THE EXPERIENCES OF PARENTS OF CHILDREN WITH DISABILITIES

BY

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A thesis submitted in partial fulfillment of the requirement of the masters in community work in the department of social work at the University of Zululand

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MARCH 2016
DECLARATION OF ORIGINALITY

I, Nozipho B. Mpontshane, declare that this dissertation titled, “The experiences of parents of children with disabilities”, is my work and that all the sources that have been used or quoted have been indicated and acknowledged by means of complete references.

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DEDICATION

This work is dedicated to the parents of children with disabilities in uThungulu district municipality, Province of KwaZulu Natal.
ACKNOWLEDGEMENTS

First of all, I would like to give honour and praise to Almighty God who is responsible for all the successes in my life.

I would like to express my sincere thanks to Professor N.H. Ntombela in the Department of Social Work (University of Zululand) for her professional support and advice towards the progress and completion of this study.

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A special thanks to my family, friends and colleagues for all the support they have given me throughout my study.
ACRONYMS

DSD    Department of Social Development
DoE    Department of Education
DOH    Department of Health
DICAG  Disabled Children’s Action Group
DPO    Disabled People’s Organisation
DPSA   Disabled People South Africa
GEAR   Growth Employment and Redistribution
INDS   Integrated National Disability strategy
NGO    Non-Governmental Organization
NPO    Non-Profit Organization
RDP    Reconstruction and Development Programme
SAFCD  South Africa Federal Council on Disability
SASA   South African Schools Act of 1996
UNCRC  United Nations Convention on the Rights of the Child
UNESCO United Nations Education Scientific and Cultural Organization
UNICEF United Nations Children’s Fund
ABSTRACT

Parents of a child with a disability cope with greater demands than those living with a healthy child. The purpose of this qualitative study was to provide insights into the experiences of parents of children with disabilities. The research was located in the phenomenological framework. Seven parents who are residing within uThungulu District municipality and whose children were diagnosed with disability participated in the study. They were selected though purposive sampling. In-depth interviews were conducted with them to gain in-depth insights into their experiences. Content analysis was used to analyse data gathered through in-depth interviews and five themes emerged i.e. parents’ realisation of the child disability, reaction towards the realisation of the child’s disability, the essence of parenting a child with a disability, parents’ social support and the needs identified by parents.

Findings of the study indicated that parents do not alter their parenting. On the contrary, they modify it to accommodate the children with disability. Secondly, it transpired in the study that several challenges are faced by parents in raising their children with disability. These challenges include, among others, lack of financial resources, finding a suitable school for their children with disability, care giving challenges, lack of suitable housing and transport allocated for children with disability. It also transpired that there are support structures within their communities despite there being no programs to support them.
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CHAPTER ONE: BACKGROUND AND ORIENTATION OF THE STUDY

1.1 Introduction

For many years throughout the world, people with disabilities including children, have been traditionally excluded from the mainstream of society as a result, they could not access or enjoy fundamental social, political and economic rights. Since 1994, the South African government has prioritised the issue of disability by introducing policies and legislations that give people with disability equal rights. Some of these policies and legislations provide the framework for addressing the situation of children with disabilities. These legal instruments include, among others, the United Convention on the Rights of the Child in 1995, (UNICEFF, 2007), the African Charter on the Rights and Welfare of the child which was ratified by South Africa in January 2000 and the Convention on the Rights of Persons with Disabilities of 2006 which serves as a blueprint to overcome discrimination and thus recognize the right to the full participation of children with disabilities in the home and community, in school, health services recreation activities and in all other aspects of life. UNICEFF (2007) points out that despite the drafting of policy initiatives and government guidelines introduced over the past decades to improve the lives of children with disabilities, these children and their families have continued to experience barriers to the enjoyment of their basic human rights and to their inclusion in society.

Philpott and McLaren (2011) aver that children with disabilities are among the most excluded of all the world’s children and as a consequence of this exclusion they face serious barriers to the full enjoyment of their human rights. Notably, their social exclusion and that of their families are hastened by legislations which create barriers that prevent them from accessing equal opportunities (Lansdown, 2002; McClain, 2002).

Furthermore, it is noted that the issue of disability has a direct impact on a person with a disability. In such situations the parents happen to be amongst the most affected in situations where the person with a disability is a child. This view is corroborated by Barnett, Clement, Kaplan-Estrin and Fialka (2003) assertion that parents of children with disabilities experience high levels of emotional and physical stress than parents with children without disabilities. It is
thus notable, therefore, that parenting a child with disability goes beyond ‘ordinary parenting’ due to the fact that parents having children with disabilities are more likely to require support than parents having children without disabilities (Beresford, Rabie & Sloper, 2007).

1.2 Research context

The study was carried out in UThungulu District Municipality. UThungulu District is located in the northeastern region of the KwaZulu-Natal province on the eastern seaboard of South Africa. It covers an area of approximately 8213 square kilometres, from the agricultural town of Gingingdlovu in the south, to the UMfolozi River in the north and inland to the mountainous beauty of rural Nkandla (uThungulu IDP 2011/12-2015/16). It has the third highest population in the province of KwaZulu-Natal. It is made up of 6 Local Municipalities i.e. Umfolozi, Umhlathuze, Umlalazi, Ntambanana, Mthonjaneni and Nkandla.

UThungulu’s unique qualities set it apart from many other regions in South Africa. It boasts as the largest deep-water port of the African continent, which imports the most bulk cargo of all African ports. Some 80 of the population is rural, and 53 % aged between 0 and 19 years. Women make up 53% of the population due to migration patterns associated with the province in general and there large disparities in settlement concentrations. The challenge in uThungulu District Municipality is to provide basic services such as water and sanitation to these people while stimulating local economic development, job creation and the growth of the small and medium business sector. The need to address poverty is one of the most critical issues in area. The rural portion of this district has poor road infrastructure which is not tarred.

The municipal area is well provided with Schools and the facilities are reasonably well distributed. There has been a decline in the higher education levels of the district. There appears to be an improved access to primary education, and numbers of learners not attending school dropped significantly. The special needs schools are not adequate to accommodate all learners, which is a problem for the numerous learners who need a structured school environment for stimulation and improvement.
However, there are various programmes for the marginalized which include various projects that fall under what is termed “Special Programmes (uThungulu-District-Annual Report 2015/2016). These include programmes targeting the Senior Citizens, the disabled children, gender issues, HIV/AIDS, and all other programmes. Furthermore, the vulnerable groups are taken care of through Community Development Interventions in uThungulu District Municipality. Inspite of the progress made by municipality in dealing with disability; there are still a number of challenges experienced by people with disabilities who live in uThungulu.

1.3 Statement of the problem

Currently, in South Africa much emphasis is being placed on minimizing barriers to learning and maximizing participation to learning. In line with this, the Ministry of Education launched the Education White Paper 6: Special Education-Building an Inclusive Education and Training System (Department of Education, 2001), with the aim of drawing attention to the barriers to learning in South Africa. One of the barriers outlined in this EWP6 is that of disability. As argued by Shabana, Jerve and Sobey (2005), public attitudes towards disability constitute one of the major barriers standing in the way of families of children with disabilities leading ordinary lives. Thus, it is worth recognizing that public attitudes manifest themselves in a number of ways in the lives of parents for a child with a disability.

Although stress and despair are frequently reported as a problem for families having children with disabilities, more recent research along with many families themselves has rejected these negative notions (Shabana et al., 2005). Shabana et al. (2005) have argued that even though many families have reported positive changes, but little research has been carried out to understand this positive adjustment to parenting a child with a disability.

1.4 Motivation / Rationale for the study

Algood, Harris and Hong (2013), argue that looking after a child with disability is different from, and more demanding than, ordinary parenting because children with disabilities require much attention from their parents. Furthermore, family problems ranging from demands for energy and
financial resources and heavy burden of stress also increase. Thus understanding how these parents develop their perspectives as they live with the situation of a child with disability can be an important area of inquiry.

From the literature reviewed by the researcher, the focus of much of the research studies on parents of children with disabilities were on the impact the disabilities have on the parents. Not much research has been done to understand how these parents adjust or cope with parenting children with disabilities. The researcher was also motivated to pursue this study because in her line of duty the researcher supports learners with barriers in schools. As it is stated above one of the barriers experienced by the learners is disability. It is in light of this, therefore, that the researcher undertook this study so as to establish how the parents of these children experience and adjust to their children’s condition.

1.5 Key Research Questions

The research questions were the following:

(a) What does it mean to be a parent of a child with a disability in South Africa?
(b) What challenges do they face as parents of children with disabilities?
(c) How are those challenges being overcome by the parents of the children with disabilities?
(d) What structures and programs are in place to support parents of children with disabilities?

1.6 Aim of the Study

The study aimed at exploring the experiences of parents having children with disabilities.

1.7 Objectives of the Study

The objectives of this study were:

(a) To gain insight into the experiences of parents having children with disabilities.
(b) To determine the challenges faced by the parents of children with disabilities.
(c) To identify coping strategies used by the parents of children with disabilities.
(d) To identify measures that have been put in place to support parents of children with disabilities.

1.8 Contribution of the Study to the Body of Knowledge

Beresford, Rabie and Sloper (2007) argue that much is known about the difficulties and challenges faced by parents with children having disabilities and what parents want for their children. However, very little is known about how parents want their own lives to be. Therefore, through listening to the parents’ voices it was possible to establish how they want their lives to be. Furthermore, the study shed light and invaluable insights and different perspectives on the experiences of parents having children with disabilities. However, positive ways which parents use to cope with children with disabilities were made visible. These will also inform the development of programs or structures that could help to support parents in the future who might encounter similar situations.

1.9 Definitions of Terms

In order to facilitate a common understanding, key terms used in the study are defined broadly.

1.9.1 Parent

A biological or not biological, parent with whom the child is living. It also includes the divorced parent with whom the child may not be living.

(a) A person who has fathered or given birth to the child.
(b) A biological father or mother.
(c) A person who has adopted the child.
(d) A protector or a guardian.

1.9.2 Children

According to the Constitution of the Republic of South Africa 108 of 1996, the term child refers to a minor who is below 18 years of age.
1.9.3 Disability

Disability is a diagnosis or reported delay in one or more areas of development including speech-language, hearing, vision, social, cognitive, self-help, fine and gross motor skills. It can be defined as a physical or mental condition that limits a person’s movements, senses or activities.

1.9.4 Impairment

Impairment refers to the loss or limitation of physical, mental or sensory function on a long-term or permanent basis.

1.9.5 Persons with disabilities

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interacting with various barriers may hinder their full and effective participation in society on an equal basis with others (UNICEF, 2007).

1.10 Theoretical Framework

The study was located within the phenomenological framework. Phenomenology attempts to generate knowledge about how an individual experiences a phenomena (Hesse-Biber & Leavy, 2010). The phenomenological research aims at understanding and describing the participants’ experience of their everyday world as they see it. In other words, understanding human behavior through the eyes of the participants in the study is its central focus. This framework was appropriate for this study as the aim was to understand the subjective experience of parents who are raising children with disabilities. This framework, therefore, allowed the researcher to establish the parents’ experiences within the specific context of their subjective realities so as develop interpretations of these experiences.

The term phenomenology is derived from the Greek ‘phainein’, which means to ‘appear’. It was first described by Immanuel Kant in 1764 as the study of phenomena or things (Cohen, 1987).
cited in (Streuber & Carpenter, 2011). Streubert and Carpenter (2011) define phenomenology as a science whose purpose is to describe particular phenomena or the way things appear as lived experience. Its central focus is the lived experience of the world of everyday life. This means that it is through lived experience that individual comes to know what is true or real in his or her life. Furthermore, it is through lived experience that gives meaning to each individual’s perception of a particular phenomenon and its influence by everything internal and external to the individual (Streubert & Carpenter, 2011).

Phenomenology as a methodological framework has evolved into a process that seeks to establish reality in individuals’ narratives of their lived experiences of the phenomena. It incorporates the following, lived experience, perception and the feelings of the participants regarding the phenomenon. It does not begin with a theory, but instead begins with a phenomenon under consideration. It requires a relatively homogeneous group of participants and these participants should have experience with the same phenomenon (Cresswell, 2007). As a result, an individual selected to participate in the phenomenological study should have significant and meaningful experience of the phenomenon being investigated (ibid).

In a phenomenological study, purposeful sampling is commonly used. Cresswell (2007) asserts that the purposive sampling requires the researcher to select the participants purposively since they can understand the phenomenon. So, the researcher can decide whether the participants share significant and meaningful experience concerning the phenomenon under the investigation or not. As regards data collection, the major data collection method in a phenomenological study involves primarily the use of in-depth interviews with the respondents, with the purpose of describing the meaning of a phenomenon that several individuals share.

Furthermore, data analysis starts with bracketing the researcher’s subjectivity and this entails clarifying preconceptions throughout the investigatory enquiry (referring to setting aside the researcher’s prejudgments and predispositions towards the phenomenon). This process begins with the researcher writing a complete description of the phenomenon. Before starting the data analysis, the researcher should read his/her subjective statement, including the description of his/her own experience with the phenomena. It describes the meaning of several individuals of
their lived experiences of the concept or phenomenon. Notably, therefore, the basic purpose of phenomenology is to reduce individual experiences with a phenomenon to a description of the universal essence. The researcher identifies an object of human experience, then she /he gathers data from the person who has firsthand experience of the phenomena and develops a composite description of the essence of the experience for the entire individuals concerned. This description consists of “what” they have experienced and “how “they experienced it.

1.11 Methodology

Information for this study was gathered from both secondary and primary sources.

Secondary sources

Useful information was obtained from various publications such as textbooks and previous studies on the subject of the experience of parents of children with disabilities.

Primary sources

More specific information that attaches weight on the experiences of parents of children with disabilities was obtained from the responses of the respondents that participated in this study.

1.12 Ethical Issues

Mindful of the requisite ethical considerations one is obliged to observe, the researcher ensured that the parents, who were at the same time the respondents, were informed about the study, purpose and the nature of the research as well as issues that relate to informed consent and confidentiality during the pre-interview discussion conducted telephonically with them. So, the potential respondents were informed that their participation in the study was voluntary. Therefore, they were free to withdraw from the research at any time without any negative or undesirable consequences to them. A consent form was explained and given to them requesting them to sign in if they were interested to participate in the research project before starting the interviews. However, the identifiable information was not used in the study in order to protect their identity.
Ethical clearance was sought from the Ethics Committee of the University of Zululand. The project data that was collected and used in this study was kept in a locked cupboard during the period of research and will be discarded after three years.

1.13 Resources

The items used by the researcher to conduct the study included items like stationery, reference materials such as books, journals, dissertations and internet access, and money for travelling, printing, photocopying, binding, editing as well as telephone expenses. Therefore, the researcher was funded through University of Zululand Research funds for the above items.

1.14 Feasibility

The area where the researcher conducted the research was accessible as it is the geographical area of operation for the researcher. The researcher used parents in the study for those children supported for their barriers to learning during the researcher’s line of duty. The reason behind this thinking was the belief that parents would be comfortable to share information with the researcher because of the trust and the relationship built during the process of supporting their children.

All 7 research participants’ home language is isiZulu. This was an advantage to the researcher because the researcher is well versed in isiZulu as a result there was no need for the co-researcher to interpret. Furthermore, owing to the fact that the data was collected over the weekends since the researcher is working during the week days, getting some of the participants to meet with the researcher was a challenging task because some parents had other commitments over the weekends. Thus, the researcher had to make the necessary adjustment as was dictated to by the situation at hand.

1.15 Intellectual Property

The only intellectual property right that the researcher observed during the research process was copyright. The researcher ensured that before the research study was undertaken, the appropriate
principles and mechanisms were in place to identify and have them protected. The rights and responsibilities of the researcher regarding the research and its dissemination and future related research projects and the participants and university regarding the research were clarified.

1.16 Knowledge Dissemination

The material generated by the research will be published at the University of Zululand library in the form of a thesis. Furthermore, few academic articles will be generated for publication in relevant journals.

1.17 Demarcation of the Study

This research study consists of five chapters.

Chapter one presents the general background and orientation to this study. The study is introduced by discussing the challenges faced by the parents and their children despite the government of South Africa’s attempts through the provisions in the Constitution of the Republic of South Africa 108 of 1996 to end discrimination against people with disabilities and their families. The aim, research context, theoretical framework, objectives, and the motivation for pursuing this study are presented. The key research questions explored are listed followed by the definition of the key terms.

Chapter two is on the literature reviewed in relation to the key research questions generated in chapter one. The reviews commence with a historical review of disability in South Africa during apartheid and post-apartheid government. The discussion of the concept of disability also follows. Secondly, the literature review maps the lives of the parents of children with disabilities. The impact of disability on the parents for children with disabilities is highlighted. The strategies used by the parents to cope with the situation of their child with disability as well as the support structures initiated by the South African government to support parents are presented.

Chapter three outlines an overview of the research design and methodology that was used in this study. The discussion of the research site follows. After presenting a brief discussion of the
research site, the research design, approach and the method used to gather data are presented. An account of the sampling techniques employed, ethical issues as well as limitations of the study is also presented.

**Chapter four** focuses on the presentation and analysis of data gathered from the in-depth interviews. This chapter begins with a brief narrative on the biography of the research participants in this study. The data is presented in terms of the themes extracted from the in-depth interviews schedule. Based on the data obtained on each topic, the researcher grouped the data into categories. The emerging trends and patterns from the presented data were then outlined.

**Chapter five** presents the findings according to the objectives of the study. After careful consideration of the findings, appropriate conclusions were drawn and pertinent recommendations were made.

**1.18 Summary of the chapter**

This chapter has presented an overview of the entire study by focusing on the following, research context, problem statement, motivation and rationale for the study, key research questions, aim of the study, objectives of the study, intended contribution to the body of knowledge, definition of terms, theoretical framework, research design, and methodology, ethical issues, resources, feasibility, intellectual property, knowledge dissemination, as well as chapter outline. The next chapter deals with the literature review relevant to this study.
CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

Society has undergone immense changes in the way it deals with people and children with disabilities. Munyi (2012) avers that over the years, perceptions towards disability have varied significantly from one community to another. Notably, therefore, throughout history, people with disabilities have been treated differently from those who are deemed to constitute the significant others. Various labels have been used for people with disability in the past such as crippled, lame, blind, dumb, deaf, mad, and feeble, idiot, imbecile and moron (Clapton & Fitzergard, 2006). In some instances, if there was any sign of disability at birth, the child was put into a hospital setting and the parents were told to forget about the tragedy and go home and make another child. These practices have disappeared throughout the years. Therefore, this literature review focuses on the historical overview of disability in South Africa with specific reference to the period spanning the apartheid and the post-apartheid governments. Secondly, the chapter discusses the concept of disability and thus maps the lives of the parents having children with disability. Lastly, it expounds on the support programs or structures that have been initiated by the South African government to support the parents who have challenges of having children with disability.

2.2 Historical Overview of Disability in South Africa

There are many specific circumstances that have influenced the living condition of persons with disabilities. History shows that ignorance, neglect, superstition, attitude and fear are social factors that have exacerbated the isolation of persons with disabilities not only in South Africa but also in the world. The desire to avoid whatever is associated with evil has affected people's attitudes towards people with disabilities simply because disability is associated with evil. Most of these negative attitudes are mere misconceptions that stem from lack of proper understanding of disabilities and how they affect the functioning of the person suffering from the disability in question. These misconceptions stem directly from the traditional systems of thought called superstitions that have led to the variations in the treatment of persons with disabilities in South
Africa as in other parts of the world (Amoako, 1977 in Munyi, 2012). This following section, therefore, embarks on the historical overview of disability in South Africa during apartheid and post-apartheid governments.

2.2.1. The Apartheid Era: Before 1994

Under apartheid the experiences of people with disabilities in South Africa were similar to the experiences of people who were living in a deeply divided and unequal society. The majority of the people with disability were not allowed to exercise fundamental political and economic, social, cultural and developmental rights such as employment, education, housing, transport, information, community life and appropriate health and welfare (Dube, 2002; INDS, 1997; McClain, 2002). The exclusion experienced by these people and their families was the result of a range of factors which included the following; the political and economic inequalities of the apartheid system, social attitudes which have perpetuated prejudice and stereotypes which conceive of people with disability as sick, dependent and in need of care, rather than as equal citizens with equal rights and responsibilities and a discriminatory and weak legislative framework which has sanctioned and reinforced exclusionary barriers (Dube, 2002, Lansdown, 2002; McClain, 2002). These inequalities and divisions between people were aimed at keeping black people subservient to white people and thus denied them access to basic rights and to ensure that they remained in condition of poverty with limited opportunities to share in the country’s wealth (Dube, 2002). This means that the lived experiences of black people and white people that had disabilities during apartheid were very different and reflected the inequalities between whites and blacks people in South Africa in particular (Ibid).

Although all people with disabilities irrespective of whether they were black or white were discriminated against and marginalized because of their disability, the conditions were worse for the black people because of the inequalities of the apartheid government. For the majority of them (black people), life was about struggling on a daily basis to cope with poverty, deprivation and violence of the apartheid system. Dube (2002) is in agreement with this statement by arguing that there were links between disability, violence and poverty fuelled by apartheid.
Consequently, the apartheid government played a pivotal role in creating the conditions of poverty and discrimination which people with disability experienced.

At the intentional level, the perceptions on people with disability began to change in 1981. This is evident in the UN’s declaration of 1981 as the Intentional Year of Disabled persons. Since South Africa was still under the apartheid regime, that particular year was not recognised in South Africa. The most important outcome of the International year of Disabled Persons was the adoption of the World Program of Action concerning the Disabled Persons during the UN decade of Disabled Persons from 1983 to 1993. The purpose of the World of Action was to promote the adoption and implementation of effective measures for the prevention of disability, rehabilitation and the realization of equal opportunities for the people with disabilities (Integrated National Disability Strategy-White paper, 1997).

During the 1980s the disability rights movement called Disabled People South Africa (DPSA) emerged in South Africa. People with disabilities spearheaded the strategy to mobilise and organise people with disabilities to resist oppression on the bases of both race and disability (McClain, 2002). This built a political foundation for the disability rights movement and a strong cadre of disabled activists. In an attempt to divert attention from violence which was ranging in the country at the time, South Africa declared 1986 as the National year of Disabled Persons. From the investigation carried out by the NGOs including the DPSA and the government on the circumstances of people with disabilities it was revealed that there was complete absence of any workable policy on disability (Integrated National Disability Strategy- White paper, 1997). Following the investigation, an Interdepartmental Co-coordinating Committee for the care of Disabled, involving state departments and the NGO sector, was established. Its role was to implement the various recommendations arising out of the 1986 investigation (Ibid). In 1991 it was disbanded because it has not succeeded in implementing a single one of its tasks and a restructured South African federal Council on Rehabilitation of Disabled Persons (SAFCD) was given responsibility for policy development.

In 1992, the Disability Rights Charter of South Africa was launched by the Disabled People South Africa and Lawyers for Human Rights. A Charter is a document which asserts the rights of all people with disabilities to live independently, in a safe environment and in a society free from
all forms of discrimination, exploitation and abuse (McClain, 2002). The aim of this assertion was to promote equal opportunities for all disabled people.

In 1993, the UN General Assembly adopted the Standard Rule on the Equalization of Opportunities for persons with disabilities in order to provide governments with clearer guidelines on action to be taken. South Africa as a member (country) of the United Nation became a signatory to the Nation’s Standard Rules on the Equalisation of Opportunities with Disabilities. The standard rules advocate for strong moral and political commitment by the state to take action towards the equalization of opportunities for persons with disabilities (Integrated National Disability Strategy—White Paper, 1997). Secondly, they offer an instrument for policy-making and action. The purpose in this regard is to ensure that all persons with disabilities exercise the same rights and obligations as other citizens. Thirdly, they outline crucial aspects of social policies in the disability field and thus provide models for the political decision-making process required for the attainment of the much-desired equal opportunities.

2.2.2. Post -Apartheid South Africa: 1994 onwards

It has been argued above that people with disabilities in South Africa have been through a long and arduous struggle to have their rights recognised and to overcome marginalisation and exclusion. Notably, people with disabilities in South Africa have made considerable progress by working together, not just as recipients of services but proactively as change agents/activists with Government disability. As a result, the South African government took major steps since 1994 to ensure that people with disabilities do not continue to be subjected to the discrimination, inequities and the exclusions of the past (McClain, 2002). The government of South Africa thus prioritized the issue of disability since 1994 as a commitment to challenging the profound, social and economic injustices experienced by people with disability. This is evident in the range, nature and status of measures introduced to achieve change. The paramount objectives have been the enrichment of fundamental human rights of all South African citizens.

Thus, since 1994, the South African government has formulated various policies to address the inequities which were embedded in the policies pursued by the apartheid government. These policies have focused on empowering previously disadvantaged groups including, women,
children and persons with disabilities. These policies are contained in various policy documents such as the RDP, Growth Employment and Redistribution (GEAR) and Integrated National Disability Strategy (INDS). It can be gleaned from these policies and legislations that they include disability components or the essential policies and legislation with disability components such as, the Employment Equity Act, the Labour Relation Act, Social security Act of 2004, Education White paper 6 on Special Needs education, Rehabilitation White paper and Convention of the Rights of the Child, Equal Employment opportunities that enable disabled people to participate actively in the economy.

One of the transformative documents adopted by the post-apartheid government is the new Constitution Act 108 of 1996 which is designated as the supreme law of the Republic of South Africa and whose major concern is to protect the rights of people with disabilities. It is notable that the new Constitution extended basic human rights to all citizens by outlawing unfair discrimination against any person on a number of grounds. It is also provided for the creation of equity among all people in the country by recognizing the need to implement specific measures that would address the disadvantages that particular groups of people have experienced in the past. Of importance to note also is the fact that the Constitution acknowledges that people with disabilities have in the past and may continue to be discriminated against because of their disability. Therefore, disability is included in the constitution and in policy documents that make up South Africa legal and policy framework.

It is arguable, therefore, that the new Constitutional framework also marked an important milestone in the struggle of people with disabilities to overcome their previous exclusion. Arguably, this recognition of disability reflects the struggle of disabled people to be treated equal and such a struggle derives support from article 9 (3) which specifically enshrines equality for persons with disabilities.

In November 1997, the government of South Africa adopted the White Paper on Integrated National Disability strategy (INDS). The INDS provides government and society as a whole with guidelines that seek to promote non-discriminatory development planning program implementation and service delivery. The INDS emphasizes the attainment of a good and
equitable quality of life for disabled persons in the country. Its main objective is systematic integration of the disabled into all policies, plans, programs and strategies aimed at enhancing the quality of life of persons with disabilities at all levels, within at all levels, within all sectors and institutions of government with the adoption of this strategy. This is when South Africa was beginning to recognize the rehabilitation need and civil rights of persons with disabilities. The legal rights were translated into a strategy for action called Integrated National Disability strategy in 1997. This strategy treats disability as a human rights and developmental issue and thus promotes a social model of disability. The strategy stresses the need for the reconstruction and the development of the South African society with the objective of addressing the developmental needs of disabled people within a framework of inclusive development. A central principle embodied in the INDS is the right to self-representation which is defined as meaning that the collective determination of disabled people must be used to inform the strategies of government. It also committed itself to the introduction of integrated and sustainable policies. In 2002, the South African Declaration on the United Nations Decade for Disabled Persons noted with concern that the majority of South Africans with Disabilities continue to live in conditions of extreme poverty and do not enjoy equal access to economic and social rights. It also reaffirmed the importance of self-representation by people with disabilities in effective transformation forums towards an inclusive society that recognizes the diverse needs and priorities of people with disabilities.

Despite the achievements in terms of policy and legislation, there has been limited impact on the lives of the people with disabilities. While there is political will to address the needs of the people with disabilities, knowledge on disability is very fragmented, and there are many gaps in service delivery. This view is corroborated by Dube (2002) in the assertion that in the case of many social problems, policy alone is not sufficient to bring about change. However, policy has to be matched with an equivalent determination in service provision within the context of an exploration of societal and cultural practices and beliefs (ibid).

Many of the pre-1994 apartheid barriers have been broken down. But many barriers remain, particularly those that relate to people with disabilities. It is clear that the breaking down of many of these barriers requires more than just laws. As such, it requires attitudinal shifts. In light of
this, it is, therefore, critical that South Africans, disabled and non-disabled be assisted in breaking down the barriers and creating a culture in which we recognize difference, celebrate diversity and ensure equality.

2.3. Cultural and Social Beliefs about Disability

Throughout history, many, if not all societies, have dealt poorly with disability. They have given different interpretations of what constitutes a disability and what it means to have a disability. Cultural beliefs about disability have played an important role in determining the way in which society perceives it. The birth of a child with disability resulted in a crisis within the family. The impact ranged from the social, cultural and to the economic levels. This was exacerbated by the absence of supportive attitudes and structures within the community.

It is argued that cultural, religious and popular social beliefs often assume that a child is born with a disability or become disabled after birth as the results of a curse, bad blood, an incestuous relationship, a sin committed in a previous incarnation or a sin committed by the child’s parents or other family members (Gupta & Singhal, 2004, UNICEFF, 2005). Arguably, a child born in a community where such beliefs exist does not put only the child at risk but also the parents. As a consequence, the child in all likelihood becomes subjected to isolated, eviction and sometimes gets killed (Lansdown, 2002). Some children with disabilities may be killed either immediately at birth or at some point after birth and sometimes years after birth. The rationale for such killings is either (1) premised on the belief that the child is evil, or will bring misfortune to the family or to the community or (2) the belief that the child is suffering or will suffer and is better off dead (UNICEF, 2005).

The belief that a child is born with a disability or becomes disabled as the result of witchcraft, evil spirits or being inhabited by the Devil is widespread in many societies in both developed and developing countries (UNICEF, 2005). Cultural and social factors have a detrimental effect on parents, the community and most importantly, the child with disability. As a result, parents of children with disabilities are put under unbearable pressure by cultural and religious beliefs by asserting that the child is the embodiment of sin and disgrace (Lansdown, 2001). They are also
denied the normal social support and celebration that is given to parents of nondisabled children. The resultant effects of superstition, fear and prejudice in some communities mean that mothers of a child with a disability may be scorned and rejected. The problems faced by the parents of children with disabilities may include isolation from the circle of immediate family and friends. This is an indication that lack of social support, limited opportunities for education, employment or participation in the community further isolates disabled children and their families, leading to increased levels of stress and hardship (UNICEF, 2005).

In some societies individuals with disabilities were considered to be in the possession of an evil spirit or demon and often went through the prescribed ritual to drive out the offending element (Clapton & Fitzgerald, 2006; Thengal, 2013). This constituted one of the responses to societal beliefs about disabilities and the attendant lack of social support systems for individuals with disability and their family excluding the actual physical condition of the child in question (UNICEF, 2005). In this regard, therefore, the life of a child with disabilities and their families are surrounded by stigma, discrimination, cultural prejudice and ill perceptions.

2.4. The Concept of Disability

Disability can affect anyone at any time regardless of age, gender, culture, ethnicity or social class. It is recognized as a universal human experience. It bears that disability is defined as a condition which may restrict a person’s mental, sensory, or mobility to undertake or perform a task in the same way as a person who does not have disability. Other scholars, however, view it as the disadvantage or restriction of activity caused by a society that takes little or no account of people who have impairments and thus excluding them from mainstream activity within multiple contexts (UNICEF, 2007). What transpires from these definitions is that disability is defined in different ways, depending on the model that is used as the basis for the definition being rendered. It is worth noting, therefore, that critical disability theory thus recognizes the need to consider both personal and social factors when trying to understand disability, without making one aspect dominant over the other (Hiranandani, 2005).
In the context of this study, a person is defined as having a disability if he or she has difficulty performing certain functions, for example, seeing, hearing, talking, walking, climbing stairs and lifting and carrying or has difficulty performing activities of daily living or has difficulty with certain social roles such as doing school work, working at a job or around the house (Agbenyega, 2003). Agbenyega (2003) further argues that a person who is unable to perform one or more activities, or who uses an assistive device to get around or who needs assistance from another person to perform basic activities is, therefore, considered having a disability (Ibid). In light of this, this section discusses the concept ‘disability’ by focusing on its models, its social construction and the rights attached to it.

2.4.1. Models of Disability
The concept of disability has been traditionally defined in medical and welfare terms and this traditional definition was the only central paradigm for understanding disability (McClain, 2002). When this concept is used in legal medicine, it implies the loss of mental or physical powers as a result of injury or disease. In this instance, any person whose ability to function in a normal manner is limited by physical, cognitive, visual or environmental factors is said to have a disability. When disability is interpreted as an illness or impairment, it is viewed as occurring in an individual’s body or mind. According to Devlin and Pothier (2006) and Hosking (2008), it is construed as personal misfortune. Thus, the source of the disadvantage experienced by the people with disabilities is identified as the medical condition.

Over the years, the meaning of disability has evolved constantly. It has shifted from the medical model which views disability as an individual deficiency to the social model which asserts that it is social and economic structures that also contribute towards the creation of disability (Michailakis, 2003; Anatasious & Kaufmann, 2011; WHO, 2011 in Baffoe, 2013). The social model of disability acknowledges that the way society is organized limit people activities. In other words, the discriminatory aspects of society disable people (McClain, 2002). Using this model, people live in a world which disabling and hostile and is largely designed to suit able-bodied people. As a result, it is now generally accepted worldwide that disability is a social construct in which most of its effects are inflicted on people by the social environment.
2.4.2. The Social Construction of Disability

Those who define disability using a social model believe that it is a social construct and not a description of a medical condition. It recognizes that the way societies are constructed, both through the characteristics of its built environment and the prevailing attitudes and assumptions, result in restricted opportunities for people with disabilities to participate on the basis of equality of opportunity (Lansdown, 2001). Thus, disability can be socially constructed through the actions of society in erecting barriers and structures that limit the ability of certain persons in society to function normally (McClain, 2002). Such physical, organizational and attitudinal barriers also limit the ability of such persons to access the opportunities, privileges and resources in society. These barriers prevent the disabled from gaining equal access to information, education, employment, public transport, housing and social / recreational opportunities.

The primary source of disadvantage is not the impairment but society’s responses to people who are considered to have disabilities. For instance, if a community allows physical, architectural, transportation and other barriers to remain in place, society is creating handicaps that oppress individuals with disabilities. If, on the other hand, a community removes those barriers, persons with disabilities can function at much higher levels. In simple terms, it is not the inability to walk or inability to sit that prevents a person entering a building unaided but the existence of stairs or the lack of benches to lie down that are inaccessible to a wheelchair-user or a person with a sitting disability. This serves as an indication that adults and children are disabled by prejudice and stigma, direct or indirect discrimination and a failure of society to adapt and accommodate their needs (Lansdown, 2001).

2.4.3. Disability and Rights

It is notable, however, that during the past decades in South Africa particularly in the 1990s disability was reframed as an issue of human rights, social entitlement and economic opportunity (McClain, 2002). Lansdown (2001) corroborates this claim by arguing that finally, disability is slowly being recognized as a human rights issue and not welfare. Therefore, adults who have disabilities and children are not victims to be protected or inferior beings to be shut away and
avoided. On the contrary, they are people with equal rights, equal responsibilities and an equal contribution to make to society. This is an indication that people with disabilities have rights to autonomy, individual rights as well as rights to full participation in society (Hosking, 2008). Several human rights legislations, for example, the Universal Declaration on Human Rights; the UN Convention on the Rights of the Child; the UN Convention on the Rights of Persons with Disabilities, clearly establish that people with disabilities have the same rights as other members of the societies they live in. Discrimination on the grounds of disability is, therefore, prohibited. Notably, the critical disability theory embraces human (and legal) rights as an indispensable tool to advance the equality claims of people with disabilities and to promote their full inclusion into all aspects of their society (Hosking, 2008; McClain, 2002).

2.5. The Lives of Parents with Children with Disabilities

Children with disabilities and their families constantly experience barriers to the enjoyment of their basic human rights and their inclusion in society. Their abilities and capacities are underestimated and as a result their needs are given low priority (Lansdown, 2001; UNICEFF, 2007). Arguably, the barriers they experience are more frequently as a result of the environment in which they live as opposed to them being a result of their impairment. In addition, the birth of a child with disability or occurrence of disability in a family often places demands on the family’s morale by thrusting into deeper poverty (Lansdown, 2001). Most parents of children with disability have concerns that range from education, access to services and other issues related to their children’s needs. Besford, Rabie, and Sloper (2007) argue that very little is known about how parents want their children’s lives to be. Therefore, this section focuses on the lives of parents of children with disability with the view of getting insight into their experiences by focusing on the following themes: the parents’ reaction to having a child with a disability, the parents’ attitudes towards children with disability, parenting a child with a disability, social exclusion of parents of children with disability, dealing with stigma as parents of a child with a disability, the impact of a child with a disability on the parents and adjustment of parents of children with disability.
2.5.1. Reaction of Parents to Having a Child with a Disability

When a family finds out that they are expecting a child, it is usually a time of celebration and planning for the future (Oeckerman, 2001). Even before the child is born, the parents and extended family talk about what the child would look like, what he or she will grow up to be and the activities that the whole family will do together (Ibid). However, when parents discover that their child has a disability, their expectations change. As a result, they are likely to have many reactions to the diagnosis of their children with disabilities and these reactions can be positive or negative ((Ferguson, 2002) in (Friend & Bursuck, 2009). In most instances, parents initially tend to react in a negative way and their reactions are similar to those related to bereavement (Heiman, 2002). They deal with greater stress and a number of care giving challenges which include among many, health problems, greater feeling of restriction and high level of parental depression than parents of children without disability. It is further argued that they face great sadness, fear, worry and more from loved ones and from family members regarding their little angels with eyes of spite, concern and even disbelief that they have a disability (McGill-Smith, 2003). McGill-Smith (2003) avers that they begin a journey that takes them into a life that is often filled with strong emotions, difficult choices, interactions with many different professionals and specialists and an ongoing need for information and services.

It bears repeating that usually, parents wish and dream for a healthy baby even before the child is born and they also hope that it will be so. But when they discover that a child has a disability, their hopes and dreams held by parents are destroyed. Such parents then start to grieve the loss of hopes and dreams (Taub, 2006). During this period of grief, they go through several emotions roughly in a sequence. Blacher (1984) in Rörich (2008) asserts that in situations such as these parents go through sequential stages in an adjustment or mourning process. Other parents might experience only one or several discrete reactions. Among other things, their reactions can include shock, denial, anger, bargaining, depression and acceptance blame/guilt, anger, fear, frustration and sorrow (McGill-Smith, 2003; Oeckerman, 2001; Rörich, 2008). Kuhler-Ross and Kessler (2005) argue that not everyone goes through these stages in a prescribed order.
**Shock**

According to Dale (2009), the initial reaction experience by most parents is an overwhelming shock, which result from the fact that parents have anticipated a normal baby. It is overwhelming because the expected child never arrives. With shock comes denial.

**Denial**

Ho and Keiley (2003: 239) assert that denial is a defense mechanism used by parents as they feel unable to cope. In most cases, parents who are in denial will avoid talking about the child’s disability. As a result they will end up making excuses and alternate explanations of the problem. Lessing and Strydom (2001) outline four common forms of denial:

(a) Refusing to recognize the child’s disability.
(b) Rationalizing the child’s disability.
(c) Seeking professional confirmation that there is nothing wrong with the child.
(d) Quickly becoming too cooperative with professional approaches in dealing with issue.

**Guilt**

The next stage after denial is guilt. Guilt revolves around feelings about what one thinks could have been done. Parents feel responsible for their children’s disabilities even when the children are well into their adult life (Niedecken, 2003). Hereafter parents may feel anger.

**Anger**

Anger occurs as denial breaks down and the child’s condition becomes more real and apparent (Lerner & Kline, 2006: 153). Anger is projected on teachers, doctors, their partners or on their siblings and towards the children. Some parents may be angry with themselves over the child with a disability due to their failure to fix the problem. If the child is struggling at school, some parents attempt to cope by believing or saying that the child is not learning because the teacher is not doing his/ her job, incompetent teacher and school staff as a whole has caused the problem.
Grief

Some parents feel grief about their child’s disability. It is necessary for parents to grieve. According to Kuhler-Ross and Kessler (2005:78) “grief is the shattering of many conscious and unconscious beliefs about what our lives are supposed to look like”. This means that the parents’ dreams for their child’s future are shattered. Therefore, they have to come to terms with this through grief. Sometimes grief stems from sorrow for the pain or discomfort that their child have to face in life, sometimes it stems from their sadness because of the added stress on the family due to a child with a disability. Sometimes it results from the sense of loss for what the child might not become. It might be temporary or can be chronic as they realize everyday how their lives are different from the lives of those families with children without disabilities. In most cases parents who grief over their children’ disabilities are usually concerned that their child might struggle for the rest of their lives. They might worry that the child would not be successful in life because of the disability. They might even feel new grief over the years if their children have difficulty of various milestones when other children succeed.

Physically, their baby is not lost; he or she is right there with them. Instead, these parents are grieving for their hoped for child, the child they were expecting who never arrived. Parents have to adjust their expectations and hopes for their child in the face of the substantial uncertainties inherent in their child’s medical, motor, intellectual and social prognosis. Emotionally and cognitively, parents must come to terms with their child’s condition.

Acceptance

A final stage is when parents come to accept that their child has a disability. According to Kubler-Ross and Kessler (2005), acceptance is often confused with the notion of being all right or OK with what has happened. It is something parents learn to live with. Acceptance is the stage at which the parents can look past the disability and accept the child as he or she is. The goal is to reach acceptance to be able to make decisions about how their child will be helped and such decisions are unclouded by undue emotions. The parents accept their child along with his her disability, while continuing to live a normal life (Learner & Kline, 2006).
2.5.2. Parental Attitudes towards (their) Children with Disabilities

According to Gibran (1986) cited in Chandramuki, Shastry and Vranda (2012), children are the perfect expectation and expression of a couple’s love and caring. Usually, every parent dreams about his/her child being ‘perfect in all respects. The emotional preparation for expectant parents is usually shaped by glamour image of the baby, a kind of ego ideal. But when the child is born with a disability, the parents are disappointed and develop negative attitudes towards the child because of the discrepancy between the perfect child of their fantasy and the real child (ibid). Very often parents develop negative attitudes towards their child with a disability as they are plagued with so many feelings which include pessimism, hostility, and shame, denial, projection of blame, guilt, frustration, withdrawal, rejection, anger, and despair that sweep through them as they are confronted by the child with a disability (Gupta & Singhal, 2004; Chandramuki, Shastry & Vranda, 2012). Understandably, loss of hope for the ‘perfect child’ causes grief, and over time the feeling is heightened by lowliness, isolation, and exhaustion. Researchers have noted that the birth of a retarded child shatters the hope and aspirations, leading to hopelessness and negative attitude towards the child (Dave, 2012; Rathore, 2014). These parents’ negative attitudes towards the child might not have been present before the diagnosis. Parents develop them once the child is diagnosed with a disability. Their behaviour patterns too might change resulting from the loss of hope about education, future of the children, home management and they also feel more hostile towards their children.

Various researchers argue that this can be a shattering experience particularly for a parent who has practically no knowledge about disability and has the child stigmatized as having the disability. Usually, parents strive to understand the disability and its implications. They struggle to cope with their own emotions and the reaction of others. Studies reveal that these negative attitudes adversely affect the parents. Their attitudes towards their child change, resulting in changes in responses towards the child. These attitudinal changes in turn might have an adverse effect on the child (Kumar & Rao, 2008). This is consistent with Govender’s (2002) assertion that all children regardless of the severity and type of disability develop self-images and feelings about who they are and how they think others perceive them. The attitude of the significant others in the child’s life determines how the child feels about himself / herself and about his/her handicap. Therefore, the most "significant others" in a child with disability are their parents who
are seen as primary socializing agents. Govender (2002) further avers that handicapped children will have positive self-concepts if they are defined positively by their "significant others" and negative self-concepts if their "significant others" do not evaluate them highly. Thus, the role of parents and others such as siblings is of vital importance, especially for a child with disability whose inter-personal experiences are mainly within the family context. The nature, severity and onset of a disability impacts less on how the child will function in the future, when compared to the impact of the attitude of his parents, first and foremost, his peers, teachers and society. Govender (2002) also argues that the parent's attitude towards their child impacts greatly on the child's sense of self. A child's personality is mainly formed by his parents attitudes towards him and a child's attitude towards himself is conditioned by the parents attitudes" (Ibid).

The arguments advanced above are corroborated by Thengal’s (2013) assertion that the behavioural reactions of the retarded child are by-products of several interacting forces which started from the time of conception. Not only these interacting forces are responsible but other factors like attitudes and personality patterns of the family members, his peers and society in which he lives, play an important role in the normal development of a child (ibid).

Furthermore, overprotection and rejection are the common parental attitudes towards children with disabilities (Chandramuki, Shastry & Vranda, 2012). Parents tend to over-protect their child and feel guilty that they are responsible for the child's disability whereas some become over-protective and fail to make realistic demands on the child. Due to unfavourable parental attitudes, children with disabilities show behavioural problems which in turn prevent them from using even their limited capacities.

Gupta and Singhal (2004) assert that in most cases parental expectations from a child with a disability are mostly negative and unrealistic. The reason behind this notion is the fact that there is belief that the member of the family with a disability could not do anything and just needed help and sympathy. Due to this parents fail to recognise that many of these children can be high achievers in various creative activities such as music, dance, drama, sports, drawing, painting etcetera. Unfortunately, parents fail to recognise and encourage these strengths unless children
show academic achievement. This state of affairs can be detrimental to the mental health of the child with a disability. However, parents need psycho-educational inputs to lower the high academic expectations and help in identifying the child’s strong points. This would reduce high expressed emotion towards the child with learning disability.

2.5.3. Parenting a Child with a Disability

For Sams (2012), the concept of parenting is multifarious as it incorporates the relationship of both parents and child as well as characteristics of each. This is because some aspects of parenting, such as nurturance or harsh discipline, have been linked to various child development outcomes, while child characteristics, such as behavioural problems, have been related to outcome in parents mainly the mother. This shows that parenting does not exist in isolation but is an ever-changing and transactional relationship. Most of the research on the experiences of families who have a child with a disability indicates that although there might be commonalities in the parenting experiences, the impact differs considerably among families (Hanson, 2003; Muscott, 2001) in Joosa and Berthelsen (2006). Therefore, this sub-section tries to explore ways in which parents raise their children with disability.

Parenting influences the child’s development and is characterized by the parent-child dyadic relationship. The aim is for the parent to socialize the child. Parenting is demonstrated as the degree and the manner in which a parent encourages the balance of conforming to social standards while encouraging the child’s individuality. This does not only incorporate the expectations for the development of children but also the manner in which parents choose to meet those expectations through methods of discipline and nurturance (Locke & Prinz, 2002) cited in (Sams, 2012). Additionally, characteristics such as child engagement, limit setting and responsiveness are found under the umbrella term of parenting, among many others. Therefore, there is a confusion of what exactly parenting entails. According to Baumrind, (1971) and Darling, (1999) cited in Sams, (2012) it does not appear that one characteristic is considered more or less important than another although it seems as if all parenting behaviors are part of a dynamic system of care. It might also be recognized not simply for the presence of behaviors, but as a result of the degree to which these behaviors occur or because of the variations methods.
For instance, discipline might be examined based on the level of harshness, such as, physical discipline, a tap on the hand versus spanking. Parenting is also defined by quality, which might encompass an array of behaviors exhibited in a variety of ways. For instance, higher quality parenting might be characterized by expressing affection demonstrated by hugging and playing (Sams, 2012).

Even though parenting has been defined in a number of ways, the most prevalent way of examining parenting is through the concept of parenting styles. The foundation of much understanding of parenting styles is based primarily on the work of the research Scientist Baumrind who identifies four main patterns or parenting styles: authoritative, authoritarian, permissive and rejecting-neglecting (Sams, 2012). An authoritarian parenting style is characterized by high expectations for the respect of authority and less dependency on a parent. This means that parents exhibiting this style of parenting might show less warmth towards their child while being more punitive in discipline techniques, appears more rigid in their rules, and be less inclined to engage in dialogue with their child about the rules (Sams, 2012). However, it is stated that parents employing permissive style employ less parental authority and more dependency to them. These parents might be considered as having warmth in their affect but are not likely to impose many rules on their children (ibid).

Considering an authoritative parenting style, Sams (2012) argues that it is a combination of both parenting styles in that there is a balance on how a parent encourages a child to conform to parental expectations with rules but allow dialogue with their children on the purpose of these rules. In addition, parents from an authoritative style are likely to understand the value of their roles as authority figures while also maintaining an awareness of the distinctiveness of their children’s contribution to the family (Baumrind, 1971) in Sams (2012). In other words, these parents are demanding and responsive. However, parents who are using rejecting-neglecting are neither demanding nor responsive. Therefore, Sams (2012) argue that it might be that it is more stressful for a parent to implement a parenting style that is inconsistent with the needs of his/her child but this has not been supported empirically. She also argues that the literature on parenting young children with disabilities is so varied that it is difficult to draw any accurate comparisons between parenting children with disabilities and those without disabilities.
Parents of children with disabilities often have two roles i.e. parents and carer. As in families of non-disabled children, the mother tends to be the children’s primary carer. Various research have shown that being a parent to a child with a disability or impairment can be emotionally engaging, as well as distressing for both fathers and mothers. It is because parents of children with disabilities play a number of different roles in relation to their children, such as tracking developmental milestones, watching the development of the disabled child on day-today level, and noticing when he or she does not develop as the same rate as other children of the same age (Dobson, Middleton & Beardsworths, 2001). They are required to take care for their children on a daily basis and play an important role in teaching their child to be independent.

As a result, parenting a child with a disability presents unique challenges to both fathers and mothers. Some parenting issues might be more acute. A comprehensive literature review reveals that mothers and fathers of children with disabilities do experience more depression, multiple-level factors such as internalized parental stress; socioeconomic status; family rules, rituals, and routines; lack of adequate insurance coverage; and inaccessible community resources which tend to compromise the quality of parenting for caregivers of children with disabilities or who have special health care needs (Algood, Harris, & Hong, 2013). These parents also encounter difficulties relating to the children’s access to health services both in terms of information, distance and physical access. The struggle with health services is caused by the misinformation and attitudes of workers that they have to deal with.

The majority of the literatures suggest that the growing body of research findings also suggest that parenting style, family dynamics, and environmental factors are important for understanding, assessing, and managing children’s disabilities and/or special health care needs. A number of studies have shown that poor parenting quality has been found to be associated consistently with negative outcomes of children with disabilities and special health care needs such as behavior problems (Hastings, 2002; Herring, Gray, Taffe, Sweeney & Einfeld, 2006). It is also suggested that research on parenting young children with disabilities have diverse findings and is actually contradictory in a few situations (Sams, 2012).
2.5.4. Social Exclusion of Parents with Children with Disabilities

Kamerman and Kahn (2003) argue that the concept of social exclusion is difficult to define because it is a multi-dimensional concept which is concerned with the inability to participate effectively in economic, social and cultural life and that it also entails some characteristics such as, alienation and distance from mainstream society. Put differently, social exclusion is defined as the inability to participate in and be recognized by society. As such, it is often described as the process by which individuals and groups are wholly or partly excluded from participation in their society as a consequence of low income and constricted access to employment, social benefits and services and various aspects of cultural and community life (ibid). Like poverty, it is not attributed to a single cause as it is concerned with the broader range of capabilities people enjoy or fail to enjoy. Notably, therefore, social exclusion involves several dimensions of deprivation and participation.

Thus, it can be gleaned from the definitions above that social exclusion, as a concept, focuses on the relationship between the individual and the society and the dynamics of that relationship. Of importance to note, therefore, is that the main groups that are potentially subject to social exclusion include those from disadvantaged backgrounds and those with disabilities. Social exclusion then shifts the responsibility to society, which is seen as erecting obstacles to progress of particular individuals and groups and to citizenship itself. It is then seen to be present in almost any of the domains of modern living, including education, employment, community life and citizenship to which individuals or groups fail to gain access or get excluded from (Boardman, 2011; Bynner; 1996).

Levitas, Pantazis, Fahmy, Gordon, Lloyd and Patsios (2007), add a composite working definition of social exclusion in their assertion that social exclusion is the denial of resources, rights, good services and the inability to participate in the normal relationships and activities, available to the majority of people in the society, whether in economic, cultural or political arenas. This approach emphasizes the inability to participate in and be respected by mainstream society as a violation of a basic right that should be open to all citizens and thus involves the restriction of access to the capabilities essential to functioning in adult life. It also affects both the quality of
life of individuals and the equity and cohesion of society as a whole (ibid).

Arguably, social exclusion goes beyond income poverty and can provide new information and insight regarding causes and solution to a wider range of problems and dimensions of the disadvantaged. Furthermore, social exclusion occurs in context of complex conditions and factors that prevents children from participating in schools, communities and society (UNESCO, 2000). Characteristically, therefore, it encompasses both prior disadvantages and marginalized status whereby the individual is effectively prevented from participating fully in the modern state.

Thus, some scholars have argued that for most people the social exclusion of children is largely associated with the social exclusion of their parents. This means that social exclusion of children cannot be separated from that of parents especially with regard to not only very young but also children with disability. As a matter of fact, families often experience discrimination because of their association with a person with a disability. This discrimination ranges from being denied access to public places, such as playgrounds and restaurants, the economic discrimination of being excluded from the labour market because of the need to care for the family members who have a disability or restricted mobility because of exclusion from transportation (Vacekauksaite, 2007).

Vacekauksaite (2007) further asserts that many groups, including people with disabilities, experienced social exclusion because of deprivation, either of resources (such as income), or of social links to the wider community or society. However, socially excluded individuals have been denied access to the resources that enable them to acquire capabilities and such capabilities relate to cognitive development and educational success although these also extend to the broader spheres of health and social participation.

In the long run, both children with disabilities and their family experience isolation and marginalization from other families within their community. Eventually, these factors might result in marital breakdown, with the mother commonly staying with the child with a disability in reduced economic circumstances. The result and effect would be that the mother and the children
experience further social alienation and loneliness. Although it is argued that disability can lead to exclusion, it is not the only key reason for being excluded. Children with disabilities and their families might face specific barriers to social participation and inclusion. Notably, social exclusion is not an intrinsic part of a disability or impairment. On the contrary, it is a particular set of circumstances that increase the likelihood of social exclusion and deprivation which can compound the situation. Therefore, an analysis of the social context, including the family’s resources and attitudes is important for understanding social exclusion as a social phenomenon.

2.5.5. Dealing with Stigma as Parents of a Child with a Disability

The parents of a child with disability are first and foremost parents. They have hopes and great dreams for their child. They identify and celebrate the same positive qualities in their child, trying hard, keep on trying and doing their best as all parents do. However, it is sad that much, if not most of the evidence, points in the opposite direction. Too often, these families are thwarted in their attempts at even the most mundane of activities by the prejudice and lack of understanding they encounter when they are out in the public domain. The attitudes and actions of the general public are unthinkingly negative, even hostile, effectively stigmatizing the child with disabilities and by association, their parents (Richardson & Fulton, 2011).

Notably, a person’s disability is perceived as extending far beyond the unfortunate limits of the disability to affected traits and functions. Eventually, stigma results from such attitudes. Stigma is seen as the single most difficult barriers to living normal and productive lives by persons with disabilities. According to Agbenyega (2003), stigma refers to the negative and prejudicial ways in which people living with disabilities are labeled. It can be used to refer to any attribute that is deeply discrediting and incongruous with our stereotypes of what a given type of individual should be (Kando, 1984) cited in (Wnoroski, 2008). Stigma arises from a number of factors and some of these are, superstition /ignorance, lack of knowledge and empathy, old belief systems and a tendency to fear and exclude people who are perceived as different from the rest (Avoke, 2002).
Goffman (1963:2) cited in Munyi (2012) avers that "Society establishes the means of categorizing persons and the complement of attributes felt to be ordinary and natural for members of these categories". When one falls into the stigmatized category or possesses an undesirable attributes those who are not of this category tend to devalue the stigmatized individual, to practice the variation of discrimination and to impute a wide range of imperfection on the basis of the original one and at the same time to impute some desirable but undesirable attributes often of the supernatural cast, such as sixth sense or understanding to the stigmatized individual (ibid). This phenomenon of stigma extension is described as it takes place when a person with a disability is seen as disabled not only with respect to the specific area of disability but also to other characteristics, such as personality and adjustment. Due to stigma, persons with disabilities are often treated with disrespect. This show of disrespect and discrimination might lead to social exclusion, bullying, aggression, ridicule and devaluation of the self-worth of the person. Such discrimination meted out against persons with disabilities results in oppression against them in all areas of life.

Various researchers agree that parents of children with disabilities experience what Goffman defined as “courtesy stigma” (Bartex, 1989, Birenbaum, 1970, Gray, 1993, Scambler, and Hopkins, 1986) cited in Gray (2002). Courtesy stigma is a stigma of affiliation which can attach to an individual as a consequence of their association with stigmatized groups rather than as a result of innate attribute or behaviour or through any characteristic of their own. These people are ‘normal yet different’. They have a biographic identity that is spoiled only through association with the stigmatized individual. In the context of families of a child with disabilities parents might become the object of courtesy stigma simply because of their relationship with the child and not because of any shared disability.

Birenbaum (1970) in Gray (2002) also argues that relatives of a stigmatized individual might go through cycles of affiliation during which they are more willing to bear the burden of a courtesy stigma at certain times than at others. As consequence of courtesy stigma, many parents tend to isolate themselves and their families from social contact with the outside world. They also tend to avoid excessive involvement with an organization that services the needs of the disabled so as to avoid over identification as a family with a disability (Gray, 2002). They restrict their
socialization to those individuals who show consideration to them. According to Dhar (2009) in Baffoe (2013), this is called self-stigma, a stigma which occurs when persons with disabilities and their families internalize society’s negative attitudes towards them, leading to low self-esteem and feeling of hopelessness. Hence, they fail to seek help from services that might have a positive impact in their lives. Therefore, the effect of stigma experienced by parents of children with disabilities should not be underestimated, not least because it is experienced in addition to, an alongside the range of challenges and stressors with the arrival of a child with a disability.

2.5.6. The Impact of a Child with a Disability on Parents

Having a child with a disability is not an experience anyone expects to have; rather, it is a journey that is unplanned (Brown, Goodman & Kupper, 2014). No parent ever wants his or her child to be sick, to have a disability, or harmed in any way. The diagnosis of a child’s disability and the adaptations that have to be made in the family have an impact on the home life of the family, on the siblings in the family, the interactions between the parents and the child (Buchman, 2006). At times, parents who have a child with a disability might have conflicting personal feelings of love, understanding and hope for their child and a society (including physicians, neighbors, school staff, and family members) that seemingly the negative aspects of the disability. When these same parents get frustrated and angry with their situation, the world around them can misinterpret that anger as "bad parenting." These conflicts might leave the parent feeling estranged from a world in which normalcy and health are best understood and viewed as the optimum.

Social acceptance

Passing judgment, accepting a child or family socially are two things a family faces in dealing with a child with a disability, especially a child who does not wear their disability out in the open for all to see. This is corroborated by Friend and Bursuck’s (2009) assertion that this is something that is experienced by all families having children with a disability. Even today in our society many children and adults who suffer with disabilities are socially unaccepted (ibid). From close friends and family, everyone has an opinion on how the family should deal with
things and issues they face. It is not easy and it can be disabiling to a family that is already struggling to cope and keep its head floating above the water.

Isolation

Families can find themselves isolated from their support circles (family and friends) when dealing with a child that has special needs or a disability. Many families stop socializing when they discover that they have a child with a disability. This is said to be emanating from fear of how that child and they will be received by the public and those around them that matter to them, how their child will be loved while they learn to deal with the issue at hand. Notably, the responses are varied with some families pulling away, making new friends and finding new families who have children with disabilities who can better understand the hardship they are facing, the struggles they are going through, the guilt, loss, anger, pain and fears that go along with raising such as child to help aid them in not feeling so alone, empty and disregarded by those who are supposed to support and love them (Sloper, 1999). Arguably, many people do not understand how great a role isolation plays for those who discover that they have a special child with special needs or a disability and that such a child needs more than just love and social acceptance which the parents wish for their child.

These parents often lack social support as family and friends distance themselves. Some of the resultant effects are that they might find it difficult to secure a school which is willing to take their child or they might be living in communities where there are few or no social services to help them with their child’s needs. As a result, parents might react violently to their child because of the social isolation and stigma they encounter from their immediate family, friends and neighbours. Some parents also report loss of friendships as a result of having a child with disabilities but also cite other parents of children with disabilities, personnel from agencies serving people with disabilities, and caring health professionals as primary members of their new friendship networks. In the interviews the researcher has had with the parents, they intimated that they might not have had relationships with such a depth if they had not had a child with a disability.
Stress

The literature is in agreement in reporting that families do experience high levels of stress. The nature of stress have been shown to span over several aspects of family life such as daily care demands, emotional distress, interpersonal difficulties, financial problems and adverse social consequences. Additionally, stress is also created by marital conflicts associated with rearing the handicapped child, extra financial burdens to obtain the necessary services and fatigue and loss of leisure time due to care-taking responsibilities (Gupta, & Singhal, 2004).

When coping strategies fall short, these challenges can detract from marital and other family relationships as well as work and careers thereby creating further tensions within families. Not only do the child’s characteristics influence parental stress levels, but also the negative reactions from others can serve as a source of stress for the families. Parents might respond to the stress of caring for a child with a disability with neglect which can involve denial of food, medicines and other life sustaining services to the children. The stress experienced by the families is influenced by the child’s specific variables such as age, sex and severity of the problem; socio-demographic variables such as social class, family income and domicile; and family coping resources and strategies such as acceptance of the child and perception of stigma associated with the disability. Notably, additional stress is created by extra financial burdens which relate, as already mentioned above, to obtaining the necessary services and fatigue and loss of leisure time due to care-taking responsibilities.

Studies reveal that family members of the children with disabilities are often perceived to experience harmful psychological effects. These extreme stress levels heighten negative health outcomes like depression and marital dissatisfaction. Parents are found with unstable emotions, constant grief, psychological ill-health, and unsatisfactory social health (Govender, 2002). Studies have found that such parents are at higher risk of being subjected to marital discord and social isolation. Studies have also revealed that having a child with disabilities affects not only the parents, but also the siblings and the relationships among the family members (Gupta & Singhal, (2004). The cause might be because some do consider them as a burden and thus feel ashamed of them. Of importance to note, however, is that the majority considers it as their duty to take care of such children.
The impact in the home life

Added stress is manifested in the home life style of a family with a child with a disability. Besides financial demands and sacrifices, parents, typically experience fatigue and significant demands on their time. Driving a child with disability around is time consuming and tiring. There are also, seemingly, never-ending series of appointments with, amongst others, the pediatrician, speech therapist, occupational therapist and tutor. When they are not in the car or waiting room, the parents might be reading a book and articles on learning problems (Sperry & Duffy, 2002). At first, it might feel that the disability is all-encompassing and this can have the effect of putting the relationship and career restraints on the parents.

Financial burden or hardship

When parents first discover that their baby or child has a disability, they do not stop to even think about the costs and how it will affect the family in the long run. All they think about is how to help their child in this condition. Medications, therapy, counseling, rehabilitation and physiotherapy, occupational therapy, social and emotional development and schooling, all of these lead to money being swept away from the family in order to help aid the child through life. The out-of pocket costs of medical care and other service might be huge. Notably, costs can run high and sacrifices will need to be made by all family members in order to make it through the trying times. All of these potential effects could have serious repercussions for the quality of the relationship between the parents, their living arrangements and future relationships and family structure. Having a child with a disability might also affect the parents’ allocation of time and financial resources to their health and unhealthy children, their parenting practices, their expectations of healthy siblings in terms of achievement, responsibility and short and long term contributions to the household and the siblings’ health development (Dobson, Middleton & Beardsworth, 2001).

2.5.7. Adjustments of Parents of Children with Disabilities

The processes by which parents adapt to or come to terms with the reactions to their child’s diagnosis are not yet understood. Various researchers have argued that there is no final stage of
absolute parental acceptance of a child with disability (Barnett, Clement, Kaplan-Estrin & Fiaka (2003). Rather, some grief and contradictory emotions are likely to persist or reappear. This means that there is no end to this process. Barnett, Clements, Kaplan-Estrin and Fialka (2003), have chosen to emphasize the term adaptation rather than acceptance. The reason is that the words resolution and acceptance both suggest an end point whereas adaptation assumes an ongoing process.

To a parent, every child is special in his or her own way. But some children have special needs or disabilities which challenge parents to find ways to best prepare these children for the future and to handle any problems that might surface. Every parent wants his or her child to be physically and developmentally perfect. The birth of the child with a disability can have profound effects on the parent and family. There is perhaps no event devastating to a family than a child born with birth defects. It is the most severe test of a family’s resilience. Upon learning that their child might have a disability, most parents react in different ways. As it has been stated previously, the initial response of the parents and the broader community to a child with defects is guilt and embarrassment.

Parents are definitely the heart of the family. They are also the ones who deal with the issues associated with their child’s disability and they are required to maintain the household. Many factors can influence the well-being and the adjustment of the parents into the situation of a child with a disability. It is stated in the literature that emotional and physical health is the most important factor in the adjustment of parents. Most of the findings in the literature show that factors such as less satisfactory marriages, less social support; lower physical well-being impact on their adjustment to the situation of child with a disability. The implication is that there is need for uplifting the parents’ social and psychological well-being as it will help them to deal effectively with their children having problems.

Different theories suggest that positive perceptions play a central role in the coping process. It has been proposed that positive perceptions might assist parents to cope better with the traumatic and stressful events. The functional role that positive emotions serve in the context of stressful events has been considered by the following theorists (Lazarus, Kanner, & Folkman cited Gupta
& Singhal, 2004). These theorists highlight that under stressful conditions, when negative emotions are predominant, positive emotions might provide a psychological break or respite, support continued coping efforts and replenish resources that have been depleted by the stress (ibid). Positive perceptions are viewed as a factor ameliorating the impact of a child with a disability on family members. It has been shown that positive emotions promote creativity and flexibility in the process of thinking and problem solving. Positive affect also facilitates the processing of important, relevant information even if that information is negative and might potentially damage self-esteem.

Scorgie and Sobey (2000) in Gupta and Singhal (2004) did a qualitative analysis of the mechanisms that led parents to achieve positive transformations in their perceptions of their child with a disability. This analysis revealed that parents arrived at a more positive state through three processes: (a) the need to form new identities, (b) attempts to derive meaning from the situation, and (c) the development of a sense of personal control. It is further argued that many parents find meaning through acquiring new roles like, group leaders, conference speakers or members of advisory council for schools, hospital or agencies representing people with disabilities. This is called cognitive adaptation because parents adapt to threatening events by searching for meaning, trying to gain mastery and enhancing themselves (Taylor, 1983 cited in Gupta & Singhal; 2004). Cognitive adaptation to disability is seen as a key process leading to psychological well-being. A key mechanism by which this adaptation is achieved is termed cognitive illusions. When these illusions are challenged, different perceptions will be generated in order to maintain meaning, mastery, and/or the self-system.

Some parents adapt by acquiring new traits like becoming more compassionate and less self-focused and learn that they can achieve rather than remain powerless. They also develop endurance or greater personal strength in the midst of their feelings of weakness, progressing from depression to being able to view life as worthwhile and of value and facing life with new boldness rather than capitulating to fear. It is evident that instead of totally depending on external agencies for rehabilitation, parents take charge of the situation and educate and train themselves. Positive attitudes social support and faith in God help parents generate psychic energy to cope with the physical, emotional and financial aspects of care giving.
A further coping approach is that of positive reappraisal cognitive strategies for reframing a situation in order to see it in a more positive light. Positive reappraisal enables the individual to appraise a difficult situation more positively. It often involves deeply held values that are activated by the stressful situation. This kind of coping encourages people to focus on the value of their efforts and is especially important in helping people sustain efforts, such as those associated with care giving over long periods of time. Coping basically involves creating, reinstating or reinforcing meaning in the midst of stress. This appraised or situational meaning shapes the emotions that the person experiences in the stressful encounter.

A further concept is that of a family schema. A positive outlook might also be a part of such a schema, the shared beliefs, meanings and values that a family develops in order to coordinate their interaction patterns and consequently cope or adapt to their situation. This notion of family schema has also been discussed in the resilience model of family stress adjustment and adaptation. Family schemas within this model are hypothesized to help maintain family stability. They are also the filters through which all experiences, including the appraisal of potential stressors, are evaluated. Having positively focused schemas assists families to maintain a more general positive view of events and thereby cope or adapt to challenges. As argued by Gupta and Singhal (2004), if parents react positively to their child with a disability, then the sibling relationship tends to be more positive. In accentuation of this it is argued that if the parents take an optimistic and caring view, then the sibling is more likely to do the same (Ibid). Thus, the parent’s ability to accept their child’s difficulties influences the ways in which a family functions.

The other way in which the family adjusts to the situation of having a child with a disability is through the use of social support. Social support has been cited as a contributory factor in counteracting the negative outcomes of stress (Plumb, 2011). Boyd (2002) defines social support as formal services one receives from professional-based organizations and/or services from more loosely structured organizations, for example, social clubs and churches) that the family deems important into their lifestyle. Social support is divided into two, that is, formal and informal. Formal social support is defined as the assistance that is social, psychological, physical
or financial and is provided either for free or in exchange for fee through an organized group or agency while informal support is defined as a network that might include the immediate and extended family, friends, neighbors, and other parents of children with disabilities (ibid). In other words, formal social support systems are perceived as being provided by professionals and informal supports are perceived as being provided by family members, friends and members of social groups that are integrated into the family’s daily life (Boyd, 2002).

Therefore, the social support provided to parents has emerged as having a consistent and strong relationship with parental stress and appears to play an essential role in family adaptation and personal well-being in general.

2.6 Support Structures and Programs in Place to Support Parents having Children with Disabilities

Parents of children with disabilities go beyond ordinary parenting. It is not surprising, therefore, that parents of such children are more likely to require support than parents of non-disabled children. Parents feel totally isolated when they have a child with a disability. It is very difficult for them to obtain accurate information both about the child's condition, prognosis, and potential. Lansdown, (2001) avers states that it is even harder to access the practical support necessary to protect the child's rights to optimum development. Research over the past 20 years has demonstrated the importance of social support for families of children with special needs and disabilities (Barnett, Clement, Kaplan-Estrin & Fialka, 2003). Therefore, there is a need to explore whether there are support structures and programs in place in South African communities to empower parents through support and information in their journey of raising a child with a disability.

Families who have children with disabilities and young people with special needs very often deal with similar life styles. Rörich (2008) argues that at the time of diagnosis of the child’s disability parents’ expectations are shattered. Many will need emotional support to adjust to their newfound situation as well as to the continued care of their child (Clarke, 1995; Russel, 2003) cited in Rörich, 2008).
Joosa and Berthelsen (2006) assert that a family might also require different levels of support to manage the demands required by specific health, behavioral and educational needs of their child for whom they have little knowledge or experience. The question arises regarding what exactly this support should look like. Helping families develop a positive outlook might be the serving point of intervention by mental health professionals. Mental health professional while working with families should strengthen the social network and support systems which would help parents overcome the stress and negative attitudes towards their children with disabilities. It has been found that most parents generally lack opportunities to share experiences and gain support from friends and even extended family members. Within support groups, they can discuss pertinent emotional issues, such as feelings of frustration and child-rearing problems. It is also an effective forum to help parents develop realistic expectations for the child and to engender feelings of competence. Such networks of support groups would help families gain confidence, improving self-esteem and assertiveness and thus enhance feelings of control. They can also form a social network of support which is often missing from the lives of the parents of children with disabilities.

In 1993, the parents of children with disabilities established their organization called the Disabled children’s action group (DICAG) in South Africa with the aim of empowering themselves to educate their children in an inclusive environment. It focuses on growing networks and advocates for better access for families and children. It has also focused its energies on working with mothers to build their confidence in accessing services, dealing with professionals’ understanding of the nature of disability, recognising that it is a social issue requiring action on the part of the whole community and the disabled children have equal rights with non-disabled children. This organization informs parents of their children’s rights to education and by providing training as well as advice on how to mobilise other parents of the disabled to be active in relation to issues that affect their children’s development.

A major illustration of its work in promoting empowerment has been in the support of mothers of the disabled to establish day care centres. It has established over 300 day care centres reaching
12-15,000 children who would otherwise have been left unsupported at home. These centers provide both mutual support for and social environment for the children.

In South Africa in July 2001, the Ministry of Education launched the Education White Paper 6 Special Needs Education: Building an Inclusive Education and Training System. The aim was to ensure that all learners pursue their learning potential to the fullest. In the field of education structures of inclusive education have been put in place to do away with all exclusionary factors against parents and children with disabilities. Beside that the government since 1994 took concrete steps to address the ways in which people with disabilities are excluded from mainstream society. Government enacted policies and legislation to redress the systemic inequalities and unfair discrimination that remain deeply embedded in social structures, practices, attitudes and the environment. These policies and legislation have been highlighted above.

### 2.7 Summary of the Chapter

The literature review started by pointing out the living conditions of people with disabilities during apartheid government. Then it concentrated on the government’s attempts after the first democratic election held in 1994 of engaging itself in a process of reconstruction and development through the introduction of various policies and legislation some of which are pertinent to the issue of people with disability. The literature review has shown that despite the government achievements in terms of policy and legislation, there has been limited impact on the lives of people with disabilities. This is indicative of the fact that an enormous task remains towards transforming the institutions, attitudes, practices, building facilities and environments that continue to deny people with disabilities their right to dignity, equality and freedom (McClain, 2002).

Furthermore, people with disabilities have long been viewed as a burden on society which generally views the presence of a child with a disability as a tragedy from which the family might never recovery (Kearney & Griffin, 2001). Ample evidence has been adduced to the effect that parents of children with disabilities go through prolonged periods of stress than do parents of children without disabilities (Gupta & Singhal, 2004). This is because of pain and sorrow which
are integral to the experience of a parent of a child with disability. It is also because of fears and worries related to their current situations and to their children’s future which translates into them having to endure many painful emotions (Kearney & Griffin, 2001). Notably, it is well documented in this literature that these parents require more support in comparison to the parent of children without disability. The literature review suggests that positive perceptions might assist parents in coping better with the traumatic and stressful events occasioned by their children having been born with disabilities.

The next chapter focuses on the research design and the methodology that was used in this study.
CHAPTER 3: METHODOLOGY AND DESIGN

3.1 Introduction

The purpose of this study was to explore and describe the experiences of parents of children with disabilities. To this end, an appropriate design was chosen. The research process and design which include the data collection methods and instruments, data analysis and target population and sample, and methods to ensure trustworthiness are discussed in this chapter. These discrete sub-topics collectively constitute what is referred to as the research design. Additionally, the research context, ethical issues and the limitation of the study are discussed.

3.2 Study Design

According to Burns and Grove (2001), research design is defined as the clearly defined structures upon which the study is premised. Thus, research design serves to plan, structure and execute the research activity towards maximizing the validity of the findings (Ibid). It serves to guide to the researcher in planning and implementing the research process to achieve the intended goal. In this study the exploratory research design was followed to explore the lived experiences of the parents of children with disabilities with the aim of gaining new insight and discover new ideas and thus increase knowledge of the phenomenon of raising a child with disability.

3.2.1 Research approach

The study used a qualitative approach to explore the lived experiences of parents of children with disabilities. The richness and in-depth of the description gained from a qualitative approach provides a unique appreciation of the reality of the experiences (Munhall, 2001). Mills and Birks (2014) argue that the qualitative research examines phenomena that impact on the lived reality of individuals or groups in a particular cultural and social context. It aims to understand how individuals make meaning of their social world (Hesse-Biber, 2010). For Bless, Higson-Smith
and Sithole (2013) qualitative research is an approach that uses words or descriptions to record aspects of the social world.

Henning, Van Rensburg and Smit (2004) assert that qualitative research is an inquiry that is grounded in the assumption that the individual construct social reality in the form of meaning and interpretations. It is concerned with meaning and the way people understand things and patterns of behaviour. In other words the researchers using qualitative approach explore how people structure and give meaning to their daily lives. It bears repeating, therefore, that its purpose is to examine phenomena that impact on the lived reality of individuals or groups in a particular cultural and social context (Mills & Birks, 2014). The aim is to privilege the exploration of the process of human meaning (Hesse-Biber, 2010). The other aim is to draw out understanding and perceptions and to explore the features of settings and culture. This means that qualitative approach is concerned with the subjective world and offer insights into social, emotional and experiential phenomena. It also emphasises the dynamic, holistic and individual aspects of the human experience and attempts to capture those experiences in their entirely within the context of those experiencing them (Polit & Beck, 2004; Streubert & Carpenter 2011).

Through this approach it was possible for the researcher to deeply engage and interact with the parents through in-depth interviews and valuable insights were elicited from their wealth of experiences.

3.2.2 Target population

Whilst Polit and Beck (2004), on the one hand, define population as the aggregated or totality of those conforming to a set of specification, Bless, Higson-Smith and Sithole (2013:164), on the other hand, referred to it as a ‘target population’ with a set of elements that the research focuses upon. In this study, parents with children with disabilities within the area of uThungulu were targeted for participation as they were already exposed to different situations of raising a child with a disability. It was thus logical on the part of the researcher to infer that give their exposure
in this regard, they would be able to reflect easily on those experiences deemed to be positive and negative through their lives.

3.2.3. Sampling of participants

Sampling refers to the process of selecting a portion of the population that conforms to a designated set of specifications to be studied. In this study, the researcher selected seven parents of children who are experiencing barriers to learning and development due to disability. The researcher supported these children in her line of duty as an employee of the Department of Education. These parents were selected through purposive sampling. Cohen, Manion and Morrison (2011) argue that in many cases purposive sampling is used in order to access ‘knowledgeable people’, that is, those who have in depth knowledge on a particular issue. In other words, it means enlisting the participation of those who are knowledgeable on the issue in question and this was predicated on their shear involvement in and experience of the situation. Therefore, the participants were selected based on their particular knowledge of the phenomenon for the purpose of having them share this knowledge and experiences with the researcher (Streubert & Carpenter: 2011).

So, in securing these participants, the researcher personally had to recruit them. Since all the participants had an African background, it can be inferred that their national identity positively impacted on the researcher’s success in recruiting them. Educationally, the participants ranged from those with post-secondary education qualifications to those who did not reach high school. They were in their thirties to sixties and some were married and some single.

3.2.4 Sampling criteria

The sampling criteria are the characteristics essential to the membership of the target population. These criteria are the characteristics that delimit the population of interest (Burns and Grove: 2001).
For this study, the inclusion criteria were:

(a) Parents of a child with a disability.
(b) Parents who are able to communicate fluently in isiZulu.
(c) Parents who are residing in the uThungulu district in the Province of KwaZulu-Natal.

3.2.5. Data collection techniques

Data was gathered through in-depth semi structured interviews. The interviews were audio-taped for subsequent analysis. Bless and Higson-Smith (2000), state that semi-structured interviews help in the clarification of concepts and problems and thus allow the establishment of a list of possible answers or solutions. In this study, this instrument helped the researcher discover new aspects of the problem by exploring in detail the explication rendered by the respondents. In this regard, Robson (2000) asserts that in the semi-structured interviews, the interviewer formulates a set of questions in advance, although he or she is free to modify the order of the questioning and this is based on her perception of what seems most appropriate in the context of the conversation. So, in the event of this happening, the researcher has a leeway of substituting the inappropriate questions with additional alternatives.

3.2.6. Research process

Seven parents were contacted telephonically and invited to participate in the study, after ensuring that they meet the selection criteria. They were informed about the ethical issues to be observed. The researcher then secured appointments with each and every parent who accepted invitation to participate in the study. Thus, parents who decided to participate were interviewed in their home environment. This environment allowed for an interview to take place in a quiet and familiar setting. Before starting the interviews the researcher explained to the parents the content of the participant’s consent form and then requested them to sign in if they were still interested to participate in the research project. (A copy of the Informed Consent Form is attached as Annexure A). They were also informed that they could withdraw from the study at any time if they wanted to do so without any consequences.
In-depth semi structured interviews schedules were used and the main focus was eliciting personal accounts of parenting a child with a disability by the respondents. Specific questions were asked regarding how, by whom and when the problem was identified and what their feelings and reactions were and the steps that they took when they discovered that their child has a disability. Further questions relating to the information that was available, challenges, public reaction, support given and the support required and support programs in place to support them were asked.

Certain standard questions were asked and these included information on demographic data, additional information such as name, age, sex, telephone numbers, marital status and the place of interview. Notably, in-depth interviews usually last about an hour and the interviews were audio taped and transcribed. At the end of the interviews the parents were thanked and informed that they should feel free to contact the researcher to discuss any issues relating to their situation that might have been raised by the research. (A copy of the Interview schedule is attached as Annexure B & C).

3.2.7. Data analysis

Content analysis was used to analyse the data gathered. In the context of this study, content analysis is conceived of as a method of textual investigation that involves establishing categories and then counting the number of instances when these categories are used in a particular item or text (Silverman, 2000; Grbich, 2007). Thus, content analysis refers to the words, meaning, pictures, symbols, ideas, themes or any messages that can be communicated (Silverman, 2000). The established practice is that when a researcher analyzes data using content analysis, he/she firstly identifies unit of analysis and then create a system for recording specific aspects of it. The system might include how often certain words or themes occur. Finally, the researcher records what is found in the material.

Thus, when the data was being collected through the semi structured interviews, the researcher listened to audiotapes and also had to read and re-read all the translated transcriptions. The
researcher’s practice in this regard is affirmed by Streubert and Carpenter (2011) in their argument that data analysis begins with listening to the participants’ verbal description and is followed by reading and re-reading the verbatim transcriptions or written responses. In this study, this was done to get a sense of the whole data and some ideas were jotted down as they emerged. The researcher then summarized the interviews keeping in mind that more than one theme might exist in one set of interviews.

Having summarized the interviews, the researcher was then able to discover patterns or themes that point to theoretical understanding of the lives of the parents of the children with disabilities. Drawing on the work of Mills and Birks (2014) the researcher engaged in open coding of the data to identify topics and units of meaning without losing focus of the research questions. The coding of the categories of meaning that emerged was the first step in this process. The next step was to group the related coded data into categories. After that, the researcher identified themes or patterns across these categories.

3.3 Ethical issues

Bless, Higson-Smith and Sithole (2013) suggest that it is essential that all ethical concerns be resolved before the research project begins. Doing this in advance would ensure that the dignity and self-respect of the participants is always preserved. In this study, several ethical issues were considered by the researcher and they are discussed below.

Various scholars have put forward the view that in conducting any kind of research, it is necessary to obtain informed consent from the research participants. In order to achieve informed consent of the participants, the following elements must be practiced: The subject must be competent, meaning that they should be responsible, mature and be capable of making reasonable decisions when given relevant information (Ramiah, 2006). They should be able to voluntarily participate in research activities. Therefore, no one should be forced to participate (Babbie, 2013). They should have received full information regarding the research and what the
data will be used for. The subject must fully comprehend the research project, even when risks are involved (Cohen, Manion & Morrison, 2000). For Burns and Grove (2001), this means that the subject needs to have a right to self-determination.

All four of these guidelines as enumerated above were followed with regard to the research. Thus, the parents were briefed regarding the purpose of the study and the nature of the research coupled with the issues relating to informed consent and confidentiality during the pre-interview discussion conducted telephonically with them. The appointments for the interviews were secured. On the day of the interviews they were assured that anonymity and confidentiality would be maintained at all times. Additionally, they were informed that their participation in the study was voluntary and that they were thus free to withdraw from the research at any time as and when they felt it was desirable to do so without any negative or undesirable consequences to such withdrawal.

A consent form was given to them requesting them to have it signed as an indication of their interest to participate in the research project. They were also shown the ethical clearance certificate the researcher had been granted by the University of Zululand confirming that the researcher had been granted permission to conduct the research in question. (A copy of the Informed Consent Form is attached as Annexure A).

Before conducting this research, ethical clearance was sought through the University of Zululand. Permission to conduct this research was obtained first from the Department of Education and then from the respondents themselves. However, the identifiable information was not used in the study so as to protect the identity of the respondents. The project data that was collected and used in the study has been kept in a locked cupboard and will be discarded after a minimum period of five years has lapsed.
3.4 Measures to ensure trustworthiness

Lincoln and Guba (1985) cited in Cohen, Manion and Morrison (2011) argue that the term validity and reliability are not suitable for the qualitative method, because they are regarded as being aligned with a quantitative approach. They further argue that they are impossible to be achieved with qualitative inquiry (Lincoln & Guba, 1985, in Cohen, Maniom, Morrison, 2011). Furthermore, scholars like Huberman and Miles (2002) and Tobin and Begley (2004:388,389) in Vosloo (2014) are of the opinion that it is inappropriate to transfer terminology across paradigms. As a result, these authors prefer to use the term trustworthiness, which they believe it will establish the true value of the study, its applicability, its consistency and its neutrality. Since qualitative research requires special criteria to establish trustworthiness, Lincoln and Guba (1985), cited in Cohen, Manion and Morrissson (2011) and Vosloo (2014) have outlined four criteria for judging the soundness of qualitative research and these criteria include credibility, transferability, dependability and confirmability.

Credibility

According to Lincoln and Guba (1985), in Cohen, Manion and Morrison (2011) credibility refers to the researcher’s ability to demonstrate that the object of the study is accurately identified and described based on the way in which the study was conducted. It involves establishing that results of the study are believable or credible from the perspective of the participants in the research. They are many techniques outlines by Creswell (2010) to gauge the accuracy of the study and those technique are data triangulation, clarifying the bias the researcher brings to the study, prolonged engagement, members’ checking, and peer debriefing.

However, the researcher employed some of the strategies outlined above to check the accuracy of this research. One of those strategies was to spend prolonged time in the field. In this way, the researcher developed an in-depth understanding of the phenomenon which was under study. This is collaborated by Vosloo (2014) that the more experience that a researcher has with participants in their settings, the more accurate or valid will be the findings. Using this concept helped the researcher understand the phenomena of raising a child with disability from the participants’ perspectives. Furthermore, the researcher also engaged with the data (recordings, notes and
transcripts) intensively to demonstrate clear links between the data and the interpretations (Vosloo, 2014). The researcher also checked transcripts to make sure that they do not contain obvious mistakes made during transcription, and to make sure that there is not a drift in the definition, a shift in the meaning of the codes during the process of coding (Gibbs, 2007) in Cresswell (2014). Lastly the researcher used peer review strategy which entails getting a colleague either familiar with the research or new to the topic to scan some raw data and then assess whether findings are plausible based on the data. In this research, the researcher used her supervisor for peer evaluation to check the accuracy of the study.

Transferability

Transferability refers to the degree in which the research findings can be transferred or generalized to other contexts ((De Vos, 2005), and the contexts can mean similar situations, similar populations and similar phenomena. It is argued that the researcher can use thick description to show that the research study’s findings can be applicable to other contexts circumstances, and situations. In other words this means that in order for the reader to evaluate the transferability of the research, the researcher is supposed to provide the readers with a thick description of the research findings. To ensure transferability of this study, purposive sampling was used. The participants the researcher used were all parents who have a child diagnosed with disability and residing within uThungulu district municipality, they were chosen because of their representativeness of the population about which conclusions were made. It was also ensured through the collection of descriptive data which could be compared to other research (Lincoln and Guba (1985) cited in Cohen, Manion & Morrison, 2011).

Dependability

Dependability ensures that the study could be repeated by other researchers and that findings would be consistent. Dependability means being able to account for changes in the design of the study and the changing conditions surrounding what was studied (Lincoln and Guba, 1985 & Mouton, 2001. The researcher is also responsible for describing the changes that occur in the setting and how these changes affect the way the researcher approaches the study. In this
research, the dependability of data collected, was ensured through describing the setting in detail, the requirements of selection of participants, how data was collected and analysed as well as asking participants probing questions. The data collected during interviews was tape recorded and kept in the form of fields notes for an audit trail.

**Confirmability**

Confirmability is defined as the degree to which the results can be confirmed or corroborated by others. Confirmability builds on audit trails and involves the use of written field notes, memo’s, a field diary, personal notes and reflexive journals. An audit trail which included the date of the interviews, the names of the participants, letters to participants seeking permission to conduct the study and notes taken during interviews were used to ensure confirmability of the study. The researcher also documented the procedures employed for checking and re-checking the data throughout the study. For further validation of data the researcher presented the participants background information and detail description of the study to enable readers to understand how data was interpreted.

### 3.5. Limitations

The size of the sample that was used in the study was very small and all the parents of the children with disability are included in one group and no distinction was made between or among different types of disabilities. Hence, the ability to generalize findings is limited. The majority of the participants in the study were females. Therefore, the ability to generalize findings to males is also limited. The study did not incorporate children with physical disabilities. Taking into account the difference in the symptoms of disabilities as well as the amount of support required from parent, physical disabilities might have different effects on parental well-being.

Another limitation is that the respondents were scattered all over and the researcher had to visit them in their homes which was time consuming. Since the interviews were conducted in the parents’ homes. At times, the interview processes were interrupted because some of the parents were distracted throughout the interview as their children were requiring some form of attention.
Because of the research being small in size and the gender composition the researcher was prevented from getting not only more but also rich data. The limitations as well as the strengths in this study related to both the selection and the usage of parents for children supported by the researcher during her line of duty. Using these parents was a real double-edged sword, on the one hand, since the parents were comfortable to share information with the researcher because of the trust and the relationship built during the process of supporting their children. On the other hand, this is also limitation because of the prejudgment and beliefs about the phenomena the researcher might have had before the data was analyzed.

Another limitation and strength, is that all 7 parents’ home language was isiZulu. It was an advantage for the researcher because the researcher is well vested in isiZulu as a result there was no need of the co-researcher to interpret. One could also say is disadvantage because if the group was diverse, rich data could have been yielded.

3.6 Summary of the chapter

This chapter has described the research design and methodology used in the study. A detailed account with regard to the methodological approach, research context, research process, ethical issues, measures to ensure trustworthiness and limitations in a study has been presented

In the next chapter, data analysis and discussion are presented
CHAPTER FOUR: DATA PRESENTATION AND ANALYSIS

4.1 Introduction

The aim of the study was to explore the experiences of the parents of children with disabilities so as to get insight into their situation. Since this study was located within the phenomenological framework, an attempt was made at generating knowledge on how the parents in question feel about the experience of having children with disabilities. So, in analyzing the data gathered the focus was on describing and understanding the parents’ experiences of their everyday world as they construed it.

Therefore, this chapter focuses on the presentation and analysis of data collected through the in-depth interviews held with the parents of the children with disabilities who were selected by means of purposeful sampling. The interviews were transcribed and various categories were identified. By probing into the relationships in meaning between all the categories that emerged in the data, the researcher was able to identify five key themes which included the parents’ realisation of the child’s disability, the parents’ reactions towards the realisation of the child’s disability, the essence of parenting a child with disability, parents’ social support and lastly, the needs identified by the parents. These are presented and discussed in the sections below.

In analysing the data, the researcher focused on the following research questions:

(a) What does it mean to be a parent of a child with a disability in South Africa?
(b) What challenges do parents of children with disabilities face?
(c) How are those challenges being overcome by parents of children with disabilities?
(d) What structures and Programs are in place to support parents of children with disabilities?

The study was conducted with the aim of addressing the four objectives relating to the experiences of the parents of the children with disability. These objectives were as follows:

(a) To gain insight into the experiences of parents having children with disabilities.
(b) To determine the challenges faced by the parents of children with disabilities.
(c) To identify the coping strategies used by the parents of children with disabilities.
(d) To identify measures that are in place to support parents of children with disabilities.

4.2 Biographic Information of the Respondents and the Contents of the Study

Seven (7) of the respondents who have children with disabilities were chosen and participated in this study. Their true identities are not reflected so as to ensure adherence to the principle of confidentiality. The parents participated are referred to as respondents. The brief profiles for all the respondents participated in the study are presented thereafter.

**Respondent 1**
Respondent number one is a 44 years old male traditionally married and lives in the community of Etsheni. He has children who have vision impairment and some of these children attend schools for the blind.

**Respondent 2**
Participant number two is a 35 years old female who is a domestic worker, and who lives in the area of Shashalazi Reserve. Her child has intellectual disability and she attends school for severely mentally challenged learners.

**Respondent 3**
Respondent number three is a 32 years old female who lives at Mawini area. Her child is a boy who has speech impairment as well as a learning disability. The child is schooling at a local Prevocational School.

**Respondent 4**
Respondent 4 is a 51 years old female. Her child is a girl who is no longer attending any school. This child is supposed to be at a skilled related placement as she is 16 years old but she is struggling to find placement in these centers. As a result of the failure to secure a
placement for the child in any centers, she is at home doing nothing. Her predicament is worsened by the fact that she has a learning disability which cannot be accommodated in the general normal schools. The respondent is a teacher in one of the local schools in Empangeni and resides in Emanzini Township.

**Respondent 5**
Respondent number 5 is a 45 years old female and her child is a girl suffering from cerebral palsy, learning disability and speech impairment. This respondent lives at the KwaMosi area and is unemployed. Her child is attending a local mainstream school and she (child) is in the process of being placed in a special school.

**Respondent 6**
Respondent number 6 is a 47 years old female and her child is a boy who has a speech and a learning disability. She is unemployed and lives at Magekeni reserve. Her child was assessed by a speech therapist as well as a psychologist and practitioners confirmed that the boy is suffering from the above mentioned disabilities.

**Respondent 7**
Respondent number 7 is a 60 years old female and her child is girl schooling at one of the local schools and she is waiting for a placement at a Special School. The respondent is married and unemployed and lives in the area of Ngenzeni. Her child has the following disabilities, speech impairment, partially deaf and dumb.

### 4.3 THEMES THAT EMERGED FROM THE INTERVIEWS
The interviews were conducted with the parents of the children with disabilities in their homes. Various themes emerged from the interview transcripts and they are presented below. These themes that emerged are representative of the voices of all parents and as such embody not only commonalities but also variations in their lived experiences. For purposes of clarity and precision, the researcher divided the themes into main themes and subthemes. The main themes are identified as follows:
(a) Theme 1: Parents’ realization of the child’s disability.

(b) Theme 2: Reaction towards the realization of the child’s disability.

(c) Theme 3: The essence of parenting a child with a disability.

(d) Theme 4: Parents social support.

(e) Theme 5: Needs identified by the parents.

4.3.1 THEME 1: PARENTS’ REALISATION OF THE CHILD’S DISABILITY

In all the data collected, the respondents revealed how they came to realize that their children have disabilities. The data revealed that most of them realized that their children are having disabilities when the children were already attending school. Following are the responses which were given by the respondents when they were asked about how and when they found out that their children have a disability. In this regard, one of the respondents asserted as follows:

“I went to school because my children were not doing well, they were struggling. I found out when they were already in school, that they were struggling to read which was saddening to them. I was told by them first then their teachers informed me. In fact I heard from them because it was like they were being ill-treated by the teachers. They couldn’t grasp what the teachers were trying to teach them. The children did not know that they have disabilities and the teachers had no knowledge that these children were having disabilities. The report given by the children was that if they are given a book to read or task to complete they didn’t know what was expected of them but they could write something else, then I realized that there was a problem and I went to school to speak to the teachers, the teachers explained to me that they did not have knowledge of what was going on as the teachers are not doctors. Teachers were amazed on what was really happening”.

Another respondent remarked as follows regarding the communication she had received from school as regards the performance of her child at school:

“As she repeated grade 1 three times, so they called me in her school to come and see what she was writing, and then for two consecutive years I used to go to school to see her work, and what I found was, she was writing something else, it was something like Chinese and Muslims writings, it was not readable. I was shocked on where does this child was getting these things”.

What transpires from the above two excerpts is that it was bewildering to the parents to realize that their children were not meeting some pre-established norm or standard of a learner in a mainstream school.
The data emanating from the respondents also reveal that most of them suspected that their children might have disabilities from early years of development since the respondents did acknowledge having been aware that something was not right about their children. Most of these respondents’ suspicion was generated by the way in which their children were delayed in some of the learning areas in school. Some reported having observed developmental regression, communication disorder or a delay in communicating with other children. Such awareness on the part of the parents of the child’s impairment is best articulated in the following assertion:

“I suspected that he has a disability because he was having a speech problem, he was not talking he was struggling with certain phonics though he could talk and you could hear him but he was pronouncing certain sounds in a different way. Also I saw that he has a disability because he did not like to play with other children he used to play alone. Sometimes children will laugh at him that he pees himself, or hit him and sometimes it would be children who are younger than him who are hitting him, and he would cry without hitting them back. Then I realize that he is not the same as others, he has a problem. But my elders used to say it is hereditary because there was nothing major that he was doing that was showing that he has a disability. I was worried because children of his age were already in a school, while he was struggling to do anything academically and his speech was not clear”.

One of the respondents remarked that although the child’s outward appearance was normal with no visible features suggesting the presence of developmental disorder, she confirmed in the interview having been confused by the fact that her child did not cry not only when she was hungry but also when she was wet. Understandably, this made her suspect that her child might have a disability as it is normal for all babies to cry not only when they are hungry but also when they are wet. To this effect she remarked that:

“When she was one year old I thought that she would be able to talk; she would talk, because when the child is 6 years old you could see that /she will babble and babble but you see yours is not doing anything and you start suspecting that this child’s tongue is hard when she was one year old and I started to believe that she would be unable to talk when she had already completed a year. This child could not cry even when she was hungry, she simple kept quiet. Sometimes she would simple stared at me and I did not know whether she was hungry or wet she kept quiet she could not say anything.

I used to think that I had not fed her for hours then I must feed her, and you could see that she was hungry because she would eat. To cry like a child who is hungry, she was unable to do it I knew that there was something wrong”.

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Notably, Matenge (2014) argues in relation to a child’s behavior that the period before diagnosis appears to be particularly difficult for parents while they try to make meaning of its (the child’s) behavior. It is further argued that parents often feel anxious and fearful at the possibility that something might be wrong with the child and get fatigued by the inability to understand the child’s development. In light of Matenge’s argument it is arguable that most of the respondents’ comments as transpired in the interviews confirm Matenge’s argument when it is asserted that:

“But most of the things that were done by her I did not understand them, she was so cheek, had anger outburst, loved to be lonely, she did not want to sit with us in most of the time she used to be alone. If I sent her to tuck shop you could see that she is struggling with the change may be you will give her R10 to buy something and she would say it won’t be enough though you sent her to buy something which is below R10. But I did not know why she was doing that. Another thing when I sent her to the tuck-shop she would be scared to go alone and she would need a company now I’ve realized that it was because she was failing to see the change and we could not understand”.

The data also revealed that all the respondents did not have knowledge of their children’s disability before being diagnosed by the health professionals despite their suspicions. This is attested to by remarks such as the following:

“I took my children to hospital to the doctors for assessment because they have vision problems which make them write something which was wrong, When the doctor test them the diagnosis confirmed that they were having a disability because the degree of vision was decreasing in such a way that they would end up with no vision”.

The excerpt below is an attestation of the fact that the health professionals’ interventions were of great help because they enlightened the respondents on the predicament facing their children and such enlightenment made them realize the reality to their children’s physical condition. Hence, one of the respondents remarked that: There were social workers who had visited the school, when they came to examine children and it was found that my child has a problem. I did not know by that time that he has a problem but I found out through the visit of the social workers to school. But also his teacher when she was talking to him he would take time for him to answer.
4.3.2 THEME 2: PARENTS’ REACTION TOWARDS THE REALISATION OF THE CHILD’S DISABILITY

A range of responses emerged when the respondents were asked to describe how they felt when finding out that their children have disabilities. As observed by Ferguson (2002) in Friend and Bursuck (2009), parents have many reactions to the diagnosis of their children with disabilities. A typical response is that they are likely to be negative and such negativity is similar to that of bereavement. The responses given by the respondents were categorized into the following: shock, denial, fear, guilt, blame, frustration, powerlessness, grief and acceptance.

Shock

All the respondents expressed their feelings of shock at the moment they came to know that their child is having a disability. This is in spite of the fact that most of them had had suspicious about the child as potentially having a disability by gauging from the signs that the child could have been displaying. Notably, is not unusual to have shock as a reaction on first hearing that one’s child may have a disability. This is corroborated by Oeckerman (2003)’s assertion that this might stem from the fact that a parent’s expectations of his/her child are shattered on receipt of the news. When the respondents were asked how they felt after finding out that their child has a disability, one respondent remarked as follows:

“I didn’t have knowledge about the children’s condition, I never though it will affect my children I thought it has ended with me. If I had knowledge that if you are blind it becomes hereditary in a way that affect your child I would have not bore any children. I would have tried other means not have to have children”.

Along the same lines, another respondent remarked as follows:

“It touched me, it really touched me because all along I told myself that it’s something that has to do with heredity, I always thought that she would be alright, she would be alright, ey, I found out that he is like this (disabled) it did not please me”.

For one of the respondents, there were mixed emotions of shock and confusion as a result of failing to understand what it was that was happening since there was no one in the family who had had a similar problem before. Hence, the respondent remarked as follows:
“I was confused because it was the first time for me to find myself in this situation because my girl child is doing very well at school, even in my family they are doing well (passing), there is no one who has the same problem”.

**Denial**

The data collected also suggests that most of the respondents were in denial which is a defense mechanism used by the respondents as they felt unable to cope (Ho & Keiley, 2003). All the respondents went through what Lessing and Strydom (2001) describe as common forms of denial namely:

(a) Refusing to recognize the child’s disability.

(b) Rationalizing the child’s disability.

(c) Seeking professional confirmation that there is nothing wrong with the child.

(d) Quickly becoming too cooperative with professional.

**Refusing to recognize the child’s disability**

Notably, the data collected revealed that almost all the respondents were refusing to recognise the fact that their children have disabilities. Although the respondents were aware that their children were delayed and struggling at school as it has been stated above, most of them never thought that it would be due to disability. The excerpt below is expressions of the denial in question and was expressed as follows by one of the respondents:

“Although I could see that he was delayed in doing things but that to me did not mean that he had a disability. Even though his teachers used to say that he was struggling but I thought it would be ok one day. But my elders used to say it is hereditary because there was nothing major that he was doing that was showing that he has a disability”.

**Seeking professional confirmation of the child’s disability**

Almost all the respondents had to seek professional confirmation of their child’s disability to confirm their suspicions. To this effect one of the respondents remarked that,
“I went to hospital for medical assessment/ I took my children to hospital to get help from the doctors, and they told me that their conditions are hereditary. To find out that they won’t be able to see again was a very painful thing to me”.

Another respondent remarked as follows:

“I was told by the doctors, they (doctors) are the ones who examined her, and confirmed that she is living with a disability. Although they (teacher) could see but they could not care because she was schooling, and they could not ascertain the kind of problem she was having, this means that by observing the way she was struggling then I realized that she has a problem and I took her to the doctor. I am the one who decided that I should take her to the doctor because I thought that it might happen that she has a problem as she was not doing well at school. At the beginning she was doing very well during the first year of schooling. When she started to experience problems I took her out of the school. I sent her back to school after finding out that she has a certain problem”.

Quickly becoming too cooperative with professional

From the data collected, it also transpired that the respondents started to be cooperative with the professionals who were providing assistance to them with regard to the diagnosis of the children. To this effect one of the respondents remarked that:

“I went to the psychologist, I started there visiting the doctor (psychologist), and she said I should come to her; I took her to the doctor for two weeks. The doctor had lessons with her and she used to conduct psychological tests with her and after assessment she told me that she has found out that she has indeed a disability. Then the doctor suggested that she must attend a school that would cater for her needs; she attended that school almost year and half and she was so happy in that school”.

Denial was also expressed more strongly by the respondents who did not bring it to the school's attention that they were taking their child to the hospital for assessment so as to confirm their suspicion of the possibility that their child is having a disability. One of the respondents thus remarked:

“I thought to myself that I must take her to the doctor. There is no one who said I must take her to the doctor. It is not the teachers who said I must take her to the doctor. I took my child to the doctor. There is nothing that I talked about with the teachers, I only requested the child from them (teachers) and said that I want to go with her because he is not progressing; I went with her on that day that. They (teacher) saw me coming back with some forms and I gave it to them. I told
them that they (medical professionals) have said I must fill it in because this child is like this and that”.

Other respondents did not tell anyone that their children were having a disability. One of the respondents simply indicated that it was saddening to her and that she was still hurting even then and that she could not tell anyone. Denial was also manifested by some of the respondents by not taking any steps towards supporting the child early during the time when they were informed by the school that the child was struggling. Instead of taking heed of such information, they resolved to ignore the matter laboring under the erroneous impression that that the child would possibly improve in his or her performance at school. Thus, sentiments as the following were expressed to this effect:

“There is nothing that I did during the time I was informed that my child was not doing well at school when she was still in grade 3. It was because I was telling myself that she would improve. There is nothing that I did she continued attending school. I took steps when she was repeating grade 9. All that time although she was struggling but she ended up passing but I realized after that she was condoned. They had started from grade 3 to inform me that she is not doing well at school”.

Fear

It is argued that fear is a common and immediate response among parents of children with disability. According McGill-Smith (2003), people often have fear of the future or unknown. Therefore, fear of the unknown was common from among the respondents interviewed. Guided by the fear of what might happen to his children in the future, one of the respondents expressed how he made a major decision of not getting more children in his life. To this, he confessed as follows:

“I was not happy; even now I am still hurting. I even took a decision with the mother of my children that it means we are not supposed to carry on having more children if we are getting children with disabilities. This was a decision that was not pleasing me, it tormented me. I’ve realized that there was nothing that I could do because everything within God’s power, so I have to accept it. This was really very painful to me”.

This is an indication that there was fear on the part of these respondents and it compelled them to make decisions based on the challenges they have encountered regarding the physical condition
of the child with disability. Such a response as displayed by this respondent was aimed at preventing a repeat of what had happened.

Another form of fear that was expressed by one of the respondents was about the safety of the child in the community. She described having to develop a sense of heightened watchfulness so as to protect the child from the outside world that is always cruel. Thus, she remarked:

“I am always terrified, because I am supposed to be watchful of her. If she comes back from school I need to know where she has gone to, what she has done and what is she doing, even if they’ve gone out to fetch some guavas I must ensure that she is in the company of other children. I will say to them go with her, she must not go alone I am doing this so that they would see if there is someone who is attacking her in the forest. I always wish that she must be next to me every time; she must not be out of my sight. I am always watchful even if I am visiting my parents I advise her sisters that they must watch her all the time”.

Guilt/ blame

The majority of the texts of the literature reviewed are in agreement on the nature of guilt which is manifested by the feelings of helplessness expressed in relation to what the parent thinks she could possibly have done to circumvent the occurrence of the undesirable physical condition of the child. From the data collected, one of the respondents expressed her guilt in a confessional manner for not taking further steps while the child was young by asserting that:

“I am supposed to find a school for her but the age is barrier, but if I took steps earlier she would have been placed in a suitable school for the skills because it will help her to have something that she can do and to have also a certificate in her hands and be independent ya”.

As asserted in the literature reviewed, guilt is also expressed, among other things, in terms of the pressure parents may be putting on their children to do well at school. Hereafter, they feel anger when they see that their child is not doing well in school. To some, it is projected on children for failing to do well in school. The comment below is a reflection of guilt and anger towards the child as is expressed as follows;
“I do understand him now but at the beginning I had anger and I used to hit him because I could not understand why he is struggling to do things, you see”.

**Frustration**

Many of the respondents expressed frustration with their child who is unable to do well at school and thus it was remarked that,

“The main problem I have is about the school, his struggling at school is the problem that I am facing but other things are alright. The school, it frustrates me that he is not doing well, I am getting confused, because every time I have to provide him with more support”.

To some of the respondents, frustration was caused by the fact that their child was struggling to remember what s/he has learnt from one day to another and as a result, they could not know how to support that child. One of the respondents thus remarked as follows:

“At first I did not accept it, I was sad, because I did not know how to teach a person who is like this. We would fight when I tried to teach him, do you see and he would forget everything, and I ended up by giving up, it is because I did not have knowledge of learners with learning disability”.

Another respondent’s frustration emanated from the homework that the child failed to remember and to this effect she remarked that:

“When she comes back from school and when she has homework, she would not tell me that she has a homework, sometimes I had to hear from other children that there is something she has to do. Another thing she would not write what is similar to what others are writing. If I check I could see that she is doing the same even at school where she would write IsiZulu in the place of English”.

Notably, most of the respondents were frustrated by the sense of loss of what the child might not become and such worry related to whether the child would ever be independent in life or not. Hence, it was remarked that:

“You always think about her all the time that is she going to be able to do things. If she is invited in a party you feel that she would not copy with all the demands, let’s says there is wedding or party in the community and I would think that she won’t be able to make it. It’s hurtful because you always think that she won’t’ be able do things you are always anxious and overprotective over her”.

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Powerlessness

Some of the respondents expressed feelings of helplessness by asserting that:

“I’ve realized that there is nothing that I can do because everything is in God’s power, so I have to accept it. This was really very painful to me”.

It should be noted that the respondents’ reasoning is informed by the fact that they cannot change the fact that their child has a disability and they had no power to change what has happened.

“One of the parents after realizing that there is nothing she can do to change the situation remarked: I did not feel bad because it could have had not helped me to be heartbroken because if something has happening it is difficult to change. I simply accepted it and decided to bear with the situation. I realized that there is nothing that I can change even if I was worried”.

Grief

Taub (2006) contends that parents grieve when or once they discover that their child has a disability. The grieving process is caused by the fact that parents had developed wishes, expectations and dreams for the child even before the child was born. This is one of the responses given when one of the respondents was asked how she felt after finding out that her child has a disability. She remarked as follows:

“I was so sad; I was sad so deeply on that particular day I came from the doctor I didn’t eat. When I arrived at home I told them (family) that I have encountered this problem and this means is the end of her and of me, because I have been wishing success and progress for her not to be like me. I have wished that she would be something one day, telling myself that I will try by all means to make it sure that she achieve something in life, not just like me, I was so sad”.

For most of the respondents, finding out that their children have disabilities was destroying their hopes and dreams which they held for their children. Arguably, parents grieve because many of their beliefs about the children have been shattered. To this effect, one of the respondents asserted that:

“If a child is born, you become happy thinking that he or she will be the same as others and he or she will grow and do things, such as working and support you as a parent like other children with no disabilities. To find out that they have disabilities was saddening to me”.

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Some of the responses given by the respondents indicated that they conceive of their lives as different from those of families with children without disabilities. According to the literature reviewed, those parents have developed chronic grief. Thus, from the data set, chronic grief is evidently expressed in remarks such as the following:

“I am going to be something, I am going to be something, this means in each and every day you always remember that your child is not the like other children, I’ve got this, and my happiness is incomplete, I don’t have complete happiness because I have been wishing big things for my child but it never happened, all the dreams and hopes I have for my child have been shattered”.

Arguably, the sentiments expressed above are indicative of not only the pain but also the sorrow that parents have to endure when they grieve for the loss of hope for what would have been the ‘perfect child’ (Kuhler-Ross & Kessler, 2005).

Acceptance

Acceptance is construed as something parents learn to live with. It is the stage at which the parents can look past the disability and accept the child as he or she is. The goal is to reach acceptance to be able to make decisions about how their child will be helped. From this study, it transpired that the acceptance stage was reached by most of the respondents after realizing that their children’s future was not totally annihilated by the disability because they were able to envision a bright future awaiting the child despite his or her disability. This view is attested to by this excerpt below in which it is remarked that:

“I decided to move on with my life. I started to feel better when I took them to schools which cater for their needs. It was hurting in each every day when they stayed at home while other children of the same age went to school, yes it was painful. But now they have managed to be admitted to the schools which are suitable for them. Though the situation is no longer the same but it was indeed painful”.

To the researcher, it was heartening to hear remarks from some of the respondents such as: “I said it’s my gift from God there is nothing I can change therefore I have to accept it as it is”. In the same vein, one of the respondents remarked that he reached acceptance because he realized
that what his children were going through is similar to what he herself had gone through too. As a result, he resolved to find a solution of how to help his children. To this effect, he remarked that:

“As a parent who has a disability and I have given birth to children with disability. I started by accepting this condition to me before accepting my children’s conditions”.

Most of the respondents reached the stage of accepting the child with a disability through the support of other people who provided counselling to them. One of the respondents confessed that:

“Because my heart was so painful having difficulties to accept their condition, I decided to go to the pastor for emotional counseling. He helped me a lot with counselling”.

Notably, scholarly theories suggest that in situations such as the ones depicted above, positive perceptions play a central role in the coping process. It is in light of this, therefore, that some of the respondents are depicted as having been able to derive meaning from this undesirable situation through developing, among other things, new identities, a sense of control and acquiring new roles as parents (Gupta & Singhal, 2004). Arguably, such a resolve to develop such made them realize that they could achieve more by not remaining powerless in the circumstances. It is against this backdrop, therefore, that one of the respondents remarked that:

“Finding out that my children have disabilities happened at the time when I was starting a project of working with people with disabilities. When it happened, it happened to a person with knowledge and skills, one of the people who are providing counseling to people with disabilities. If the person is involved in an accident and find herself/himself losing his or her leg, I provide counseling to that person, showing her or him that he still going to lead a normal life. So my children’s disabilities happened right at the time I was busy working with people with disabilities, that’s what made things easy for me to bear and not to feel more pain. I also provided counseling to my children in the same way I’m doing to the community. To me to have a disability is like any other things in life”.

4.3.3 THEME 3: THE ESSENCE OF PARENTING A CHILD WITH A DISABILITY

Parents play a vital role in caring for and rearing their children irrespective of whether the child has a disability or not. Therefore, this category represents what the respondents describe as
expectations for them as parents of children with disability and how they perceive their parenting roles in relation to their child with a disability. It also represents their descriptions of the challenges which they encounter in their journey of parenting a child with a disability.

**Parenting expectations and roles**

The respondents described what it means to be a parent of a child with a disability and what they perceived as should be done by parents in raising a child with a disability. There were commonalities as well as variations in ways in which they perceived their roles as parents of children with disabilities. When they were asked what it means to be a parent of child with a disability, one of the respondents remarked that,

“You have to be a parent with perseverance, you need to be a parent who is persevering because a person with disability is naughty like my child if I ask her to make tea for me, she simple says I can’t, I can’t do, do it yourself in other days. But in some days she will be happy and she will plug a kettle, boil water and make tea for me and bring it to me”.

The data revealed that there are specific skills and qualities that parents of children with disability need to possess. Thus, it was remarked in this regard that,

“What is important is that you need to have love, compassion and take care of her or give her more attention because she needs that, because she is behaving like a child, she loves to be loved and every time you must make sure that you boost her self-esteem all the time make her see that she is important like other children”.

It was evident from the data that the respondents were normalizing the child disability and try and look beyond the child disability. The respondents indicated that they have to treat the child with a disability in the same way as they would do to the child without a disability.

“I think it means I should treat my child as a child without disability, to raise her I should do it as if I am raising a child without disability, I must not say she must not do this and that for instance let’s say she wants to wash clothes I must not say she must not do it, I must allow her to do it in her own way and then check it thereafter”.

There was also recognition that a major goal in parenting a child with a disability is to ensure that the child can become independent irrespective of any disability. The respondents indicated that as a parent one needs to do everything in her/his power to help their child develop to his or
her full potential. The respondents are of the conviction that the child has the ability to learn, grow and be independent.

“To raise a child with a disability is the same as raising a child without disability. As a parent you don’t have to dwell on the issue that your child has a disability, but you need to treat the child as normal, encourage a child to do things as a normal child, and be independent and to do things for himself or herself, for instance if is he or she has to cook encourage him/her to cook, make tea, to bath him/herself, prepare meals etc. Encourage the child to be independent so that the child would not feel discriminated against”.

There were also variations in the way the respondents conceived of their roles in raising a child with a disability. Some of the respondents described parenting a child with a disability as different from parenting a child without a disability. The following comments were given by some of the respondents who indicated those variations. To this effect they remarked:

“Raising a child with disability is not the same as raising a child without disability, because my child is so close to me. He loves me so much and I have to take care of him. He is not independent and always wishes that I can do everything for him though he can dress himself and bath himself especially over the weekend but during the week I had to supervise him as I am always there”.

From the data sets it also appeared that the respondents who are parents of the children with disabilities tend to be overprotective of their children. Thus, one of the respondents remarked that:

“Another thing I am always protecting him from his sister because she (sister) sees as if I love him more that her, then I had to protect him because I see him as different from others and he love to be loved”.

Notably, one of the respondents further explained how she defends and protects her child from siblings. To this effect she remarked:

“I always protect and defend her from her sisters requesting them not to beat and scold her because she is sick and she is not normal. If I find out that she has been beaten by them I make it sure that I scold them that they must not hit my child because she is sick sometimes you will find them telling one another not to do it”.

b) Parenting challenges

It has been ascertained from the literature reviewed that parents of children with disabilities face many challenges. The data collected suggests that being a parent of a child with a disability can
be emotionally engaging as well as distressing to a parent. It is in this light, therefore, that this category focuses on the accounts given by the respondents who are parents of the children with disabilities regarding the challenges they encounter in raising their children with disabilities. Probing into the challenges faced by the respondents whose children have disabilities culminated the development of five subthemes. These themes included financial problems, transport problems, finding suitable school for the child, perceptions by the community and challenges relating to care giving.

i) Financial challenges

All the respondents represented in the data collected mentioned that the main problem they are facing as parents of children with disabilities is mainly financial. This is accounted for by the fact that the grants that their children receive from the government are inadequate to cater for the children’s’ necessities. They indicated that the expenses are usually too heavy for them and these include visiting hospitals and their (boarding) schools which are not nearer as well as caring for their child.

Therefore, the lack of enough financial resources was shown to be a great factor that causes stress among parents of children with disabilities. When parents were asked about the challenges they encountering as parents of children with disabilities, one parent gave the following response as a response towards the question:

“Even now I am still having challenges though I’ve gone a long process. The main challenge that I have is money. He is receiving a grant but it is not enough to cover all his necessities as I am not working. It would be enough if I was working but everything must be done through the grant. Sometimes it is compelling that I have to go visit him in his (boarding) school but I would not go I would have to wait for his grant payment then will go”.

A lack of money for transport to hospital was also a major barrier to other parents as a result parent would fail to serve the needs for their child.
“The support that I wish to get is money, her chronic medication is collected far away, sometimes you will find that I don’t have money to collect it, and you will find out that I have to use transport and it’s difficult if I have to take her with me to hospital for some checkups. I have to keep the due date in my mind; I need to ensure that her medication is collected. You wish like you must get more money because if you don’t come on the date you are supposed to collect those medications you are being scolded for not coming and they say don’t even tell them that you had no money. They will say the first thing to consider once you put your child on treatment it’s to make it sure that you have money that you will use for transport to hospital to collect medication for your child because money problem is something they don’t want to hear”.

ii) Finding suitable school for the child with disability

The second major challenge mentioned by the parents was a problem of finding a school suitable for the child with a disability.

“The problem I have is of getting a school for him. He’s struggling at (ordinary mainstream) school it is a problem that I am facing but other thing are alright. Finding a school frustrates me and is so frustrating and confusing to me that he is not doing well at school because I have given him more support every time. Failing to find his school is hurting me, since he is in the new teacher this year, I don’t know how he is treating him. If it is according to my will he would have been moved to the school suitable for his needs so that my mind will be at rest. It hurts me because I don’t know whether at school he is learning in a proper way and whether they are supporting him because we can do homework but I don’t know what he does when he is alone at school. When he gets a suitable school I will be indeed free”.

One of the parents expressed explicitly the way this is a challenge for her and how is affecting her on everyday life. The comment indicated that this indeed a stress and a burden that she has to contend with on a daily basis,

“It’s difficult, because my soul is not resting; my heart is not at peace until my child gets a suitable school. This is heart breaking that she is not getting school suitable for her”.

iii) Care giving challenges

Most parents spoke about the various difficulties they themselves have to cope with. Most of them mentioned that they always worry and fear that the child would not cope with anything in life. This is an indication that parents of children with disabilities experience greater stress and a larger number of care giving challenges than parents of nondisabled children (Algood, Harris & Hong, 2013; Gupta & Singhal, 2004; Heiman, 2002). The response below is a reflective of that stress in the lives of parents of children with disabilities.
“Raising a child with a disability it’s a challenge on its own because there is no time where you will see a child with disability doing things independently. Every time you need to be behind him, reminding him of what he is supposed to be doing”.

Parents became super parents by focusing on every aspect of their child.

“But I need to supervise him when he is doing things and remind him now and again, and it does not bother me anymore if he is bathing and not rushing anywhere he must do it for himself but I had to remind him that he must wash his face, head until he is done”.

The other challenge that was highlighted by parents is that of a child struggling at school and parents did not know how to help their children to achieve their full potential.

“The main challenge that breaks my heart is about the school, when she comes back from school and she has homework, she does not tell me that she has a homework, sometimes I had to hear from other children that there is something she has to do. Another thing she does not write what is similar to what others are writing. If I check I could see that she is doing the same even at school where she would write IsiZulu in the place of English”.

The data also revealed that raising a child with a disability is not difficult to someone who has received training; therefore, training was seen as crucial in equipping parents with knowledge and skills on how to raise a child with a disability. The comment below is a reflection of that,

“Raising a child with a disability is difficult to a parent who has not received training on disability. To me it is easy to raise a child with disability because I was trained by DSD and now I am the one who is training others on disability. That’s while my children are in boarding schools so that they will learn to be independent because in those schools they have to learn to do things independently. So I am training my children to lead a normal life, just like children without disability”.

iv) Transport

Transport for children with disabilities was reported as an area of concern for a parent whose child is attending a local Special School within uThungulu district. The concern was that there is no bus that is assigned to transport children with disabilities residing in the area of KwaMosi. As a result these children are using the local community bus which is sometimes unreliable and often uses inflexible times that do not accommodate these children with disabilities.

The excerpt below shows that:
“I wish there is a bus allocated for our children only, as their school closes at 12h30 or 1h00, ours (children) arrive back home at 16h00 o’clock in the afternoon. Another thing, my child has to wake up early in the morning at 6 am and go wait at the bus stop, as it is winter now, there is need that there must be someone to accompany her, once she misses it she would go back home. If it (bus) does not arrive she would stay at home”.

v) Perceptions by the community

The data revealed that most of the parents highlighted that their communities are not discriminating them on the basis of having children with disabilities, but events related to teasing and ostracism of their children by children of the same age were stated by the parents.

“I don’t blame them (community) they are not treating me differently. Its only children when they are playing with her, they are saying this and that but old people do not have a problem”.

One of the parents explained how the community is worrying her through so many questions that they are raising regarding the child’s condition.

“The community is always troubling me because they are always inquisitive and want to know why my child is sitting at home and I have to tell them that, it’s because she is supposed to go to a school suitable for her needs. This is a problem in the community because you always have to explain yourself, it would be better if it is educated people or those with knowledge because it’s easy for them to understand. They don’t discriminate me only the questions that they are posing to me that are worrying me”.

One of the parents highlighted the positive way in which the community views him. He stated that he has become someone that the community trust and look up to, someone the community request assistance from.

“The community sees me as a champion because I behave similar as a parent of a child without a disability. They end up requesting assistance from me by seeing that it is no longer bothering me to have children with disability. They ask me how do I do it, when the situation is like this, how am I not stressed by the fact that my children have disabilities. They see me as a person who is a hero I don’t want to lie they are not sympathetic towards me, because I have made sure that they don’t sympathise with me as a I am a parent who has a disability and I also gave birth to children who have disabilities. Although people were sympathetic with my mother, but now they see her as a mother who gave birth to a leader, who would lead and help the nation. This means her lamentations have ended now”.

4.3.4 THEME 4: PARENTS SOCIAL SUPPORT

Parents often raise their children within the context of powerful societal barriers where disabilities are devalued. As a consequence of this, they often feel emotionally burdened. Most
of the literature reviewed suggests that parents or families with children with disability have more stress than those whose children have no disabilities. However, it is notable that parents might also require different levels of support to manage the demands required by parenting a child with a disability. It is against this backdrop, therefore, that this section focuses on the coping strategies and support structures used by the respondents (who are parents) of children with disabilities. From the data collected, it transpired that all the respondents did not cope on their own but instead had support structures affording them the necessary assistance as dictated to by the circumstances towards reducing their stress and the need to cope with the child with a disability. In this regard, the respondents emphasized the importance of social support not only from within but also outside one’s family. These forms of support received by the respondents as parents of the children with disabilities are grouped into three (3) categories namely, family support, organizational support and community support.

a) Family support

It is evident from the data that the kind of support used by the respondents included their family members or siblings, and significant others. Most of the respondents had an open discussion and consultation with family members. Support from family members included words of encouragement. It benefited the respondents to have reliable relatives who help them carry the burden. The family members were pillars of strength to them in times of need. To this effect, one of the respondents remarked:

“I spoke to my family only at home, and some started to find out bit by bit that she has a disability. I did not speak to anyone regarding my emotional status because I was hurt and sad except my family, and they were sympathetic towards me, it was hurting and my family said I must accept this situation because my mother also has a son who has a disability, my brother has a disability. My mother said I must accept this situation because my child will carry on with her life, like other children because even her uncle is alive”.

It appeared from the data that the respondents viewed parenting as a team effort. As result of this, they recognized the importance of standing together by supporting each other in finding solutions with regard to their children with disabilities. Those respondents who are married mentioned that their spouses were a source of social support for them and they tried to be in tune
with one another in all aspects of parenting and assisting the child. One of the respondents thus remarked:

“The mother of my children and me were advising one another on what steps to follow and which channel to take”.

One of the respondents also remarked on how she was supported by the child’s siblings. In this regard she said:

“I also get support from her sisters; they do listen to me that ease the burden from me. I also tell them about the problems that I am facing”.

It was also evident from the responses that there was support in the form of taking care of the child. This is inferred from remarks such as:

“Yes I get support from home only. My family does not say you (to the child) are for a special school if she has made a mistake; you are not clever as children are saying that when they playing with her. My family cares so much about her. Her uncle and my mother accompany her to the bus stop until the bus that ferry the learners with disabilities arrives. In the afternoon they wait for her in the bus stop. They take turns”.

One of the respondents expressed her frustration relating to her not getting social support from the family and friends. To this effect, she remarked:

“I have never ever received any support from home I always do things on my own and in my own way”.

b) Community support

This kind of support comes from the community. A typical example in this regard is a group with similar interests and needs in a geographical area. This may include other parents or families of children with disabilities. However, it is evident from the sampled data that these respondents are able to get support from their communities. Following are some of the responses given by the respondents when they were asked whether they get any support from the community or not. In this regard, one of the respondents remarked:

“Yes friends and neighbours support me in what I’m doing, because all my children are having disabilities but they are able to go play with neighbours’ children even though they are blind, they are able to go to the shop, the community is accepting them and they have friends who are not
blind, who plays and walk with them and watch them so that they won’t be hurt so there is support from, friends and community.

Yes I get support, I get support from my friends, my colleagues also give me support, my neighbours, I share my concern with them”.

One of the respondents indicated that he found one source of strength from his minister. This is attested to by the following pronouncement on his part:

“I discussed the matter with my pastor who was able to provide emotional counseling to me because I was hurt. It was so painful because my hope of an expectant child was shattered. But with the help of the pastor I accepted it”.

c) Organizational support

Organizational support is support from entities or organizations set up to provide support for the child with a disability or and their families. These may include doctors, teachers, social workers, psychologists and therapists, etcetera. Therefore, the data collected suggested that most of the respondents were able to access support from different medical professionals. They engaged in what McGill-Smith (2003), describes as a journey that takes them into a life that is often filled with strong emotions, difficult choices, interactions with many different professionals and specialists and an ongoing need for information and services.

i) Support from medical professionals

Furthermore, Professionals were the most frequent source of information about the child’s condition, management and services available, with several mentioned in every interviews. The comment below indicates that the respondents rely on professionals for services available….

“Before she started schooling I did not have any idea of how to get a special school but in the hospital one of the social workers told me that she is able to look for schools for children with disabilities, and she promised to get one for my child. She did not explain to me how do you look for the special school”.

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Most of the respondents remarked that they use psychological services for the child and these services were referred to for psychological testing. To this effect one of the respondents remarked that:

“I went to the psychologist; I went to the psychologist, I started there to attend a doctor, she said I must come to her (psychologist) I took her to the psychologist for a period of two weeks. She had lessons with her, and she also conducted psychological tests with her. After the assessment the psychologist informed me that she is indeed has a learning disability”.

Some of the respondents indicated that they use psychological services for themselves and or siblings for guidance and emotional support. One of the respondents thus remarked:

“The doctor (psychologist) provided counseling to me; she called me into certain sessions so as to help me. She also had sessions with her sisters so as to make them understand her condition”.

The respondents also indicated that they visit the hospital to access medical services. One of the respondents thus remarked:

“I went to hospital for medical assessment/ I took them to hospital to get help from the doctors, and they told me that their conditions are hereditary”.

ii) Support from the teachers

The data also revealed that teachers were seemingly of great help to most of the respondents in the study as they helped the respondents with the identification of the children with disabilities. In this regard one of the respondents remarked:

“She identified him within a week and she said my child has a problem because he writes something which is incorrect. I would say his teacher was the one who said I should take certain steps. She was the one who had opened my eyes”.

Regular contact with the teachers meant that the respondents as parents have someone to advise them on services they should access. One of the respondents thus remarked:

“His teacher invited me to school and explained to me that he is not doing well in academic work. She gave me a letter that was requesting me to take him to the speech therapist and he also had a problem with his eye so he was supposed to be seen by the optometrist. His teacher helped me by telling me to take my child to the doctor. The following day I went to the doctor”.

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The data also revealed that teachers provided support to the respondents by identifying schools that are suitable for the respondents’ children with disabilities. One of the respondents remarked that:

“The principal told me that since the child is in the school, the school would intervene by trying to search for the suitable school for her. Then I stop looking for a school for her and I waited for the school”.

It is evident from the data that teachers were able to guide the respondents on the required procedure which had to be followed for the child to be supported. This is attested to by the remark of one of the respondents who that:

“The principal said she needed to go to the doctor and I told him she won’t be going to the doctor because she had already visited the doctor and was given an assessment report. And he said I must submit that report to the school and I submitted that report which recommended that she must be placed at a special school and he made copies and filed it”.

It also appeared from the data that teachers also helped by providing guidance to the respondents on how they should treat and look after their children. One of the respondents thus commented:

“Finding out that my child has a disability made me unhappy. It was better because his teachers used to tell me that I need to love him, and treat him like other children”.

The comment below indicates that teachers also played a role in providing counseling to some of the respondents who are parents of the children with disabilities. To this effect, one of the respondents remarked that:

“His teachers were providing me with counseling. They used to tell me that I must not keep it in my heart that he has a disability because there are those(children) who are worse than him I must be thankful that he is not worse, I ended accepting his situation”.

iii) Support from the government

Most of the respondents remarked that their children receive support from the government and the form of support that they receive is in the form of social security. It is in this regard that one of the respondents remarked:

“There is support from the community and the government indeed especially the disabilities grant that is given to my children which help with the schooling of my children. The grant that I am getting for them from the government concentrates on their school expenses”.

One of the respondents gets support from the municipality. To this effect, he remarked:
“The support that I am getting from municipality, so municipality is able to support us with vouchers for food parcels, especially during the school holidays the expenses become too high, so the municipality is able to support me in that poverty by giving us food parcel. So it is food parcels from municipality and disability grants from the government, and this is the only support that I am getting there is nothing else. There is a lot of support, even from the ward councilors and municipality”.

Some of the respondents confirmed that the government supports them through the special schools which are in existence. In this regard, one of the respondents remarked:

“I got support from the government; the government supports me, by giving me a school for my child and disability grant. The schools for learners with disability are there now. Even his uncle went to a special school but he started at a mainstream school but when he was assessed they find that he is having a learning disability. I will say they do support me because they do not discriminate me. Even the government supports me through the grant and schools that cater for my child are in existence now”.

### 4.3.5 THEME 5: NEEDS IDENTIFIED BY PARENTS

All the respondents interviewed identified different forms of support programs that would help them cope with a child with a disability. Apart from the programs identified several basic needs were pointed out by the respondents. All these needs identified were viewed as crucial in parenting a child with a disability and were grouped into six sub-themes, that is, support groups, training sessions, counseling programs, financial support, transport, special schools as well as shelter.

When the respondents were asked about any support programs which are in place to support parents of children with disability within their communities, most of the respondents commented that programs designated to support parents for children with disabilities are non-existent in the community despite there being a need for them.

Another respondent in the study identified the need of programs for vulnerable people. She asserted that there are so many orphans and disabled in the community and that there is no one who raises problems on their behalf. For this reason, she wishes that there must be programs that would look after the orphans, the disabled and the poor.
a) Support groups

One of the needs identified by the respondents is the need for the establishment and existence of support groups within their communities. The data revealed that these respondents need a forum that would provide them with the opportunity to express their frustration and share their experiences within the support groups. In other words, they would discuss pertinent emotional issues, such as feelings of frustration and child-rearing problems within the support groups (Chandramuki, Shastry & Vranda, 2012). In this regard, they remarked:

“There is a need for the support programs in our community. Because most of the times parents of children with disabilities feel that they are being discriminated against so they need to have support groups where they can share their problems and experiences, because they are feeling sad about having children with disabilities”.

The respondents are of the conviction that support groups would give them valuable information regarding ways of dealing with their problems. Thus, one of the respondents remarked as follows:

“I think support groups because it would help parents for children with disability to understand and come to terms with disability of their children”.

The respondents felt that support groups will benefit their members from the experiences of others. They would learn how others have coped as well as gain support from one another regarding parenting a child with disability. They must form a support group where they will share their experiences and insights. In their view, this must be constituted only by the parents of children with disabilities.

This indicates that the respondents interviewed are of the conviction that support groups would allow them to have their experiences validated through the account of others. This would allow them to feel a commonality and thus reduce the feeling of isolation they might otherwise suffer and see that they are not alone.
It was evident in the data that the support group was also construed as a platform where the parents would educate one another on how to raise a child with disability. To this effect, one of the respondents remarked as follows:

“I wish we could have support groups where we as parents with children with disability could meet and share our experiences of raising a child with disability”.

The respondents also felt that support groups would put them into contact with people in similar situations as themselves where the process of normalising their own situation will be evident. Thus, one of the respondents remarked as follows:

“What I want to talk about is the question that says which programs you think parents need. I think many people need to be supported because you as a parent for a child with a disability there is that, that your child is not the same as other children, and if they are able to talk with those people with children with disabilities they must see that they are able to live with them (disabled children) without a problem and that person should come and explain on how s/he has come to the acceptance of a child with disability and explain to them how s/he lives with a child who has a disability. It must be parents of children with disability that they must meet. They must form what is called support groups where they will meet to share experiences so that the one who is struggling to accept can see how they have accepted and living with their children”

Some of the respondents indicated that they wish that the officials from the department of education could address the parents within the support groups as they believe that this would enlighten the parents on how best to raise a child with a disability. To this effect, one of the respondents remarked as follows:

“I also wish that the officials from the department of Education because they possess certain experiences about children with disabilities to come and address those support groups about their experiences. What I am saying is, if those parents with children with disability are having meetings, they must invite officials from the department of Education to come share their experiences of a children with disabilities and explain to them that it is possible for a child with a disability to be schooling if he or she is still of a school going age”.

b) Training

The respondents remarked on the importance of educating the parents of children with disabilities about the ways of raising a child with disability so that they will know how to deal with a situation of a child with a disability. As a result, they indicated that training of the parents of children with disability needs to be conducted towards the eradication of the stigma attached to the parents of the children with disabilities. By so doing, it is hoped that this will in all
likelihood prevent those parents who are struggling to cope with the situation of a child with a disability from committing suicide. This view is attested to by the comment below which states that,

“This training are needed because it became apparent that most of the people in the community want to commit suicide and even afraid to be seen in public”.

The respondents also felt that training will help curb the inhumane practices to which the children with disability are subjected. Thus, it was remarked that:

“There are many cases that I’m receiving that indicate that most families are still putting their children with disabilities in the hidden, leaving them in close doors. In one case a child was chained in the tree, because they say the child was wandering, the child used to soil himself; this happened because the child’s parents were not trained on disability and on what to do if a child has a disability rather than chaining the child on the tree as a dog”.

Notably, the respondents are of the conviction that training on disability would transform the attitudes, practices and belief systems that continue to deny children with disabilities their rights to life, dignity, equality and freedom. Evidently, there is an objective necessity for practical solutions to the problem at hand in view of the fact that in most hospitals, children with disabilities are being born on a daily basis and their mothers are not happy about it. The young mothers feel that they are being punished and as such they live under a curse for having giving birth to these children. Inevitably, they get frustrated so much so that they end up feeling like running away from home leaving the child with their mothers (grandmothers to the children) and at times they even contemplate killing the child.

Thus, training was suggested as something that would hopefully empower the parents by imparting knowledge and skills on how to take care of a child with a disability. In other words, this will serve as a guide on how to treat these children. To this effect, the following remarks were made:

“The programs that we need are the one where parents could be taught on how they should love and care for their children, because it appears that some of these parents give their children with disabilities away as gift to others, some of them desert them and some kill them, if the parent sees that the child is disabled, he simply kills the child so as to remove the burden in his/ her shoulders, some mothers leave the child under the sewerage, or leave the child in the forest, on the street or leave the child in the orphanage/ shelter, so do you see that there is need to train
these parents to love their children, so as to know that these children are a gifts from God and their spirit is not different though their bodies cannot do everything”.

One of the respondents suggested that these training programs on disability should happen on a daily basis as opposed to having them only when an accident has happened. Thus, the following remark was made:

“There are no programs in the community to support parents of children with disabilities, because there are only conducted, if there is an incident which has happened, the government then step in, but it is not supposed to wait for an incident to occur but it must be conducted on a daily basis, because in now days the number of children being born with disabilities is increasing at an alarming rate”.

It was stressed by one of the respondents that training on disability is needed because there are so many children with disability in schools. It is arguable, therefore, that they need to be trained on how to support these children with disabilities. Hence, one of the respondents remarked thus:

“I wish they could train us because they are so many learners who have disabilities. It’s not a single program that we need, it’s many. They must tell us that, do you see, if a child is like this you must try this or that, whenever they (officials) arrive they have to see that you have tried something, and exhausted all the avenues and they must see what to do. I wish they could invite us to training”.

One of the respondents differed from the rest of the respondents by confirming that there are programs in place to support parents of children with disabilities in her community. In this regard, she stated that,

“Yes, because they come to schools and they are helping us. The government is providing support to us because different departments visit our schools to guide us on how to support a child with disability and also how does a teacher identify a child with a disability. Also the social workers do support us. The departments that are supporting us are the department of Education, health and the Department of Social Development”.

The respondents also felt that training will help with the raising of awareness on disability. To this effect they stated that:

“Those people who have encountered the challenges of having a child with disability need to conduct awareness in the community about disabilities, and explain to the community. So training and awareness must be conducted to the communities before incidents take place so as to prevent people from committing suicide, because of having children with disabilities, some of them become the murders, and some of them locked them in the house or abused them”.
c) Counseling sessions for parents

Counseling of the respondents who are parents of the children with disabilities was raised as one of the needs they want to have met in their communities. The respondents felt that counseling would help those parents with children who have disabilities to come to terms with what has happened to them and thus help them move on. Therefore, they suggested that:

“There must be someone who will talk to the parents, and try to make them aware that they can live a normal life with these children without any problems or anyone looking down upon them or else”.

Counseling was viewed as a crucial factor towards lessening the burden which the respondents carry. Thus, it was hypothetically argued that:

“Let’s say the child is not able to sit independently or to walk so the parent needs to be supported, and trained so that she or he won’t feel the burden of having a child with disability so as prevent her from praying for the death of the child, so the counseling is needed for those mother for disabled children because it is not nice or its difficult to have a child with disability especially young mothers are the one who are getting these children”.

The respondents also suggested that Non-afflictions Organizations should play a role in forming the contemplated social support programs and also assist with the counseling of the parents of the children with disabilities. To this effect, it was remarked that:

“There is a need for NPO and NGO’s to be supported financially although the government has social workers but because of the challenges they are facing in these communities, they do not stay long and they resign quickly or they leave the area, and you find that the community end up having no one to support them. Therefore, the NPO and NGO’s can do the work of social workers and sometimes get the parents of the disabled children on board, to help them with these programs in the community because they have experiences in these challenges, they can also be able to support the families who are encountering the same challenges in the future and support them emotionally and psychologically and assure them that it is not that God does not love them as they encountering these problems, or they have been cursed or is because the wife was being unfaithfully, so these people will be able to explain to the community why they are getting a child with disability”.

d) Financial support

Most of the respondents expressed the need for financial assistance for purposes of meeting the child’s expenses. It is in this regard that one of the respondents declared as follows:
“I need financial support because I could see that I won’t manage if he goes to the school for disabled children. When he attends that school he will need a uniform, so I need support”.

The respondents also indicated that they need financial assistance for transport to and from the hospital. Thus, one of the respondents remarked that her daughter’s chronic medication is collected far away and that sometimes she is without money to enable her pay for transport to go and fetch the medication.

e) Transport

Transport was also raised in the interview as a need by one of the respondents in the study. Thus, one of the respondents remarked as follows:

“I wish there was a bus that ferries children with disabilities to KwaMosi from the school in the afternoon. It must also collect them even in the morning because there is only one bus that we are relying on”.

f) Schools

Most of the respondents indicated that finding a suitable school that caters for the needs of the children with disabilities is a challenge. One of the respondents stressed how she wants the government to help with regards to the school. To this effect she remarked as follows:

“I wish the government should build a school for children with disabilities (special school) in our area of kwaMosi even if it could be a school with a boarding school”.

g) Housing/ Shelter

One of the respondents in the study stressed the need of having a suitable housing. To this effect she remarked as follows:

“I’m looking at our place there are no houses. I thought the government is going to build houses for us, it is the house which I don’t have I want the government to build a house for me, a RDP house so that there will be a big space where my child with a disability would have her own big bedroom and stop sharing the bedroom with her parents. What I’m saying is she needs to have her own bedroom”.

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4.4 Summary of the chapter

This chapter has engaged in the presentation and analysis of data collected through semi-structured interviews. Through listening to parents’ voices from data collected pertinent findings of the study were drawn. From the discussion it has appeared that parents in the context of the study are vulnerable and struggled with the loss of a normal child, the disruption of one’s lifestyle and sense of shame or humiliation that is experienced with the family. Parents grieve when trying to accept and adjust to the situation of a child with a disability. They also had to modify their parenting so as to accommodate the child with a disability. The study has also revealed that parents in this study had to access different levels of support to manage the demands required by parenting children with disabilities. It is well documented that the kinds of social supports they received were from the family, community as well as organizational support. The following chapter discusses the findings and recommendations of the study.
5.1 Introduction

This chapter presents the findings of the study and thus contributes to the existing knowledge dealing with the experiences of parenting children with disabilities. The chapter also deals with the recommendations which are deemed to be pertinent to the critical issues which have been established as constituting the essence of the experiences which parents, more often than not, have to endure as a result of the physical condition of their children. Subsequent to the discussion of the recommendations, conclusions for the entire study as informed by the discussion of the findings are drawn.

5.2 REINSTATING THE OBJECTIVES

The objectives of the study were:

(a) To gain insight into the experiences of the parents having children with disabilities.
(b) To determine the challenges faced by the parents of the children with disabilities.
(c) To identify positive coping strategies use by the parents of the children with disabilities.
(d) To identify measures in place to support the parents of the children with disabilities.

5.3. FINDINGS OF THE STUDY IN TERMS OF THE OBJECTIVES

In this section, the findings of the study discussed are based on the information obtained from the respondents. Notably, the findings are discussed in relation to the objectives of the study with the view of addressing all the key questions as set out in Chapter One. It is worth noting, therefore, that the first objective of the study was:
5.3.1 To gain insight into the experiences of parents having children with disabilities

It is notable that in relation to the objective above, one of the most conspicuous findings that emanated in this study is that the respondents do not necessarily alter their parenting. Instead, they in fact expand it. Thus, reference is made in this regard to the kind of modification they often make in order to accommodate their child with a disability. For instance, they have to engage in a process of describing their expectations and meaning-making with regard to their role as parents of children with disabilities. In an effort to best raise the child with a disability the respondents remarked that it is important for them to have certain attributes such as perseverance, love and compassion to be able to give the child with a disability the attention required as dictated to by the circumstantial condition of the child. This is consistent with some of the sentiments expressed in the literature review to the effect that children with disabilities require much attention from their parents which in turn has the potential of increasing parental stressors (Joosa & Berthelsen, 2006)

These respondents indicated that more often than not, they need to be physically present in the immediate vicinity of the child and take the child’s abilities into consideration when taking decisions which have a direct impact on the well-being of such a child. Notably, nearly every moment and action required some additional thought and modification on the part of these respondents in their dealings with the children with disabilities. Arguably, this is indicative of the fact that parenting a child with a disability also requires that they make certain concessions and thus also develop a positive disposition towards children with a disability.

The respondents are of the view that they are required to take care of their children on a daily basis and thus play an important role in the teaching of the child. The respondents indicated that their major goal in parenting a child with a disability is to ensure that the child becomes independent irrespective of the existence of a disability. Thus, they deem it necessary that they should ensure that they do everything in their power to help their child develop to his or her full potential because they believe the child has the ability to learn, grow and be independent. Additionally, some of the respondents asserted that the goal they have for their child is related to boosting the child’s self-esteem all the time and strive to make the child feel important like other
children in the family. This view is attested to by Dobson, Middleton and Beardsworths’ (2001) assertion that the parents of children with disability need to be responsive to their needs. Such responsiveness must be greater than that displayed towards children without disabilities since there are a number of roles such as tracking developmental milestones, watching the development of the disabled child on day-to-day basis, and take notice when the child does not develop at the same rate as other children of the same age. It was notable that these respondents are proactive in identifying and responding to the children’s needs and thus display a calculated approach to parenting.

Many of the respondents in this study exhibited an over protective propensity towards their children with disability. Chandramuki, Shastry and Vranda (2012) concur that over protection is the common parental attitude towards children with disabilities. In addition to their perspectives which they uphold on parenting a child with a disability, some of the respondents admitted that it is important to normalize the child’s disability and look beyond it. Mindful of this, they deemed it imperative to treat their children in the same way as those children who do not have disabilities. The respondents asserted that their expectations remained the same regardless of their children’s disabilities. This stems the quest to have their children not only to be the best but also to be good, loving and independent. This is consistent with what transpired in the literature review wherein it is asserted that parents of children with disabilities are expected and encouraged to treat their children in the same way as those without disabilities and love them regardless of their physical condition with its attendant challenges.

When the researcher examined the data more clearly, it is evident that the life of a parent of a child with a disability is full of distress before and after diagnoses. The study has revealed that before diagnosis respondents became confused and anxious as they could not make meaning of their children behaviors and what was wrong with the children. A number of the respondents reported that something was not right since the child’s infancy, this uncertainty about child’s problem also increase parental stress level. This study concurs with other previous studies that first day’s even months after diagnosis, parents tend to be overwhelmed because of the loss of
hopes and aspiration when they realized their child has a disability (Reichman, Coreman & Noonan; 2008). The loss of hope for the ‘perfect child’ therefore, caused grief to most of the respondents in this study because they started to see their children’s lives and theirs as being incomplete, destroyed as well different from the rest of the community. This was indeed disappointing and a threat to their egos.

It is also well documented that these respondents in this study experienced chronic stress when they discovered that their child has a disability and they began a journey that took them into a life that was often filled with strong emotions, difficulty choices, interactions with many professionals and specialists and ongoing need for information and services (McGill-Smith; 2003). This was indeed emotionally engaging as well as distressing to these respondents because the dreams, fantasies and the future they had about their children were shattered. As a result these respondents are faced with a complicated, draining, challenging, frightening and consuming task as they raise the child they have, while letting go of the child they dreamed of (Kaur & Kiran, 2015). The study has revealed that the respondents find it difficult to let go of the lost dreams, and generate new dreams. To do all this, the respondent had to experience the process of grieving (ibid). They also face a lot of difficulties in order to accept and cope with their children disablement while making many adjustments that were necessary to acclimatize the family to their children’s disability.

There are also multiple factors that are identified as causing psychological distress among the respondents of children with disabilities. One of the factors is attributed to the heavy care giving burdens that many of these respondents assume. For instance they have to help with daily activities of children with a disability which may take a tangible toll to the respondents’ psychological wellbeing. It is also heightened by loss of the opportunities and ambitions which their children may not be able to fulfill. The study also have shown that the respondents worry about the future of the child as they wish the child can have something in life because they see the child’s future as being destroyed.

It appeared that when the respondents are raising a child with a disability, they experienced the situation as more demanding and complex. Most of the respondents voice out various difficulties
they have to cope with. The respondents revealed that they always focused on every aspects of their children’s life by teaching these children various activities to help them make progress developmentally. As a result most of them mentioned that they always worry and fear that their child would not cope with anything; they worry about child not doing well at school, the child self-caring ability to make a living and become independent as well as the sense of loss of what the child may not become. Moreover, they felt that their role as parents went beyond ordinary parenting. This is an indication that they always have never ending emotional and/ or physical fatigue and the feeling of lack of freedom. The findings also suggested that parents of children with a disability also experienced stress because of the challenges they encounter when raising a child with a disability, and this will be elaborated more in the next objective.

5.3.2 To determine the challenges faced by the parent of children with disabilities

Reichman, Coreman and Noonan (2008) argue that caring for a child with a disability brings multiple challenges to parents such as additional financial burden for treating their child’s condition, having to deal with the child problematic behavior and social stigma associated with disabilities. The findings of the study are consistent with Reichman, Coreman and Noonan’s (2008) argument since the majority of the respondents identified several challenges which they have to deal with on a daily basis. One such challenge relates to the struggle of not having adequate financial resources to properly care for and bring up their child with a disability. This is so in spite of the government’s attempt of providing these children with social grants. Most of the respondents indicated that the expenses towards taking care of the children are extremely exorbitant. Thus, finances are deemed to pose not only a serious challenge but also a barrier towards rendering meaningful parental care for the children living with disabilities.

The findings also revealed the struggle of respondents in finding suitable schools that would cater for the needs of their children. They reported that it was frustrating because there are few schools that cater for children with disabilities in uThungulu, the ones that are available are either full or far as a result they need more money if they have to take their children to those schools which are far.
Furthermore, the findings also revealed that some of the respondents who participated in this study stressed that there were lack of suitable housing and transport allocated for children with disability. These were adding stress towards extra-ordinary demands associated with caring for the child with a disability to parents.

It is evident in this study that raising a child with a disability is a challenge on its own because respondents reported being super parents always focused on every aspect of their child. It also appeared in this study that respondents rely on someone when they encounter difficulties in meeting the needs of their child with a disability; they search for appropriate services and helpful professionals which can also be challenging to them because they are not always available to them. This increased the demands on time and energy for them. This also suggests that although parents of young children with disabilities are faced with unique challenges, they also have distinctive opportunities resulting from their child’s disability.

Although the literature review has suggested that having a child with disability was associated with social stigma, however, the current study did not yield strong evidence that having a child with a disability is associated with stigma, curse and punishment. In other words findings are inconsistent with this argument.

5.3.3 To identify positive coping strategies used by parents of children with disabilities

Beresford, Rabie and Sloper (2007) point out that it is not surprising that parents of children with disability are more likely to require support than parents of non-disabled children. Furthermore, literature review suggests that the presence of positive interactions is imperative in adjusting to the stress of having a child with disability. Whereas different theories have suggested that positive perceptions play a central role in the coping process. The researcher finds it essential to report some coping strategies used by the respondents in this study as it is important in assisting other professionals when they are dealing with parents who would be in the same situation of raising a child with a disability.
The findings have revealed that respondents arrived at a more positive state through engaging in the process of defining situation, describing their expectations as well as meaning making with regards their role as parents of children with disabilities. In doing that they were forming new identities in relation to the situation in order to accommodate the child with a disability. They made some modification in their parenting. However, some of them adapt by acquiring new traits like becoming more compassionate, loving caring, persevering etcetera. It is also evident in the study that some respondents adapt and find meaning in a situation through acquiring new roles. For instance one of the participants in the study indicated that he was able to deal with his children’s disability because he discovered it at the time when he was establishing an NGO for people with disability and providing support and counseling to those people in the community. He developed as sense of personal control and learnt that he can achieve rather remain powerless.

Furthermore, respondents also described both informal and formal forms of social support that played major role in raising a child with a disability. These forms of supports included family, organizational and community as it has been stated in the previous chapter.

**INFORMAL SUPPORT**

Findings revealed how the respondents have trusted their family members to support them and their children. In most cases the respondents described how their families were source of strength in their lives. In other words the family members seemed to be pillars of strengths to them in times of need. The kind of support included words of encouragement and assistance in caretaking for the child with a disability. Parenting was viewed as a team effort as a result the importance of standing together by supporting one another in finding assistance for the child with a disability was recognized. The aim was to work together and provide unified care to their children with disabilities. It benefited them to have reliable relatives who help them carry the burden. This in agreement with what is stressed in Gupta and Singhal, (2004) that if parents react positively to their child with a disability, then the sibling relationship tends to be more positive. If the parents took an optimistic and caring view, then the sibling is more likely to do the same.
Thus the respondents’ ability to accept their child’s difficulties influences the ways in which a family functions.

The study also revealed that the respondents were able to get support from the community. The kind of support they talked about was that their children were not discriminated against in the community and they have friends who play and walk with them. The respondents also pointed out that they are able to share their concerns with friends, neighbors and colleagues. One of the respondents indicated that he was able to receive support from the pastor who was able to provide emotional counseling in a way that he accepted the situation.

**FORMAL SOCIAL SUPPORT**

For the respondents to cope they had to cooperate with professionals. They mentioned several professionals or service providers that provided some sort of formal social support for them and in decisions regarding their children’s disability. The professional respondents collaborated with are social workers, doctors, psychologists, and therapists as well teachers. It has appeared in the study that respondents consulted these professionals for information about the child’s condition, diagnosis, management and services available. They also provided guidance and support to the respondents on how they should treat and look after their children. Most of the respondents noted that they used psychological services for the psychologically assessment of the child. For some of the respondents they accessed psychological services for themselves and or siblings for guidance and emotional support. The study suggested that teachers were also a source of help to the respondents by identifying those children with challenges in schools and then advised the respondents on services they could access to support their children. They also provided support regarding the search for schools suitable for these children needs.

The government was also mentioned by respondents as playing a role in supporting their children through social grants and special schools. One of the respondents went further by mentioned that even municipality and ward councilors are source of support to their family in terms of providing food parcels and vouchers.
Although the respondents indicated that they are receiving support from various sources, but it has appeared that, it is not reaching the majority of the respondents of children with disabilities. This is evident by the lists of needs identified by most of the respondents that are viewed as crucial.

5.3.4 To identify measures in place to support parents of children with disabilities.

It is well documented in the study that as a part of the care giving responsibility, the respondents encounter a variety of challenges such as overcoming the disappointments attendant to the original diagnosis and the need to coordinate the child’s multifaceted medical, educational, and developmental interventions while balancing family needs. Furthermore, caring for a child with a disability often requires additional physical, emotional, social and financial resources. It is also noted that having a child with disabilities affects not only the parents, but also siblings, therefore, there is need for programs and structures to support the respondents of children with a child with a disability so that they would be able to respond to the increasing demands of a stressful and difficulties situations through developing coping strategies to reduce tension and anxiety thus adapting their new situations new situations.

Although this study has revealed that that there are structures of support in place, in the area which includes family, organization and community structures, but most of the respondents indicated that the programs or measures to support them are nonexistent in their communities. They further mentioned that there is a shortage of social workers in the area who would help with the provision of such programs. It appeared in the study that such support is provided whenever there is an incident that has taken place. Due to nonexistent of programs to support the respondents of children with disability, the respondents emphasized the need of having those programs in their area. Professional counseling support, training and support groups were identified as crucial for them for developing realistic expectations for their children and know how to handle their children’s conditions. In several interviews the respondents voiced the need of contact with other respondents within the support groups where they would have mutual sharing of their experiences because of having similar concern. The respondents voiced the needs
of being skilled and informed through trainings and awareness programs conducted with them. They believed that these programs would help with proper treatment of the children with disability also with prevention of the respondents from committing suicide as they cannot cope with children’s disability. As a result they pointed out that it would be of great help if the officials from the Department of Education assist with the establishment of such programs in the area. The study also revealed that there is need for programs which would equip the teachers on how to support children who have challenges in schools as they are so many children struggling in schools.

Although one of the respondents differed from the rest by stating that there are programmers in place to support parents for children with disabilities by mentioning that the government conducts those programs in school through the DoE, DSD and DoH but those programs focused more on supporting learners with barriers to learning and development.

5.4 RECOMMENDATIONS

(a) Based on the findings of the study, it is recommended that support groups for parents of children with disabilities should be formulated and be functional. Support groups would provide parents with safe environment where they can share their experiences of raising a child with disability and gain information from one another. In a support group parents would be able to discuss pertinent emotional issues such as feelings of frustration and child rearing problems. It will help them see that they are not alone and their problems are not unique.

(b) It is recommended that there must be a training conducted with parents of children with disabilities on how to raise their children so as to know how to deal with a situation. It also appeared from the study that there are cases where parents of children with disabilities are still ignorance about the rights and their responsibilities with regard to their children. Due to superstitions and stigma parents tend not to want to be associated with the children with disabilities. It came up from the study that training would equip parents with knowledge and skills of how to take care of a child with disability. The reason behind this notion is the fact that findings revealed that some parents want to
commit suicide if they are not coping with a child with a disability. It also appeared that there is still some cases where children with disabilities are still ill treated by their parents as they don’t know how to raise them. Conducting training will help to transform the attitudes, practices and beliefs systems that continue to deny children their rights to life, dignity, equality and freedom. Training would serve as prevention programmes.

(c) It is also recommended that awareness programmes should be conducted with parents of children where parents would be made aware that they can live a normal life with their children. Those awareness programmes would focus on educating parents about child disability so as to provide them with understanding and nature of disability, information on how to raise a child with a disability, guidance in terms of accessing services information, where and whom to consult whenever they have with a disability, informing parents about their children’s right. They will help to empower parents about the knowledge and skills on disability. It may also be useful to conduct awareness in a variety of places such as in schools during parents meetings, churches and community meetings as it would educate others in the community while empowering parents to maintain their parenting practices in public.

(d) Ongoing counselling programs should be initiated and conducted with parents of children with a disability in this area. The reason behind this is that parents of children with a disability face so many challenges and demands in their lives; therefore they need to have someone to support them emotionally so as to ease the burden and help them come into terms with their situation.

(e) Social workers must be available to provide counselling to these parents and also help with the establishment and provision of support programs in the area. The government needs to ensure that more social workers are deployed in the area so as to reduce overload. Programmes to raise and improve morale need to be conducted with social workers.

(f) Since the experiences of parenting a young child with disabilities are both similar and different from parenting a young child without disabilities, practitioners must be aware
that their experiences are unique and service delivery should correspond with these differences.

(g) More schools for children with disabilities should be built in view of the fact that there is a shortage of schools that cater for children with disabilities within their communities and it was a concern for most of the respondents in this study.

(h) NPO’s and NGO’s should be used to provide ongoing support to parents of children with disabilities. They should also assist with the establishment of and monitoring of these support programs working hand in hand with social workers in the area

5.5 FUTURE RECOMMENDATIONS

- There must be on-going support programs to empower parents in their journey of raising a child with a disability.

- In the present study, the researcher relied exclusively on parent report to develop an understanding of experiences of parents with children with disabilities. A next step should be taken to verify the findings with observation of parent and child behavior within a naturalistic setting, such as the home. It may be informative to follow parents throughout a day of observing interactions that occur throughout the day in their homes.

5.6 CONCLUSIONS

This study has discussed various experiences of the parents of children with disabilities residing in the uThungulu District Municipality. These experiences are not distinct from the experiences of the respondents who are parents of children with disabilities from the research of previous studies. For instance it transpired in the study that the parents do not alter their parenting. On the contrary, they modify it to accommodate the children with disability. It also transpired that the parents experienced high levels of stress in all the domains which result from the challenges that they are facing. Some of the challenges cited by the respondents as the source of stress among the parents of children with disability include amongst many, lack of financial resources, finding
suitable schools for their children, lack of adequate housing, transport allocated for children with disability and support programs. This serves to indicate that disability does not only affect the individual with disability, but it touches this person’s family, friends and fellow community members. It causes pain and bewilderment to many families. Therefore, different forms of social support programs that would help the parents cope with a child with disability should be put in place in the communities. Being skilled, informed and well equipped were raised in the study to be critical to the parents of the children with disabilities’ sense of competence, their ability to make the right decision and their ability to support their children’s well-being and development (Beresford, Rabie & Sloper, 2007).

The researcher used the phenomenological framework because of its suitability to examine the experiences of the parents. This framework allowed the researcher to explore and analyze this particular phenomenon to arrive at a description of the lived or subjective experiences of the parents of children with disabilities. It also allowed a researcher to establish the true reality in the respondents’ narratives of their circumstances of parenting a child with disabilities.
6. REFERENCES


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ANNEXURES

ANNEXURE A: PARTICIPANT INFORMED CONSENT DECLARATION

INFORMED CONSENT DECLARATION

(Participant)

Project Title: The experiences of parents of children with disabilities

Nozipho B. Mpontshané from the Department of Social work, University of Zululand has requested my permission to participate in the above-mentioned research project.

The nature and the purpose of the research project and of this informed consent declaration have been explained to me in a language that I understand.

I am aware that:

1. The purpose of the research project is to explore the experiences of the parents of children with disabilities so as to get insight into their situation.

2. The University of Zululand has given ethical clearance to this research project and I have seen / may request to see the clearance certificate.

3. By participating in this research project I will be contributing towards the body of knowledge and towards making the public understand and accept diversity.

4. I will participate in the project by giving accounts of my experiences of having a child with a disability.

5. My participation is entirely voluntary and should I at any stage wish to withdraw from participating further, I may do so without any negative consequences.

6. I will not be compensated for participating in the research.
7. There may be risks that are not anticipated. However every effort will be made to minimize any risks.

8. The researcher intends publishing the research results in the form of thesis, however, confidentiality and anonymity of records will be maintained and that my name and identity will not be revealed to anyone who has not been involved in the conduct of the research.

9. I will receive feedback in the form of summary report regarding the results obtained during the study.

10. Any further questions that I might have concerning the research or my participation will be answered by Nozipho Mponenthane, (083 360 2031).

11. By signing this informed consent declaration I am not waiving any legal claims, rights or remedies.

12. A copy of this informed consent declaration will be given to me, and the original will be kept on record.

I, .................................................................have read the above information / confirm that the above information has been explained to me in a language that I understand and I am aware of this document’s contents. I have asked all questions that I wished to ask and these have been answered to my satisfaction. I fully understand what is expected of me during the research.

I have not been pressurised in any way and I voluntarily agree to participate in the above-mentioned project.

................................................................................................................
................................................................................................................

Participant’s signature  Date
ANNEXURE B.

INTERVIEW SCHEDULES FOR PARENTS OF CHILDREN WITH DISABILITIES

Biographical details

<table>
<thead>
<tr>
<th>Name</th>
<th>Contact NO.</th>
<th>Age</th>
<th>Sex</th>
<th>Marital status</th>
<th>Place of interview</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Date:

An in-depth interview

1. When did you find out that your child has a disability?
2. How did you find out that your child has a disability?
3. How did you feel at that time?
4. What was your reaction?
5. Did you speak to anyone about what you have found out?
6. What steps were taken?
7. Who took them?
8. Did you have any information regarding your child’s condition?
9. What does it mean to be a parent of a child with disability?
10. How does it feel to raise a child with a disability?
11. What is public reaction towards you?
12. What challenges do you encounter as a parent having a child with disability?
13. How do you deal and overcome those challenges?
14. Do you get any support from your family, friends, and community?
15. If not, what kind of support do you feel you need?
16. Are there any support programmes in place to support parents with children with disability?
17. If not, what sort of programmes do you feel you need?
18. Any other comments?
ANNEXURE C:

IMIBUZO EBHEKISWE KUBAZALI BEZINGANE EZIPHILA NENKUBAZEKO

Iminingwane yomzali ____________________________ Usuku

Igama ________________________________________

Inombolo yocingo ______________________________

Iminyaka ______________________________________

Ubulili _________________________________________

Isimosokushada _________________________________

Indawo _______________________________________

Imibuzo enzulu

1. Wathola nini ukuthi ingane yakho iphila nokukhubazeka?
2. Wathola kanjani ukuthi ingane yakho iphila nokukhubazeka?
3. Wazizwa unjani emva kokuthola ukuthi ingane yakho inokukhubazeka?
4. Wenzani ngenkathi uthola ukuthi ingane yakho inokukhubazeka?
5. Ukhona yini owakhulumanaye emva kokuthola ukuthi ingane yakho inokukhubazeka?
6. Iziphi izinyathelo ezathathwayo?
7. Ubani owathatha izinyathelo ezingenhla?
8. Wawunalo yini ulwazi ngesimo sengane yakho?
9. Kusho ukuthin iukuba umzali enengane ephila nokukhubazeka?
10. Kunjani ukukhulisa ingane enokukhubazeka?
11. Umphakath iukubukakanjani?
12. Iziphi izinhlelo ezikhona zokweseka abazali abanezingane eziphila nokukhubazeka?
13. Umelana kanjani nalezo zokweseka abazali?
14. Uyakuthola yini ukwesekwa emndeni, abangani kanye nasempakathini?
15. Uma ungakutholi, yikuphi ukwesekwa ocabanga ukuthi ungakudinga?
16. Zikhonayini izinhlelo ezikhona zokwesekwa abazali abanezingane eziphila nokukhubazeka?
17. Uma zingekho, iziphi izinhlelo zokwesekwa ocabanga ukuthi uyazidinga?
18. Ukuphi okunye ukuphawula ongabanakho?
ANNEXURE: D

P.O.Box 8089
Empangeni Rail
3910
2015
01 July 2013

CES: Circuit Management
The Department of Education
UThunglu District
Empangeni
3910

Dear Sir

THE REQUISITION TO CONDUCT A RESEARCH STUDY

I am student at the University of Zululand conducting a research on the experiences of parents of children with disabilities. In order to fulfill the requirements for the degree I request permission to interview parents whose children are diagnosed with disabilities and while attending the schools situated Imfolozi Circuit Management Centre. The aim of the interviews is to get insights of their situation so as to be able to find ways to support parents whose children are diagnosed with a disability in the future.

Although the information obtained from the interview will be used in the dissertation, all participants will remain anonymous. Debriefing will be provided by me should the need arise. I will be so thankful to receive a permission to conduct my study as the accomplishment of my degree.

Thank you for continued support.

Yours Sincerely

__________________________________

Nozipho B. Mpontshane  Date

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Annexure E:

Miss N.B. Mpontshane
P.O. Box 8099
Empangeni Rail
3910

Dear Madam

PERMISSION TO CONDUCT RESEARCH IN THE IMFOLOZI CIRCUIT MANAGEMENT SCHOOLS

Your letter dated 01 July 2013 in respect of the above subject has reference.

Kindly be informed that permission is hereby granted to you to conduct your research. Please note the following during and after the completion of your research.

1. Schools and office personnel will participate on a voluntary basis.
2. Teaching, learning and office activities will not be interrupted.
3. Access to schools/office will have to be negotiated with the CES: Circuit Management and/ Principals of Schools
4. Submit a report to the Head of the Circuit Management on completion of your project.

Make sure that you return the completed KZN DoE Application for Permission to Conduct Research form before the commencement of your research.

I wish you success in your undertaking.

Thank you

CES: Circuit Management

KWAZULU-NATAL DEPARTMENT OF EDUCATION
IMFOLOZI CIRCUIT MANAGEMENT
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