THE EXPERIENCES OF PARENTING A PHYSICALLY DISABLED CHILD IN THE THOHOYANDOU VHEMBE DISTRICT OF THE LIMPOPO PROVINCE

A DISSERTATION SUBMITTED IN PARTIAL FULFILLMENT OF AN MASTERS DEGREE IN DISABILITY STUDIES

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# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>TITLE</th>
<th>PAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>DECLARATION</td>
<td>1</td>
</tr>
<tr>
<td>TABLE OF CONTENTS</td>
<td>2</td>
</tr>
<tr>
<td>ABSTRACT</td>
<td>3</td>
</tr>
<tr>
<td>ACKNOWLEDGEMENTS</td>
<td>4</td>
</tr>
<tr>
<td>DEFINITION OF TERMS</td>
<td>5</td>
</tr>
<tr>
<td>CHAPTER 1 – INTRODUCTION</td>
<td>8</td>
</tr>
<tr>
<td>CHAPTER 2 - LITERATURE REVIEW</td>
<td>14</td>
</tr>
<tr>
<td>CHAPTER 3 - RESEARCH METHODOLOGY</td>
<td>27</td>
</tr>
<tr>
<td>CHAPTER 4 – FINDINGS</td>
<td>42</td>
</tr>
<tr>
<td>CHAPTER 5 - DISCUSSION OF FINDINGS</td>
<td>59</td>
</tr>
<tr>
<td>CHAPTER 6 – CONCLUSION</td>
<td>73</td>
</tr>
<tr>
<td>REFERENCES</td>
<td>77</td>
</tr>
<tr>
<td>APPENDIX I - LIFE STORIES</td>
<td>92</td>
</tr>
<tr>
<td>APPENDIX II - THE STUDY SETTING</td>
<td>96</td>
</tr>
<tr>
<td>APPENDIX III - CONSENT FORMS</td>
<td>98</td>
</tr>
<tr>
<td>APPENDIX IV - OUTLINE OF THE INTERVIEWS</td>
<td>103</td>
</tr>
<tr>
<td>APPENDIX V - THEMES, CATEGORIES AND SUBCATEGORIES</td>
<td>104</td>
</tr>
</tbody>
</table>
ABSTRACT

This study explored the experience of parenting a physically disabled child in the Thohoyandou Vhembe District of Limpopo Province, from the perspective of mothers. The objectives of the study were to investigate feelings linked to parenting a physically disabled child in the community within which the parents find themselves, to explore the impact of raising a physically disabled child, as well as strategies that parents employ in coping with raising a physically disabled child.

Phenomenology was the study design followed. In-depth unstructured interviews were conducted with four mothers. Five themes emerged from a process of inductive analysis: “A zwi leluwi” (“It is not easy”); Seeking Help from Various Sources in Vain; “Ndí semiwa ngae” (“I am called names because of him”); “Ndo mu beba e wavhudi” (“I gave birth to a healthy child”); Help from the Government.

The findings of this study in part confirmed what other researchers revealed by indicating that raising disabled children is not easy. The novelty of this research was its situation in the Vhembe district, bringing forth specific contextual factors that relate to difficulties with access to information, educational facilities for children with multiple disabilities, and health care services, and an overall poor awareness of causes of impairment and disability. The care dependency grant and wheel-chairs were singled out as providing some relief in caring for and raising a disabled child.

Further reflection on the themes pointed to how much the participants' life circumstances lead to a complexity of needs, where a dependency grant and wheelchairs alone are insufficient supportive measures.
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My friend, Dr. U. Ushotaneffe, thanks for your encouragement, guidance and valuable contribution throughout this study.

Thanks to the parents of physically disabled children for their cooperation in the study.

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DEFINITION OF TERMS

Impairment:

Impairment is the loss or abnormality of body structure (WHO, 1997).

Marks (1997) states that disability as an attribute is accorded the same status as other classes of identity such as gender or race.

Attitude:

Attitude is a psychological tendency that is expressed by evaluating a particular entity with some degree of favour or disfavour. The evaluation can occur in any form - overt or covert, cognitive, affective or behavioural (Lord, 1997).

The measure of positivity or negativity of parents' attitudes in this study is based on their first emotional responses to the discovery of their child's disability.

Disability:

Disability is the restriction of a person's activities as a result of impairment. This may be musculoskeletal, neural, sensory (WHO, 1997) or restriction of activities resulting largely or solely from either social responses to bodies that fail to meet social expectations or assumptions about the body reflected in the social or built environment (Weitz, 1996).

Physical Disability:

Disabilities resulting from physical, visual and/or hearing impairment shall in this study be referred to generally as physical disabilities so as to differentiate them
from multiple, learning and mental disabilities. Deafness is universally regarded as a physical disability and usually classified along with blindness and other physical disabilities (Aarons & Akach, 2002). Eloff (2002) describes physical disabilities in terms of a range of severity and a range of duration from temporary to permanent or life threatening. These might include neuro-motor impairments (cerebral palsy, seizure disorders and spinal cord disorders), degenerative diseases (muscular dystrophy and spinal muscular atrophy) and orthopaedic and musculoskeletal disorders (limb deficiencies). Disabilities are sometimes differentiated from health impairments. According to Marks (1997) the nature and extent of impairments occur on a continuum rather than on one or other side of a clear boundary distinguish ability and disability.

Distinctions between Impairment, Disability and Handicap:

The aspect that perhaps creates most misunderstanding about disabled people is the distinction between a disability and a handicap. At a basic level part of the problem arises because the description of what constitutes a handicap has to some degree been explained in terms of disability (Badley, 1993).

According to Wagstaff (1982) & WHO (1997) the most widely utilized international definition of disability is the International Classification of Impairments, Disabilities and Handicaps (ICIDH) which is a supplement to the World Health Organisation's (WHO) International Classification of Diseases. This set of definitions describes disability' as any restriction or lack of ability to perform an activity in the manner or within the rage considered normal for a human being which results from an impairment.

'Handicap' on the other hand is the disadvantage an individual experiences as a result of an impairment or disability. This disadvantage limits or prevents the fulfilment of a normal role depending on age, sex or social and cultural f actors. The concept of 'handicap' therefore recognizes that the cause of disablement
may be social (Locker, 1991; Badley, 1993; Imrie 1997; Marks, 1997; WHO, 1997; & Philpott & McLaren 1998).

According to WHO (1997) the overall distinction between impairment and disability is fairly clear. Some difficulties have arisen where a problem could be described appropriately by either an impairment or disability. For example, someone who is blind might equally well be described as having ocular impairment such as absence of an eye or profound impairment of visual acuity or, alternatively, as a disability in seeing. In a health care setting impairment may be an important focus; the response to such problems could be medical or surgical interventions, or the prescription of spectacles. In the context of other service provision, it is often the number of people with disability in seeing that may be of more relevance, particularly bearing in mind that not all blindness is the result of ocular impairment. A further example is the contrast between focusing on the absence of a limb (skeletal impairment) or on the possible consequence of locomotor disability. Once again the type of concern will dictate the way the problem is described.

Weitz (1996: 155) reiterates that 'impairment' is any loss or abnormality of psychological or anatomical structure or function. Thus impairment relates to the actual physical, anatomical level; disability relates to consequences of the impairment; and handicap relates to the consequent social perceptions of the deficient ability.
CHAPTER 1
INTRODUCTION

See Appendix II for the description of the study setting.

This research was conducted in the Vhembe district of the Limpopo Province of South Africa and focused on the experiences of a group of parents of disabled children.

I began this study with the assumption that the experience of parenting a physically disabled child is different to that of parenting an able-bodied child. As a parent of both a physically disabled child and an able-bodied child I have much
interest in comparing and relating to the parenting experiences of others with disabled offspring.

**Reflexivity (Personal Experiences)**

Parenting a physically disabled child can be difficult because it often entails numerous hardships such as being rejected by the community. I gave birth to a disabled child at the age of fifteen. I struggled immensely at that time, especially because I received no support from my parents or friends. There was no one I could turn to for advice or even simply to talk about the challenges I faced. This lack of emotional assistance lead to an escalation of the stress I already suffered due to the circumstances.

My best friends laughed at me and they used to tell me that having a child was a burden because it would have to be carried wherever I went like "a handbag." At that time the analogy seemed too moderate; my child then was to me more like a big suitcase filled with stones. The burden seemed to be more than I could bear. Crying was part of my daily routine and my parents were constantly angry with me because they still expected me to attend school which I was unable to do.

After six months I realized that my child was not developing at the same rate as other children of his age because he was too weak to sit upright. I then started wondering about his condition. I took him to the hospital and explained my concerns to the health authorities. I was told that all he needed was to practice certain exercises and that with time he would be able to walk. I was then advised to take the child for physiotherapy every second week. I followed their suggestions faithfully even though it was quite a task, as I had to carry him on my back for some distance. I was still so young and naive that I never asked why the child had to be brought to the hospital every second week. I just knew that children were supposed to be taken there for check-ups regularly.
The other problem I faced was a fear of the nurses since they were reputed to scold those who asked too many questions. The hardest thing to deal with however was the false promise that the child would eventually learn to walk. I believed them and when nothing happened I lost confidence in the nurses. I really trusted the physiotherapy assistants (Qualified therapists were rare in my area during this time) as professionals and I thought that they knew everything and had all the correct answers. I had expectations for my child as great as any other mother’s but as time went on I realized that these expectations had to change because what I was told by the physiotherapy assistants was not true.

Since I had no social or emotional support in the challenge of raising a disabled child I used to avoid public situations with him and hide him away from people. I always let him sleep in the bedroom and if someone wanted to see him I would tell them that he was asleep even if he was awake. If people saw him crawling outside I would rush to put him on my back and hurry into the house. The child would cry because he wanted to play outside but I felt I had to attend to my concerns first or else rumours would spread about me in the community. The major problem with this system of avoidance came in the child’s need to visit the clinic. On those days I knew that the child and I would be exposed to the public and so I devised a plan to combat this. Usually I would just stand and linger until all the other parents and children had finished their sessions and I could be the last one to enter.

I felt ashamed because I was such a young mother and I used to ask myself constantly why I gave birth to such a child, what the cause could have been and whether it was because I was a minor. Did I do wrong in any way? Was it God’s punishment? Was I bewitched? These are some of the questions I asked myself in vain and cried over every day. The most painful part of all was that I could not find anyone with whom I could share my misery. My brother used to insult me and say that I did not want to attend school but would rather be a wife. He would
tersely say, "You should go and live with your boyfriend together with your disabled child."

In 1993 a physically disabled woman who was a member of DPSA introduced me to a parents' organization called the Disabled Children Action Group. The first day she came I refused to acknowledge that I had a child with a physical disability.

She had heard about my child from some mothers at the clinic and as she knew me she wished to share information with me that might be helpful. After speaking to her I began to question my situation and lifestyle and to wonder whether I should use the information she gave me to make changes or continue to live in the way I had been. I finally decided that if she ever came back to visit me again I would try to follow her advice.

The following week she returned and invited me to a meeting of people with disabilities and parents of disabled children. This meeting provided an opportunity for me to speak to other parents of physically disabled children and to realize that I was not alone in this circumstance. After this I began to participate in various meetings and was able at last to share my experiences and gather more information on how other parents faced and overcame the challenges of parenting a disabled child.

Another thing that helped me was becoming aware of the Care dependency grant for children with disability. After finding out about it I immediately registered my child and the application was successful. The grant allowed me to buy my child clothes and food, which previously had been a struggle. Today I am a very active, proud mother committed to advocating equal opportunities for persons with disabilities and I serve as the Deputy National Chairperson of the Disabled Children Action Group. I salute DICAG because I was unhappy in my ignorance and now with the knowledge it has given me I have the strength to cope correctly
with the challenges I am faced with. I was ashamed, now I am proud to raise awareness among my family, neighbours and the community at large. With the wealth of information that I possess I am able to have a positive attitude towards persons with disabilities as well as dealing with disability in the home environment.

The development of my coping attitude was encouraged by other parents of disabled children as well as the process of understanding and relating to the hardships they faced.

My son, Andrew, is now eighteen years old and a member of the Disabled Children Action Group. He too advocates equal opportunities for disabled people and is aware of his rights.

**Arrangement of the Thesis:**

**Chapter 1: Introduction**
Chapter 1 introduces the study setting, and background on the researcher.

**Chapter 2: Literature Review**
Chapter 2 introduces literature on parenting a physically disabled child, and provides a brief rationale for this particular study.

**Chapter 3: Research Methodology**
Chapter 3 presents the problem statement, study aim, purpose and objectives, and a full description of the methods used in this study.

**Chapter 4: Findings**
Chapter 4 reveals the findings of the study formatted into themes and categories.
Chapter 5: Discussion of Findings
This section focuses on a theme by theme unpacking of the findings.

Chapter 6: Conclusion
The conclusion includes the limitations of the study as well as the researcher's recommendations.
CHAPTER 2
LITERATURE REVIEW

Introduction

As highlighted under 'Definition of Terms', disability is the restriction of a person's activities due to an impairment that may be musculoskeletal, neural or sensory (WHO, 1997). This inability to perform activities may also result from social responses to bodies that fail to meet common expectations or assumptions about how bodies should look and perform in the environment (Weitz, 1996).

The medical model focuses on an individual's pathology and attempts to find ways to prevent or cure disability or simply to care for the disabled person. Finkelstein (1993) believes that the medical interpretation of disability dominates service provision models for disabled people. In some respects this dependency created by the medical model disempower disabled people by isolating them from mainstream society and preventing them from accessing fundamental social, political and economic rights (Integrated National Disability Strategy (INDS, 1997). Imrie (1997) reiterates that people with disabilities remain at the mercy of society, often seen as pitiful and tragic characters worthy only of the charity supplied by their 'able-bodied' counterparts. Rehabilitation workers have criticized this narrow medical approach because it seems to overlook the potential for improved functioning through collaboration with other professionals (Goodwill & Chamberlain 1995).

Marks (1997) states that the social model sees the oppression of disabled people as being a result of the actions and prejudices of institutions as opposed to those of individual people. The social model is based on the belief that the discrimination and difficult circumstances faced by disabled people are socially created phenomena and have little to do with their actual, physical impairments. Disability movements are therefore calling for 'rights' not charity (Campbell &
When considering how individuals and their families view disability the context of their social environment must be considered. Their interpretation often reflects attitudes that are held within the community, mirroring to a degree the public understanding of disability as well as the historical realities within which that interpretation emerges (Ferguson, 2002).

**Historical Context**

Parenting a child with disability is by no means a small challenge, especially for mothers as often they tend to take a greater responsibility for the child. Historically in Sparta of the Greco-Roman world, the abandonment of handicapped and sickly infants was required by law (Gerland, 1992). According to the report of the National Information Centre for Children and Youth with Disabilities (NICHY, 1994) perceptions of disability differ according to the gender of the child. The NICHY (1994) indicates that the differences in the way genders are socialized, counselled and educated affect the attitudes of parents to children with disabilities.

Stayt (1931) undertook research in Venda during the early twenties. He reported that a baby born with any 'anomaly' or makes an unusual entrance into the world was not regarded with any particular joy. Often reasons to explain the 'anomaly' were sought, as in the father having his clothes on at the moment of conception. Babies born feet first and those born with any deformity were killed by having boiling water poured over them by the midwives. The 'mishap' was considered to be the work of an evil spirit. Such children were often buried inside the hut, near the wall, so that their bodies will be in perpetual shade - if the sun ever shined on their remains the mother was apparently going to be afflicted with abdominal pains. Stayt further reported that the birth of twins was fairly common amongst the Venda people but their advent was regarded as being unnatural and should
they be allowed to remain alive any misfortune that befalls the family, or possibly even the whole tribe, was attributed to them. Bone diseases were believed to be caused by evil spirits while people with leprosy were isolated (Stayt, 1931). People who died from leprosy had their huts and belongings burnt.

In South Africa, the INDS (1997) was introduced in by the government to address the issues of disability. Historically disability has been regarded predominantly as a health and welfare issue and the responsibility for the care of disabled people has thus generally fallen on civil society. People who provide services to the disabled usually control the organizations for people with disabilities. Their aim is usually to provide treatment or to create alternatives to begging or ‘hiding away’ from the rest of society (INDS), 1997: 9).

According to the INDS (1997) social attitudes that emerged from the perception of disability as a health and welfare issue have invaded all areas of the society. The result is that disabled people and their families have been isolated from their communities and mainstream public activities. Dependency on state assistance has disempowered people with disabilities and has seriously reduced their capacity and confidence to interact on an equal level with other community people. Disability scholars have argued that a physical disability is not simply an attribute of a person but rather a complex collection of conditions, activities and relationships, many of which are created by the social environment (Birkenbach, 1999).

History is replete with examples of disabled people worldwide being killed, ridiculed, and abandoned to die or condemned to permanent exclusion in asylums (Prichard, 1963). Kromberg & Jenkins (1987) report the customs of killing disabled children at birth and myths about them that were widely believed. Disability was looked upon as a curse, a result of witchcraft, an embarrassment. Where these cultural ideologies existed they were deeply ingrained in the community. As a result the family of a disabled person remained stigmatised and
restrained from participating within the society.

Thus historically the attitudes towards disabled people have been a mixture of persecution as well as tolerance. However, the tolerance shown has been patronizing. Disabled people were perceived as incapable of making their own decisions or taking control of their own lives; they were viewed as people who always need to be helped or as objects of pity and charity (Coleridge, 1993). Modern practices recognize and respect the disabled person as a person first and as disabled second. Disabled people are not perceived as inferior or second-class citizens but rather as capable of communicating, participating and entering into dialogue with other people (Freire, 1973).

Coleridge (1993) traces the abuse and oppression of disabled people through history. Spartan law dictated that disabled persons must be killed; Martin Luther endorsed that disabled babies be killed because they were 'incarnations of the devil'; the English eugenicists eliminated the disabled under the Darwinian evolution theory of the 'survival of the fittest' and the Nazi Euthanasia Programme exterminated them because Hitler believed they could not make any contribution to society. These persecutions recorded in western cultures are still evident today. Still today there are some who are strongly in favour of non-treatment of newborns with severe disabilities, their beliefs very similar to the nineteenth century eugenicists (McDaniel, 1989).

**Disability and Culture**

The social understanding of disabilities varies widely according to culture. In some traditions in Africa people seem to have a very different opinion to the Westerners. Lamorey (2002) suggests that in the Yoruba society in Nigeria congenital disability is understood as an indication of family sin that requires punishment by ancestors or gods, and the subsequent need for parental atonement. Another study amongst a multicultural, non-westernised group shows
different cultural beliefs that societies hold regarding the causes of childhood disabilities. For example a mother cutting her hair during pregnancy is believed to cause a miscarriage or to shorten the life of the baby. Other beliefs are that if a mother simply sees a person with deformities during her pregnancy she will give birth to a similarly deformed child, and, if she has sexual interaction during pregnancy it will cause her to produce a child with disabilities. Also included in the myths regarding disability are that: God causes disabilities in order to examine a couple's patience; the baby should not be taken out for forty days or it will become ill; if a pregnant mother lies face down to sleep her baby will be deformed; and finally, the newborn should wear a red ribbon to protect it from harm (Lamorey 2002: 67-68).

Stress and Parenting a Physically Disabled Child

The negative attitude from the public towards disabled children is a constant stigma and is seen as a major stress for the parents. The reaction of the public to the disabled child typically includes stares, whispers, inquiries, insensitive remarks and looks of pity. Such reactions occurring daily invoke a broad range of feelings, most commonly anger, hurt, a sense of helplessness andaloneness due to the parents tending to avoid taking the child out in public. Safilios-Rothschild (1970) indicates that discriminatory practices against people with different forms of impairment are different and not equally distributed.

The history of how black Africans have managed disabilities has so far attracted a very modest amount of research (Miles, 2002). Livneh (1982) indicated that there are four main prejudicial attitudes towards people with disabilities in general. They perceive those attitudes to be determined by psychodynamic, situational, socio-cultural and historical factors.

The Fuller & Rankin (1994) study found that mothers of disabled children experienced more stress than parents with non-disabled children. Cuskelly,
Pulman & Hayes (1998) believe that mothers of disabled children are less able to cope with stress partly because they are less likely to have a full time job and an extended social network.

Having a child with a disability affects not only the stress level of the parents but major life decisions as well. According to the study conducted by Cuskelley et al (1998) a small percentage of mothers of disabled children are employed full-time compared with mothers of able-bodied children. All the working mothers of disabled children in the study work only part-time, whereas only half of working mothers of able-bodied children work part-time. These statistics indicate that having a child with a disability restricts the ability of the mother to work when they might want or need to. For these reason parents of disabled children might experience a sense of loss and social isolation. A reduction of their social networks through work relations or colleague’s decreases the ability for the mothers to cope with stress. In addition the mothers may feel further isolated due to loss of friendships if their friends do not understand their situations and may even feel discomfort when dealing with the disabled child.

The experiences of parenting a physically disabled child can cause significant levels of stress. Uncertainty about what to expect from the children creates stress as well as parents’ sensitivity about what other people might think of their disabled children (Lui, 1997).

**The Attitude and Behaviour of Parents**

The Fuller & Rankin (1994) study also looked at parent-child relationships. It found that the attitude and behaviour of mothers affect the attitude and behaviours of children and vice-versa. Parents of emotionally impaired children reported that their relationship with their children “lacked in positive experiences”. They also felt rejected by their children and inadequate in dealing with them. Olshansky (1962) stresses that every parent, whether he/she has a normal or a
defectives child accepts his/her child and rejects his/her child at different times in various situations.

Parents whose children were older than infancy when the disability occurred may feel guilty for not recognizing the problem sooner or for not having been more tolerant and understanding towards the child. Guilt can lead to the parents being totally dedicated to the child. When this occurs the parent may fail to relate adequately to the other family members or parents may blame each other for the child's disability. Blame can prevent communication and warmth between the parents and the child will sense this (Fortier & Wanlass, 1984). Kromberg & Jenkins (1982) states that a source of great anguish and shame for parents occurs as a result of the stigma associated with albinism.

According to Droter, Baskiewicz, Irvan, Kennell and Klause (1975) most parents' initial response to the news of this child anomaly is that of overwhelming shock. These emotional reactions of shame and guilt will without doubt affect the attitudes and behaviour of parents of physically disabled children. Jackson (1989) states that negative attitudes can lead to neglect, outright rejection and lower self-esteem as well as reduced opportunities for education and skills development, family life, employment, social integration and independence for both the parent and child. Olshansky (1962) believes that all parental reactions reported in the literature such as guilt, shame and anger could be intertwined with chronic sorrow.

Barker et al (1953: 74-75) in an earlier study identified the following attitudes that were considered distinctly harmful:
(i) Inconsistent behaviour involving provision for necessary physical care together with resentment at the burden this entails.
(ii) Overprotection, false sympathy, neglect and indulgence, or 'spoiling' of the child.
These attitudes are induced by emotional pain, which is described by Simon & Smith (1992) as pain that surfaced as children with impairment matured and ventured outside the family. The emotional pain is experienced at various times of the child's development apart from the time of diagnosis (Melnyk, Feistein, Moldenhauer and Small 2001) or the 'beginning' (Simon & Smith, 1992). Melnyk et al (2001) also reported that as normal unimpaired toddlers and pre-school children struggle with common developmental issues children with chronic conditions also are challenged to develop autonomy, initiative, and mastery over their environment.

Parents wish to promote their child's development but simultaneously want to protect and assist their child with what they perceive he or she is unable to accomplish. As a result of their tendency to view their child as fragile, vulnerable and different parents tend to engage in overprotective parenting. This style of parenting according to Perrin (1989) places children at risk for the "vulnerable child syndrome."

**Support Services**

Managing long-term treatment involves a complementary relationship between the health care team and the child's family. Successful care of the disabled child depends on the family's willingness to modify family life in response to a complex and time-consuming daily regimen of treatment. Effective treatment involves a consideration of both medical competence and parental ability to exert a lifetime of daily effort on the child's behalf McCubbin & Patterson (1983). Safilios-Rothschild (1982) believes that when impairment is discovered in most cases the physicians inform the individual and the family. According to Strauss & Munton (1985) a concern frequently mentioned by parents is lack of positive feedback about their infant's developmental progress from health-care providers. The manner in which they learn about their child's problems and the feedback given about long-term developmental outcomes also upset parents.
Loss of the 'Wished For' Child

As reported by Callaway (1996) Chinese professionals note the traumatic impact of the diagnosis of deafness in a child on Chinese parents and point out that this is exacerbated by the one-child family planning regulations that produce a situation in which parents put all their hopes and expectations onto only one child. Unwillingness to accept their child is deaf or to consider the implications of deafness lead Chinese parents to take their child to one doctor after another, first to repeat the hearing tests in the hope that the initial diagnosis was mistaken, and then to search for a cure for deafness. The majority of these Chinese parents spend enormous amounts of time, energy and money trying to find this cure; the efforts made towards this end detract from the efforts parents could have been making to habilitate their child (Callaway, 1996).

Parents of physically disabled children are aware of the disappointment felt at giving birth to a disabled child whilst having expected an able-bodied child during pregnancy. Initial responses include shock, guilt and a feeling of "loss." Gerland (1992) reveals that in some Africa societies disability is perceived as a curse from the gods.

Cohen (1962) states that anger is expressed in many ways and sometimes parents feel that they have been singled out or victimized by fate. They cannot understand why this punishment should have been inflicted on them. Parents may react to this by isolating themselves from society because they fear that they will be unable to disguise the anger they feel towards those who are more fortunate. Sometimes their anger is increased by a lack of understanding from others, or on the other hand, by the subtle displays of pity from others.

This grief reaction is not, as was once believed, a result of the parents' inability to accept the handicapped child. According to Cohen (1962) some parents wish so intensely that their child did not have a handicap that they tend to reject the doctor's diagnosis. In this early period of grief there is often a great deal of
searching for other medical opinions. When the grief behaviour persists beyond the initial two to three months the grief process has become chronic because the internal process of decathexis of the lost child has not been carried through (Wikler, 1981).

The Media and Disability

Writers over many years in a number of different genres of literature have used physical disabilities to signify evil, horror or a state of something being wrong. There are various, clear examples of this from Shakespeare's Richards III to Doris Lessing's *The Fifth Child*; from Captain Hook to *The Phantom of the Opera*. The absence of physical 'impairment' is associated to such a degree with popular culture's concept of masculinity that filmmakers are able to use visible physical disability as a comment about characters. In the past the usual connotation linked to disability was that of evil and wickedness. More recently filmmakers have used disability as a metaphor for dependency and vulnerability and as a vehicle for exploring such experiences for men (Morris, 1991).

As indicated by Scorgie & Sobsey (2000) professional journals and the news media often focus on the negative aspects of parenting a disabled child. Any positive experience is said to be the parents' attempt to rationalize the situation. This is not however what Scorgie & Sobsey (2000) found in their study. Their research was done in two parts. In the first phase fifteen parents of disabled children who had been identified as "good copers" were asked open-ended questions which allowed the individual to tell their own stories and to describe the impact of having a disabled child on their lives.

The answers from these questions were incorporated in another questionnaire that was given to another sample of parents with children with a wide range of disabilities. The questionnaire asked them to state how much they would agree
with the statements made by the first group of parents on a scale of one to fifty. The results were grouped into three categories: Personal Transformation, Relational Transformation and Perspective Transformation. The parents in the second phase agreed with most of the statements made by the parents from the first phase in all the three categories. In the Personal Transformation category an overwhelming majority of the parents agreed that they had learned to share their feelings and face challenges as a result of parenting a child with special needs.

As well as being the child's parent they also had to act as his/her advocate. New roles such as group leaders, conference speakers or members of advisory councils for organizations representing disabled people were common among the parents. One parent stated, “I have had opportunities which I never would have dreamed possible.” Many parents reported becoming more compassionate, less self-focused and developing a greater personal strength. Many parents agreed that their marriages had been strengthened through the experience of having a disabled child. Relational transformation occurred with friends as well as family and expanding friendship networks was the common relational transformation experienced by the respondents.

Overall the parents described the experience of having a child with a disability as a kind of advantage because it creates an opportunity to develop wisdom and to confront some of the more difficult aspects of life, which might not have happened with an able-bodied child. The parents described a journey in which, often to their own surprise, they realized how much they had grown.

**Guilt, Shame and Anger**

Guilt is probably the most commonly invoked category of neurotic responses within the psychodynamic interpretations of parents with disabled children.
Indeed guilt is seemingly unavoidable because it can supposedly occur as either a cause or an effect of other emotions. Even the parental reaction of self-involvement has been interpreted as based on an underlying guilt resulting from the belief that they are somehow responsible for their child's disability (Solnit & Stark, 1961; & Ferguson, 2002). The emphasis in this approach is the interplay of parental emotion with the environmental circumstances in which the family finds itself. The feeling of guilt that arises during the grief stage may be intense. Parents feel that they are being punished for some past event.

**Grief and Stress**

Grief involves feelings of great sadness and a sense of loss that may become overwhelming. Grief may vary in intensity according to the length of time after birth that the diagnosis is made because if there has been a relatively long period of time of being unaware hope for the child has lasted longer and the bond of affection between child and parent is stronger. The grief faced by parents at the birth of a defective child is complex. The experience of the parents of the wished-for baby is that of fear (Bristor, 1984). The stages of grief that parents and family suffer at the birth of a handicapped child are similar to the grief caused by death or divorce (Bristor, 1984).

Parents in the grief stage question why they were singled out by fate and they often seek someone to blame. Alternatively they blame themselves, the doctor, their spouse, society or God (Fortier & Wanlass, 1984). Parents sometimes reach a point where they are angry with the disabled child for disrupting the family routine and causing great stress in their lives (Epperson, 1977). Fortier & Wanlass (1984) state that during the grief stage, parents begin to experience self-doubt and humiliation. They need reassurance that they are acceptable people even though their child is disabled. Putting them in contact with others with similarly diagnosed children may help counteract their feelings of being different and isolated from society.
The role of support groups

Scorgie & Sobsey (2000) discovered that when parents of disabled children seek out social networks they are able to form many meaningful relationships. Personal and interpersonal strengths can be drawn from such relationships.

In South Africa there is an organization of parents with disabled children called Disabled Children Action Group (DICAG) that was established in 1984 as a Disabled People South Africa programme. In September 1997 Disabled Children Action Group became an Independent National organization that focuses on two spheres - Advocacy and Development - and allows parents to share their experiences. This sharing is a strengthening experience that involves working together to advocate the rights of their children. The Disabled Children Action Group has strived for disabled children to enjoy participation in normal life such as integration into mainstream education. This is stated in the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (United Nations, 1993).

DICAG has played a significant role in direct service provision such as running centres for early childhood development, peer counselling and lobbying for the provision and improvement of basic services (Philpott & McLaren, 1999; PMRG, 1988). Like the women described by Featherstone (1980) these mothers recognized the importance of associating with and sharing information and support with other parents.

Conclusion

This chapter highlights the experiences of parenting a physically disabled child as reflected in the literature. It appears that parenting a physically disabled child can create significant levels of stress and is accompanied by experiencing
prejudice. This study focuses on the experience of parenting a physically disabled child in the African context, in particular within the Vhembe district in Limpompo province. The following chapter deals with the methodology of achieving the set objectives for this study.
CHAPTER 3
RESEARCH METHODOLOGY

Problem Statement

This research assumes that the experience of parenting a physically disabled child is different to that of parenting an able-bodied child. This assumption stems partly from the personal experiences of the researcher who is herself a parent of both a physically disabled child and an able-bodied child.

In the past disability research has often focused on the negative aspects of disability in the home such as family disruption. The Disabled Children Action Group, an organization which advocates the rights of disabled children and promotes the sharing of experiences between parents, offers a far more encouraging attitude than many literary studies. This contrast makes evident the general, theoretical over-emphasis on negative aspects.

There is little documented literature on the experiences of parenting a physically disabled child in Limpopo Province and very few of these studies take an open approach to the research. The findings of this research are thus partially aimed at raising awareness of the experiences of raising a physically disabled child, particularly within the Vhembe district.

Research Aim

The aim of the study is to gain an understanding of the experience of raising a physically disabled child from the perspective of parents of the Vhembe district.
Research Objectives

1. To investigate the emotions connoted with parenting a physically disabled child.
2. To understand the impact of having a physically disabled child within the family.
3. To understand the impact of raising a physically disabled child within the community as a whole.
4. To explore the impact of raising a physically disabled child on the parent.
5. To reveal strategies that parents employ to cope with raising a physically disabled child.

Research Purpose

The purpose of this study is to gain an understanding of the experiences of parenting a physically disabled child and to raise social awareness of these experiences. No prior research has explored this topic within the Vhembe District in the Limpopo Province and generally very few studies have taken an open approach to exploring the experience of parenting a physically disabled child. The purpose of the study is to empower the parents of physically disabled children by making their circumstances better understood socially.

The study will create awareness to stakeholders involved in disability issues as well as the community on the challenges faced by parents of physically disabled children. The open-minded approach of the research will create an opportunity for both the positive and negative experiences of parenting a physically disabled child to emerge. The outcomes of this study will provide insight into developing and/or improving support structures for parents with physically disabled children.
My Stance as Researcher

As outlined in the introduction, I am the parent of both a physically disabled child and an able-bodied child. The most painful part of my experience of parenting a disabled child was the lack of support from my family and the community. I did not enjoy anything because I told myself that to have a disabled child is an embarrassment because I grew up in a community where the community did not accept disabled people. However I eventually accepted my child and became able to cope with the challenges presented by society by associating myself with people who were members of the organization of parents of the disabled children (Disabled Children Action Groups).

I hope that my research study will assist other parents of disabled children, families and the community. As an activist I am attempting to help other parents of disabled children and educate society about disability issues. I am currently working for Disabled People South Africa in the Limpopo Provincial office as Provincial Development Coordinator based in Polokwane.

Study Design

Qualitative research is best used in unexplored areas where it would be premature to define and measure patterns and variables. Kirk & Muller (1986) state that qualitative research involves the descriptive understanding of phenomena. This approach allowed the researcher to develop rapport with the interviewee, to have flexibility in the way the interview was conducted and to make use of both verbal and non-verbal information. Emphasis is placed on the meaning that the studied phenomenon holds for the participants (Creswell, 1998). A qualitative framework gives the researcher the opportunity to explore, illuminate and represent personal understandings and their meanings as perceived by the participants (Firestone, 1987). A qualitative framework also recognizes and allows for the sometimes-contradictory nature of people's
understandings (Parker, 1994).

Phenomenology as a study design was used in this study. As stated by Moustakas (1994: 13) the aim of such an approach is "to determine what an experience means for the persons who have had the experiences and are able to provide a comprehensive description of it." This description is appropriate for the aim of the study.

Phenomenology is the study of experiences and the ways in which we put them together to develop a worldview. It carries an assumption that there is a "structure and essence" to shared experiences that these can be determined (Patton, 1990: 70). This theoretical orientation implies that phenomenology can be referred to either as the subject matter of inquiry or as the methodology of the study.

In this study the research process reduced experiences shared by participants on parenting a physically disabled child to a central meaning or the "essence" of the experience (Moustakas, 1994). This term emphasizes in phenomenological studies the importance of individual experiences of socially conscious people. This leads to a textural description of what was experienced and the structural depiction of how it was experienced (Moustakas, 1994).

The researcher delved into perceptions of participants; explored how parents experience raising a physically disabled child; displayed this phenomenon and searched for the meaning of the participant’s experiences.

The sample of biological parents of physically disabled children was selected from the Vhembe District in the Limpopo Province. Four families were involved in the study. One parent per family was interviewed. There was no discrimination between fathers and mothers and the choice of which depended on which of the two parents in the family was willing to participate in the research. Purposeful
sampling was used and the participants were encouraged to share their experiences with the researcher.

The following inclusion criteria were used.

The participant had to:

1. Be a mother or father of a physically disabled child;
2. Be a biological parent of a physically disabled child;
3. Live in Vhembe District;
4. Be single or live with husband or partner. The support received from the partner would be recorded because it directly influences the psychological well being of the mother (Walker et al, 1999; Giunta & Streissguth, 1988 & Viljoen et al, 2002).

Selection of Participants

The ages of the physically disabled children ranged from four to eighteen years old. The reason for this was that the children were old enough for their presence to have a large impact on the parents but not so old that parents would struggle to recall the parenting experience.

As suggested by the definition of phenomenology and supported by Morse (1991), a sample in a phenomenological study needs to meet criteria for appropriateness and informational adequacy. Purposive sampling according to Morse ascertains that participants that are selected are those best able to meet the informational needs of the study.

The purpose and the aim of the research were shared with the parents before being invited to participate in the research. Parents from the first family were approached and asked to suggest another family who could provide valuable
Table 2: Description of Children

<table>
<thead>
<tr>
<th>Child Description</th>
<th>Age</th>
<th>Gender</th>
<th>Description of Physical Disability</th>
<th>Formal Education</th>
<th>Other Impairments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child A</td>
<td>17</td>
<td>Male</td>
<td>- Paralysed right hand and leg</td>
<td>None</td>
<td>Intellectual Impairment</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- Able to walk without using any assistive devices (with a limp)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child B</td>
<td>17</td>
<td>Female</td>
<td>- Paralysed hands and legs (Crawls to get around)</td>
<td>None</td>
<td>Epilepsy</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Unable to speak</td>
</tr>
<tr>
<td>Child C</td>
<td>13</td>
<td>Female</td>
<td>- Paralysed hands and legs</td>
<td>None</td>
<td>Unable to speak</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- Using wheelchair</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child D</td>
<td>12</td>
<td>Male</td>
<td>- Paralysed hands and legs</td>
<td>None</td>
<td>Speech difficult to understand</td>
</tr>
</tbody>
</table>

Data Collection

See Appendix IV for an outline of the interviews. The method of data collection was unstructured interviews using open-ended questions. Participants were given the opportunity to describe their experiences in their own words. Semin & Gergen (1990) state that phenomenology seeks to emphasize the actual experience not the ‘knowledge’ about the event or the phenomenon.
All participants were interviewed in their homes. Individual semi-structured interviews were used in the study. Mouton & Marais (1990) state that interviews enable the interviewees to answer as fully as they choose and to expand on their responses.

The researcher approached the interview with an open-minded attitude in order not to appear judgmental. This enabled parents to speak about their experiences and feelings freely. The sequence of the questions in the interviews was flexible and guided by the answers given by the participants.

The interview with each individual was conducted one on one because this provided the opportunity to establish rapport and to be aware of any misunderstandings immediately. The researchers own reflections were recorded in notebook. Tapes were transcribed in order to have written text of the interviews. Raw data was therefore included in transcriptions from the interviews and the researchers own reflective notes.

The tape recorder and a notebook were used during the process of the interview and the researcher always tested the tape recorder before she began to make sure that it was working.

A narrative approach was taken as this allowed the participants to tell their experiences while the researcher listened (Holloway & Jefferson, 2000). Interviews were captured on tapes. All interviews took place in Tshivenda as the sample population is mainly Venda speaking people. The interviews were done over a period of four months.

The participants had a period of at least two weeks between interviews. This was to allow participants to have time to think about what they had told the researcher during their participation in the interview and what had transpired during the interview. The researcher felt that it was important for the participants to be able
to reflect on what they shared on their experiences of parenting a physically
disabled child.

**Data Management**

All raw data was classified according to which parent was interviewed. Parents
were assigned alphabetically and their names were not mentioned in any
material related to the research including transcriptions of interviews, journal
entries or reflective notes, tapes etc. The tapes and notebook were stored in a
safe place. All transcriptions of interviews and reflective notes were made
available for analysis. Interviews supplied rich, descriptive information on the
experiences of parenting a physically disabled child.

Some principles about data storage are well suited for qualitative research
including the following:

6 Using high-quality tapes for audio recording information during interviews.

7 Protecting the anonymity of participants by masking their names in the
data e.g. using alphabets.

8 Developing a data collection matrix as a visual means of locating and
identifying information for a study.

**Data Analysis**

Coffey & Atkinson (1996) observe that there is no single correct way to analyse
qualitative data. Bearing this in mind the transcribed interviews were analysed in
order to identify recurring and pertinent themes. An inductive approach was used
for the truth to be revealed or uncovered based on the perceptions of the
participants (Depoy & Gitlin, 1994). Open coding was used whereby the data was
examined and emerging trends named and categorised (Strauss & Corbin,
1990).
The following system taken from Creswell (1998) was also used to classify data:

- The researcher reflected on her own experience of parenting a physically disabled child, capturing all information in writing. Although bracketing is often suggested within phenomenology the researcher for reasons explained below under "reflexivity" attempted to use her own experience differently. The researcher maintained interrogation of findings as they emerged, against her own captured experiences, in order to elucidate the extent to which her own experience has influenced what emerged from the data.

- Transcripts were read several times by the researcher to allow for immersion into the data.

- Significant statements were extracted from each description offered by a participant, by employing open-coding, and later focusing on phrases and sentences that directly pertain to the parenting of a physically disabled child. Colour coding was used to highlight these meaningful pieces of data. Statements that contain the same meaning or appear to do so were collapsed into sub-categories, then categories (See Appendix V). The next level was to collapse similar sub-categories into a total of 22 categories. Finally the 22 categories were collapsed into five themes. Assertions were again made and interpretations formed about what the data told the researcher.

- Themes were aggregated from all categories emerging from the different meanings of parenting a physically disabled child. This allowed for the emergence of common themes to all the participants' descriptions. At this point discrepancies were noted among and between themes. Discrepancies were read several times.
• The final findings were an exhaustive, integrative description of parenting a physically disabled child.

• After collection of data the researcher performed member checking and went back to the participants to find out if the information captured reflected what they had shared during interviews. The feedback was valuable because it gave the researcher the opportunity to make changes and to allow for the representation of participants voices.

Ensuring Trustworthiness and Rigour

At the core of qualitative research is an orientation towards exploring concrete experiences in their temporal and local specificity (Flick, 1998). It is further argued that social scientists cannot capture the lived experiences directly. The lived experiences as a 'captured experienced' exists only as a social text written by the researcher (Denzin & Lincoln, 1998).

Reflexivity

The researcher was clear about her research objectives and planned questions and prompts in order to answer the research question. Briggs (1986: 39) states that it is not uncommon for the researcher's own discourse rules to "infiltrate" the interview.

Peer auditing and reflexive methodological accounting were used to enhance the credibility of coding. The researcher continuously monitored how she related to the topic of research and the issues that were highlighted by it.

Instead of entirely bracketing (Moustakas, cited in Creswell, 1998) her experiences of mothering a physically disabled child the researcher sought to demonstrate "reflexivity" (Altheide & Johnson, 1998). This was an upfront
approach regarding bias, which allowed contamination of findings in some instances, to be conscious of the researcher, and explicit to the reader.

The researcher kept a notebook wherein she reflected her experience of mothering a physically disabled child and noted her emerging understanding of issues accompanying the research. The personal notebook acted as a space in which the researcher could write down her thoughts and emotions about interactions with participants as well as the context and her reactions to discussions with participants. In this way any preconceived beliefs and opinions were made explicit (Holloway & Wheeler, 1996). The notebook also offered a place in which the researcher could self-inquire as a way of clarifying her thoughts (Finlay & Gough, 2003). An advantage of keeping regular written accounts of the research process was that it enhanced reflexivity and ensured that the researcher was at all times aware of how her assumptions influenced the research process.

**Reliability within Qualitative Research**

What is often contested within qualitative research is the possibility of assuming reality exists outside subjective or socially shared viewpoints and on which we can validate its 'representation' in texts or other products of research (Flick, 1998,p 31). Social constructivists put forward a case that such an assumption is based on faulty suppositions. Their standpoint is that reality is a relational construct of contexts to which participants, including the researcher, ascribe meanings.

Adopting the principle of mimesis (Flick, 1998) seems to help resolve the crisis of representation. The concept of mimesis suggests that a biographical narrative of one's own life is not a representation of factual processes. It becomes a mimetic presentation of experiences that are constructed in the form of a narrative for the purpose of the interview. Consequently, reliability in the orthodox sense of
explicability is absurd.

**Appropriateness and Adequacy of Data**

Morse (1998) suggests two criteria that can ensure rigour in qualitative research. These are adequacy and appropriateness of data. Adequacy pertains to the amount of data captured. Prolonged exposure (Flick, 1998) was a strategy used in the study (See appendix IV which outlines the length of involvement of participants in the interviews). Building trust and a good relationship for collaboration emerges over time through complex interactions. The researcher allowed for settling time before the participants could speak freely about their experiences and their feelings of parenting a physically disabled child.

Appropriateness refers to following a research process that is in accordance with the conceptual sampling and framework underlying the study. The audit trail and the verification of the study with participants are two strategies that Morse suggested in this regard. The audit trail ensures that the final thesis reflects truthfully what transpired in the research process. Tapes from the interviews, transcripts, and reflective notes were correctly labelled and kept until the completion of the research. This was to ensure that it was documented and could be made available to the supervisor and peer reviewers.

**Thick Description**

This was made possible by sharing as much detail on participants as possible (See Tables 1, and 2, and Life Stories in Appendix I). In this way other researchers who may wish to apply all or part of the findings are able to make judgments about the degree of fit or any similarity in future studies (Lincoln & Guba, 1986).


**Member Checking**

Verification of the study with participants was satisfied by member checking as part of the ongoing research process.

**Ethical Considerations**

Ethical approval was gained from the Research Ethics Committee at the University of Cape Town before commencement of this study. The respondents in the study were informed thoroughly beforehand about the potential impact of the research. To ensure that they would not be harmed psychologically, emotionally and physically they were not forced to participate in the research project. The researcher was sensitive and committed to the dignity and privacy of the participants. Ethical issues were addressed to protect the rights of the respondents. The principles of ethical propriety include simple considerations of fairness, honesty, openness of intent, disclosure of methods, the ends for which the research is executed, a respect for the integrity of the individuals, the obligation of the researcher to guarantee individual privacy unequivocally and an informed willingness on the part of the subject to participate voluntarily in the research activity (Leedy, 1997).

The researcher met with the participants to provide them with information regarding the study. Participants were given time to ask questions for clarity about the research study. This process made it easy to finally make agreements with participants about appointments. Participants then signed the consent forms (See Appendix III) after they had a clear understanding about what the study involved.

Participants were assured of anonymity and confidentiality was maintained. Participants were also informed about their right to terminate the interview at any
point should they wish to do so. Participants were informed about the findings of the study on completion. The findings will also be shared with the Disabled Children Action Group (DICAG). An attempt will also be made to publish the findings where other Disabled People’s Organisations as well as institutions of Higher Learning can gain access to them.

**Conclusion**

This chapter presents the aims and objectives of the study as well as the instruments and methods for achieving these objectives.

Also documented in this chapter were ethical considerations of this study, the research design used, the procedure for data collection and how the data collected were analysed. The results obtained are presented in the next chapter.
CHAPTER 4

FINDINGS

Twenty-two categories and five themes emerged from the data analysis as presented below.

Table 2: Themes and Categories

| Theme 1: “A zwi leluwi” ("It is not easy") | 1. Concentration of attention on the disabled child only |
|  | 2. Expenses |
|  | 3. Pity from others |
|  | 4. Personal Guilt |
|  | 5. Lack of special needs schools |
|  | 6. Transport problems |
|  | 7. The disabled child is a burden |
|  | 8. Relatives avoid the family |
|  | 9. Having a job is difficult |
|  | 10. The parent is unwelcome at home |
| Theme 2: Seeking help from various sources in vain | 11. Traditional doctors |
|  | 12. Ministers of religion |
|  | 13. Hospitals |
|  | 14. Prophets |
| Theme 3: “Ndise miwa ngae” ("I am called names because of him") | 15. The belief that disability is God’s punishment |
|  | 16. Rumours that disability is caused by parental sin |
|  | 17. Social labelling |
| Theme 4: “Ndo mu beba e wavhudi” ("I gave birth to a healthy child") | 18. Parents were uninformed |
|  | 19. The disability developed with time |
|  | 20. Taking time to accept the disability |
| Theme 5: Help from the government | 21. Help from the Care dependency grant |
|  | 22. Assistive devices |
Theme 1: "A zwi leluwi" ("It is not easy")

This theme articulates the challenges faced by the participants as a result of having given birth to a disabled child.

1. Concentration of Attention on the Disabled Child Only

All the participants in the study indicated that spending more time with one child creates an impression that she/he is the only child or that she/he is given more preferential treatment or attention than the others.

"Other children end up being neglected because the disabled child needs more attention on each and every aspect of life day and night."

Furthermore, findings revealed that it became difficult for the participants to get involved in many community activities because one's free time is seriously restricted.

"If there is a funeral in the community as women in the neighbourhood you have to assist with peeling vegetables and cooking for the funeral but I am unable to be part of this because I just don't have free time."

"The other task we have to assist the bereaved family with is fetching water from the river as we live in a village were there is no running water from the tap but I am still unable to go with."

2. Expenses

All the participants emphatically agreed that a disabled child is expensive to raise. The statements below illustrate the cost implication of having a disabled child.
"One has to buy napkins even when the child is grown up as he/she is sometimes not able to help him/herself in the bathroom, or indicate in time that he/she needs to go to the toilet because of speech difficulties."

"Extra pairs of pants need to be always available as crawling can make them tear around the knees."

"It is necessary to do washing every day since the pants of the disabled child become dirty very quickly and this can be costly."

It also became evident that participants used strategies to further save cost and get longer life from their children's clothes.

This is seen in this statement:

"If this happens the best option is to turn the pants around since the other side is still intact and sometimes you shorten or pass them on to the younger siblings."

3. Pity From Others

All the participants indicated that being pitied was the most painful challenge of their lives. Two participants reported that utterances such as "shame" had become the norm every time they arrived at the clinics in their area.

"For example when I go to the clinic with my disabled child the other mothers of able bodied children used to ask me how old is the child and I would tell them three years old. They would ask me why is he not walking and I would say my child is disabled. The next phrase I would hear would be, "e.g shame."

These kinds of display of pity acted as a barrier between them and others, making them feel isolated during the treatment process. It became so unbearable
that some of them no longer went to the clinics.

"Then you would get the next clinic date, you do not go or you skip one month because you assume that everybody would be asking you about your disabled child again and looking at you with pitiful eyes. Eventually, you stop taking your child to the clinic."

4. Personal Guilt

The findings revealed that all participants in the study struggled to accept that their children were disabled because it was unexpected. They also stated that they were filled with questions on the issue.

Participant A said that she asked herself the following question:
"Could it have been because I quarrelled with that woman when I was expecting?"

The question most participants asked themselves was, "Why did it happen?"

5. Lack of Special Needs Schools

All four participants expressed that special schools focused on multiple disability were not available in their areas. The authorities of the schools that were in their vicinity explained to them that they were unable to accept children with multiple disabilities but referred them to other institutions where such children could be well looked after.

"It is a dilemma to have a child with multiple disabilities. Let's say that your child has a physical disability and a mental disability. The special school for physically disabled children would say we do not admit children with a mental disability. Then you would go to a school for children with mental disabilities and they will
say they do not have facilities for physically disabled children."

"The institution that I was being referred to I knew of and things were not what they seemed to be there. There were no educational and stimulation programmes. It was an old age home that accepted disabled people for the sake of keeping them."

"It was not at all catering for disabled children and it was sort of a dumping place."

Knowing the services that were on offer at the said institutions the participants decided to instead look after their children at their homes. Another option was to take their children to crèches in the neighbourhood but again the parents were told that such children had to be looked after by people specially trained for their needs and so the crèches could not accommodate them.

6. Transport problems

All participants in the study mentioned transport problems which included waiting for buses for hours, complaints from taxi passengers about the time taken to fold the wheelchairs and subsequently taxi drivers complaining that they could lose some of their business as well as sometimes demanding an increased fare to pay for the space which the wheelchair occupies. Some passengers also complained that the wheelchairs dirtied them in the bus or taxi. Two participants indicated that it was necessary to organize separate transport when undertaking a journey with their disabled children.

"For transport it is usually necessary to use private taxis so that other people will not be inconvenienced, but this can also be expensive."
Participant B and C remarked about the behaviour of some passengers who disapproved of their children being in such close proximity to the disabled child, as if the impairment were contagious.

"When I get into the taxi with my disabled child and people would move to other seat to distance themselves from us."

"It is not said but the actions like this show the attitude of people, even when their children are really excited by the wheelchair, they are told by their parents not to touch it."

7. The Disabled Child Is a Burden

All participants were emphatic that raising and looking after a disabled child is difficult and at times a burden because he/she cannot do things on his/her own and depend on assistance of others for activities of daily living. It also became evident that the burden of caring after disabled children falls on the lap of their mothers. They mentioned among other tasks feeding them, washing them, dressing them and taking them to and from hospitals for therapy.

Participant A said:
"It is a burden that you carry for the first nine months and go on with it for the rest of your life on your own without anyone helping you."

Another problem identified was that when the disabled children fell ill they were unable to utter a word or point at where they felt pain.

"In all this as a parent you have to think on their behalf and there are times where you could misinterpret them."
8. Relatives Avoid the Family

Findings showed that having a disabled child often leads to seriously diminished contact with relatives. One participant revealed that she noticed that her husband's relatives never visited and she knew that the reason was because of her disabled child.

It also became apparent that it was also painful for her to realize that her mother used to carry the other grandchildren, and even taking them to family gatherings, but with regards to her disabled child she openly told the mother:

"Carrying your child around is a problem as in the end I end up speechless as everyone looks at me with amazement."

9. Having a Job Is Difficult

All the participants agreed that it was not easy to be involved in any work as the responsibility of looking after the disabled child then become a burden to other members of the family. Two participants reported that they once managed to take some temporary jobs as they had found people to look after their children but it was short-lived.

In one case the person said:

"Your child is a grown up and his stools are very smelly and I do not want to risk getting ill. I can manage to live through my pension and do not think I will die of hunger if I leave."

10. The Parent Is Unwelcome at Home

Participant D explained that because of the pressure she faced at her home and the bad treatment she got from her mother she had no choice but to move out of her mother’s house.
"I decided to go and stay with the father of my child when I was not yet ready because I could not stand being insulted about my disabled child."

**Theme 2: Seeking Help from Various Sources in Vain**

"Ndo tshimbila nda neta" ("I travelled all over in vain").

11. **Traditional Doctors**

All participants confirmed that they spent a large amount of money in an attempt to find help for their disabled child. However, they were not prepared to divulge the exact figures. The findings revealed that the parents of disabled children were continually told by people about supposed experts to go and see. This led the participants to seek help so that their children could at last be healed and walk like other children. The participants aspired to see their children developing like other non-disabled children in their community especially taking more responsibility towards the livelihoods of their family.

"I wished to see my disabled child standing up and running around, especially when I saw other children of the same age running around and being sent on errands by their parents."

It became evident that the participants spent much of their modest savings to pay traditional doctors for help.

There were cases when some of them would claim:

"I can deal with this in a very short space of time."

Participants showed that the traditional doctors focused more on making money than the healing of their child. The longer it took to heal the disabled child the
more money traditional healers accumulated. Others would say:
"Let me deal with the problem, you can pay me when the child is able to walk."

It is clear that these parents often parted with large amounts of money. Participants B indicated:
"If I hadn't wasted money trying in vain to help my child I would be able to afford a car".

12. Ministers of Religion

Two of the participants went to all of the main churches in their area seeking spiritual healing for their children. Furthermore, they sought healing from charismatic churches where people worshipped in large groups and there were claims of miracles occurring.

"On these occasions while praying for the child as parents we would be told to have faith and if the disabled child was not healed then the parents were blamed for their lack of faith."

One participant said "It was painful and deeply hurtful because I thought that I had faith and expected my child to heal".

The only advantage of spiritual healing is that the financial costs were minimal as parents had only to pay for the transport of their children to these events, as the services offered in the form of prayer were free.

13. Hospitals

All the participants unanimously agreed that the hospital services were inadequate. One of the main issues was that when a new wheelchair was needed the authorities would tell them to return at a later stage because the old
one could still be used.

One participant was accused of acting as if she were a qualified doctor when she explained that the wheelchair was hurting the child. Participants B claimed that she had no problem with health authorities because she is aware that most of them are wary of the social organizations that are associated with disability.

"I recommend putting a jersey with the disability organization logo onto the child because it effectively promotes disability advocacy."

Participant B explained that she was once mocked when she told her doctor she suspected that the Tegritol pills prescribed for the child were too strong because after taking them the child would sleep for the whole day.

She suggested that the amount be decreased but was answered with:
"Where actually were you trained as a medical doctor so that we too can go?"

The participants felt this type of treatment was unfair because they have an in-depth understanding and a lived experience with regards to the disability of their own children.

14. Prophets

Two participants searched for long periods of time for famous prophets who could possibly help their children to walk. The prophets apparently gave them water that had been blessed and instructions to follow.

Participant A claimed that her child did walk after a prophet attended her.
"On arrival I paid ten rand and was given water that had been blessed in a two litre container and a tennis ball that had been blessed too. I was given
instructions to wash him with the water in the morning and let the tennis ball bump in front of him twice for three days and that he would be able to stand up and walk and indeed it happened. This to me was a miracle I will not forget in my life.”

**Theme 3: “Ndi semiwa ngae” (“I am called names because of him”)**

This theme highlighted the social ostracization faced by participants because of having given birth or raising a disabled child.

15. **The Belief that Disability Is God’s Punishment**

This category illustrated the many assumptions held by parents of disabled children when they do not have reasons for the cause of the child’s disability. All participants said that they have always asked themselves why they in particular had disabled children. Further, they questioned themselves if maybe they had done something wrong, especially to God.

One question that constantly arose: *“Why did I become the target as not even the hospital authorities can really identify the cause behind the disability of my child?”*

Social ostracization also became evident and in the following statement one participant told:

“One day I reprimanded neighbour’s children for not looking after their goats because they were destroying the mealies and their mother heard me and shouted, “Stay away from my children, they did not come to your homestead. Concentrate on your disabled child and leave mine alone.”

Despite the fact that the strong feelings of having done something wrong to God,
parents they decided eventually to put their trust in medical experts:

"They are the people who could perhaps tell me the cause and also to correct any problem affecting my child."

16. Rumours that the Disability Was Caused by Parental Sin

One category that emerged was related to rumours related to disability being caused by parental sin.

This was shown in one participant’s statement:

“If my child ever makes a mistake or differed from the other children in the neighbourhood their sins would be attributed to me, the mother who had given birth to a disabled child. It would no longer be only about my child being naughty”

Since sinfulness in Vhavenda culture is associated with witchcraft and is a stigma in their community they always felt disillusioned when they noticed people looking at them suspiciously.

Participant D said;

“Everywhere I went with my child if people gazed at him I immediately felt guilty and suspicious.”

From their accounts it was clear that the parents were hurt and that what they said came from a deep internalised, emotional pain. They felt that they had nowhere to turn as they faced hardship in their homes, among relatives and in their communities as a whole.

17. Social Labelling

Two participants revealed that they are stigmatised because people in society
refer to them with technonyms that associate them with their disabled children.

For example the participants said "I am called, 'Mme a tshihole,'" means 'mother of (it) the disabled' and the prefix 'tshi' in Tshivenda is usually used for inanimate objects or animal classes. The term thus indicates that the child is not a human being but an animal and is very derogatory.

**Theme 4: “Ndo mu beba e wavhudi” (“I gave birth to a healthy child”)**

This theme portrays the lack of adequate information offered to the participants with regard to the possible causes of their children's disability, from the health sector.

18. **The Parents Were Uninformed**

Participants reported that when they left the hospital after the birth of their children they were not informed about the disability and believed their children to be unimpaired. It was only later when their children displayed huge differences to other children in terms of what is generally regarded as normal stages of development that they suspected anything.

When one parent consulted health authorities on her concerns she was simply told, "Do not worry, she will be a bit slow."

She believed this because she trusted in the expertise of the health authorities without question.

"Only when it became evident that the child was too weak to walk did I realize that a wheelchair was necessary."
"I must admit, I did not have a picture of him on a wheel-chair, I saw him walking like other children in my mind"

The hospital offered no counselling to them and this made it even more difficult especially since the health authorities had disillusioned them by implying that their children were simply a little slow in their development. As a result of this disillusionment the participants lost confidence in the competence of modern nurses and doctors and they began their search for traditional doctors, prophets and ministers of the gospel all over the country.

19. The Disability Developed with Time

The findings showed the disability in children is developmental and its consequences are most of the time noticed when disabled children go through their development milestones. Hence, as they grow their disabilities become more pronounced. Two parents reported:

"When my child was born he appeared healthy with no signs of disability."

"When he began to learn to walk, however, he continued to fall occasionally and then returned to crawling."

Participants D said:

"I was hurt because my child was not developing like other children of his age"

The participants therefore believed that the disability developed with time because the nurses and doctors would have informed them otherwise at the birth or immediately afterwards.
20. **Taking Time to Accept the Disability**

The findings showed that the hope of every parent is to give birth to a healthy child. Two participants revealed that for some time they hid their newborn, disabled infants because they feared mockery from their communities. There was also a parent who said that she nearly killed herself when she discovered that she had given birth to a disabled child.

She said, "I took a rope usually used for tying wood, got into a hut with my child. When I was about to tie it I looked at the child who was smiling at me, he looked very pretty, and then gave up."

Participants showed that they heard about an organization of parents of children with disability and decided to enquire about it. Participants revealed that they were satisfied with all that they learnt about the institution they preceded to meet other parents and share ideas and experiences with them about how to look after children with disability. The findings highlighted power of collectiveness and the feeling of belonging as this mentioned by this parent:

"In the end I was able to accept the situation I was in because I realized that I was not alone and was inspired by others coping with their own disabled children."

**Theme 5: Help from the Government**

"Muvhuso wo thusa" ("The government has helped")

21. **Help from the Care Dependency Grant**

This category focuses on how the participants survive, cope and make a living within the family. It became evident when all participants confirmed this, that the
care dependency grant brought some relief to their lives.

Participant A said, "I will start to live the better life like other families because I will be able to buy food and clothing for my children".

Even though in actual fact the money was insufficient to alleviate all the financial problems it could at least provide for sustenance needs of the family.

22. Assistive Devices Useful

The findings showed that the participants found assistive devices extremely useful.

"The wheelchair is especially helpful because it enables transport of the child other than by carrying he/she on one's back and also offers the possibility for the child to play to a degree with his/her siblings on the wheelchair."

Two of the participants said: "The wheelchairs also make a difference because they allow the children to change position from lying down to sitting upright which they would be unable to accomplish on their own."

On my two visits to one of family however, I found the disabled child in a sleeping position both times.

On the process of finally securing assistance devices, this does not seem easy.

Participant B said that "It is not easy to get the assistive devices from my nearest hospital because you have to be on the waiting list for a year, which makes life difficult".

58
The findings revealed that assistive devices such as wheelchairs were not always matched to the immediate environment.

"In some areas the roads are too stony or sandy and they can become muddy on rainy days, making it impossible to push the wheelchair through."

**Conclusion**

The themes and categories of the data analysis from the findings reflect the experiences of the participants in this study. The following key issues emerged from the findings and these key issues will be discussed in the next chapter.
CHAPTER 5
DISCUSSION OF FINDINGS

This chapter discusses the themes that emerged through analysis of the findings. The first section discusses the themes as they are, with reference to literature as well as relevant personal accounts from the researcher. The second section is a deeper reflection on the themes, which allowed for a conceptualisation of the extent to which the living circumstances of the women in this study reflect a complexity of needs.

Discussion of Themes

Theme 1: "A zwi leluwi" ("It is not easy"

As far as the concentration of attention on the disabled child alone, seen in the study, Tiroler (1995) confirms that caring for disabled children often takes time and saps the energy of women who play the main caring role. As the main caregiver of the child, the mother faces huge expectations. Often the child is completely dependent on the mother for even basic needs (Read, 2000). When the child also has an intellectual impairment the dependency is accentuated. The mother often then needs to think of other ways to cue the child to perform tasks, and may even have to make decisions and solve problems on behalf of the child (Adams, 2005). Need for vigilance related to safety also increases since the child is often more susceptible to injuries, and may also have less clear ways to indicate presence of illness.

This time consuming role of caring which can last a mother's life-time (Read, 2000) dictates the mother's schedule (Adams, 2005), in turn impacting on her own personal needs (Olson & Esdaile, 2000).
Disabled children need to be taken to hospital occasionally for rehabilitation services. Most of the parents in this study revealed that it is very difficult to do this without their own means of transport, as the children are very heavy. This problem sometimes prevents the trips to the hospital from occurring at all. The study of Anderson & Phohole (2003b) confirms this reality.

It is not surprising that participants in this study struggled to have their children access educational facilities. In 2005 the whole of Limpompo Province had only 25 institutions for Special Learning Needs (Department of Education, 2006). It is unclear how many such institutions exist in the Vhembe District. Criteria for entry in many of these include that the child be educable, which excludes most children with intellectual impairment. Transport problems are also barriers to education as these institutions are not always near to where children with disabilities live.

Difficulties experienced in raising disabled children are accentuated by poverty (Department of Social Welfare, 1997; Sait, 1998). The result of a lack of opportunities in the long-term is often expressed in terms of accumulating costs which place additional strain on family resources (Fortier & Wanlass, 1984; McConkey & O'Toole, 1995; Tiroler, 1995 & Oliver & Barnes, 1998). Contrary to what is found where there is no impairment, where children grow up and eventually leave home, in these instances this relief usually never happens.

It is unavoidable that children growing under these circumstances then end up believing that their disability is an inconvenience to their families and "perceive themselves to be worthless" (ODP, 1997: 5).

As described in the literature review, personal guilt on the part of the parent is usually inevitable, with the parent's involvement in caring for the child often seen as based on an underlying guilt reaction by parents who may believe themselves as somehow responsible for their child's disability (Solnit & Stark, 1961;
Ferguson, 2002). This self-blame is not without consequence for the relationship between the mother and her child. Self-blame can prevent communication and warmth between the parent and the child, which will inevitably be felt by the child (Fortier & Wanlass, 1984).

Participants indicated that they do not feel welcome when they are among other people who do not have disabled children. According to Kromberg & Jenkins (1987), shame is often the reason parents keep children with physical impairments away from the public. Physical impairments as compared to other impairments are often more visually obvious, making them difficult to conceal.

Personally, I can relate to some of the difficulties in raising a disabled child, particularly feelings of guilt and shame, that so often accompany the responsibility as a whole. I remember well how I used to hide my child. If people wanted to see the child I would always tell them that he was asleep. I did this because all my friends had deserted me when I became pregnant and I was afraid of how others would react to the child. I would always sit next to a window so that I could see if anybody approached the house and had time to hide him if I was holding him.

The Department of Social Welfare (1997) reveals that it is usually the mothers of disabled children who are prevented from seeking employment because of the burden of caring for the disabled child, which in turn affects household incomes and increases financial pressures in the family. As expressed in the literature review, unemployment is usually linked to a limited extended social network (Cuskeley et al, 1998)

Spending time with other parents of disabled children seems to decrease the stress experienced by participants. This idea was reinforced by observations that I made in one interview in particular. In the middle of a discussion with the parent the electricity suddenly went off and we waited for an hour until we decided it
best to make another appointment to meet. On the first day I noticed she had put a jar of water close by so that she could drink from it occasionally and her eyes were red and it was evident to me that bringing up her disabled child was not an easy task.

The next time I visited the participant she told me that after I had left she had felt very worried about the difficulties she faced in bringing up her disabled child. She said that she had wanted to share her feelings with someone but struggled to do so and as a result felt even worse. The following day she had gone to the clinic and explained that she was feeling unhappy about her personal issues that she could not share with anyone and they gave her some pills. She then indicated that because I had returned she would be able to share her feelings and explain everything that was bothering her and as a result finally feel free.

**Theme 2: Seeking Help from Various Sources in Vain**

All the participants in this study related that they travelled all over in search of help so that their children could walk like others and so that their own personal guilt could be alleviated. This pursuit for cure can be likened to what was Callaway (1996) noted of Chinese parents. Coleridge (1993) notes that it is very rare to find a parent who did not want to do the best in the interests of a disabled child. Parents will use whatever means available for them to do this. If their knowledge of possible assistance is limited to traditional healers and churches, this is where they will seek it.

One of the participants in this study reported that she once went to one of the well-known churches because there were rumours that miracles would happen when the minister prayed for the child and touched his feet and hands but nothing happened. The minister then told her that her child could not be healed because the mother did not have faith, effectively blaming her for the child's disability. This perpetuates the self-blame that was referred to above, in relation
to the first theme. It also perpetuates poverty. This participant had done whatever she could to get the necessary transport, even though it was expensive.

The practice of many churches to pray for the healing of impairment as if it were a sickness needs to be problematized. Often this goes unquestioned across societies. The media plays a part in this as well, where church ministers or evangelists are often seen on TV or heard on radios indicating that it is possible for impairments to be cured through the help of the church. This begs the question, “Do people not have a right to have impairments?” Perhaps it is reasonable to view prayer as a solution where impairment exists, just like when there is sickness. It however becomes even more problematic when impairment is seen as a consequence of demonic possession.

I remember at one stage I took my disabled child to a church in the hope that he would be healed. When it was time he was wheeled to the front to be prayed for. As I listened to the prayer I could hear that the minister was attempting to deliver him from demons. As the parent I felt disturbed because it had not occurred to me that demons could be seen as the cause for his disability. The prayer upset me very much, especially because after all its offensive implications it made no physical difference in my son. This linking of impairments and disabilities to demon possession relate closely to the next theme.

Theme 3: “Ndí semiwa ngae” (“I am called names because of him”)

A universal barrier towards social participation by disabled people and their carers is often disabling attitudes, which cause stigma (Venkatesh, 1993). Participants in this study report facing mockery from others, which is the main cause of feelings of shame. Beneath mockery within communities is often an unfavourable public understanding of disability (Ferguson, 2002; Hopkins, 2001, & Safilios-Rothschild, 1982), as well as the historical realities upon which that interpretation is grounded (Ferguson, 2002).
In the study executed by Francis-Connolly (1999) mothers felt that they were held accountable by society and believed that society held them responsible for the growth and success of their children. Seen in this light, it is therefore follows that far from enjoying support from the community the participants in this study often received hurtful remarks.

Livneh (1982) reveals that in some African societies disability is perceived as a curse from the gods. This is seen as punishment for the evil that had been committed by parents, extended family or ancestors. African societies are not the only ones plagued by this belief. Prayer can also often mask a general belief among churches that the birth of a disabled child signifies punishment from God, some form of sinfulness on the part of the parents, or even demon possession.

The consequence of this social labelling is the exacerbation of an already difficult experience of raising a disabled child, as seen in theme 1. This can in turn, lead to parents feeling that they have been singled out or victimized by fate (Cohen, 1962).

Theme 4: "Ndo mu beba e wayhudi" ("I gave birth to a healthy child")

The Office of the Deputy President (ODP) (1997) reports that more than 80% of black children with disabilities in South Africa live in impoverished communities, with poor access to health care services, among other things. The limited access to health care services in the Vhembe district reflects this national reality. There are difficulties even in accessing reliable statistics describing what services and expertise is available in the district. Most of the information reflected here was gained through interviews with health professionals in the region. Retrospective data was even more difficult to access as information was never kept electronically, and there is not a common place where historical documents are filed.
As reported in Appendix II, the 2001 census statistics indicated that the Vhembe District had a total population of 1199885 (Demarcation (2003). It is not clear how many of these are children. According to Dr Nndwamato there is currently not even a single neurologist in the whole of Vhembe district. Patients who desperately need to be seen by a neurologist are referred to Polokwane Hospital. There are presently 70 doctors in public hospitals. Most of them are either MBCHB graduates on community service, or general practitioners who also do locums in local private clinics. For the 8 public hospitals that are in the district, there are 32 rehabilitation specialists according to Ms Manenzhe. Rehabilitation specialist refers to anyone with some training in physiotherapy, speech or occupational therapy. This picture still reflects an improvement in expertise within the region compared to the situation 12 to 17 years ago (Nndwamato, 2007), when participants in this study gave birth to their disabled children.

National statistics indicate that Limpompo has over 2, 6 million children, 14% of the country's child population (Meintjies, Leatt, & Berry, 2006). A telephonic interview with Dr Muloiwa, a paediatrician, revealed that there is only two paediatricians in the Vhembe district, one of them who started in January 2007, is registered with the Health Professions Council. Dr Muloiwa added that for every 1 paediatrician in Limpompo Province, there are 40 in the Western Cape Province. At 1.5 million, the Western Cape Province has 9% of the country's child population (Meintjies et al., 2006). Dr Muloiwa indicated there is not a single paediatric neurologist in Limpompo province. He added that children from Vhembe District get referred to a neurodevelopmental clinic in Polokwane (About 200 kilometres away) for proper diagnosis, with acute cases often prioritised over long – standing ones.

All the participants expressed that they did not know the cause of the disability that affected their children. Given the apparent lack of trained specialists in the region during the time their children were infants this lack of information comes at no surprise. The participants speak of giving birth to children who seemed
healthy, without any sign of disability. However, as time passed, these children became disabled. There was no explanation to why the children were disabled. This explanation should have been given at the time of birth, by the health professionals. The reason it did not happen probably stems from the fact that these professionals did not have the necessary training. Without such specialists, it is difficult for parents who give birth to disabled children to receive proper diagnosis, and the counselling that goes with this.

As indicated by Cohen (1962) in the literature review, some parents wish so intensely that their child did not have a handicap that they tend to reject the doctor's diagnosis. Although it is probable that such could happen, it would be unjust to see participants' lack of information solely from that angle, given the realities of access to services in their context. What is of general concern across different contexts is a general lack of feedback about long term development outcomes for the child (Featherstone, 1980).

Difficulty in finding out that a child is disabled only after some time has passed since the birth is probably exacerbated because at that stage hopes for the child have already begun to grow. Clubb (1991) indicates that some parents may suspect that things are not what they seem, without being able to confirm this, or hope their fears are never really realised. He says this can lead to further chronic emotional complications. When parents are made aware of the child's condition they may feel relieved and expectations they have of the child may even change or become held with a degree of flexibility. Milo (1997) reveals that parents who are aware of the disability are able to let go of their original dream of the wished for, able-bodied child and generate new dreams that accommodate their disabled child. Participants in this study were denied this opportunity. Fortier & Wanlass (1984) correctly advocate for each family to find a comfortable place where there is both hopefulness for the disabled child's development as well as a firm grasp of what is realistically possible.
Theme 5: Help from the Government

Support services for disabled people are a pre-condition to equalization of opportunities (Philpott & McLaren, 1998).

All participants in this study indicated that the care dependency grant made it easier for them. They all expressed that the grant enabled them to buy groceries and pay school fees for their other non-disabled children which, being unemployed, they could not have otherwise afforded. Robinson & Sadan (1999) state that a social security net is crucial for the protection of children with disabilities to, alleviate poverty and to facilitate access to social services.

Participants also expressed their gratitude for the assistive devices, especially wheelchairs that the hospitals supply free of charge. They all indicated that the wheelchairs have brought some change as they enable these children to sit up whereas before they would spend the day in sleeping positions. According to the INDS (1997) assistive rehabilitation technology enables individuals with disabilities to participate on equal terms.

Philpott & Sait (2001) concurred with these findings, in that they explain how the government of South Africa has made a number of specific attempts to address the many difficulties facing disabled children in this country.
FURTHER REFLECTION ON THE THEMES

1. Marginalized place in society

Gender inequality is pervasive across many cultures (Giddens, 2001), and has been found to be more pronounced in sub-Saharan Africa where women often occupy multiple roles (Barret, 1997). Some authors have even blamed the child-bearing role that women have inherently, making them 'natural' bearers of the burden of caring for children, their partners, as well as communities they live in (Miers, 2002). Men on the other hand, are often afforded more valued roles (Giddens, 2001; Hope & Timmel, 1999) and free-time that they often use for their own self-development (Adams, 2005), leaving women even further behind.

In communities where there is no conscious effort to raise the positions that women fill in society, the 'status quo' continues without question, even from the women themselves, who bear the brunt. In South Africa, this was the situation until recently when President Mbeki made it part of his vision to improve women's participation in politics and economic development (Mbeki, 1999). It will take a while however before this vision is fully realised. The majority of women, particularly mothers of disabled children in South Africa, still fill the most marginalised places in society.

The Disabled Children Action Group (DICAG) reports an estimated 98% of mothers of disabled children who live in rural and underdeveloped areas in South Africa, who are unemployed, semi-literate or illiterate, discriminated against by the community, and abandoned by their loved ones (ODP, 1997). Two out of the four participants in the study lived alone with their children and reported that they received no support from extended family. Sait (1998) indicates that families where there are disabled children often become the poorest of the poor. This contributes towards their marginalization. The reported high unemployment and illiteracy of the parents has an effect on access to resources even at household
level. Chalklen (1998) suggests that poverty is closely linked to disempowerment. Furthermore, he suggests that the absence of fathers in the upbringing of disabled children worsens the poverty situation in the family and deepens the disempowerment experienced.

2. The information gap & its impact on mothering

Every parent approaches the birth of their child with high hopes. Even though having a disabled child is always a possibility most parents keep this a remote possibility. Unless health professionals point it out at the onset, subtle differences between a child who will have difficulties later, and those with no impairment, are never picked up by parents. Newborns generally look more or less the same, with likelihood for disability later never being obvious. Participants in this study report being given incomplete explanations even when they themselves started noticing that their children where not developing as conventionally expected. Without this clear explanation these mothers must have struggled immensely in fulfilling tasks associated with motherhood. Mothers need skills and knowledge to be successful in fulfilling their role. According to (Adams, 2005) parents need to receive adequate knowledge on the impairment of their children and how to manage the resultant disability. When the child grows up and begins to ask questions, it is disempowering for a parent not to have clear answers for their child.

3. Rendered Vulnerable

Beyond having an impact on the immediate mothering role, not having an answer that explains the impairment rendered participants vulnerable at a number of levels.
Living in a context where witchcraft is used to explain any 'misfortune' may mean that this is where these mothers could lay the blame for their children's impairments. 'Solutions' to this 'misfortune' may also be seen to lie in this realm. It is then inevitable that the mothers would then be open to traditional healers who claim to be able to cure, or church ministers who claim to can exorcise demons from the children. In some cases large amounts of money were spent in seeking answers. Albertyn (2000) cites Freire (1973) as indicating that powerlessness leaves people at the mercy of others.

Having no clear explanation for their children's impairments made these women also vulnerable to ostracisation by family members and some members of the community. It must have been quite easy to internalise whatever negative comments were thrown at them, if there was no other plausible explanation that the women could use to explain their children's impairments. These family members and people in the community who would link impairment to witchcraft or demon possession were also effectively acting within their frame of reference. Philpott (1995) indicated in her study that professionals are responsible for the assessment of impairment and the articulation of the problems of disabled people to the public at large. In this case, professionals failed these women in that information that could have served to protect them against the consequence of ignorance was neither shared with them nor their communities.

"Poverty is not simply a lack of money; it is a denial of fundamental rights to the decent things of life: health, education, dignity, choice, opportunity" (Coleridge, 2004: 7). The latter statement is in accordance with Max-Neef's theory of Human Scale Development (Van Zyl, 1994) who says that poverty occurs when any one of the nine fundamental human needs are not satisfied. These needs are subsistence, creation, affection, protection, participation, understanding, freedom, identity, and rest/idleness. Participants in this study were denied protection, understanding, and even identity, as incomplete information robs one of a full understanding of who one is.
4. Perpetuating the cycle of poverty

Being largely unemployed, and unable to leave their children with someone else so they can find work or generate income, means the women in the study used money they scarcely had to consult with traditional doctors and travel to places where prayers were offered. They also report that they went to several of these until they realised that they were following mostly empty promises. This is after they had parted with significant amounts of money, perpetuating their financial hardships. Preoccupation with finding a cure for the child possibly robbed these women of time to engage in activities for self-development, ensuring that they remain trapped in the cycle of poverty.

5. The Complexity of Needs

Given the multitude of levels at which the women in this study face marginalisation, as well as limited possibilities through which they can disentangle themselves from the spiral web of disempowering factors, it follows that care dependency grants and assistive devices as a way of addressing their needs is inadequate. The diagram below (Fig 2.) illustrates the interrelation of factors within the women's living circumstances. The explanation of this interrelation will be expanded on in the next chapter.
Fig. 2 The Complexity of Needs

- Rendered vulnerable
- Perpetuating the cycle of poverty
- Marginalized place in society
- Information gap & its impact on mothering
CHAPTER 6
CONCLUSION

The findings of this study in part confirmed what other researchers revealed by indicating that raising disabled children is not easy. The factors that bring about difficulties in bringing up a disabled child in the Vhembe district are however specific to a context where there is acute limitation in terms of access to information, educational facilities for children with multiple disabilities, and health care services, and overall poor awareness of causes of impairment and disability. The care dependency grant and wheel-chairs were singled out as providing some relief in caring for and raising a disabled child.

The findings also importantly point to the complexity of needs faced by the four mothers of disabled children in the Vhembe district. Fig 2. shows how these women started off already from a marginalized position in society. Being women, unemployed and illiterate placed them in a position where accessing resources was already difficult, if not impossible. They then gave birth to children with impairments, without adequate information on what caused the impairment, or how to manage with the resulting disabilities. This in turn, made them vulnerable to abuse, both from people who take advantage of their situation and claim to have solutions, as well as from community members who associate impairments and disabilities with a range of discriminatory ideologies. The consequence of this was the perpetuation of a cycle of poverty as they parted with a lot of finance in their search for answers in vain, as well as their lack of participation in activities for self-development or economic empowerment. This saw the women back in a marginalized place in society, which inevitably was more pronounced in its oppressive state, than when they started off.
Limitations of the Study

Selection of Participants

The researcher selected four biological parents of physically disabled children to participate in the study. Unfortunately males were not available. It might have been a good idea to explore the experience of parenting a physically disabled child from the fathers' perspectives. Since all the participants were women the attitudes generated here might have a gender bias. All participants were from Vhembe District and spoke Tshivenda. Their response might have been influenced by exposure to Vhavenda beliefs. Parents who are Tsonga-speaking from the area of Malamulele or Northern Sotho which also fall under the Vhembe District might have different experiences because of their possibly different cultures and beliefs. Three parents who participated in the research study had children with multiple disabilities. Had I met and interviewed parents with children with a purely singular disability, such as limping or one who could use a wheelchair and so could at least do something on their own, there could have been some differences. The ages of the children ranged from 12 to 17 years, which gave the research findings richness in terms of the long term implication of raising a disabled child. The disadvantage however is that the mothers' experience could have related to contextual factors that currently present differently.

The Researcher

The fact that the researcher herself has a disabled child could have meant that the participants knew that she could relate to some of their experiences, and possibly allowed them to share their stories with ease. On the other hand, this could also have prompted them to share particular kinds of information, especially knowing the researcher's activist role within DICAG.
Recommendations

1. Participants were informed about the findings of the study. An attempt will also be made to publish the findings where other Disabled People's Organisations as well as institutions of Higher Learning can gain access to them.

2. Since there seems to be insufficient expertise in the Vhembe district to diagnose the presence of impairment correctly and timely, correcting this should be a priority. Barriers that prevent the employment and retention of properly trained professionals should be researched and addressed. No single stakeholder can address this alone. Disabled People's Organizations (DPO's) including DICAG, Institutions that train health professionals, as well as the Department of Health should collaborate in this. The importance of the provision of early diagnosis and information to parents in the process of care and rehabilitation of the child with disability cannot be over-emphasized.

3. In providing diagnoses, and information related to disabilities, family members should be included wherever possible. This could limit blaming within families and could strengthen the support base for the parents.

4. In-service training should be provided to current health care professionals who are working directly with children with disabilities to teach them skills on screening for disability and referring appropriately.

5. Parents of children with disabilities could be incorporated into the membership of all government committees that deal with issues and policies concerning disabilities.

6. DICAG could strengthen the formation of parents' support groups at grass roots levels and encourage them to meet regularly as the sharing of challenges and information could have a positive impact. Continual efforts to raise awareness about the rights of disabled people within the society
through community radio stations and traditional councils would reduce the challenges experienced by parents within their communities.

7 Further research should include parents of physically disabled children in other cultures such as Tsonga-speaking people and those who speak Northern Sotho within the Vhembe District so that the findings could reflect broader cultural perspectives. Fathers should also be included.

8 A greater availability of special schools and stimulation centres could help free parents so that they could have the time seek employment.
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APPENDIX I - LIFE STORIES

Life Story of A

A is a 43 year old mother of two children. Her firstborn is 25 years old and the younger child a girl who is seventeen years of age and physically disabled. A was married but her husband was unfaithful and so they separated. A found life difficult, especially when she began to realize that her child was physically disabled. Her husband could not support the family and he would tell A that his salary had not arrived. This was worsened by the fact that he would only come home when he wished. A decided that she could not continue to survive in this fashion and she eventually left her home and took her children to stay with her mother.

Presently A lives with her mother who is dependent on a social grant. They share a three-bedroom RDP house with her two children, her two unemployed brothers and her younger sister. A is unemployed and relies on the Care dependency grant which is meant for her daughter to buy food and pay school fees. A's mother sells mopani worms which also assists the family financially.

A left school after Standard 8 because of family problems. Her father worked on a farm and could not afford to pay for her school fees as well as her two brothers'. When A left school she began to work at a shop on the farm where her father worked. She also wanted to help her brothers to continue with school.

After the first interview A admitted that she wished she could have a job because the Care dependency grants are insufficient to cover all her basic needs. She cannot do this because she feels a pressure to stay at home as her mother is too old to have to look after the disabled child.

A accepts the disability of her daughter in that she participates in parents'
meetings and she used to encourage other parents to attend the meetings.

A is presently staying in the three-bedroom RDP house of her younger sister who died two years ago to look after her sister's child.

**Life Story of B**

B is a 55-year-old single mother with seven children - five boys and two girls. The lastborn boy is physically disabled and was born at home in 1985. The two daughters are married and B is living with the five boys as well as five nephews.

The father of the disabled child is a man who came to her area while working on a building contract. B realized that she was pregnant only after the man had left the area because the building contract was over. She could not find him because she did not have his contact details.

B finds temporary jobs doing washing and farming. She relies on the Care dependency grant to buy food for the family and lives in an RDP house with three bedrooms.

B never went to school and she is unable to read or write. B grew up looking after goats and cows that belonged to her grandmother. She worked at a farm and was paid in fruit and vegetables instead of money. B's parents died when she was still very young.
Life Story of C

C is a 59-year-old mother. She lives with her nine children in a five-bedroom house. The lastborn are twins and one of the twins has cerebral palsy. Her husband works in Johannesburg. He usually comes home only during holidays because he has another wife in Johannesburg.

C never went to school and as a result she cannot read or write. She sells African beer and chicken feed. C is looking forward to receiving her social grant when she turns sixty because it will help to maintain the family.

C enjoys dancing because she often entertains customers with music to compete with other sellers of African beer in her area. C is proud of her business and believes that her success is due to her good people skills when handling customers. According to C it is important to know what customers want to keep her business going well.

The profits C makes help to pay the school fees of other children and buy food for the family.
Life Story of D

D is a 32-year-old mother of three - two boys and a girl. Her firstborn is a fifteen-year-old disabled child who does not attend school. D wanted the child to go to school but she could not find a suitable school for the child.

D left school after STD 8 because she could not find anyone to look after her disabled child and even though she wished to be an educated person her dreams could not come true. D is unemployed and relies on the Care dependency grant and the child support grant of the other two children to buy food.

The day after the first interview D went the clinic because she thought of other issues that she had not expressed and felt depressed because she could not share them with anyone. The second time I visited she was happy because she knew that she would be able to discuss the other issues that she had thought of since I had last seen her.

D's kitchen had a very strong odour on both of the days that I visited her. This was because her child was using a toilet bucket because there was no flashing toilet in the house and the pit toilet outside was not accessible for a wheelchair.

When D married she was unprepared for the pressure of parenting a physically disabled child. Her husband is unemployed and when he does temporary jobs he uses the money to buy beer and dagga.

D is presently staying in a two-bedroom house. D complains about mosquitoes because the house is next to a river.
APPENDIX II - STUDY SETTING

The study took place in a community of Venda-speaking people found in the Northern region of the Limpopo Province of South Africa. The community is found in the Vhembe District Municipality with Thohoyandou as the administrative capital (Map1). The Vhembe District was established in 2000 through the process of transformation of Local Government. It was established in terms of the Municipal Structures Act 117 of 1988 as a demarcated sphere of governance. It is composed of four local municipalities, namely: Makhado, Musina, Thulamela and Mutale. It spans 21 407 square kilometers and has a population of over a million living in 274 480 households. The District is one of the Limpopo province's six district municipalities established in 2000, the others being Mopani, Capricorn, Waterberg, Bohlabela and Sekhukhune.

The Vhembe District is situated in the northern region of the Limpopo Province. It borders Zimbabwe and Botswana. Venda lies between the Limpopo and Letaba rivers and between Makhado (Louis Trichardt) in the west and the Kruger National Park in the east. It includes the Zoutpansberg Mountain. The climate is always hot in summer and even in winter it very rarely becomes intensely cold but it is frequently windy (Becker, 1979).

The census 2001 statistic indicated that the Vhembe Municipality has a total population of 1199885 with 1181672 (98.5%) of African descent, 1658 (0.14%) coloured, 2928 (0.24%) Indian and 13627 (1.1%) Caucasian (Demarcation, 2003). According to Demarcation (2003) the census of 2001 also reveals the distribution of the highest education levels attained by over twenty-year-olds as follows: 15% have no formal education; 6.3% have some primary education; 2.7% have completed primary school, 12.5% secondary education; 6.7% matric and 3.5% tertiary education. The individual monthly income statistics revealed that 881737 (73.5%) persons had no form of income while only 130 (0.01%) persons had a monthly income of over R200,00. The dominant impairments were
visual 13710 (1.14%) persons, physical 10810 (0.9%) persons and auditory 9688 (0.8%) persons.
APPENDIX III - CONSENT FORMS

UNIVERSITY OF CAPE TOWN

RESEARCHER: Christina Sadiki

Consent Form 1

Research Participant's name:

Research number:

CONSENT TO TAKE PART IN RESEARCH

Topic

The experiences of parenting a physically disabled child in the Thohoyandou Vhembe District of the Limpopo Province.

Purpose and Background

This study seeks to explore the experiences of parenting a physically disabled child as well as the impact on the family as a whole. It also assesses the feelings and consequences that are connoted with having a physically disabled child.

The sample of biological parents of physically disabled children for the study will be selected from the Vhembe District in the Limpopo Province. The parent interviewed could be either the father or the mother depending on which parent is willing to participate.
(Initials: .........)

**Service/ Procedures**

If I agree to take part in this study, the following steps/procedures will be followed:

1. I will be asked questions about my experiences in and feelings about parenting a physical disabled child. Conversations will be recorded and reflective notes will be taken.

2. I may be asked about the past or current impact of raising a physically disabled child on the family. Some questions might concern strategies that I employ in coping with raising a physically disabled child. I may refuse to answer any question at any time.

3. The interview will be conducted in a venue where I feel comfortable and at arranged times so that it is convenient for both interviewer and myself. Before the final report of the analysis is produced a last interview will be arranged to check that the researcher interpreted correctly what was said during the interview/s.

4. The interview will be conducted in Tshivenda.

If the interview reveals issues that concern the health of myself or my child, the information will be first presented to me and only with my written permission to the health professionals at a hospital or clinic.
Risks and Discomfort

1. Some questions are of personal nature.

2. The information I have given will not be given to any health professionals or legal authorities except in the case of child abuse or neglect or when there appears to be a risk of me hurting myself or someone else.

(Initials ............)

Benefits

There will be no financial reward for my involvement in this study. My participation may provide an opportunity to learn helpful information regarding community services and insight into parenting methods. The information I share might aid others in understanding the experience of parenting a physically disabled child in similar situations and could be useful.

Confidentiality

All the information I provide for research will be treated with the strictest confidentiality. Only a reference number, not my name, will be used to identify the source of information in the study. My name will not be linked in any way to research results, nor will my name be used when results of the study are published.

Cost of the study

Participation is free. The interview should not be seen as counselling or treatment of any kind. If I identify a need for treatment of any kind, every effort will be made to refer me to the relevant service or professional if available.
Compensation

During the research process the researcher will refer me if necessary to services like counselling, rehabilitation or community health workers or support groups. I will be reimbursed for any expenses that incur as a result of the research such as the cost of telephone calls to the researcher or transport costs for any activities related to the researcher study.

Withdrawal

Participation in this study is completely voluntary. I have the right to participate in or to leave the study at any point with no future consequences. If I feel uncomfortable at any point during the interview I may discontinue the interview.

Questions

If I have any questions about this study I may contact the researcher at the following telephone number: 015-2915326 (8h00-16h30) at Disabled People South Africa (DPSA) at any time during the study.
Consent

I will be given a copy of the consent form to keep. By signing this consent form I do not resign any of my legal rights. If I have queries about my rights as a research participant I may contact the Institutional Review Board at the University of Cape Town at the following telephone number: 021-4066210.

I have read (or someone has read to me) the contents of this consent form. I have had a chance to ask questions and all of my questions have been answered to my satisfaction. I am aware that all raw data will be destroyed after the completion of the study. I willingly agree to take part in the interview.

.............................................................. ..............................................................
Name of participant (print) Signature of participant

Date.........

.............................................................. ..............................................................
Name of witness (print) Signature of witness

Date.........

(Initials:.........)
APPENDIX IV - Outline of the Interviews

<table>
<thead>
<tr>
<th>Interviewee</th>
<th>Number and Duration of Interview</th>
<th>Purpose of Interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant 1</td>
<td>3 (1.5 hours) 1 (30 min)</td>
<td>Data collection</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Member checking</td>
</tr>
<tr>
<td>Participant 2</td>
<td>2 (1.5 hours) 1 (30 min)</td>
<td>Data collection</td>
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<tr>
<td></td>
<td></td>
<td>Member checking</td>
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<tr>
<td>Participant 3</td>
<td>2 (1.5 hours) 1 (30 min)</td>
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<td>Member checking</td>
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<tr>
<td>Participant 4</td>
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<td></td>
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<td>Member checking</td>
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</tbody>
</table>
**APPENDIX V - Categories and Sub-Categories (see Chapter 4)**

**Theme 1: “A zwi leluwi” (“It is not easy”)**

<table>
<thead>
<tr>
<th>Categories</th>
<th>Sub-categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Concentration of Attention on the Disabled Child Only</td>
<td>The parent spends more time with him/her. The parent appears to love him/her more than other siblings. The disabled child is attended to at all times.</td>
</tr>
<tr>
<td>Expenses</td>
<td>The disabled child needs more clothes. Excessive washing.</td>
</tr>
<tr>
<td>Pity from Others</td>
<td>You are spoken of behind your back. You are pointed at repeatedly.</td>
</tr>
<tr>
<td>Personal Guilt</td>
<td>It was difficult to accept. I did not expect it. I had many questions.</td>
</tr>
<tr>
<td>Lack of Special Needs Schools</td>
<td>Children with multiple disabilities.</td>
</tr>
</tbody>
</table>
| Transport Problems | Public transport is a problem  
|                    | You wait for a bus for an hour  
|                    | The wheelchair takes time to fold  
|                    | The passengers complain that the wheelchair dirties them  
|                    | Some drivers make you pay for transporting the wheelchair  
|                    | You have to hire a car if you are undertaking a journey  
| The Disabled Child is a Burden | You have to do everything for the child  
|                               | You must feed the child  
|                               | You must wash the child  
|                               | You have to go to hospital now and again during pregnancy  
|                               | Looking after the child  
| Relatives Avoid the Family | There is discrimination against the child in the family  
|                           | It is difficult to visit home  
| Having a Job is Difficult | There is no one to look after the child in your absence  
|                          | The child soils itself  

### Theme 2. Seeking Help from Different Sources in Vain

<table>
<thead>
<tr>
<th>Categories</th>
<th>Sub-categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Traditional Doctors</td>
<td>Expensive</td>
</tr>
<tr>
<td></td>
<td>Everyone claimed to be an expert</td>
</tr>
<tr>
<td></td>
<td>Disclaiming the disability</td>
</tr>
<tr>
<td>Ministers of the Gospel</td>
<td>We went everywhere seeking for help</td>
</tr>
<tr>
<td></td>
<td>The belief that if no miracle occurs then the parent has no faith and is a sinner</td>
</tr>
<tr>
<td>Hospitals</td>
<td>The service is inadequate</td>
</tr>
<tr>
<td></td>
<td>Wheelchairs are only replaced when the old one is dilapidated</td>
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<tr>
<td>Prophets</td>
<td>The parent seeks the most famous prophet</td>
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<td>The service is free</td>
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<td>Blessed water that came with instructions</td>
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<tr>
<td>Theme 3: “Ndi semiwa ngae” (“I am called names because of him”)</td>
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<td>---------------------------------------------------------------</td>
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</tr>
<tr>
<td><strong>Categories</strong></td>
<td><strong>Sub-categories</strong></td>
</tr>
<tr>
<td>The Belief that Disability is God’s Punishment</td>
<td>You cannot reprimand anyone</td>
</tr>
<tr>
<td>Rumours that Disability is Caused by Parental Sin</td>
<td>My children are told that your mother is a bad person</td>
</tr>
<tr>
<td>Social Labelling</td>
<td>A mother of a disabled child</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Theme 4: “Ndo mu beba e wayhudi” (“I gave birth to a healthy child”)</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Categories</strong></td>
</tr>
<tr>
<td>Taking Time to Accept Disability</td>
</tr>
<tr>
<td>Parents Were Uninformed</td>
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<tr>
<td>The Disability Developed with Time</td>
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<th><strong>Theme 5: Help from the Government</strong></th>
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<tbody>
<tr>
<td><strong>Categories</strong></td>
</tr>
<tr>
<td>Help from the Care dependency grant</td>
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<td></td>
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<tr>
<td>Assistive Devices</td>
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