid down. Lastly the structure of this dissertation was outlined. In the next chapter, the literature review will be discussed.

CHAPTER 2

EXPOSITION OF PARENTS OF CHILDREN LIVING WITH DISABILITIES

2.1 INTRODUCTION

The researcher conducted a literature review on disability, theories on and approaches to disability in order to get an understanding with existing material and research on the topic. The literature review covered books, journals, reports, and policies on disability in South Africa and other parts of the world. This chapter puts the concept and the dynamics of disability into perspective using available literature. Under the chapter, the definitions, classification and causes of disability are provided as well as disability amongst children as argued by various writers and authors. The chapter also examines the experiences of parents of children with disabilities from other contexts such as India, other African countries such as Zimbabwe and India. Different policies of disabilities in South African context will also be discussed in brief.

2.2 DEFINITION AND CLASSIFICATION OF DISABILITY

Mitra, Posarac and Vick (2011), stated that, there is no consensus on a definition and measurement of the controversial and complex phenomenon of disability. Different conceptual models have been developed for definitional purposes, including the charity, medical, economic and social models (Altman, 2010). The charity model views persons with disabilities as elements of pity, and therefore to be helped by welfare approaches. The medical model considers disability a problem of the individual directly caused by a disease, an injury, or some health condition, and requiring medical care in the form of treatment and rehabilitation. Individuals with any impairment are considered disabled, where "impairment" is used for their condition, irrespective of whether the individuals experience limitations in their activities. The medical model is often opposed to the social model, which views disability purely as a social construct where the problems of the disabled are either caused or exacerbated by the society in which they live (Mitra et al., 2011). Various authors and institutions have often defined this phenomenon based

on the context and purpose for which the definition is meant. Scholars have been at loggerhead over defining disability as a social problem, rather than a medical problem (Reindal, 2010).

According to the World Health Organization (2011), disability is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure, an activity limitation is a difficulty encountered by an individual in executing a task or action, while a participation restriction is a problem experienced by an individual in involvement in life situations. Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives. Overcoming the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers. An impairment is lacking part of or all of a limb, or having a defective limb, organism or mechanism of the body (WHO, 2011). Disability is the disadvantage or restriction of activity caused by contemporary organization which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities.

The Social Assistance Act No. 13 of 2004 of South Africa understands a person with a disability to mean a person, who is, owing to a physical or mental disability, unfit to obtain by virtue of any service, employment or profession the means needed to enable him or her to provide for his or her maintenance (Government Gazette, 2004).

The term disability can be summarized as a great number of different functional limitations occurring in any population in any country of the world. People may be disabled by physical, intellectual or sensory impairment, medical conditions or mental illness. Such impairments, conditions or illnesses may be permanent or transitory in nature.

The most accepted definition of disability in South Africa by the government and other organizations comes from The Convention on the Rights of Persons with Disabilities which the South African government ratified in 2007. The Convention states that persons with disabilities include those who have long-term physical, mental, intellectual,

or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. In support, Thomas (2007) defined disability as, the result of a relationship between an individual's health condition and personal factors, and external factors due to the circumstances in which the individual lives.

There are also effects of language in which some terms used to refer to the person with a disability may be viewed as inappropriate in some sections of the society. According to Blair and Davidson (2003) the language used to describe persons as disabled, handicapped, impaired, challenged and retarded is crucial in the construction of the broader discourse that in turn comes to be experienced as social reality by those being described.

2.3 CAUSES OF DISABILITY AMONGST CHILDREN

Disability is caused by many factors which range from health, political, economic and social. There is a lot of literature available to try and explain the causes of disabilities locally and internationally. According to Helander (2009), the causes of disabilities among children vary across countries and that the structure of disability in the developing countries varies markedly from that in the developed world. Altman (2014), states that the proportion of disability caused by communicable, maternal and prenatal diseases in developing countries is much higher than in developed countries. All these causes can be eradicated with an improvement in the health system as well as making the health system accessible to all (Altman, 2014).

2.3.1 POLITICS - ARMED CONFLICTS

According to the UN Special Report on disabilities (2006), the world spends over 839 billion dollars a year on conflicts, arms and equipping armies. Landmines and random explosions result in the largest number of disabilities caused by wars and armed conflicts. Lebanese army reports in June 2005 put the number of landmines victims since 1970 at 1835 deaths and 2140 injured with permanent disabilities. Landmines and random explosions constitute the main threat to Iraq civilians causing to date between

15 000- 20,000 disabilities a year (UN Special Report on Disabilities, 2006). Politics has played a bigger role in disabilities in Japan and Vietnam". In Japan, the United States of America dropped an Atomic bomb on the 6[th]of August 1945. It was a direct order from the then President of U.S.A, Harry Truman. The effect of this bomb was the birth of children in Japan with defects as well as those with Spina bifida (physical disabilities).

One of the most conspicuous signs of the horror is the children whose mothers were hit while carrying them. Most of them perished before birth, but of those who survived some were born with heads abnormally small and were severely mentally retarded. Miscarriages were common in women who were within the vicinity as well as carrying a baby to full term and then when they were born realizing that they literally had no brain (British Broadcasting Corporation, 2004). These were the after effects of the atomic bomb on children. In Vietnam the US army employed an operation called "Agent Orange" to clear the dense forests of Vietnam where their opponents, the National Liberation Front fighters were based. The Agent Orange had harmful chemicals which had effects on unborn babies. Most children born in this era had birth defect, brain damage and physical disabilities. The US army in the 1956 to 1975 Vietnamese war dropped small sweet like bombs which attracted children. These bombs denoted and caused scars amongst children hands thus causing physical disabilities.

According to the British Broadcasting Corporation (BBC) 2004, Angola is among the worst land-mine affected countries in the world. The Angolan Civil War between 1976 to 2002 led to the planting of landmines which some estimate to be around 2 million. Nobody knows how many landmines lurk beneath the soil of Angola. Some experts say it may be somewhere between five hundred thousand and one million, others say there may be as many as six million. The worst affected province in Angola is Bie which bore the brunt of nearly 30 years of conflict between Angolan government forces and the Jonas Savimbi led Unita rebels. Half of the land in Angola is considered too dangerous to walk on. Effects of these land mines were the maiming of innocent children who lost legs or hands thus becoming disabled. Some of the children became deaf due to the deafening noises of the landmines (BBC, 2004).

2.3.2 POVERTY

It is widely accepted amongst activists, researchers and others that disability and poverty are dynamic and intricately linked phenomena (Mitra, Posarac & Vick, 2011). It is a vicious circle. Disability leads to poverty through a number of exclusion processes, whilst poverty is a threat to daily life activities, social participation and health, and consequently creates disabling conditions and disability. Whilst disabled people in poor contexts are and have been deprived of basic services, the inclusion of individuals with disabilities will in many instances be a challenge due to lack of education, experience and not least due to weak organisations. The world's poor are significantly more likely to have or incur a disability within their lifetime compared to more financially privileged populations. The rate of disability within impoverished nations and communities is notably higher than that found in more developed countries. Physical, cognitive, mental, emotional, sensory, or developmental impairments independently with one another may increase one's likelihood of becoming impoverished, while living in poverty may increase one's potential of having or acquiring special needs in some capacity (Eide & Ingstad, 2011).

Poverty almost necessarily leads to insufficient nutrition, sub-standard or crowded housing, and inadequate physical and mental healthcare. These factors alone or in combination lead to an increased risk of impairment which in turn lead to disability. This notion is supported by Watermeyer (2006), who states that, disability is both a cause and consequence of poverty. Disability increase risks to poverty, while poverty creates conditions for increased risks to disability.

Some schools of thought as well as world bodies links disability to poverty because most of the immediate causes of disability relate to people's well being and can be or have been eradicated by improving their living conditions especially through advances in economic growth and human development. According to Braithwaite & Mont (2009), poverty causes disabilities and can furthermore lead to secondary disabilities for those individuals who are already disabled. Disability is a result of poor living conditions, health endangering employment, malnutrition, and poor access to health care and education opportunities. Together, poverty and disability create a vicious circle (Loeb,

Jelsma, Ka'Toni& Muart, 2008). Children growing up in poverty are at higher risk for malnutrition, childhood diseases, exposure to environmental health hazards and often receive inadequate health care. These factors increase the risk of physical and intellectual disability. Also, children in disadvantaged areas or communities with disabilities may be deprived of many common cultural and educational experiences provided to other children.

2.3.3 PROBLEMS AT BIRTH

Prematurity and low birth weight predicts serious problems more often than any other conditions of causing disabilities in children. Difficulties in the birth process such as temporary oxygen deprivation or birth injuries usually cause intellectual disabilities (WHO, 2011). This is a major cause of cerebral palsy. After birth diseases such as whooping cough, chicken pox, and measles, may lead to meningitis and encephalitis can damage the brain thus intellectual disability.

Difficulty in delivery can cause temporary stoppage of oxygen supply to the brain of the baby. It damages nervous tissues of the brain or spinal cord and this effect is permanent. This can cause mental deficiency in the baby. Sometimes the baby becomes physically disabled. When the doctors take help of various equipments during the delivery, for example, in forceps delivery, the brain or nerve is pressed by the forceps. If the doctor or nurse is not very well trained, they can cause damage to the baby.

As a result, the part of body with which the pressed or damaged nerve can be related to is permanently damaged. It is always advisable that delivery should be done at a nursing home or hospital under the guidance of the doctor or trained nurses.

2.3.4 GENETICS

It has been demonstrated in genetic research that the risk in the offspring of a parent with a disability especially intellectual, is eight times higher than in the general population (Wong, Wong, Martinson, Lai, Chen & He, 2004). There is a 25% probability that each child of a parent with genes hypothesized to cause dyslexia will inherit those

genes (Karam, Riegel, Segal & Black, 2015). The contention that dyslexia occurs in families across generations is a well known fact (Sawyer, 2006). Dyslexia, or intellectual reading disorder, is characterized by difficulty with learning to read fluently and with accurate comprehension. Dyslexia is a specific learning disability that is neurobiological in origin.

Abnormalities of genes inherited from parents, errors when genes combine, or from other disorders of the genes caused during pregnancy by infections, overexposure to x-rays and other factors is a leading cause to intellectual disability (Wong, 2004). Tuttle and Paquette (2003) state that there are many genetic diseases associated with intellectual disability. Some examples include phenylketonuria (PKU), a single gene disorder. Due to a missing or defective enzyme, children with PKU cannot process a part of a protein called phenylalanine. Without treatment, phenylalanine builds up in the blood and causes intellectual disability. Down syndrome is an example of a chromosomal disorder. Chromosomal disorders happen sporadically and are caused by too many or too few chromosomes, or by a change in structure of a chromosome (Tuttle & Paquette, 2003).

2.3.5 DRUGS

Use of alcohol or drugs by the pregnant mother is a cause of intellectual disability. Alcohol is known to be the leading preventable cause of intellectual disability. Smoking is also increasing the risk of intellectual disability. Other risks include malnutrition, certain environmental toxins, and illnesses of the mother during pregnancy including sexually transmitted diseases such as syphilis and gonorrhoea (WHO, 2011).

2.3.6 MALNUTRITION

In the 1980s, the major causes of disability among children were inadequate nutrition of mothers and children, including vitamin deficiencies, abnormal pre-natal and or peri-natal events, infectious diseases, accidents, environmental pollution, and impairment of unknown origin (WHO, 2011). Durkin, Gottlieb, Maenner and Cappa (2009) highlighted that nutritional deficiency was found to be the most influential cause of disability in children. Malnutrition has been seen as influential especially in child disability (WHO,

2011). Moreover, child malnutrition is linked to impaired intellectual development to child malnutrition (WHO, 2011). In infancy and early childhood, iron deficiency and anaemia can delay psychomotor development and impair cognitive development. Malnourished children have lifetime disabilities including impaired capacity for learning. In young children, the effects of malnutrition impair mental and cognitive developments, thus reducing their interaction both with their surrounding environment and with their caregivers. Folate deficiency in expectant mothers can cause birth defects in infants, such as spina bifida. Vitamin E deficiency can lead to poor bone formation, including rickets leading to intellectual disability. Deficiency of vitamin 'A' can cause blindness in the children.

2.3.7 HIV/AIDS

Human Immunodeficiency Virus (HIV) is a virus that causes progressive failure of the immune system. The failure of the immune system can lead to life-threatening opportunistic infections as well as disability. In almost all cases, HIV will develop into Autoimmune Deficiency Syndrome (AIDS). HIV/AIDS has become a cause for disabilities. UNAIDS (2009) estimates that more than 33 million people including two million children are infected with HIV/AIDS worldwide, a proportion of whom are suffering from varying degrees of disability. The growing relationship between HIV/AIDS and disability is an emerging issue and cause for concern as persons with disabilities are at higher risk of exposure to HIV (Nixon, Forman, Hanass-Hancock, Mac-Seing, Munyanukato, Myezwa & Retis, 2011).Furthermore, there is a growing understanding that persons living with HIV or AIDS are also at risk of becoming disabled on a permanent or episodic basis as a result of their condition (Groce, 2004). In South Africa, the relationship between HIV and disability is on the rise.

People with disabilities are at increased risk of exposure to HIV (Groce, 2004) and that people living with HIV are at risk of developing impairments that can lead to disability as a result of their illness or their treatment. The toxicity and associated adverse reactions and sometimes poor absorption of ARTs can lead to disability (Nixon et al., 2011).

On the one hand, people with disabilities are seen as an at-risk population because they are exposed to well-known HIV risk factors such as poverty, inadequate sex education, poor access to health services, risk of sexual abuse, and partner fluctuation, to which women and girls with disabilities are particularly vulnerable (Banda 2005; 2010; UNAIDS 2009; Watermeyer, Schwartz, Lorenzo, Schneider, & Priestley, 2006)

2.4 CAUSES OF DISABILITIES AMONGST CHILDREN IN SOUTH AFRICA

No reliable data on the causes of disability among children in South Africa exists. Clinic derived reports suggest that a number of causes of disability in South Africa have a similar prevalence to developed countries (Adnams, 2010).

2.4.1 Nutritional deficiencies and growth stunting

Nutritional deficiencies and growth stunting represent multiple biological and psychosocial risks. In South Africa childhood under nutrition is generally associated with concurrent and long-term global deficits in cognition, behaviour and motor skills, although the relationship is likely to be confounded by socio economic factors (Adnams, 2010). Mostly, the result is cognitive mild intellectual disability with or without specific learning difficulties. There is a strong and consistent relationship of growth stunting and poor child development with moderate-to-large effects, and early childhood stunting has been shown to be a good predictor of poor school achievement and cognition in 7-year-old South African children (Grantham-McGregor, Cheung & Cueto, 2007).

2.4.2 HIV / AIDS

South Africa is severely affected by the HIV/AIDS epidemic, with both the highest reported prevalence of HIV / AIDS per capita and the world's largest population (over 15% of the population aged 15–49 years and 280 000 children 0–14 years old) living with HIV. Joint United Nations Programme on HIV/AIDS estimated that in 2015 the total number of persons living with HIV in South Africa was 5.7 million (UNAIDS, 2009).

Ninety-five percent of children infected with HIV in sub-Saharan Africa (SSA) acquire infection from their mothers. HIV/AIDS is a leading cause of death in South African children under 5 years. Children in SSA, including South Africa, who survive without early treatment have a high prevalence of cognitive disability, visual spatial and motor deficits which leads to physical disabilities as well as neurological impairment, seizures and encephalopathy (Smith, Adnams & Eley, 2008).

2.4.3 TUBERCULOSIS

There is a high incidence of tuberculosis in most provinces of South Africa with the highest being the Western Cape region of South Africa (van Well, Paes & Terwee, Springer, Roord, Donald, & Schoeman, 2009). Tuberculosis associated with high morbidity and mortality rates, especially in younger children. Children with a poor outcome develop severe neurological and multiple disabilities. HIV confection increases the risk of developing Tuberculosis with a higher rate of complications. Hydrocephalus, a common complication of Tuberculosis, may be associated with a poor cognitive outcome if treatment is delayed. Tuberculosis is an important cause of moderate and severe intellectual disability in young South Africans.

2.4.4 FOETAL ALCOHOL SPECTRUM DISORDERS

The burden of mental and physical disease associated with high levels of alcohol abuse in South Africa has major implications for intellectual and physical disabilities. Foetal Alcohol Spectrum Disorders result from prenatal alcohol exposure owing to excessive maternal drinking. FASD is a major public health problem in South Africa and places a burden on a number of systems, including health, education, social services, labour and criminal justice, at both fiscal and societal cost. Alcohol is known to be the leading preventable cause of intellectual disability. Smoking is also increasing the risk of intellectual disability. Other risks include malnutrition, certain environmental toxins, and illnesses of the mother during pregnancy including sexually transmitted disease such as syphilis and gonorrhoea (WHO, 2011).

Many children who are born on farms where their parents are poorly paid, live in appalling housing and grow up in abject poverty. Common on these farms is the practice of the 'dop' system of payment whereby wages are paid in part with wine (Lansdown, 2002). This practice resulted in high levels of alcoholism with foetal alcohol syndrome as a major problem. In the Western Cape Province of South Africa, there has been incidence of 6% of children suffering from foetal alcohol syndrome, the highest in South Africa and the whole world, (Democratic Alliance report, 2015). The impact of foetal alcohol syndrome on the development of children is profound. The intelligence of the children is significantly affected. The children have distinct facial features, exhibit life-long behavioural problems and remain very small in stature. Adolescents and adults exhibit high levels of mental illness including depression and anxiety. Although the 'dop' system has now been officially banned, there is evidence that it continues on many farms in South Africa. The combined effect of the 'dop' system and the poverty of farm workers continue to raise major barriers to the healthy development of farm children. Children on commercial farms have relatively the highest prevalence of stunted growth. There is evidence that the wine used in payment of the workers is shared with children, thus perpetuating the risk of high levels of alcoholism. Inadequate nutrition, unhygienic living conditions, overcrowding, exposure to pesticide poisoning, accidents and violence all contribute to high levels of disability to these children.

2.4.5 VIOLENCE AND INJURY

In South Africa violence and injury carry a high burden of disability and mortality (Lalloo & van As, 2004). Traumatic brain injury contributes significantly to this burden. TBI is an important preventable cause of intellectual disability in children across the developmental span and also of cognitive impairments in older adolescents and adults. The road traffic death rate is amongst the highest in the world standing at 33.2 per 100 000 population, (WHO, 2011). Morbidity for survivors of road traffic accidents is estimated at 20 fold higher than the rate of fatality, suggesting a high burden of disablement. In a report of 37 610 children with head injuries treated at a paediatric tertiary hospital in Cape Town between 1991 and 2001, over one-third of children were injured in road traffic accidents and physical assaults (May, Gossage & Marais, 2007).

Almost two thirds of the children involved in road traffic accidents were pedestrians. Of the survivors of head injuries of all causes, 17.9% of children had moderate or severe head injuries. Alcohol plays a significant role in the accidents, both in children and adults who may be victims of violence and motor vehicle accidents.

2.5 THEORETICAL MODELS OF DISABILITY

According to Watermeyer, Schwartz, Lorenzo, Schneider, and Priestley, (2006) models of disability are tools for defining disability and, ultimately, for providing a basis upon which government and society can devise strategies for meeting the needs of people with disabilities. They are a useful framework in which to gain an understanding of disability issues and also of the perspective held by those creating and applying the models.

Models are influenced by two fundamental philosophies. The first sees people with disabilities as dependent upon society. This can result in paternalism, segregation and discrimination. The second perceives people with disabilities as customers of what society has to offer. This leads to choice, empowerment, equality of human rights, and integration.

Models change as society changes. Given this degree of understanding, our future objective should be to develop and operate a cluster of models, which will empower people with disabilities, giving them full and equal rights alongside their fellow citizens. Every disabling condition is seen as a cultural or social construction rather than as a personal or private problem. This study examined the systems, medical, social, rights based cultural / religious and economic models of disability.

2.5.1. The Systems Model

The environment plays a major role in disabling individuals. Understanding how the environment affects people living with disabilities requires one to go beyond simply thinking about the physical environment, (Riddell & Watson, 2014). It is important to also consider how social systems and dominant discourses shape disability and how a

person living with a disability operates in the social environment. A systems model understanding of disability enables one to understand that a person living with a disability enters into particular systems in society, already at a disadvantage because of how the systems or organizations use labels to organize people in order to operate the way they like. By doing so, the abilities of a person living with a disability are overlooked in favour of focusing on the disability since it is the disability that challenges the system.

The systems model points out that a person living with a disability must overcome entering such a system at a disadvantage. But it is important to note that systems do not exist in isolation but rather interact with the broader environment. According to Llewellyn and Hogan (2000), a systems approach to disability encourages consideration of the dynamics that can drive and accelerate the course of development by examining the influence of the characteristics of a person, and of the environment .The systems model encourages an assessment of the broader environment surrounding the person living with a disability. The systems model therefore encourages an understanding of how conditions of poverty limit the ability of a person living with a disability to such an extent that their disability places them at a severe disadvantage.

The model subsequently focuses on speaking to people living with disabilities in settings of poverty in order to understand how their environment constrains or supports their abilities (Llewellyn & Hogan, 2000). Altman (2010) pointed out that the political environment should be able to recognize persons with disabilities. In the modern political thought, people living with disabilities are almost always framed in a disabling way as either lacking autonomy or being dependent, which ultimately undermines their personhood and citizenship (Arneil, 2009).

2.5.2 Charity Model

The Charity Model sees people with disabilities as victims of their impairements. 'It depicts disabled people as victims of circumstances who are deserving pity, (Drake, Skinner & Bond, 2009). Depending on the disability, the disabled persons cannot walk, talk, see, learn, or work. Disability is seen as a deficit. Persons with disabilities are not able to help themselves and to lead an independent life. Disabled people are seen as

tragic victims, who need care. They are not capable of looking after themselves or managing their own affairs, and need charity in order to survive.

Persons with disabilities situation is tragic and they are suffering. Society's responsibility is to meet their needs. Consequently, they need special services, special institutions, such as special schools, residential facilities or homes because they are different (Dube & Charowa, 2005) . People with disabilities are to be pitied and need our help, sympathy, charity, welfare in order to be looked after. Sometimes people with disabilities themselves adopt this concept, in which case they usually feel unable and have a low sense of self-esteem. This can explain why some persons with disabilities are seen begging at street corners or robot intersections.

This model emphasizes the role of community organizations such as churches, government departments and non-governmental organizations to assist people with disabilities. Traditionally, the model was used by charities in the competitive business of fund raising. The Charity Model is condemned by its critics as disenabling, and the cause of much discrimination.

2.5.3 Moral / Cultural Model

The Moral Model is historically the oldest and is less prevalent today. There are many cultures that associate disability with sin and shame especially in Africa and India. Under this model, a person with a disability is seen as sin. Disability was considered as punishment from God for the wrongs done in the past, (Altman, 2010). Thus persons with disabilities were treated as aliens. They have no right to live in the mainstream society. They are not entitled for any right to education, social life and employment. Neither government nor society was concerned with the problems faced by them. This model has been associated with shame on the entire family of a person with a disability. Charlton (2001) states that families have hidden away their loved ones with disabilities, keeping them out of school and excluded from any chance at having a meaningful role in society. Persons with disabilities are locked in small back rooms such that they are not seen by the entire world. This model has resulted in general social exclusion and self-hatred of people with disabilities.

The Cultural Model views disability as a punishment inflicted upon an individual or family by an external force. It can be due to misdemeanours committed by the person with a disability, someone in the family or community group. Birth conditions can be due to actions committed in a previous reincarnation. Sometimes the presence of evil thoughts is used to explain differences in behaviour, especially in conditions such as schizophrenia and intellectual disability (Davies, 2002). In some cases, the disability stigmatizes a whole family, lowering their status or even leading to total social exclusion.

2.5.4 The Medical Model

The Medical Model came about as modern medicine which began to develop in the 19th century, along with the enhanced role of the physician in society. The medical model also holds that disability results from an individual person's physical or mental limitations, and is largely unconnected to the social or geographical environments. Under this model, the problems that are associated with disability are deemed to reside within the individual **(**Harris & Enfield, 2009)**.** In other words, if the individual is cured, then these problems will not exist.

The Medical Model considers people with disabilities as persons with physical problems which need to be cured (Madans, Loeb, & Altman, 2011). Since many disabilities have medical origins, people with disabilities were expected to benefit from coming under the direction of the medical profession**.** The individual with a disability is in the sick role under the medical model. When people are sick, they are excused from the normal obligations of society for example going to school, getting a job, and taking on family responsibilities. They are also expected to come under the authority of the medical profession in order to get better**.** This pushes people with disabilities into the passive role of patients. The aim of a medical approach is to make people with disabilities normal which of course implies that people with disabilities are in some way abnormal.

The issue of disability is limited to the individual in question. In case of disability, the disabled person has to be changed, not society or the surrounding environment. Thus society has no underlying responsibility to make a place for persons with disabilities, since they live in an outsider role waiting to be cured. Boorse (2010) states that in simple terms the medical model assumes that the first step solution is to find a cure to make disabled people more normal.

According to Watermeyer et al., (2006) persons with disabilities need special services, such as special transport systems and welfare social services. For this purpose, special institutions exist, for example hospitals, special schools, residential facilities and sheltered employment places where professionals such as social workers, medical professionals, therapists, special education teachers decide about and provide special treatment, education and occupations.This fails because disabled people are not necessarily sick or cannot be improved by remedial treatment.

In the medical model, professionals follow a process of identifying the disability and its limitations and taking the necessary action to improve the position of the person (Mitra et al., 2011). This has tended to produce a system in which an authoritarian, over-active service provider prescribes and acts for a passive client. This relationship has been described as that of "fixer" (the professional) and "fixee" (the disabled person) and clearly contains an inequality that limits collaboration.

The Medical Model has dominated the formulation of disability policy for years. We should however not reject its therapeutic aspects which may alleviate the physical or mental condition of many people with disabilities. It however does not offer a realistic perspective from the viewpoint of people with disabilities themselves. Most disabled people would reject the concept of being abnormal or sick. They view these statements as abusive.

The medical model may be also the basis for exclusion of the disabled. Perceived exclusion and segregation of the medically disabled, led organizations to design patronizing welfare programmes as well as ways to cure the afflicted in the hope that their afflictions would be eradicated permanently (Yeo & Moore, 2003). The model

concentrates on care and ultimately provides justification for institutionalization and segregation. This restricts disabled people's opportunities to make choices, control their lives and develop their potential. If the decisions are made by the professional, the client has no choice and is unable to exercise the basic human right of freedom over his or her own actions. In the extreme, it undermines the client's dignity by removing the ability to participate in the simplest, everyday decisions affecting his or her life.

The only remaining solution is to accept the disabilities and provide the necessary care to support the incurable disabled person. Policymakers are therefore limited to a range of options based upon a program of rehabilitation, vocational training for employment, income maintenance programs, building residential facilities and the provision of aids and equipment.

2.5.5 The Social Model

The Social Model regards disability to be a result of the way society is organised. The social model of disability sees the issue of disability as a socially created problem and a matter of the full integration of individuals into society (Watermeyer et al., 2006).In this model, disability is not an attribute of an individual, but rather a complex collection of conditions, many of which are created by the social environment. Hence, the management of the disability requires social action and is the collective responsibility of society at large to make the environmental modifications necessary for the full participation of people with disabilities in all areas of social life.

Shortcomings in the way society is organised mean that people with disabilities face discrimination and barriers to participation. Discrimination can be in the form of environmental barriers. This results in physical inaccessibility affecting all aspects of life (market and shops, public buildings, places of worship, transport, etc.). Discrimination is also seen through institutional settings. This means persons with disabilities are excluded from certain rights (e.g. by not being allowed to marry or to have children), or from school. These two types of barriers make people with disabilities unable to take control of their own lives. According to Beaudry (2016) a disability not only depends on

the individual but also on the environment, which can be disabling or enabling in various ways.

Anastasiou (2013) states that, in the broadest sense, the social model of disability is about nothing more complicated than a clear focus on the economic, environmental and cultural barriers encountered by people who are viewed by others as having some form of impairment whether physical, sensory or intellectual.

Social model of disability was developed from the 1970s within the disability movement in the United Kingdom. It offered a radical alternative to the individualized medical conception of disability by asserting that disabled people were disadvantaged not because of their impairments, but as a result of the limitations imposed on them by social, cultural, economic, and environmental barriers. Disability according to this formulation is not about health or pathology but about discrimination and social exclusion. The issue of disability is thus viewed as requiring individual, community, and large-scale social change. From this perspective, equal access for someone with a disability is a human rights issue of major concern.

From a social model perspective, disability is a socio-political issue. This in turn leads to fundamentally different policy priorities and choices, mainly around the removal of disabling barriers, as well as a strong emphasis on human and civil rights (Altman, 2010).

Unlike medical model assumptions of individual abnormality and sickness, the social model, acknowledges the normality of impairment. Furthermore, it is recognized that medical advances far from reducing the number of disabled people have led to an increase, as people not only live longer but are also better able to survive illness and injury **(**Harris & Enfield, 2003).

The Social Model also views disability with the concept of, "Nothing about us without us". It puts disabled people into a leading role in defining and controlling their lives. The social model offers a powerful device for the liberation of those who remain the poorest of the poor in all countries, both developed and developing. The model is so powerful

because it illuminates the fact that the roots of poverty and powerlessness do not reside in biology, but in society (Palmer, 2012).

The social model of disability represents a challenge to traditional thinking about disability. If applied in the development context it has the potential to transform policies and practice as well as the lives of disabled people.

2.5.6 The Rights – Based Model

Harris and Enfield (2003) state that,the rights based model focuses on the fulfilment of human rights, for example the right to equal opportunities and participation in society. Consequently, society has to change to ensure that all people including people with disabilities have equal possibilities for participation. Most persons with disabilities often face a denial of their basic human rights, for example the right to health (physical and psychological) or the right to education and employment. Laws and policies therefore need to ensure that these barriers created by society are removed.

The Rights-based Model states that support in these areas is not a question of humanity or charity, but instead a basic human right that any person can claim. The two main elements of the rights-based approach are empowerment and accountability. Empowerment refers to the participation of people with disabilities as active stakeholders, while accountability relates to the duty of public institutions and structures to implement these rights and to justify the quality and quantity of their implementation.

2.5.7 ROLE OF THE SOCIAL MODEL ON DISABILITIES TO THE STUDY

The social model has been developed and applied to understand the experience of disabled children in relation to their relations with their parents, immediate family, siblings, extended family, neighbours and the community (services) at large (Malacrida, 2005) . The social model on disabilities views the immediate family playing an important role in providing and advocating for the inclusion of the child with a disability in everyday life outside the family (Brown, Goodman & Kupper, 2014). For instance, a family with a child who uses a wheelchair has to advocate at their local church such that there are wheelchair friendly facilities for their child. It is the role of the family to change negative

attitudes of people towards their child. Since charity begins at home, the family is responsible for making all accessibility aspects of the child with a disability available before advocating for the community to follow suit. Dowling and Dolan (2001) are of the view that the social model approach can be used to identify the inequalities experienced by disabled children and their families.

The social model of disability is about a clear focus on the economic, environmental and cultural barriers encountered by people who are viewed by others as having some form of disability - whether physical, sensory or intellectual. The barriers disabled people encounter include inaccessible education systems and working environments, inadequate disability benefits, discriminatory health and social support services, inaccessible transport, inaccessible houses and public buildings and amenities, and the devaluing of disabled people through negative images in the media - films, television and newspapers (Shah, Arnold &Travers, 2004).

The social model of disability can importantly be used to understand the family lives and personal relationships of disabled people. This is because the cultural environment in which we all grow up usually sees impairment as unattractive and unwanted. Consequently parents often do not know how to bring up a child born with impairment so their feelings and the way they treat them are dependent upon what they have learned about disability from the world around them (Brown et al., 2014).

Though the social model of disability is becoming widely accepted, and more services are being put into place for both disabled adults and children, parents of disabled children still face the problem of finding out what is available and gaining access to it for their children. This issue is further confused by fragmented social structure and a lack of standardization. Services for children with special needs depend on where they live, not on what they need. Parents face a multitude of tasks to ensure their disabled children are treated equally and have the support structures so that they can be independent members of society (Brown et al., 2014)

2.6 EXPERIENCES OF PARENTS OF CHILDREN LIVING WITH DISABILITIES

The birth of a child with a disability or the discovery that a child has a disability is an intense and traumatic event for the parents. When it is learned at birth that the child is in some way abnormal, the effect on the parents can be devastating. A parent's initial reaction is likely to be negative and similar to those related to bereavement (Blachar & Bakar, 2007). This is followed by a period of questioning which may go on for many years, as to why this should have happened to them. Hill and Rose (2009) illustrate that the parents may tend to blame themselves or each other. Some may react in an emotionally and physiologically negative way to the diagnosis of their child's disability. The transition in a family with a child living with disabilities brings about significant changes in that family's social life. Some experience considerable stress, as well as feelings of depression, anger, shock, denial, self-blames guilt and confusion Therefore, the sequence and time needed for adjustment is different for every parent (Hill & Rose, 2009)

Parents of children with disabilities do have varying experiences cross cutting from social (emotional wellbeing), economic (financial) and hostile communities. These experiences are also affected mainly by the geographical locations they find themselves in. For instance, parents in the third world countries such as India and Southern Africa where poverty is rife, parents face difficulty financial problems in raising their children. In third world countries, poor or lack of legislation for disabled children leave the parents with a heavy burden on their shoulders since the community is systematically hostile to their children with disabilities.

Several factors are associated with caring for children with disabilities. These include the support system from immediate family members at home, cultural values and beliefs, financial resources and stability for seeking treatment and rehabilitation services for the children with disabilities (Monk & Wee, 2009). However, the social and emotional demands caused by the child's disability vary across the different racial and ethnic groups, given the diverse cultural norms, resources and support available to the parents (Arisha, Seema, & Ghazala, 2013).

2.6.1 Experiences of Parents of children living with disabilities in Zimbabwe

There is no recent statistical data on the total number and percentage of children with disabilities (CWDs) in Zimbabwe. The Inter-Censal Demographic Survey recorded a total of 218 421 PWDs in the country, which was approximately 2 per cent of the country's total population. Of these, 57 232 were CWDs, which was about 26 per cent of the total population of People with Disabilities, (Choruma, 2007).

In most parts of Southern Africa including Zimbabwe, children born with albinism used to be killed immediately after birth. The parents had to endure the pain of watching their children being killed as they did not have power to stop the killings. Further, people with disabilities in Zimbabwe were marginalized and treated as if they were not capable of functioning on their own. Disability was equated with inability. In most parts of Africa with Zimbabwe included, disability is viewed as either a form of punishment or as a curse by angry ancestral spirits (Chimedza & Peters, 2006).

In Zimbabwe and other African nations, the family has been responsible for taking care of its disabled members. However, pressures from urbanization and changing patterns of employment leading to urban migration have resulted in the breakdown of the extended family system (Chimedza & Peters, 2006). Due to more limited family support, children with disabilities have been locked in houses and placed in institutions, and are generally seen as burdensome (Chimedza & Peters, 2006). Tolerance of people with disabilities has also tended to diminish sharply during periods of economic hardship (Choruma, 2007). This has left the burden on the parents who have to bear the brunt of looking after the children with disabilities.

It is not surprising that some of the above cited attitudes still apply in Zimbabwe today (Choruma, 2007). Socially, there is still a lot of misunderstanding and lack of knowledge about disabilities. This mainly stems from cultural misgivings about disabilities. Disability is still an issue that is surrounded by myths. In the social setting, people with disabilities are invisible because generally the country's social amenities have not been structured in a way that is inclusive for people with disabilities. As such, children with disabilities are less likely to participate in most social activities. Instead, children with disabilities belong to institutions where specialized activities are developed for them. Society's

attitude towards children with disabilities reflects a view that people with disabilities are useless liabilities who have no role to play in society.

Choruma (2007) states that Zimbabwe's most new buildings have ramps with rails. In many cases, the recommended gradient of the ramps is not adhered to. The buildings may also lack signs to indicate where the disabled person's entrance, elevators or toilets are located. In urban areas, doors to offices, hotel rooms or toilets are heavy and handles too high, making it difficult for a person with a disability to manoeuvre with ease. The visually impaired complain about buildings with no guiding rails, elevators with no recorded voice, and elevators too small or narrow to accommodate a wheelchair. These problems are left on the shoulders of the parents who do not have any choice but to isolate their children from the hostile disability unfriendly environments. Likewise, the parents are forced to segregate their children from the mainstream society due to lack of policies to protect them.

2.6.2 Experiences of parents of children living with disabilities in India

In India, 1.67% of the 0-19 population has a disability. 35.29% of all people living with disabilities are children (Ministry of Information and Broadcasting India, 2011). Other estimates say that India has 12 million children living with disabilities. Only 1% of children with disabilities have access to school and one third of most disabilities are preventable. Under-nutrition is a severe problem with children who suffer from cerebral palsy. In India, 80% of children with disabilities will not survive past age forty (Miles 2000).

There are many protection issues that also lead to disability, especially mental disabilities. Children who are trafficked, abused and sexually exploited are at risk for psychological effects as well as physical retardation. Other forms of violence against children can also lead to a disability such as corporal punishment in schools, children living on the streets, and purposefully created disabilities for begging. Children from poor families face a double disability (Gupta, 2011). Parents in onus turn their children into begging machines for a living.

Disability in India is still functioning in the realm of social welfare instead of a rights perspective. Teachers are not trained and schools do not have the infrastructure to deal

with children with disabilities (Gupta & Singhal, 2014). Neither are paediatric wards of hospitals equipped to deal with them. There is not enough data on the number of children living with disabilities to allow the government to provide the necessary services. Mental health disorders account for one sixth of all health disorders yet India spends 0.83% of its health budget on mental health. Child labourers are also at a higher risk of becoming disabled especially in hazardous industries.

There are many medical professionals who kill children with disabilities and write them off as mercy killings in India. According to Hastings and Beck (2004) 90% of the children in India with disabilities will not survive past twenty years of age. Children with disabilities face discrimination not only in services but also in the justice system as they are often not considered credible witnesses. Thus the parents are left with the entire burden in the criminal justice system segregation of their children with disabilities.

In India, children with disabilities mainly come under the purview of the Ministry of Social Justice & Empowerment. Some of the issues are dealt with by the health ministry. But no single ministry has been assigned the protection of these children, which leads to varying data about occurrence of disability amongst children (Hastings & Beck, 2004). This has also led to the ignorance for children with disabilities by the government.

Parents of children with disabilities in India face the challenge of poverty associated with disability. A large number of children with disabilities live in families with income significantly below the poverty level. According to Miles (2000), while disability causes poverty, it is also possible that in a country like India, poverty causes disability. The combination of poverty and disability results in a condition of simultaneous deprivation.

The attitudes of the non disabled are proving to be a major barrier in the social integration of children with disabilities. The more severe and visible the deformity is, the greater is the fear of contagion, hence the attitudes of aversion and segregation towards the crippled (Miles, 2000). Such attitudes reinforced by religious institutions may militate against any attempts to include students with disabilities into regular schools. Hindus (who constitute 85 percent of the total population in India) believe that disability is a

consequence of misdeeds performed in the previous life. Many Hindu religious institutions and temple trusts, therefore, do not think a part of their duty is to help children with disabilities because they consider the disability to be the result of a person's misdeeds in his previous life. Parents of the children are left to suffer emotionally to this hostile society (Hastings & Beck, 2004).

In India, disability is still viewed in terms of a "tragedy" with a "better dead than disabled" approach, the idea being that it is not possible for disabled people to be happy or enjoy a good quality of life (Padencheri, Swamidhas & Russell, 2011). Cultural beliefs about disability play an important role in determining the way in which the family perceives disability and the kind of measures it takes for prevention, treatment and rehabilitation. In rural India, parental expectations for their disabled child are mostly negative and unrealistic (Gupta & Singhal, 2014). Cultural beliefs and attitudes are very common for most Indian rural families with children who are disabled. Most parents are of the view that the disabled children in their families cannot do anything and just need help and sympathy.

2.6.3 Experiences of parents of children living with disabilities in Swaziland

According to Mazibuko (2011) the Swazi people like many others of different cultures in Africa in the past looked at disability as a curse from the gods and as a sign of bad omen. Children with disabilities as well as their parents were excluded from all spheres of life. The parents were viewed as practicing witchcraft thus also faced isolation and exclusion from their societies. In the previous centuries children born abnormal or disabled were killed at birth to avoid humiliation of their parents and families. These killings were mostly done without the approval of the parents. Culturally this practice was not viewed as killing, but as a way of life for dealing with abnormalities and relieving the parents of the burden of looking after their disabled children. If for some reason the child survived this ordeal, daily survival was very difficult because the child would be neglected to a point of death. The very few that made it to adult life were kept hidden from general society. Disabled children were seen as the source of shame in the eyes of the community members. They brought emotional distress and suffering to the

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parents and the family as a whole. Children with disabilities were a sign of bad omen to strike the family. That is why there were few disabled people in the African society in the past centuries (Gona, Mung'ala-Odera, Newton, & Hartley, 2010).

According to the United Nations Children's Fund Programme (2013) children, adolescents and youth with disabilities in Swaziland are at increased risk for physical and emotional neglect, social isolation and physical and sexual abuse with the concurrent risk of pregnancy and sexually transmitted diseases, including HIV/AIDS. This is mainly due to lack of strong parental figures and a hostile society. In essence, the parents are burnout and do not have a knowhow of taking care of their disabled children.

2.7 SITUATIONAL ANALYSIS ON POLICIES OF CHILDREN WITH DISABILITIES IN SOUTH AFRICA

Legislation has contributed to the social exclusion of children with disabilities. Firstly, legislation fails to protect the rights of children with disabilities. Secondly, through legislation, barriers are created to prevent children with disabilities from accessing equal opportunities. Although there has, since 1994, been some attempt to identify and eliminate discriminatory legislation from our statute books, many aspects of past discriminatory legislation remain. In addition, some new laws and amendments contain sections which directly or indirectly lead to discrimination against people with disabilities. As a result, large sections of the legislative framework in South Africa still fail to meet international human rights standards and principles with regard to the rights of children with disabilities. Post apartheid South Africa has been commended for putting in place many disability policies in different sectors of the government.

South Africa has been moving towards ratifying international disability conventions and policies. Locally, a number of policies have been drafted in order to guide and evaluate programs and services for children with disabilities. To begin with, the Constitution of the Republic of South Africa (Act No 108 of 1996) bill of rights protects the rights and dignity of people with disabilities and promotes and supports the full equalization of opportunities of people with Disabilities, and their integration in society, within a social model and human rights policy framework. Chapter 2 of the 1996 Constitution

guarantees fundamental rights to all citizens. It includes, in Section 9, the equality clause, and the right to freedom from discrimination based on a number of social criteria. Discrimination based on disability is specifically mentioned and disabled people are thus guaranteed the right to be treated equally and to enjoy the same rights as all other citizens. The white paper on Disabilities namely the Integrated National Disability Strategy of 1997 extrapolates on the rights of persons with disabilities.

2.7.1 The Reconstruction and Development Programme White Paper of 1994

During the government of National Unity of 27 April 1994 to 3 February 1997, The RDP White Paper was established. The Reconstruction and Development Programme is geared towards alleviating poverty, promoting equality, and striving towards an equal distribution of wealth among South Africa's society. The RDP strategy states that government will, in consultation with persons with disabilities, design a comprehensive programme that will enhance mobility for, and remove discriminatory systems against, persons with disabilities. The Programme further commits government to retaining continuous discussions aimed at devising means of integration for Persons with Disabilities, especially those who are victims of the severest discrimination. Government will also discuss means to reintegrate mentally and physically disabled people into their communities. (RDP, 1994)

The RDP White paper was the first document/policy on disabilities in South Africa. It led to the formulation of the White Paper on Disabilities namely the Integrated National Disability Strategy of 1997.

2.7.2 Integrated National Disability Strategy White Paper of 1997

The White Paper on Integrated National Disability Strategy (INDS) was introduced in 1997, after an extensive consultative process where persons with disabilities participated through their various organizational affiliations. This document reiterates government's policy integration process throughout all spheres of government. The policy integration approach that is advocated by the INDS seeks to achieve disability coherence throughout all government processes, particularly in an attempt to address the social, economic and political inequalities that persons with disabilities experience

due to disability. The Strategy is aimed at mainstreaming disability and curb marginalization on the grounds of disability.

The INDS was established as the yardstick by which to measure a society's respect for human rights. It also focused at the status that is accorded to those members of society who are most vulnerable, disabled people, the senior citizens and its children. The INDS White Paper represents the government's thinking about what it can contribute to the development of disabled people and to the promotion and protection of their rights.

The Integrated National Disability Strategy is aimed at kick starting a process involving disabled people in the development of specific policies and legislation with a view of giving effect to the recommendations contained in the White Paper. People with disabilities are a natural and integral part of society as a whole, and should have opportunities to contribute their experience, talents and capabilities to national and international development.

The objectives of the 'Integrated National Disability Strategy' include facilitation of the integration of disability issues into government developmental strategies, planning and programmes. The second objective is the development of an integrated management system for the co-ordination of disability planning, implementation and monitoring in the various line functions at all spheres of government. The third objective is the development of capacity building strategies that will enhance Government's ability at all levels to implement recommendations contained in the 'Integrated National Disability Strategy. Fourthly, a programme of public education and awareness raising aimed at changing fundamental prejudices in South African society is envisaged.

2.7.3 White Paper 6 on Special Needs Education of 2001

The White Paper on Special Needs Education provides a framework for government's long-term, though phase-planned, goal to achieve an inclusive education for children with disabilities. This policy aims at facilitating the provision of education for learners with special educational needs who are intellectually and physically disabled. This model of education entails admitting all learners with special needs to the mainstream public school. This process will investigate and address barriers to learning, recognize and accommodate the diverse range of learning needs. It is part of the twenty-year

programme that aims to build an open, lifelong and high quality education and training system for all citizens, including children with disabilities.

According to the Department of Education (2001) this entails that the education system be transformed so that schools can accommodate learners with special needs, and that the necessary support services be developed. The vision of the White Paper on Education is good quality education for children with disabilities.

Implementation of the policy on inclusive education and training will involve children with disabilities, organizations of Persons with Disabilities, and parents of disabled learners. There will be transformation of schools to meet special needs children and thereby becoming effective resource centres.

2.7.4 White Paper of Social Welfare 1997

This White Paper on Social Welfare 1997 states that, "disability in a family increases the impact of poverty", while poverty contributes to the incidence of illness and disability. It states the needs of government and non-governmental organizations to create equal opportunities for Persons with Disabilities and to develop appropriate programmes aimed at enhancing their independence and integration into the mainstream of society.

The objective is to facilitate the provision of appropriate developmental social welfare services to all South Africans, especially those living in poverty, those who are vulnerable and those who are disabled. These include rehabilitative, preventative, and protective services and facilities, as well as social security, including social relief programmes, social care programmes and the enhancement of social functioning.

The vision of this policy is to create a system of welfare that facilitates the development of human capacity and self reliance within a caring and enabling socio-economic environment. It also promotes the integration and inclusion of Persons with Disabilities by seeking to correct past discriminatory practices through Social security programmes and mental health programmes.

2.7.5 The Department of Social Development Policy on Disabilities of 2002

This policy has been developed to provide strategic guidelines in the delivery of social

services that are compliant to departmental mandates and legislation within the social development context. The policy is intended to guide and inform the department on the mainstreaming and integration of disability within social development practices and aims to facilitate the transformation shifts in line with the current policy framework to promote inclusion for People with Disabilities. It outlines a broad agenda for the department to follow in addressing disability issues.

Policy on disabilities is an overarching policy that has been developed to ensure that all People with Disabilities, who are poor, vulnerable and marginalized receive adequate economic and social protection, attain access to social welfare programs which will promote development and enhance their social functioning. It encompasses, in its context, an integrated system that supports a broader effort by People with Disabilities themselves and a comprehensive system of social services, developed to promote social development, social justice and the social functioning of People with Disabilities, to bring about sustainable improvements in their well-being and that of their families and communities.

The policy aims to facilitate the achievement of priorities of the department through the development of integrated developmental services to people with disabilities and parents of children with disabilities. It further sheds light on the rights of people with disabilities by analyzing all the relevant disability instruments, supporting equality and accessibility as a coherent whole. In conjunction with other government efforts, it raises public awareness of their rights, challenges stereotypes, and facilitates removal of false perceptions of disability.

2.7.6 Social Assistance Act

The South African government implemented the disability grant system. This is provided under the Social Assistance Act (Act 59 of 1992/Act 13 of 2004) which provides that individuals are eligible for a Disability Grant (DG) if they pass a means-test and if, as a result of mental or physical disability, they are unable to provide for themselves through employment or professional activity (Nattrass, 2006; Mitra, 2009). The Child Dependency Grant is designed for children with any type of disability from the ages of 1

until 18. As of March 2016 the Care Dependency Grant stood at R1500. The grant is aimed at providing financial needs for the provision of services for the disabled child, (Nattrass, 2006). Disability grant recipients may receive an additional grant if they require personal assistance or personal care (Nattrass, 2006). Although this grant is relatively generous, the means-test and targeting people of a certain age have been found to be problematic practices.

South Africa has some of the most comprehensive legislation and policies protecting and promoting the rights of children with disabilities as envisaged by the numerous policies which I have discussed above. The constitutional principles of human dignity, the advancement of human rights and freedoms, although applicable to everyone, are especially important for children with disabilities.

While these principles are proper in terms of improving the lives and rights of people with disabilities, there are gaps and problems inherent in the system which threatens the objectives for which they are meant. My research is going to focus on these gaps which are currently available and try to bring them out.

2.8 ROLE OF SOCIAL WORKERS WHEN WORKING WITH PERSONS WITH DISABILITIES AND THEIR FAMILIES

Social work is an academic and practice based professional discipline that seeks to facilitate the welfare of communities, individuals, families, and groups. The main goal of social work is to improve a society's overall well-being, especially for the most vulnerable populations which include persons with disabilities, children, the elderly and women (Miley & Du Bois, 2007).

Social work has always reached out to those with limited power in society, including the poor, homeless, children, the elderly and people with disabilities. Miley and Du Bois (2007) also argue that in line with its mission as a human and helping profession, social workers' interventions are generally initiated to strengthen human functioning and to enhance the effectiveness of societal structures that provide resources and opportunities for clients and beneficiaries of services, including people with disabilities.

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Various organizations and professions in South Africa render services to persons with disabilities (Strydom, 2015). Non – Governmental Organizations delivering social work services form part of these organizations. Research in South Africa found that 31% of respondents with a disability indicated that a social worker was the predominant form of social support available to them (Graham, Selipsky, Moodley, Maina, & Rowland, 2010), while young people with disabilities seem to be more aware of social workers than of home-based carers, community rehabilitation workers and rehabilitation therapists (Lorenzo & Cramm, 2012). Social workers are thus important role players in rendering services to people with disabilities.

In South Africa, social workers work in Government departments and Non-Governmental Organizations (NGOs) where they provide various services to people with disabilities (Strydom, 2015). In the Department of Social development where most social workers are employed, social workers' roles include preventive, curative and rehabilitative services for disabled persons. Disability care includes improving capacity for caregivers and parents to care for their disabled children and facilitating integration of disabled children into mainstream schools and other social settings. NGOs also provide a host of services for persons with disabilities which include residential, rehabilitation, protected work, advocacy, and stimulation. The role taken by social workers in NGOs is primarily admission of persons with disabilities in residential facilities until they are reintegrated back into the community when discharged.

Residential social workers provide counselling services to both persons with disabilities and their families. They also arrange reintegration services when the disabled clients are to be discharged from the residential facilities. Residential social workers also work with other professionals within the residency such as health professionals (nurses), psychologists, and physio therapists in a psycho social team with the aim of providing a holistic service to persons with disabilities.

Social workers also provide counselling to people with various forms of disabilities to help them adjust to their disability. In this context, counselling usually involves a wide range of problems such as personal, interpersonal, family, financial, vocational adjustment and educational adjustment. In some situations, social workers do not

always provide counselling to people with disabilities directly, especially if the disabled is a young child. Instead, social workers provide counselling to the family of the person with disability, and other close parties such as siblings, peers and relatives. Working with the family is initiated to help them understand the nature of a disability and the prognosis, to make the essential adjustments to help the people with disabilities and to deal with personal and interpersonal concerns associated with the disability (Mullins, Chueng & Lietz, 2011)

Another role for social workers is to raise awareness of issues of disability in the country. As noted earlier on, there are still negative connotations about disabilities in the country hence social workers must be in the forefront of highlighting the plight of people with disabilities. This can also be linked to the advocacy role whereby social workers can lobby government to pass legislation specifically targeting people with disabilities.

People with disabilities often need a variety of services from other community agencies, such as financial assistance, wheelchairs, and prosthetic services as well as transportation (Chitereka, 2010). Social workers link people with disabilities with community resources.

2.9 CONCLUSION

Disability in South Africa is usually defined from the Social Model which views disability as a socially created problem and a matter for the full integration of individuals into society. Nevertheless, there are varying definitions of disability emanating from different authorities such as the medical model, right-based model as well as the political model. Thus legislation and policies put in place by the South African government tries to incorporate children with disabilities into the mainstream society.

The literature review presented above indicates what other scholars and authors have researched on experiences of parents of children with disabilities in other societies such as India and Zimbabwe. Financial and emotional impact of parents of children with disabilities has been discussed. The literature available has also revealed how parents react to the news that they have given birth to children with disabilities.

Policies which try to assist parents of children with disabilities have been discussed in detail. The Social Assistance Act of 1992 introduced the Care Dependency Grant which is aimed at helping parents of the children financially. The Integrated National Disability Strategy of 1997 also supports the medical view on disability in that it attempts to address the social, economic and political inequalities that children with disabilities experience.

The research methodology is presented in the next chapter.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 Introduction

The previous chapter looked at the literature review on disability in general and also in particular to children. The literature review looked at the experiences on parents in other parts of the world notably Zimbabwe and India. Definitions, models as well as causes of disabilities amongst children were also discussed.

Research methodology encompasses, the methods and techniques by which data are collected, where and from whom these data are collected as well as the sample size used (Rubin & Babbie, 2011). It covers research design, population, sampling procedures, data collection instruments, data analysis procedures and ethical issues of the research. Research methodology encompasses a set of analytical procedures and techniques used to collect and analyze information appropriate for evaluation of a particular project or activity. This chapter therefore outlines the research methodology used in the present study. The chapter further describes the population, sample, sampling method, measuring instruments and the methodology used to gather data for this study.

In this study the word methodology refers to how the research was done and its logical sequence. The main focus of this study is the exploration and description of the experiences encountered by parents of children living with disabilities at Lehlaba Protective Workshop. Therefore, the research approach is qualitative.

3.2 Research Design

De Vos, Strydom, Fouche, and Delport (2011), defines a research design as an integrated statement of and justification for the more technical decisions involved in planning a research project and a process analogous to the activities of an architect

designing a building. A research design involves a set of decisions regarding what topic is to be studied among what population with what research methods (Babbie, Mouton, & Strydom, 2011). It involves deciding how the research strategy and methods will be implemented in the context of a specific inquiry, indicating more precisely where, when and how data will be obtained and the method to be used to analyze and interpret that data.

According to Babbie, Mouton, and Strydom, (2011), social research can be done for explanatory, descriptive or exploratory purposes. Explanatory studies aim to provide causal explanation of phenomena. On the other hand, descriptive studies are used when the researcher wants to describe situations and events that have already taken place. Exploratory studies are used when making preliminary investigations into relatively unknown areas. Therefore, in choosing a research design, a researcher should come up with an approach that allows for solving the problem in the best possible way within the given constraints (Lietz, &Zayas, 2010).

An exploratory approach was appropriate for this research because the researcher's purpose was to explore the experiences of parents of children living with disabilities at Lehlaba Protective Workshop. Exploratory studies are used to make an initial investigation into unknown areas of research (Terre Blanche, Durrheim& Painter, 2006), thereby allowing the acquisition of data in an open, flexible and inductive manner. The researcher's choice of the exploratory research method allowed him to gain insight into a relatively new topic of researching in the disability field.

A descriptive approach was also used by the researcher. Descriptive design features were used in this study, in order to obtain information through interviews and then to describe the phenomenon with the purpose of providing new information. The descriptive design aims to observe a phenomenon, to describe it and may then classify the findings, (Rubin and Babbie 2011). This study involved describing experiences of parents of children living with disabilities at Lehlaba Protective Workshop.

3.3 Sampling

Sampling means taking a portion or a smaller number of units of a population as representative or having particular characteristics of that total population (De Vos et al., 2011). The notion behind sampling theory is that a small set of observations can give an idea of what can be expected in the total population of the intended study (De Vos et al., 2011). Sampling refers to the procedure of selecting specific cases to include in a research study and is necessary for many reasons, including reducing the cost and time required for collecting data on the whole population and for analyzing that data (Padgett, 2016). Sampling is the selection of people to participate in a research project, usually with the goal of being able to use these people to make inferences about a larger group of individuals. Sampling also involves making decisions about which people, settings, events or behaviors to consider during investigation. In the study, the units of analysis were the parents of children with disabilities.

3.3.1 Sample

The smaller group that the study observes is called their sample (Rubin & Babbie, 2011). A sample comprises elements or a subset of the population considered for actual inclusion in the study, or it can be viewed as a subset of measurements drawn from a population in which we are interested (De Vos et al., 2011). A sample should not only be selected so as to be representative of the population from which it is drawn, but it should be large enough so that the investigator can be reasonably sure that if a different sample had been drawn, using the same procedure, similar results would be obtained.

The study consisted of fourteen participants who are parents of children living with different types of disabilities. The parents included biological as well as foster parents. Motivation for using Lehlaba Protective workshop is that it has children with a variety of disabilities and that it is easily accessible to the researcher.

3.3.2 Sampling Procedure

According to Blanche et al. (2006) sampling procedure refers to the method used by the researcher in the selection of cases to observe. There are two types of sampling procedures namely probability and non-probability that a researcher can use. The

researcher utilized non probability sampling method. Non probability sampling is defined by De Vos et al. (2011) as a sampling procedure where the odds of selecting a particular individual are not known because the researcher does not know the population size or the members of the population. Examples of non-probability techniques include purposive, convenience and snowball sampling. In this study, the researcher utilized purposive sampling to select the participants.

3.3.3 Purposive Sampling

According to Babbie and Rubin (2011) a researcher may appropriately select a sample on the basis of own knowledge of the population, its elements, and the nature of the research aims. De Vos et al. (2011) state that purposive sampling is based entirely on the judgment of the researcher, in that a sample is composed of elements that contain the most characteristics, representative or typical attributes of the population that serve the purpose of the study best. In short, it is based on the judgment of the researcher and the purpose of the study. A purposive sample, also commonly called a judgmental sample, is one that is selected based on the knowledge of a population and the purpose of the study (Padgett, 2016). Purposive sampling is based entirely on the judgment of the researcher, in that a sample is composed of elements that contain the most characteristics, representatives or typical attributes of the population (Babbie, Mouton, & Strydom, 2011).

Because the researcher is knowledgeable to the population and purpose of the study, purposive sampling procedures were used as discussed above, to ensure that the number of required participants required for the study were reached. Three key variables informed the selection criteria for participants of this study, namely disability and family relationships. The disability variable looked at the types of disabilities such as physical and intellectual, amongst the children of Lehlaba Protective Workshop. Family relationship meant acquiring participants from the children's family who are responsible for the welfare of the children. The researcher noted that some children are staying with their relatives namely aunties, sisters and uncles mainly through foster care placements.

Gender and population groups were not part of the selection criteria. Gender balance was not considered because the purpose of the research was not to conduct a comparative study between female and male parents of children living with disabilities, but rather to focus on the experiences of the parents.

3.4 Data collection

3.4.1 Data collection methods

The following data collection methods were utilized in this study because of their applicability and usefulness in a study whose research approach is to investigate fewer samples and for the purpose of gathering in depth data.

3.4.2 In Depth Interviews

In depth interviews were used to collect data. The interview is a social relationship designed to exchange information between the participant and the researcher (De Vos et al., 2011). Interviewing is a technique of gathering data from humans by asking them questions and getting them to react verbally. A qualitative interview is an interaction between an interviewer and a respondent in which the interviewer has a general plan of inquiry but not a specific set of questions that must be asked in particular words and in a particular order (Rubin & Babbie 2011). The study utilized in depth interviews for individual participants and these were particularly useful to this study because they encouraged the participants to respond freely and for the researcher to probe for more information. They also enabled the participants to develop interest and bring in other emergent but relevant issues the researcher did not know. The process of collecting information using this method involved presenting the participants with a warm friendly welcome environment that was comfortable. Since the participants were parents of children living with disabilities, it was important to create and maintain a conducive facilitation process so that they could participate freely. The parents of children with disabilities were interviewed in offices at Lehlaba Protective Workshop so as to make

them relax and avoid nervousness among them. Although the order of questions was respected, the researcher was flexible so that the participants.

3.4.3 Data collection instrument

Interview Schedule

A questionnaire written to guide interviews in called an interview guide (De Vos et al., 2011). This provides the researcher with a set of predetermined questions that might be used as an appropriate instrument to engage the participant and designate the narrative terrain, (De Vos et al., 2011).

A semi-structured interview schedule was used in a flexible way to guide the interviews with parents of children living with disabilities. The interview schedule was made up of a set of predetermined and open ended questions, and was constructed using the research objectives as the guideline. Rubin and Babbie (2011) supports this by pointing out that the interview schedule ensures that different interviews will cover the same material and keep focused on the same predetermined topics and issues while remaining conversional and free to probe into unanticipated circumstances and responses.

The questionnaire on the interview schedule was simplified such that the parents of children with disabilities could understand easily. Both open ended and closed ended questions were used in the interview schedule.

3.4.5 Data collection apparatus

Data collected through the interviews was recorded electronically through the use of a tape recorder. The permission of the participants was sought beforehand. The use of a tape recorder was an advantage to the researcher as it captured the interviews accurately and also allowed the researcher to concentrate on establishing a rapport with the participants. The data collected served as a verbatim account of the interview. Written notes were also used to record non verbal cues from the participants.

3.5 Pilot study

De Vos et al. (2011) define a pilot study as a small study conducted prior to a larger piece of research to determine whether the methodology, sampling, instruments and analysis are adequate and appropriate. (Padgett, 2016), also defines a pilot study as a dress rehearsal to the actual investigation which assists in identifying potential problems that could be encountered during the main study. It allows the data collection instruments to be tested for possible problems using a small sample of participants. Three pilot interviews were conducted to test the interview schedule and to identify any limitations in the research questions. Three participants who did not form part of the main study were asked to participate.

After listening to the first pilot interview recording and getting feedback from the supervisor, the researcher identified some gaps, particularly around his need to sharpen his skills in probing, reflecting and summarizing which could be attributed to his lack of experience. The pilot interviews also helped the researcher to fine-tune the questions and to gain confidence.

3.6 Data analysis

Data analysis strategy

Qualitative data analysis is the non numerical examination and interpretation of observations, for the purpose of discovering underlying meanings and patterns of relationships (De Vos et al., 2011). Data analysis is a process of bringing order, structure and meaning to the mass of collected data (Padgett, 2016). Qualitative data from in-depth interviews and observations was analyzed according to themes that emerged during brief direct observations and from the discussions with the participants.

The researcher transcribed all the interviews, a process that entailed listening to each interview and typing it out word for word. The researcher read the transcripts several times to become familiar with the information and during this process he made memos and looked at the similarities and differences emerging from the data. The researcher also made marginal notes on the transcripts, which helped, in the initial process of exploring and analyzing the data.

The researcher went on to classify information by grouping together similar responses, a process described by Rubin and Babbie (2011) as taking apart text or qualitative information and looking for categories, themes or dimensions of information. This process is called coding. Coding is the process of combing the data for themes, ideas and categories and then marking similar passages of text with a code label so that they can easily be retrieved at a later stage for further comparison and analysis (Padgett, 2016). In this study, data was coded using themes that emerged from the discussions.

The researcher identified themes, categories and sub-categories which fell in line with the main research objectives. The researcher continuously examined the information, comparing and categorizing the data, and breaking the categories down into fewer and more inclusive terms. This manual process enabled him to analyze the results as well as to develop an initial awareness of issues that came up in the interviews. The themes that emerged from this data analysis are presented in chapter four of this research report. The demographics of the participants of this study were discussed in a tabular format with the use of frequency and percentages.

3.7 ETHICAL CONSIDERATIONS

De Vos et al. (2011) define ethics as a set of widely accepted moral principles that offer rules for, and behavioral expectations of, the most correct conduct towards experimental subjects, and respondents, employers, sponsors, other researchers, assistants and students. Padgett, (2016), define ethics as a code of behavior considered correct. It is crucial that all researchers are aware of research ethics. Ethics relate to two groups of people, those conducting research, who should be aware of their obligations and responsibilities, and the researched upon, who have basic rights that should be protected. Research should be based on mutual trust, acceptance, cooperation, promises, and well-accepted conventions and expectations between all parties involved in a research project, (De Vos et al., 2011). The study therefore had to be conducted with fairness and justice by eliminating all potential risks.

The ethics considered in the study are as follows;

3.7.1 Permission to conduct the study

Permission to conduct the study was obtained from University of Limpopo Turfloop Research and Ethics Committee. An ethical clearance letter was provided in this regard. It is available as Appendix C of this research report. Permission was also sought from the management of Lehlaba Protective Workshop.

3.7.2 Confidentiality and Anonymity

Confidentiality is a basic ethical principle while anonymity is one way in which confidentiality is maintained. Anonymity means that no one including the researcher should be able to identify any subjects afterwards, (De Vos et al., 2011). To ensure anonymity in the study, steps were taken to protect the identity of the participants by neither giving their names when presenting research results, nor including identifying details which could have revealed their identity such as work place, personal characteristics and occupation. The interview schedule also did not carry the actual names of the participants but rather tags in the form of numerical numbers and alphabetical letters. Confidentiality was also preserved by conducting the interviews in private rooms. Data collected from the study was kept confidentially in a safe locker at the Department of Social Work offices.

3.7.3 Informed Consent

Informed consent implies that, all possible or adequate information on the goal of the investigation, the procedures which will be followed during the investigation be rendered to potential subjects or their legal representatives, (Babbie & Rubin, 2011). Participants were asked to give verbal consent for those who cannot read or write. Written consent was sought from those who could write to participate in the study. Informed consent was also sought for the recordings of all the interviews from the participants. Appendix B of this research report has got the consent form.

3.7.4 Voluntary Participation

Voluntary participation refers to the willingness of an individual to participate in research, as no one should be forced to participate (Babbie & Rubin, 2011). Participants of this study were informed beforehand that participation in the study would completely be voluntary and that they could withdraw from the study at any stage without any consequences. Annexure B also supports this claim.

3.7.5 Avoidance of Harm

Research should never injure the people being studied, regardless of whether they volunteer for the study. Subjects can be harmed in a physical or emotional manner (De Vos et al., 2011). In the study, psychological and emotional harm was the probable risk the parents of children with disabilities could encounter. Discussing disability experiences is sometimes an emotional topic. The researcher minimized sensitive questions. The researcher also made arrangements with the local social work office at Lehlaba Protective Workshop and also psychologists at the nearby Dilokong Hospital should the services be required.

3.7.6 Competence of the researcher

The researcher is ethically obligated to ensure that he/she is competent and adequately skilled to undertake the research project (Babbie & Rubin, 2011). The researcher acquired the necessary interviewing skills as part of his undergraduate studies. A pilot interview was also conducted which enabled the researcher to refine his interviewing skills and the questions in the interview schedule.

3.8 DATA VERIFICATION AND TRUSTWORTHNESS

Trustworthiness in research is demonstration that the evidence for the results reported is sound and when the argument made based on the results is strong (Denzin & Lincoln, 2008). Four criteria to ensure valid interpretation of data was used in the study namely truth value (credibility), applicability, consistency, and neutrality.

3.8.1 Credibility

In addressing credibility, investigators attempt to demonstrate that a true picture of the phenomenon under scrutiny is being presented, (Shenton, 2004). Credibility refers to demonstrating that the inquiry in a study was conducted in such a manner that the subject was accurately identified and described, (De Vos et al., 2011). Shenton (2004) states that credibility can be achieved by the development of an early familiarity with the culture of participating organizations. The researcher has been working with the organization (Lehlaba Protective Workshop) since 2012. Thus a relationship of trust had already been established by both parties.

Credibility was ensured by using a qualitative approach to determine the experiences of parents of children with disabilities. The use of a purposive sample by the researcher ensured that the responses obtained are credible. The selection criteria used was that the respondents should be biological or foster parents of children living with disabilities. The use of a structured interview schedule allowed the researcher an opportunity to use open ended questions in an effort to get authentic responses. Open ended questions ensured that participants provide their opinions without the influence of the researcher. The interview also allowed the researcher to note nonverbal communication.

Credibility can also be ensured by frequent debriefing sessions between the researcher and his or her superiors such as a project director or steering group (Shenton, 2004). The researcher made use of pilot study findings to fine tune data collection techniques. The researcher's supervisor also gave inputs and guidance in accordance to the results of the pilot study. The researcher is also competent enough having acquired the necessary interviewing skills as part of his undergraduate studies.

3.8.2 Transferability

Transferability relates to the extent to which the findings of one study can be applied to other situations (Rubin & Babbie, 2011). To allow transferability, researchers provide sufficient detail of the context of the fieldwork for a reader to be able to decide whether the prevailing environment is similar to another situation with which he or she is familiar and whether the findings can justifiably be applied to the other setting (Shenton, 2004). In this regard, background data which include detailed information of the field area under study which is Sekhukhune District of Limpopo Province is given in Chapter One.

To allow readers of this study to know to what extent the findings of this study may be relevant to their situation, background information about the population being studied is presented in Chapter Four of this study and demographic data of the sample selected is presented in Table 1 and 2 of the same chapter.

3.8.3 Dependability

Dependability entails that researchers should at least strive to enable a future investigator to repeat the study (Shenton, 2004). It entails that if the work is to be repeated, in the same contexts, with the same methods, and with the same participants, similar results will be obtained (Shenton, 2004). In this study, in Chapter 3 of research methodology, the researcher described in detail the research design which is a framework for the collection and analysis of data. The researcher mentioned the method of data collection which was in depth interviews. To achieve this, the data collection instrument of an interview schedule was mentioned. Such detailed description of the methods in the research provides information on how repeatable the study can be.

3.8.4 Conformability

Conformability refers to that researchers must take steps to demonstrate that findings emerge from the data and not their own predispositions (Shenton, 2004). Conformability refers to that findings of the study are the result of the experiences and ideas of the informants, rather than the characteristics and preferences of the researcher. Conformability was assured in this study by providing a detailed and informative research methodology. To achieve conformability, detailed records of data collected were kept in this study for peer review or outside audit if required.

3.9 CONCLUSION

In conclusion, a qualitative design was selected for this study. In depth interviews were used to collect data from fourteen participants. An interview guide was used in this

study to gather information from the research participants. The next chapter deals with research findings and data analysis.

CHAPTER FOUR

DATA PRESENTATION AND ANALYSIS

4.1 Introduction

This chapter presents and analyses data obtained through one - on - one interviews with the research participants. The demographic characteristics of the study sample were described and the main themes that emerged during the study presented. The demographics of the participants of this study were discussed in a tabular format with the use of frequency and percentages. Data was collected from a sample of fourteen (14) participants who are parents of children with disabilities. Purposive sampling was utilized to select the participants. .

4.2 Demographic characteristics of participants

Table 1: Demographic characteristics of the participants

Name	Age	Sex	Marital Status	Occupation	Relationship
Tebogo	33	M	Married	Electrician	Father
Thapelo	29	M	Married	Boilermaker	Father
Puleng	42	F	Single	Unemployed	Mother
Dimakatso	37	F	Single	Unemployed	Mother
Thembeka	42	F	Single	Unemployed	Mother
Senzo	29	M	Married	Motor Mechanic	Father
Andile	38	M	Married	Builder	Father
Mr Thabang	43	M	Married	Mine Worker	Father

Mrs Nkoana	34	F	Single	Unemployed	Mother
Miss Malope	37	F	Single	Unemployed	Mother
Mrs Semenya	29	F	Married	Secretary	Mother
Ms Mashabela	38	F	Single	Unemployed	Mother
Ms Malatji	36	F	Single	Unemployed	Auntie
Margaret	24	F	Single	Receptionist	Sister

The personal details of the research participants are tabulated above. For confidentiality purposes, real names of the participants were replaced by pseudonyms (pen names)

4.2.1 Age Distribution of the participants

Table 2; Age of Participants

No	Age range	Frequency	Percentage %
1	24 - 30	4	28.5 %
2	31- 38	7	21.5 %
3	29 - 43	3	50 %
TOTAL		**14**	**100%**

The ages of the participants ranged from twenty four to forty three years. A total number of fourteen (14) people participated in the study. Out of these, nine (9) were females and five (5) were males.

4.2.2 Employment

Seven of the parents are unemployed whilst the other seven are employed.

4.2.3 Marital Status

Six of the respondents are married whilst eight are single. Of importance to note is that seven of the single parents are unemployed.

4.2.4 Relationships

Twelve of the participants were biological parents being the father or the mother whilst two were legal guardians one being an aunt and another being a sister. The legal guidance was facilitated through the Children's Act (Foster Care)

4.3 THEMES

The following themes and sub themes were identified from the research participants;

Table 3 Themes and sub themes

Theme	Sub Themes
1. Resources for children with disabilities	• Stimulation Equipment • Daily Activities • Assistive Devices • Professionals • Medium of Communication (Sign Language)
2. Services for children with disabilities	• Social Development • Health • Education • Rehabilitation
3. Role of Non Governmental organizations	
4. Care Dependency Grant	
5. Cultural beliefs towards disability	• Parents beliefs on the causes of disability • Parents beliefs about a cure for disability • Parents understanding of disability
6. Attitudes about children with	• Parents attitudes towards children

disabilities	with disabilities
	• Caregivers attitudes towards children with disabilities
	• Family members attitudes towards children with disabilities
	• Emotional Burden
	• Social Life of the family
	• Parents acceptance of disability
	• Parental Support
7. Community attitudes towards children with disabilities	• Family Friends
	• Neighbours
	• The Church
	• Support Groups
8. Perceptions of parents on their children attendance to Lehlaba Protective Workshop	
9. Parents dream for their children with disabilities	
10. Perceptions of parents in regards to institutionalization of their children	
11. Psycho – social experiences	• Fears of another child
	• Distress on time
	• Employment
	• Economic Burden

4.4 Resources for children with disabilities

Resources for children with disabilities remain an issue of concern according to the responses from the parents of children attending Lehlaba Protective Workshop.

4.4.1 Stimulation Equipment

Stimulation equipment for children with intellectual disabilities is scarce. This was derived from the responses of the research participants.

Tebogo one of the parents had this to say, "*Specialized stimulation educational toys, puzzles, crayons and educational charts are extremely expensive for us as parents to purchase. The organization requires us to buy this equipment for our children*".

Dimakatso a parent also supported this by saying, *"children with disabilities need stimulation equipment specific to their disability. That equipment is very expensive and is ordered from Cape Town. Before it is ordered we have to hire an occupational therapist to do an assessment of our children such that we order the correct stimulation equipment. The occupational therapists are expensive themselves and this puts a lot of financial distress at us as parents as myself I am unemployed."*

Stimulation equipment is of paramount importance since it encourages the children with disabilities to grow intellectually. For instance puzzles are in three phases which is beginners, intermediate and seniors. The different phases denote the different challenges they face in fixing the puzzles.

4.4.2 Daily Activities

Daily activities are the program, or programmes or activities which are followed by the centre for children activities. These activities are set on a timeline or timetable format. The aim of the daily programme is to control time between activities, such that there is no confusion and boredom to children with disabilities. The activities may include colouring, reading, writing, basic arithmetic, puzzling, outdoor games etc.

Mr Thabang had this to say about the daily activities at Lehlaba Protective Workshop, "usually *the whole day I observed that they only do colouring from morning until lunchtime then in the afternoon it is outdoor playing games. This colouring does not help my child in any way. It is the same thing all over and over again"*

Mrs Nkoana echoed this sentiment, *"I have realized my child is only doing puzzles almost every time. He is not tried on other things and I guess it becomes boring to him."*

From the above conservations, it can be noted that there is no coherent daily activities program being followed or adhered to. The notable activities are colouring, puzzling and outdoor games which do not have an effect on their children with disabilities.

4.4.3 Assistive Devices

Assistive devices are tools or equipment designed for the mobility of persons with disabilities. Assistive devices can be in the form of wheelchairs (standard or motorized), crutches, walking frames, eating frames (WHO, 2011). Responses from the participants were as follows;

"My child uses a specialized wheelchair known as the Buggy. This buggy is more expensive than the standard wheelchair. This specialized wheelchair offers rehabilitation and avoids secondary disabilities. Since it is expensive, I have to use a standard wheelchair and sometimes a wheelbarrow which is not suitable for my child and can cause secondary disabilities. I cannot afford the specialized wheelchair since I do not have any reliable source of income." Thembeka

From the above discussion, it can be opined that the parents are struggling to purchase assistive devices. Some of the parents' resorts in using wheelbarrows as the wheelchairs are scarce. This has got a negative effect since it causes secondary disabilities.

4.4.4 Professionals

Allied Health Professionals are paramount in the rehabilitation and upkeep of children with disabilities. Allied Health Professionals include Social Workers, Psychologists, Occupational Therapists, Physiotherapists, and Speech Therapists.

Margaret a guardian (foster parent) of a child with epilepsy reiterated that, *"We do not have even a social worker. If we want the professionals, we go to Dilokong Hospital which is roughly 55 kilometres away. Imagine travelling with a child with a disability for such long distances. And she really needs the services of a physiotherapist to rehabilitate her bodily movements".* The physically disabled require constant exercises from different therapists such as physiotherapists to avoid secondary disabilities.

Mrs Nkoana a parent asserted that, *"my child has never received any help from a physiotherapist or speech therapist as my child has problems with mobility and speech."*

It can thus be noted that Allied Health Professionals are not accessible to children with disabilities because of the distance.

4.4.5 Medium of communication

Sign language is a medium of communication used by people who are deaf or having speech problems. It is the use of mainly hand signs and gestures to express needs, desires and feelings. The researcher quoted one of the participants, Mrs Malatji; a parent with a child with cerebral palsy and hearing loss saying;

"Communication is very difficult with my child at home. Just imagine if he is at Lehlaba Protective Workshop and in the community. Myself as a parent, at least I have got an understanding of his communication gestures. What about others who are not patient and do not understand his communication gestures who cannot speak. He is not able to convey his needs effectively and it is difficult to help him.

Children with communication difficulties are usually isolated by their peers in daily activities due to barriers in communication. The children have their own group and they become socially isolated.

4.5 Services for Children with Disabilities

4.5.1 Social Development of children with disabilities

Department of Social Development is acquainted with the purpose of the management of all NPO's including Lehlaba Protective Workshop. This is done through a number of policies notably policy on Stimulation of persons with disabilities as well as the policy on protective workshops. Policy on Financial awards also gives guidelines on the funding of the NPO's through government subsidy. Three of the parents are in the board of Lehlaba Protective Workshop. They reiterated that;

"The finances through subsidy are very erratic. We sign the Memorandum of Agreement at the beginning of each fiscal year and only get paid five or six months later. The current subsidy is R15 per child per day at the centre. The R15 is divided into transport,

food, and equipment. Just imagine what R15 can do in one day for a child with special needs. It is not enough at all". Mrs Semenya, parent / board member

Children with disabilities need specialized treatment in the form of equipment and also food. For instance, the children who cannot eat properly need semi processed food since they are not able to chew properly. The staff and volunteer salaries and stipends are also on the Department of Social Development Subsidy. Late payment of subsidy affects the morale of the staff members hence it will have a negative impact on the delivery of services to the children with disabilities.

"Caregivers work involves feeding and changing nappies of children with disabilities who are not independent. Just imagine the morale of the caregivers if they go for 3 months without a salary. "Mr Thabang, parent / board member

The late payment in subsidy by Department of Social Development affects to a greater extent the morale of the staff. Many staff members are lost in the process as they look for greener pastures. New staff members who are recruited would need training in disabilities and the process is continuous.

4.5.2 Health Care for children with disabilities

Department of Health is responsible for the wellbeing of the citizens of South Africa. Access to health facilities is a challenge to children with disabilities at Lehlaba Protective Workshop which has proven to be detrimental to their development and wellbeing. The nearest health facility is Dilokong Hospital which is approximately 30 kilometres away. The parents raised concerns mostly of the inaccessible health facilities as well as the expensive transport to access health facilities.

Senzo a parent illustrated that, *"My child is using a wheelchair and the public transport is problematic to wheelchair users so I end up hiring a private taxi which becomes expensive to me".*

Mobile clinic points need to be set up especially at Lehlaba Protective Workshop such that the children can easily access health services.

*"I always ha*ve *to interpret for my daughter who is deaf every time I am at the hospital such that the health officials can understand her"* – Mrs Malatji - parent.

Interpretation breaches the right to confidentiality within the health setting. For instance, the child would want to divulge sensitive issues to the health professionals but will not do so mainly because of communicating via a third party.

"We used to have the mobile clinic visits once a month in 2012 but ever since we have not gotten anything. Children especially who are epileptic and cerebral palsied require contact medical attention. We often do have constant medical emergencies with our children and we rely on well-wishers to transport the children to Dilokong Hospital which is 55km away". – Miss Malope

Some parents pointed out that the hospitals nearby do not have enough Health allied staff in the form of therapists to provide exercises for their children.

"My child is on the list for speech and physio therapy for many years now. I was informed that if the therapists are available, I will be informed. I am still waiting until now" - Tebogo, parent

4.5.3 Education for children with disabilities

Section 29 of the South African Constitution indicates that all children are guaranteed the right to a basic education and to further education which the State, through reasonable measures, must make progressively available and accessible. Likewise, according to the UN Convention on the Rights of the Child (UNCRC) and the Convention on the Rights of Persons with Disabilities (UNCRPD), children with disabilities have the same right to education as all other children, and shall enjoy this right without any discrimination and on the basis of equal opportunity (Omu & Reynolds, 2012). Children with disabilities have the right to education without discrimination and on the basis of equality of opportunity. The global goal of universal access to primary education cannot be achieved without including children with disabilities (UNICEF, 2013).

Lehlaba Protective Workshop is providing an educational function to children with disabilities. This is evident with their stimulation activities namely numeracy, literacy, reading and writing. The stimulation instructors teach the children with disabilities these activities which are educational in nature.

The parents had to say this about education of their children;

"I believe my child is capable of learning something since he is now able to count, read and write. The department of education need to come with a curriculum for our children such that they can learn like any other children"- Dimakatso parent

"My child is epileptic and intellectual disabled. However she functions at a much higher level. She was rejected at a mainstream school since the teachers said she is a slow learner. The special schools are always full. I hope the department of education can come up with measures such that they can also be educated whilst they are here at Lehlaba Protective Workshop". Puleng, parent

The parents pointed out that there are scarce Special schools for disabled children. They pointed out that due to lack of them, they end up enrolling them at Lehlaba Protective Workshop. The department of education needs to come with a proper curriculum which caters for the children with disabilities in accordance to their intellectual levels.

4.5.4 Rehabilitation of children with disabilities

Rehabilitation is a process unearthed to assist the injured child, who is experiencing or likely to experience disability, to achieve and maintain optimal functioning in interaction with their environment. By addressing evolving needs and building on the strengths and resources of the child and their family, early initiation of rehabilitation can reduce acute health care costs and prevent disability, (WHO, 2011). In support, the United Nations on the Rights of Persons with Disabilities article 26 points out on the rehabilitation of persons with disabilities such that they can maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. This in essence should be achieved through a community rehabilitation model (CBR) (Wang & Dovidio, 2011). The parents however had this to say in relation to rehabilitation of their children

"Maybe the rehabilitation of children with disabilities is happening in cities or towns. Here in the rural areas there is nothing like that". Miss Malope

"I once heard *that at Lehlaba Protective Workshop, they will send rehabilitation professional every week but I guess it was just hearsay. We never saw anyone who came to rehabilitate our children".* Andile

4.6 Non-Governmental Organizations

Non-Governmental Organizations (NGO's) play a pivotal role in providing services to children with disabilities. They provide equipment, food parcels, information and training as well as assisting in fundraising.

"Most NGO's notably Association for Persons with Disabilities in Limpopo (APD), Epilepsy South Africa, assists us parents in various ways. For example APD assist us in assistive devices such as wheelchairs and crutches. They also provide training to us as parents on how to handle our children with disabilities". Andile, parent

"I have no idea that there are NGOs for persons that provide persons with disabilities-this statement is not clear. If they are available they are probably in Polokwane or in Johannesburg. They never come this side of rural Limpopo. I wish if they can come and assist our children this side". Thabang*, parent*

"I am only aware of Epilepsy South Africa who once came this side to provide training to us parents of children with Epilepsy. It was once off 2 years ago and we never saw or heard from them. We really need their support down here". Senzo, parent

The parents did not seem to know which organizations or government departments were dealing with issues that concerned children with disabilities. When questions were asked about NGOs, and if parents knew of them or had registered their children with these sorts of organizations or clubs, parents seemed to have no idea about the local organizations.

4.7 Care Dependency Grants

Care Dependency Grants (CDG) are provided by South African Social Security Services (SASSA) under the Social Assistance Act of 1997. The grants are given to all children with disabilities below the age of 18 years. SASSA is responsible for conducting the assessments and administration of the grant. The care dependence grant is aimed at

financing the up keep of the children with disabilities in all the aspects of their life. The Care Dependency Grants are administered by biological parents or legal parents who would have been appointed by the court of law (Department of Social Development report, 2009). As of April 2016, the care dependency grant stands at R1500. The CDG is awarded in terms of the Social Assistance Act, and is given to poor parents, foster parents or primary caregivers of children with disabilities who require permanent care but are not in state-run institutions. The responses below are from the parents in relationship to Care Dependency Grants.

"My child uses diapers / nappies at least four times a day because she cannot control her bowl. She also has to eat semi – processed food which are expensive. The care dependency grant is too little". Ms Mashabela, parent

"*The R1500 is little. My child is physically disabled. Transport is expensive since I do not have to use public transport. I rely on hiring private cars which is expensive*. Mrs Semenya, parent

The parents complained that the care dependency grant is too little to cover the needs of their children. This parent in particular pointed out that she uses close to R3000 a month for the upkeep of her child who has cerebral palsy.

"*I use approximately R3000 a month. My child has severe cerebral palsy. She needs diapers daily and the cost is around R1400. I have to buy chronic medication for her every month which is not available at public hospitals. The medication is around R700. On top of that I have to buy semi – processed food which is the range of R550. You can see for yourself that the disability grant is too little*   ". Dimakatso, parent

4.8 Cultural Beliefs about disability

Cultural beliefs define who people are, how they interact with the world and how they behave in certain situations, and can be considered a combination of religious beliefs, socially accepted norms and traditions. Different cultural groups have vastly different perceptions of the causes of disability (Omu & Reynolds, 2012).

4.8.1 Parents beliefs on the causes of disability

These findings on causes of disabilities were from the responses of the parents

"*I suspect witchcraft because during my pregnancy one of my neighbors who I owed money told me she was going to fix me. I had prolonged labour and I suspect her for bewitching me*". Miss Malope, parent

"*My husband was having another wife before she married me. The former wife told me she was going to curse me. It became a reality when I gave birth to my epileptic disabled child*". Ms Mashabela, parent of a disabled child

The responses above stipulate that some of the parents believe that their children disabilities are a result of witchcraft.

"*I got into labour when I was home and alone. My neighbors who came for assistance were not skilled in any way to assist me. When the ambulance came I had already delivered the baby. I was told by the nurses that my baby did not have enough oxygen during delivery*". Mrs Nkoana, parent

This parent believes that the disability of her children was caused by lack of qualified medical personnel to assist her in the safe delivery of her child.

"*My child had Polio. I did not act quickly since I realized it late that my child was having difficulty in crawling and walking. When I went to the hospital for treatment it was too late*". Mrs Semenya, parent

The parent in the above response is acknowledging the fact that her son's disability was caused by a medical condition which is Polio.

"*My son was involved in a minibus taxi accident in 2011 when he was 5 years old when coming from holiday in Pretoria. He sustained head injuries which caused brain damage. The doctors also said his spinal cord was disturbed*". Mr Thabang, parent

The above responses point out that the child's disability was perpetuated by a motor vehicle accident.

The above responses postulate that the causes of disability amongst the children are varied. Some parents voiced out that witchcraft (use of "Black Magic") was the cause of their children disabilities. Some echoed out that problem at birth were the cause whilst some attributed their children disabilities to motor vehicle accidents.

4.8.2 Parents beliefs on a cure for disability

Parents look for a cure for disability of their children in the early years. Parents spent a lot of money trying both the Western and African medicine for a cure of their children's disability, (Dillenburger & McKerr, 2011)

The parents had different views and responses when it came to a cure of their children.

"*I believe one day the medicals will come up with a medical solution for my intellectually disabled son. I do get a drug called Epilim every month at Dilokong Hospital. That drug helps my son to desist from aggression. I believe one day they will come up with a permanent drug to end his disability. Just look at ART Therapy (Anti- Retroviral Therapy). Now they are going towards finding a drug to treat HIV / AIDS completely*". – Margaret, foster parent

This guardian is of the belief that his son will be cured completely of his disability one day.

"*I have accepted that my son will spend his whole life in a wheelchair. I have tried by going to most Churches even attending crusades of foreign preachers in Gauteng but nothing has changed on the condition of my child. I do now believe that miracles happened during Jesus times unless the Son Of God resurrects again. It is a hard decision to take but I have to accept the reality that my son is disabled for the rest of his life.*" – Mr Thabang, parent

"*I have been to prophets who come to Gauteng from other African countries hoping that my child will be cured. I just have to admit that it has failed and I have to accept and live with the reality".*Tebogo

"*I have gone from one traditional healer to the other both locally and to Mozambique and Zimbabwe but no "Sangoma" has cured the disability of my child".* Thabang.

It can be summed up that all the parents of children with disabilities searched for a cure of disability for their children. Some are still hoping to find the cure whilst some have accepted the disability of their children.

4.8.3 Parents understanding of disability

Parents' understanding about their children disability was surprising. All the parents did not understand their children disabilities well. They provided a general view about their understanding of disability.

"*I only know that my child has got a condition called cerebral palsy but I do not know what it means. After giving birth no one (medical staff) bothered to inform me what I need to do in order to take care of my child. The experiences I am having are teaching and guiding me. It is like I am learning from the experiences I have*". – Miss Malope - parent

"*My child is autistic. He is 8 years. No one has ever informed me about handling a person with autism. Sometimes you are not sure if you are doing the right thing. It is just scary not to know and understand your child*". – Ms Mashabela

"*Her abilities and limitations is what I do not know. This led me to under estimate her on her abilities sometimes. I was of the opinion that we should as a family do everything for her since she is on a wheelchair. One day she surprised us by saying she can make her bed alone. I felt guilty because I did not understand her disability*". – Mrs Malatji, foster parent

These three parents' / guardian expressions unearthed that they are not sure of their children disabilities. Their understanding of disabilities is limited. This leads to unintentional harm to their children with disabilities.

4.9 Attitudes about disability

4.9.1 Parents / guardians attitudes towards children with disabilities

All the parents were affirmative about their relationships with their children with disabilities. All the parents ratified that they enjoyed a positive healthy relationship with their children.

"*She has cerebral palsy and I have to do almost everything for her. I do not mind at all because she is my child. I change nappies, bath and feed her daily. She is part of me and I am part of her*". – Miss Malope, Parent

I take him on my back when going to the Malls or to Church because he cannot walk. I am used to it. I just want him to enjoy every sphere of life. – Margaret, foster parent.

He is my child and I treat him like any other of mine. Wherever we go as a family, he is there. Even when we go to Peter Mokaba Stadium in Polokwane for soccer matches, we do not leave him behind. – Mr Thabang, parent

"I try to accommodate him in every possible way I can. His intellectual ability is limited but I try to accept him as my child". – Mrs Malatji, foster parent

4.9.2 Parents perception about caregivers at Lehlaba Protective Workshop

Parents of children with disabilities opined that carers at Lehlaba Protective workshop attitudes towards children with disabilities were mostly negative mainly because they are not skilled and trained to look after their children with disabilities. However one parent differed. The response from the parents is as follows;

"*They try their best to assist our children from their capabilities. They are difficult to handle sometimes because most of them are not able to communicate to you properly what they want. For instance my child is using nappies; it is difficult to tell if they need to be changed. They can sometimes go for long hours without being changed because the careers do not know."* – Puleng, parent

"*What I have seen is that the children with disabilities need patience. The care givers at Lehlaba Protective Workshop shout and hurry the children. This is not right since our children are very slow in completing tasks and activities. I feel they need proper training to understand our children*". Tebogo, parent

"*They also take the role of the mother when handling our children with disabilities. They feed them breakfast and lunch. They do it whole heartedly like it is their own children. I do know that my child is in safe hands when i leave him with the careers at Lehlaba Protective Workshop"*. Miss Malope, parent

4.9.3 Family Members attitude towards children with disabilities

Family members who reside together with children with disabilities play a vital role in providing emotional, financial and social support. However, in some families it might not be like this. Responses from the participants confirm this.

"*Ever since I gave birth to my child, my husband ran away from me and I was left alone. My in laws accused me of witchcraft and I had to leave and go back to my family. I thought my problems had ended but were actually beginning. No one wanted to take care of this child and I had to do it alone 24/7. No one understood disability in my family. The situation has changed a bit as my mother is the one who sometimes assist me with the child*". Mrs Semenya, Parent

"*I am like stuck with this child. I only get reprieve during the week when he attends Lehlaba Protective Workshop. During holidays or weekends I cannot send him for holidays with my other children to my relatives because they do not know how to take care of him. In other words my family structure is not assisting me emotionally and socially*". Miss Malope, parent

"I stay with like my own *and my other children assist me a lot when it comes to looking after my child. They push him around the wheelchair when going to shops, church and social gathering. They are supportive and it makes him feel loved.*" – Mrs Malatji. Foster parent

These responses can authenticate that most of the parents do not receive support from other family members when taking care of the disabled children.

4.9.4 Emotional Burden

Most of the parents pointed out that they face emotional distress associated with taking care of their children with disabilities. The parents pointed out that they are mostly on a 24 hour alert when it comes to looking after their children. Even when their children are at Lehlaba Protective Workshop, they are always alert of any emergency notification from the workshop.

When I sleep, I begin to think about my son's condition, it may happen that as we sleep with him, he may just die. It means I have to be alert the whole night. Senzo, parent

Some of the parents pointed out that they are unable to sleep due to the behaviours at night of their children with disabilities

"M*y child has brain damage. He is 16 years old but behaves like a 2-3 year old baby. He can wake up midnight and want to play. It means I have to wake up and attend to him. It is very stressful.*"Mrs Nkoana, parent

"*My in epileptic and I have to watch her all the night because she might have the epileptic fits or seizures. I have to be awake most of the time in case it happens and I have to help her otherwise she can die.*" Dimakatso, parent

4.9.5 The Social Life of the family

Having a child with a disability tremendously affects everyone in the family. This includes the child's immediate family members who can be brothers or sisters. The presence of a disabled child affects each sibling individually, as well as the relationships between siblings (Legg & Penn, 2013). Parents of children with disabilities brought to attention that isolation is now common in their life, as they no longer have a life other than looking after their disabled child. The following responses are in support of the above statements;

 "*I always have a very busy day at home. I have to make sure that everything is in place*". Miss Malope.

"*My other two children sometimes complain that I do not give them attention since most of the time I am always looking after their disabled young brother*" Mrs Semenya

It should be noted that parents' isolation is more evident in the mothers, because the functions inherent to being a mother, housewife and permanent caregiver is time consuming. The same does not apply to the fathers who are mostly breadwinners and at work most of the time.

Leisure activities for disabled people require an additional effort from parents, since society still does not recognize leisure as an essential right of disabled citizens (Duncan, Sherry, & Watson, 2011). Responses from the participants highlighted that parents do not go out for leisure activities with their disabled children.

"I do not go out with him since it is costly as I have to hire a private car" - Puleng*;*

"He spends the weekend at home, lying down or sitting in bed" - Mr Thabang

4.9.6 Parents acceptance of disability

The birth of any child is filled with hope and enthusiasm which is short lived if the child has a disability. In the African context, children represent the satisfaction of social and cultural expectations. Children symbolize the unification of different ancestral spirits and the continuation of the family name and culture, thus the birth of a child with a disability disappoints most of these expectations and purposes (Mpezeni & Mutswanga 2015). When parents learn that their child has a disability, they embark on a journey that takes them into a life that is often filled with strong emotion, difficult choices, interactions with many different professionals and specialists, and an ongoing need for information and services. Initially, parents may feel isolated and alone, and not know where to begin their search for information, assistance, understanding, and support (Dillenburger & McKerr, 2011). Thus the happiness is short lived. Responses from the participants validate the statements above;

"I was so happy at first to have a son since I had two daughters. I knew I had a son who can take the family forward when God calls me one day. But now I am back to square one. How can my disabled son carry my name forward?" - Mr Thabang

"I was so happy that finally I have a child after years of trying. But the joy only lasted for a year when I realized my daughter has cerebral palsy. Now i have to live with it". Thembeka, parent

It can be concluded from the above responses that parents of children with disabilities develop hopes and dreams about who their baby will be in the world. This process of creating an internal life of the child is a natural part which all parents go through. Not any parent will dream of their child being disabled. The phases which the parents go through can be identified as;

Denial

 When parents of children with disabilities deny that their child is disabled and goes the extra length of seeking a cure (Brown et al, 2014). This is usually in the first 1 -2 years after discovering that their child is disabled. One parent had this response

"*I have gone from one traditional healer to the other both locally and to Mozambique and Zimbabwe but no "Sangoma" has cured the disability of my child.*"Thabang

Fear

The parent (s) fears the unknown. (Brown et al., 2014) For instance some parents pointed out that they are afraid that their child may die due to the disability

"*I had had stories that disabled children die in their sleep. I was just terrified that this will happen to my child*". Andile

Guilt (Why Me)

Some of the parents felt guilt for conceiving a disabled child. Some who believed witchcraft as a cause thought they could have avoided giving birth to a disabled child

Depression

The parents felt depressed, angry and confused after learning that their children are disabled.

"*I just lost it when I was informed by the doctor that my child is disabled. I had to take special leave from my work since I could not do anything. I was afraid of the stigma associated with disability*". Mrs Semenya

Acceptance

The parents of children with disabilities finally accepted that their children were disabled. However most of the parents took between four to eight years to accept the

disability. A few accepted cautiously or partially since they thought a cure will be found. The responses from the participant to confirm this are as follows;

"*I have accepted that my son will spend his whole life in a wheelchair. I have tried by going to most Churches even attending crusades of foreign preachers in Gauteng but nothing has changed on the condition of my child. I do now believe that miracles happened during Jesus times unless the Son Of God resurrects again. It is a hard decision to take but I have to accept the reality that my son is disabled for the rest of his life.*" – Mr Thabang, parent

"*I have been to prophets who come to Gauteng from other African countries hoping that my child will be cured. I just have to admit that it has failed and I have to accept and live with the reality".* Tebogo

4.9.7 Parental support

Parental support for the purpose of this study refers to the amount of participation a parent (mother and father) has or plays when it comes to caring, upbringing, psychosocial care, and financial needs of a disabled child from birth until the rest of the life. This study found out that parents who are single especially the mothers were left alone in responsibilities of taking care of the children with disabilities. Responses to confirm this are,

"*When my husband found out that the child is disabled he just vanished and moved to Johannesburg where I hear he has married again. I think the challenges of raising a child with a disability were too much for him".* Miss Mashabela

"*My boyfriend just left me alone with this burden of looking after the child. He only sends money but financial support is not enough. He needs to be part of the day to day upbringing of the child"*

4.10 Community attitudes towards children with disabilities

In the African culture, there is a saying that it takes the whole community to raise a child, hence it is the responsibility of the community to look after the disabled children (Omu & Reynolds, 2012). These responses were taken from the parents of the children.

The community include significant others namely friends, social gatherings, churches etc.

4.10.1 Family Friends

Friendship plays a pivotal role in providing support to each other when needed. Most parents pointed out that they turn to their friends in time of need.

"All my friends always try to assist me in times of need when I have problems with my child. I remember one time when I had to take my child to Polokwane for an operation and I was penniless. My friends contributed some money and I was able to take my child there". - Ms Mashabela, parent

"*I had to attend a funeral in Butterworth, Eastern Cape. It was extremely difficult to go with my child there. My friend agreed to look after my child for a period of three days and i am very grateful for that*". Mrs Nkoana, mother

"*My friend who is staying in Jane Furse sometimes comes and take my child during school holidays. This relives me as I am able to refresh and gather more strength. It also gives the child a holiday and to change the environment*". Mrs Nkoana, parent

The family friends play a chief role in the lives of children with disabilities as it can be noted in the aforementioned responses.

4.10.2 Neighbours

Neighbours are people who live close to each other and usually help each other in need especially in rural areas like Burgersfort. Most parents pointed out that they do have good relationships with their neighbours.

"*My neighbour is very helpful. He helped me during the night when my brother fell sick. We had to use his car free of charge to Dilokong Hospital in the middle of the night*". Margaret, guardian sister

"*My child is Autistic and epileptic. If he is happy sometimes or anxious he makes a lot of noise. My neighbours are so understanding that they have not ever complained of the noise whatsoever. They also bring toys for him to play with*". Ms Mashabela, mother

"*My neighbours do not want their children to be near my disabled child. They think that their children will also get Epilepsy if they play with my child. It is because they do not understand disability*". Mrs Semenya, parent

4.10.3 The Church

The church is a place of worship and spiritual support. Most of the parents attend church services with their disabled children.

"*The sermon and prayers help us a lot in giving us strength to look after my child. I feel that The Almighty is also helping me to look after my child*". Mr Thabang, father

"*My pastor and other church members visit me once in two months at my house for prayers. They also help me clean the house and they make nappy donations. This gives me the strength that I am not alone in taking care of my child*". Mrs Nkoana, mother

"*At every Christmas party of the Church, I get donations varying from nappies to food stuffs for my child. This removes the burden on my shoulder.*" Margaret, foster parent

4.10.4 Support Groups

Toseland and Rivas (2013) postulate that support groups are there to support group members with the same need to accomplish tasks and goals. The support may be emotional, financial and physical. A support group is a collective of people with the same needs with the aim of encouraging each other. Figueiredo (2007) brings to light that social support can contribute to generating less stress in the parents of children living with disabilities. The parents pointed out that they do have a support group but is not functioning properly as they do have only two meetings per year.

"*The support group helps me when we share information regarding disabilities. We exchange ideas on how we can take care of our children*". Miss Malope, mother

"*We understand each other well as parents. We support each other emotionally. The problem is we are no longer meeting frequently due to various factors*". Mrs Semenya

The parents were positive on the constructive outcome the support group was doing in their lives when taking care of their children with disabilities.

4.10.5 Community members' perceptions towards children with disabilities

Rural communities lack of knowledge and understanding of disability. This has resulted in parents and families of children living with disabilities facing a stigma of being different (Hoogsteen & Woodgate, 2013).

The parents had negative responses when it came to community perceptions regarding their children with disabilities.

"*Some community members take advantage of our children with disabilities especially teenage girls. They are often taken advantage of and raped. We do have a recent case involving one of our disabled girls and the police was involved. Boys are also taken advantage of as they are often asked to do odd jobs like cleaning houses, gardening etc. and it is abuse*". Thembeka, parent

"*The community does not accommodate my child. I see this when I go for shopping at Burgersfort Mall. Many people will be looking at my child as if they are seeing a creature. This really upsets me*". Miss Malope, parent

"*When I go to football matches at Peter Mokaba Stadium in Polokwane it is the attitudes of people which I hate. I can see that people will be wondering as to why I brought my child with to the stadium. One of the security personnel had to ask me why I trouble myself in bringing my son to a football match*". Mr Thabang, parent

"*The taxi drivers do not even accommodate me and my daughter. I offer to pay double but they often say that I take a lot of time in seating my child and they do not have time all day. Also most of the passengers become irritated. They do not say it openly but I can see that they are irritated*". Mrs Nkoana, mother

"*At social gatherings like the Stokvels it is problematic. I have decided not to go at all after I noticed that most of the members did not like my child. I could see it in their body language*". - Ms Mashabela, mother

These responses depict that the community is not welcoming to children with disabilities and their parents. The parents and the children are painted with the same brush.

4.11 Experiences of parents on attendance to Lehlaba Protective Workshop

All the parents were positive about their children attending Lehlaba Protective Workshop. They illustrated that the workshop is doing a great job.

"I am now able to go to work in Burgersfort because I know my child is in safe hands. I can make an income which will assist me to take care of my brother. Margaret, guardian sister

"I was always stuck at home with my child. Now I know that during the day I can send him to Lehlaba where he plays with other children of his condition. At least I can have time to rest". Mrs Nkoana, parent

"He is now able to do *tasks on his own. He can now go to toilet alone as he is able to transfer himself from the wheelchair to the toilet seat without assistance. He was taught this at Lehlaba Protective Workshop".* Mrs Semenya, parent

"These past few months she is able to communicate her needs although not clearly. She can give a sign if she wants to go to the toilet and this has saved me a lot of money as I am now using nappies during the night". Ms Mashabela, parent

"He is being taught sign language since he is deaf. It is now a challenge for myself to learn sign language such that I can communicate with him". Mrs Malatji, foster parent

"My daughter is now able to read, write and count. I can now send her to the spaza shops to buy some groceries alone". Miss Malope, parent

"My son is now able to do household chores especially gardening since they taught him at Lehlaba. What puzzles me is that he is now able to even write his own name". Mr Thabang, father

These responses from the parents signify that they value the services which are being provided by Lehlaba Protective Workshop in changing the lives of their children.

My child is in the gardening and poultry group. They are taught how to look after the chickens and grow vegetables like carrots, cabbages and spinach. Miss Mashabela, parent

"Last November 2015 they went to Polokwane airport and Pretoria Zoo for a trip. My child was excited and he is still telling us about the trip eve now". Andile parent

One parent of a child who is only physically disabled was not satisfied with the activities

"They only teach him how to do colouring and it is boring repeating the same things. I wish if I could find a better school to admit him. However it is better than staying home". Senzo, parent

4.12 Parents dreams for their children

Parents of the children with disabilities had positive different dreams and aspirations about their children. Here are some responses of their dreams;

"I wish one day if my son would be able to be enrolled at a mainstream school and do Grade 12. His intellect is fine; the problem is only that he is physically disabled". Mr Thabang, parent

"I hope one day my daughter would be able to communicate and also be able to do tasks like toilet and eating alone. Then I will know that my job as a mother will be done". Mrs Nkoana, parent

"Since she is deaf, I hope one day she will be able to communicate her needs well to everyone. It is also my homework to learn sign language so that communication is better". Thabang, parent

"My dream is for my son to start his own poultry project one day. I was told he is good in looking after the chickens and I hope he can be a business man one day". Mr Thabang

These responses augured very well with what was stipulated by Brown et al. (2014) that parents have diverse dreams and visions for their children.

4.13 Residential accommodation for children with disabilities

Most of the parents pointed out that it would be good for them if their children could be accommodated in a residential facility. This would at least remove a heavy load on their shoulders. However, some pointed out that they had tried to look for the facilities but there was only one the whole of Limpopo in Bela Bela.

"I applied for space for my child 4 years ago but I am always told that they do not have space yet. I have now lost all my hope that he will be admitted there". Mr Thabang. Parent

"I went to the centre personally to apply at the centre and what I saw is amazing. They have all the professionals under one roof to look after the kids who include a social worker, physio therapist, medical nurse etc. The only problem is that they are always full. My daughter would greatly benefit from their services". Dimakatso Parent

4.14 Psycho social experiences

4.14.1 Distress on time

Most parents spend most of their time taking care of their children living with disabilities. Some of the responsibilities of the parents include bathing, preparing special dietary meals, feeding, toiletry duties and changing diapers / nappies. There was a sense of frustration in the amount of time devoted to caring for the children with disabilities. One parent was of the view that only death of the child is an end to the time spent on caring for the child.

Actually all my time is spent on looking after her since I have *to do almost everything for him; bathing, feeding, and changing clothes. Almost everything. It means I do not have time for other things"* Ms Semenya

"All my time is now bound on taking care of my child with cerebral palsy, I have to do any little task for her as there *will not be anyone to do it for her. I am scared to say it will be until God's will but that is the reality".* Puleng, parent

4.14.2 Fears of another child

All the biological parents voiced their fears of having another child. Both males and females were of the view that they will never try to conceive again since they are scared of having a second child with a disability.

"*I am facing a lot of untold challenges in raising this child. This makes me* reluctant *to have another child. What if I conceive a disabled child again*?" Thembeka

"*This one who is disabled is the last born in a family of three children. I do not want to risk having another child who might turn out to be disabled".* Thabang

"*This is my first and last child. I do not want to end up having two disabled children. If I have a disabled child now, what can stop me from conceiving another disabled child"* Mrs Nkoana

4.14.3 Employment

Seven of the parents are not employed. Of those employed, four are working full time whilst three are working half day. The parents who are not working pointed out that it is the nature of the disability of their children which makes them not look for employment. Some of the responses are as follows;

"*My child is autistic and epileptic. He is prone to epileptic attacks. I cannot go to work because Lehlaba Protective Workshop phones me when there is an emergency with* my *child so I have to always rush there. Who can employ me when I am always on the road to check on my child*". Puleng, parent

"*I have to sign for a half day job because I have to drop off my child at Lehlaba Protective Workshop in the morning and pick him again in the afternoon"* Margaret

4.14.4 Economic burden

Half of the parents were not employed. Although they commended the Care Dependency grant, it was little. Even for those employed, they highlighted to be experiencing an economic burden. Some of the parents had to sell their personal belongings such as livestock (cows and sheep) in order to provide financially for their disabled children. The parents postulated that their immediate family members mostly did not help them financially to look after their disabled children.

"I had to sell one time my cow in order to send my child to a private hospital in Polokwane when he had a big epileptic seizure". Thabang, parent

I am employed as an electrician but my salary cannot complement the needs of my disabled child. I have to buy diapers, food, medicine and I need to have cash at hand just in case of emergencies. Tebogo, parent

Other parents pointed out the lack of financial support and that there is no external support even if they wanted to talk about it.

"Eish I am just alone in this struggle. I do not get any financial assistance from anybody. It is me alone with this burden". Margaret, foster parent

One caregiver indicated that caring for someone living with a mental disorder has a negative impact on her finances and emotional health.

4.15 CONCLUSION

This chapter presented the results as provided by the respondents who were parents of children living with disabilities. Parents demonstrated different views as to the cause of their children disabilities. Some were of the view that witchcraft was the cause whilst others blamed medical professionals. Most of the parents also pointed out that they do not believe that there is a cure for disability. Lack of professionals to assist children with disabilities such as the rapists (occupational, physio, speech) was also noted by parents as hindering their rehabilitation. Most notably the parents of children with disabilities went through a cycle upon the birth of their children which are denial, fear, guilt, depression and acceptance.

CHAPTER FIVE

SUMMARY OF FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

Chapter four aims to give a summary of the study conducted in brief. Conclusions, recommendations and areas for further research will be discussed. This chapter will also give a summary of whether the objectives of the study were met.

5.2 Aim of the Study

The aim of the study was to explore the experiences of parents of children living with disabilities at Lehlaba protective workshop. The aim of the study was met.

5.3 Objectives of the Study

The objectives set for the study were;

5.3.1 To describe the experiences and life circumstances of parents of children living with disabilities at Lehlaba Protective Workshop.

This objective was met since experiences and life circumstances of the parents of children living with disabilities were revealed in the study. These included;

- Stigma associated with having a disabled child.
- Attitudinal barriers from community members.
- Service barriers in the form of transport and health for their children.

5.3.2 To identify the challenges experienced by parents of children living with disabilities

This objective was met since the study revealed that;

- Parents are facing financial challenges in raising their children living with disabilities.
- Parents are failing to source employment since most of the time they are looking after their children.

- Parents do not get support from family members in looking after their disabled children.
- Lack of assistive devices for their children.

5.3.3 To identify the services which are available for parents of children living with disabilities.

This objective was met since services available for parents were revealed in the study

The study revealed that there are very limited services available for parents of children with disabilities. These include among others;

Support group of the parents of children living with disabilities. The support group is available but not functional. It is operating below the standards and the way it should be functioning.

5.3.4 To establish the coping mechanisms for parents of children living with disabilities

This objective was partially met since parents pointed that the church plays a pivotal role in making them cope with the work and "burden" associated with looking after children living with disabilities. The study found out that the sermons and prayers from the church help them spiritually to take care of their children. However, besides the Church, no other coping mechanisms were observed in the study.

5.4 Major findings of the study

5.4.1 Stigma, attitudinal barriers

The study found out that the more the children living with disabilities are stigmatized, the more their parents are painted with the same brush. The study noted that the parents are subjected to name labelling since they are viewed to be practicing witchcraft or to be paying from their sins they committed.

The study also found out those attitudinal barriers from the society (community members) is very rife and happening since people do not understand disability.

5.4.2 Resources for children with disabilities

The parents of children with disabilities were mainly concerned by the unavailability of services for their children. The lack of services affected and frustrated the parents since they were the ones left with the burden of looking for them. For instance, the study findings revealed that there is lack of stimulation equipment at Lehlaba Protective Workshop and it is left to the parents to buy the equipment. It proved to be an expense for the parents since the stimulation equipment is unaffordable. The study also revealed that parents face a daunting task in purchasing assistive devices in the form of wheelchairs, crutches and Braille materials for their disabled children. The study also revealed that there is lack of allied health professionals to assist their children with disabilities. Of particular note was the unavailability of professionals such as therapists to assist their children.

5.4.3 Services for children with disabilities

The study revealed that parents are extremely frustrated by the lack of services to their children. Services noted by the parents include;

- Rehabilitation

  The study noted that the parents believe strongly that rehabilitation is very crucial for their children with disabilities. According to WHO (2011) rehabilitation is a process unearthed to assist the injured child, who is experiencing or likely to experience disability, to achieve and maintain optimal functioning in interaction with their environment. However, there is a lack of therapists such as (speech, physios, occupational) to assist their children. The local hospital which is supposed to provide this service, has a few to none therapists available to assist their children.

- Social Development

  The parents of children with disabilities were also frustrated by the Department of Social Development's lack of funding to Lehlaba Protective Workshop. They claimed that the centre is not funded adequately and this has got a negative impact on the quality of services provided to their children. They pointed out that

the poor services provided are a result of the poor funding model employed by the department of Social Development.

- Health

The study also revealed that parents of children with disabilities have a dilemma when it comes to the health welfare of their children. The study noted that the nearest health facility is approximately 55 kilometres away. The inaccessibility of the hospital due to the distance makes the parents fork out extra financial resources in order to transport their children to the health facility. The hospital environment itself is not disability friendly.

- Education

The study noted that some of the children with disabilities are capable of attending the mainstream schools or special schools. However, they are stuck at Lehlaba Protective Workshop due to limited and few special schools to accommodate them. In the whole of Limpopo Province, there are only 34 special schools which do have a long waiting list. Thus space in the special schools is very limited. The children living with disabilities are deprived of a constitutional right to education.

- Care Dependency Grant

The Care Dependency Grant (CDG) is awarded in terms of the South African Social Security Services (SASSA) under the Social Assistance Act of 1997. The study found out that the R1 500 as of 1 April 2016 is too little in comparison to the financial needs of children with disabilities. The study noted that the parents of children living with disabilities spend over R3000 a month in taking care of their disabled children. As most of the parents are not working and do not have an income besides the (CDG), they find it very hard to provide financially for their children.

5.4.4 Psychosocial experiences

- Fears of another child

The study excavated out that the biological parents are afraid to conceive another child after the disabled one. The study found out that biological parents are afraid mainly due to the burden associated with taking care of disabled children. The study noted that it is far better to have one disabled child than having two since biologically there is a possibility of giving birth to another disabled child.

- Family responsibilities

The study noted that parents of children with disabilities do not have a social life. The family life is totally affected negatively. Most of their time revolves around looking after the disabled child hence no time is left for socialization with friends and family as well as recreation. Some siblings within the same family also suffer since all the parents' attention goes to the disabled child. The parents' tasks include bathing, feeding, dressing, and toilet obligations hence they have to be on a twenty four hour care giving duty.

- Employment

The study noted that most parents of children living with disabilities are not employed at all due to the fact that they have to keep a close eye on their children. Although the children are at a disability centre during the day, the study found out that they are called most of the time due to emergency situations concerning their children.

- Economic Burden

Raising a non-disabled child is an expense in itself hence raising a child with a disability with special needs requires good financial muscles. The study found out that it is extremely expensive for the parents to raise a child with a disability. The parents would have to make financial provisions for the upkeep of their children. For instance children with severe cerebral palsy require semi processed food, a regular supply of diapers, and constant medical attention. All these requirements

are costly. Most of the parents are unable to meet their children's needs since they are unemployed.

5.4.5 Disability Acceptance

The study found out that parents of children living with disabilities took time to accept their children's disability. The study also found out that parents were not informed adequately about their childrens' disabilities by health professionals. The parents also tried in vain to look for a "cure" in the first years hoping that they might be able to find a cure for their children's disability. Some of the parents would consult traditional healers even from neighbouring countries with the hope of finding the "cure". The study also found out that the parents of children with disabilities go the extra mile of attending religious sermons and crusades from prophets who come from outside South Africa especially West Africa. It was also revealed that the parents of children with disabilities went through a phase of fear, guilty, depression and then acceptance upon realizing that their child is disabled.

5.4.6 Parental Support

The study found out that parental support is a cause of concern since fathers "run away" upon realizing that their child is disabled. Biological mothers are left alone without support in the caring of the disabled child. Single mothers pointed out that they used to have husbands and partners but they vanished upon realizing that the child was having a disability. Women in essence are left alone in taking care of their disabled children. The study proved that women are strong, courageous and never give up when it comes to raising their children with disabilities.

5.5 Conclusions

- The researcher has come up with the following conclusions based on the research findings;

- Parents of children with disabilities are in their own battle in raising their children

- Raising a child with a disability is expensive, time consuming and straining.

- The Child Dependency Grant (CDG) of R1500 as of 1 April 2016 is too little to cover the costs associated in raising a disabled child.

- Parents of children with disabilities believe that if their children are given enough resources and opportunities, they are able to be like any other children.

- Health facilities are not equipped with necessary professionals such as therapists (physios, speech and occupational).

- The community is hostile towards children with disabilities mainly due to lack of knowledge on disability issues.

- Attitudinal barriers are common in rural areas towards both children living with disabilities and their parents.

- There is lack of support structures available for parents of children living with disabilities.

- There is lack of legislation available for protecting and promoting the rights of children with disabilities.

5.6 Recommendations

The findings, conclusions and literature review from this study have prompted the following strategic recommendations;

Care Dependency Grant (CDG)

The CDG needs to be awarded according to the nature of disability of the children. For instance, children with severe disabilities like cerebral palsy needs to be awarded more financial resources since it is costly to look after those children. The Department of Development through its distributing agency South African Social Security Agency (SASSA) needs to conduct a feasible study on the impact of CDG in relation to the nature of disabilities.

Health Care / Rehabilitation

The Department of Health Limpopo Province, need to come up with mobile clinics such that their services reach children with disabilities. The nearest health facility is approximately 55 kilometres away and it makes it difficult for parents to transport their children for medical services. Therapists (occupational, speech and physios) need to conduct field work visits to centres for children with disabilities to foster community based rehabilitation.

Legislation

Legislation available for children with disabilities is the Constitution of South Africa as well as the Social Security Act. There is need for a Comprehensive Disability Act like other European and Western countries such that rights of children with disabilities can be advanced.

Support Groups

Parents endure a lot of emotional stress and burn out when taking care of their children with disabilities. The Department of Social Development needs to vigorously implement the forming of support groups for parents of children living with disabilities. These support groups will be instrumental in providing psycho –social support to parents of children living with disabilities. Sharing ideas and meeting each other's emotional needs helps to remove the burden on the shoulders of the parents through support groups. The parents also need to start support groups through social media platforms such as whatsapp and facebook. This is less expensive and less time consuming.

Education

Department of Education has to mainstream children with disabilities through capacitating local schools with resources for children with disabilities. Since there are only 34 special schools in the Limpopo province, children with disabilities need to be integrated into the mainstream schools such that their right to education can be fulfilled. Local schools need to be made accessible and have staff to cater for the children living with disabilities.

Social Development

Department of Social Development is the custodian of stimulation centres of children with disabilities. Funding of these centres should be improved because they are providing important services to children with disabilities who have special needs. The study noted that the current subsidy for a child at the centre is R15 as of April 2016. This amount has to be divided into food, transport and equipment for the child with a disability. This little amount is many miles away adequate to maintain the needs of a disabled child. It is thus recommended that the Department of Social Development Limpopo Province conduct a feasibility study on financing disability centres. The Department of Social Development also needs to pay timeously the subsidy as according to the financial awards agreement. Any delays in payment to the disability centres negatively affects service delivery to children with disabilities.

Financing of disability centres

Disability centres also need to look at other ways of financing their activities. This can be done through other corporations such as Vodacom foundation, Telkom charities, and MTN foundation amongst others. National Lotteries Commission is also providing funding to small Non-Profit Organization. This will help in financing equipment and materials needed in providing services to children with disabilities.

5.7 Recommendations for further academic research

In view of fact that this research study was not reflecting all geographic locations, the researcher recommends a follow-up study, which should comprise a sample specifically including parents of children living with disabilities from urban environments.

Further research can also focus on experiences of adults living with disabilities in government and private institutions.

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APENDIX A: INTERVIEW GUIDE

Research Topic: Experiences of parents of children living with disabilities at Lehlaba Protective Workshop in Sekhukhune district of Limpopo Province

INTRODUCTION

My name is Brian Tigere and I am a Social Work Masters student at the University of Limpopo in the Department of Social Work. I am carrying out a research which attempts to investigate the experiences of parents of children living with disabilities. Your participation in this study will be confidential, names and addresses will not be included for confidentiality purposes. The information you provide is highly confidential and will be used for academic purposes only.

Answering questions from this interview may be difficult and sometimes distressing and therefore apologize in advance for any inconvenience. Your cooperation in participation of this interview is greatly appreciated and would like to thank you for your careful and honest responses to the questions thus making the study more authentic.

SELELEKELA

*Lebitso la ka ke Brian Tigere me 'na ke e le seithuti se Social Work Benghali Univesithing ea Limpopo a Lefapha la Work Social. Ke phetha ea ho etsa lipatlisiso e leng leka ho fuputsa liphihlelo tsa batsoali ba bana ba phelang le bokooa. Ho nka karolo ea hao ho sehlooho sena se tla ba lekunutu, mabitso le liaterese ke ke ba akarelletsa merero lekunutu. Boitsebiso boo u fanang ke khupamarama le tla sebelisetsoa merero akatemi feela. Araba lipotso tsoang hlahlobeloa ena ka ba thata ka linako tse ling a sithabetsang 'me ka hona kōpa tšoarelo esale pele ka tšitiso leha e le efe. Tsebelisano hao ho nka karolo ea hlahlobeloa sena se ananela haholo le rata ho le leboha ka likarabo tsa hao tsa ka hloko le ka botšepehi, lipotsong tse ka ka tsela eo ba etsa ea thuto tšeptjoang haholoanyane***QUESTIONS**

1. What type of disability does your child has and what challenges have you faced in raising your child?

   Ke eng e mofuta ofe oa bokooa ha ngoana oa hao e le qaka efe U tobane ho hōlisa ngoana oa hao?

2. Do you get any support from your family, friends, government departments and the community at large?

   Na u tshehetso leha e le efe ea lelapa, metsoalle, mafapha a 'muso oa lona le a sechaba ka kakaretso?

3. Is the child receiving care dependency grant from SASSA and how is it assisting you financially in providing for your child?

   Na ngoana amohela itshetlehileng tlhokomelong tsoang SASSA hona ho thusa u thusitse licheleteng ka ho fana ka ngoana oa hao?

4. What special needs or assistive devices does the child require?
   Litlhoko tsa kapa disebediswa thusang efe e khethehileng ha ngwana hloka?

5. Is your child attending Lehlaba Protective Workshop regularly and what skills or training is he / she receiving?

   Na ngoana oa hao ea Lehlaba Sireletsa kokoano kamehla le seo fumants'a litsebo tsa kapa thuto ea ha a / o ile a amohela?

6. Does your current employment have any positive or negative influence on your capabilities of looking after your disabled child?

   Na khiro ya hao ya hajwale na le tšusumetso e ntle kapa e mpe ho bokgoni ea hao ea ho hlokomela ngoana oa hao ea holofetseng?

7. How does your child interacts (relationships) with peers of his / her age group and as a parent are you part of any support group?

   Joang ngoana oa hao le sebedisana (dikamano) le lithaka tsa hae tsa / thaka ea hae 'me joaloka motsoali u karolo ea sehlopha leha e le efe tshehetso?

8. Do you get support from other professionals such as Social Workers, medical Professionals, Therapists (Physios, Occupational, and Speech etc.)? How frequent does your child seek medical services?

   Na u tshehetso ho tswa litsebi tsa lintho tse ling tse kang Basebetsi Social, litsebi tsa bongaka, litsebi (Physios, Occupational, 'me Puo jj)? How khafetsa ha ngoana oa hao batla ditshebeletso tsa bongaka?

APPENDIX B

STUDENT NUMBER: 201647452

CONSENT FORM FOR PARTICIPATION IN THE STUDY

I hereby consent to participate in the research project. The purpose and procedures of the study have been explained to me. I understand that I am not bound to participate in the study and that it is my right as the participant to withdraw from this study if I feel not comfortable. I understand that my responses will be kept confidential though there is a possibility that I might be identified regardless of my name being excluded in the final report.

Note that there are possibilities that the study might bring back painful emotional memories. However, the researcher has made arrangement with the local psychologists at Dilokong Hospital in Burgersfort should the need for counselling arise. The researcher has also made arrangement with the local social worker's sub office at Lehlaba Protective to provide social work services should the need arise. By putting my signature and date on this consent document is to declare that I agree to be interviewed.

Name of Participant: .... Researcher (as witness)…………………….

Date:.. Date…………………………………………

Signature: .... Signature……………………………………