

**EFFECTS OF CARING ON MOTHERS OF
INTELLECTUALLY DISABLED CHILDREN IN
ALICE, EASTERN CAPE, SOUTH AFRICA**

Nothandathu Monica Gara

A dissertation submitted in partial fulfilment of a
Masters in Philosophy in Disability Studies
in the School of Health and Rehabilitation Sciences,
Faculty of Health Sciences, University of Cape Town

Supervisor: Associate Professor Theresa Lorenzo

15 November 2007

The copyright of this thesis vests in the author. No quotation from it or information derived from it is to be published without full acknowledgement of the source. The thesis is to be used for private study or non-commercial research purposes only.

Published by the University of Cape Town (UCT) in terms of the non-exclusive license granted to UCT by the author.

ACKNOWLEDGEMENTS

To the participants in my study, who shared their stories so freely with me, without you this research would not have been possible.

To my daughter, Nolusindiso, who remained patient and stood by me waking me up every hour in the middle of the night to get up and work!

To my colleagues and friends for their love, support and belief in me unconditionally through many days and nights of reading and writing.

To Associate Professor, Dr Theresa Lorenzo, my supervisor, I have been most privileged to have you as a mentor. Your encouragement, support and perseverance at times when I thought I would never make it have made all the difference to me.

To the people from the University of Fort Hare who gave me much support and supervision.

To my personal assistant, Nodibanisile, who is always willing to push my wheel chair whenever I need assistance, without her this study would not have been successful.

Last but not least, my Creator, who has bestowed on me this gift, an opportunity to be able to share in the lives of these amazing six women.

To Judy Mckenzie, without your assistance and support this study could not be a success.

To Ncumisa Mongo, your wonderful patience and tolerance with me whenever I need help can not be forgotten.

DEFINITION OF TERMS

Abuse refers to any form of harm or ill-treatment deliberately inflicted upon a person and includes assault, physical abuse, emotional, verbal and psychological abuse, financial abuse, sexual abuse, harassment, intimidation and exploitation (Harro, 2000).

Care refers to a holistic provision for people's physical, psychological and material needs where they are unable to provide these for themselves in order to live a quality life (Ward and Webster. 1993).

Disability denotes the collective economic, political, cultural and social disadvantages encountered by people who have a physical, sensory, intellectual or psychological deviation or loss, and which results in restrictive participation in life situations (Oliver & Barnes, 1998).

Diversity refers to "how society has come to think about certain differences in such a way that they end up making a difference to the way in which people feel and think about those they perceive as different to them". (Harro, 2000).

Poverty implies more than an income insufficiency; it includes a lack of opportunity, lack of access to assets and credit as well as social exclusion (Turmusani, 2000).

Respite is short term, temporary care provided to people with severe disabilities, chronic illness or terminal illness. It is designed to give families a break from the demands of daily care living. Respite care can be for a few hours, overnight, or for days. The amounts of care can change with the needs of the family, and those of the person with chronic illness and disability (Harro, 2000).

ABSTRACT

The current study describes the experiences of mothers of intellectually disabled children living in Alice communities in the Eastern Cape, South Africa. A purposive sample was utilised to select five mothers of intellectually disabled children at uMzamomhle Disabled Centre in Alice. A qualitative study was utilised as it is appropriate for the study of life experiences and feelings of the participants. This phenomenological study explores the experiences of mothers who care for their intellectually disabled children through a parent support group. The study looks at how the presence of these children affected their families.

Data was collected by means of semi-structured interviews and a focus group. This enabled the researcher to conduct an in-depth exploration and clarification of complex issues about disability at family and community level (DeVos, 1998). To supplement the data, participant observation was used to study the behaviour of these mothers. Data was analysed by the process of inductive thematic analysis in which common themes were identified.

The findings revealed three themes namely: the burden of mothering; from despair to hope; and lifestyle changes. These mothers experienced mixed feelings about the difficulties of meeting the physical, emotional, and spiritual needs of themselves and their children. Stigmatisation, isolation, exclusion and segregation were experienced by them because of the burden of caring their children.

The themes described the constant, routine of life of the mothers which served as the foundation of their transition process. Lack of awareness of disability issues led to the exploitation and neglect of mothers of intellectually disabled children by their fathers and family members. The negative attitudes imposed by the community members also affected these mothers and their children as they were found to be kept out of school due to their disability. Mothers were fully involved in a parent support group which enabled them to overcome their challenges in caring for a disabled child. The capacity building acquired through the mini workshops provided by Disabled Children's Action Group, a support group, enabled them to change their lives and

embark on the implementation of programs directed at their development. By so doing, it is hoped that the disability of their children will be regarded as a development issue.

In conclusion, mothers of intellectually disabled children can contribute more to the development of their children if they can be capacitated with the necessary skills. It is recommended that the findings of this study be used by all stakeholders, for example, Officers from the Department of Education, Department of Health, Department of Agriculture, Psychologists and Practitioners from the Department of Social Development in the Eastern Cape Province, in their plans to empower and deliver adequate services to disabled children and their mothers.

TABLE OF CONTENTS	Page
Declaration	i
Acknowledgements	ii
Definition of terms	iii
Abstract	iv
CHAPTER 1: INTRODUCTION	1
<i>1.1 Relevance to current legislation in South Africa</i>	1
<i>1.2 Background to the present study</i>	2
<i>1.3 Problem Statement</i>	3
<i>1.4 Purpose</i>	3
<i>1.5 Aim</i>	3
<i>1.6 Objectives</i>	4
CHAPTER 2: LITERATURE REVIEW	5
<i>2.1 Introduction</i>	5
<i>2.2 Disability and poverty</i>	5
<i>2.3 Psychological and emotional impact of mothering</i>	6
<i>2.4 The role of women in households</i>	9
<i>2.5 The role of religion in gendering as woman</i>	10
<i>2.6 Lack of education access for children</i>	11
<i>2.7 Advocacy by mothers of children with intellectual disability in SA</i>	13
CHAPTER 3: METHODOLOGY	16
<i>3.1 Method of Inquiry and Design</i>	16
<i>3.2 My Research Journey</i>	16
<i>3.3 Gaining Access</i>	18
<i>3.4 Sampling</i>	18
<i>3.5 Participants profile</i>	19
<i>3.6 Data Collection Methods</i>	20

3.6.1 <i>Semi-Structured Interviews</i>	20
3.6.3 <i>Focus Group Discussions</i>	22
3.6.4 <i>Journaling</i>	23
3.7 <i>Data Analysis</i>	23
3.8 <i>Ensuring rigour</i>	24
3.8.1 <i>Credibility</i>	25
3.8.2 <i>Transferability</i>	26
3.8.3 <i>Confirmability</i>	26
3.8.4 <i>Dependability</i>	27
3.8 <i>Ethical considerations</i>	27
CHAPTER 4: FINDINGS	29
4.1 <i>Theme 1: The burden of mothering</i>	29
4.1.1 <i>Suffering in silence</i>	30
4.1.2 <i>Inadequate support system</i>	32
4.1.3 <i>Dealing with cultural beliefs</i>	33
4.2 <i>Theme 2: From Despair to Hope</i>	34
4.2.1 <i>Struggling to provide</i>	34
4.2.2 <i>Being vulnerable to poverty</i>	35
4.2.3 <i>Loving your baby</i>	37
4.2.4 <i>A spirit of change</i>	37
4.2.5 <i>Starting a new life</i>	38
4.3 <i>Theme 3: Belonging to a parent support group</i>	39
4.3.1 <i>Building a sense of coping</i>	40
4.3.2 <i>Empowered by group experiences</i>	41
4.3.3 <i>Feeling reassured</i>	42
4.3.4 <i>A sense of Ubuntu</i>	42

Declaration

I Nothandathu Monica Gara hereby declare that I conducted a qualitative research at uMzamomhle Day Care Centre for intellectually disabled children. The clients were made aware of the purpose of the research. Permission to take photos and conduct interviews and support groups was sought with positive results. I swear under Oath that their names will be treated confidentially.

I declare that the work on which this mini thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

I empower the university to reproduce for the purpose of research either the whole or any portion of the contents in any manner whatsoever.

Signature: 

Date:15/08/2007.....

CHAPTER 1: INTRODUCTION

The inspiration for this research evolved out of a project, within the District of Alice, initiated by intellectually disabled children's mothers with the assistance of social workers in the Department of Social Development in 2003. The project focused on empowering the mothers to learn how to take care of their intellectually disabled children, so that they become self sufficient within a developmental approach.

Coleridge (1993) states that development is about people understanding the causes of their under development so that they work to change their situation, i.e. people have control over their own lives. He believes that action on disability:

...is an important part of the process by which a community gains more control over its life and more hope about its capacity to solve immediate problems (p.69)

...the struggle for personal dignity by people who have been disempowered through social inequality, injustice, and violence and wearing down that comes from a life lived on the edge of survival (p.113).

Alice is a predominantly black settlement that has a population of 18- 24 000 people with high unemployment (Social Development, 2003). Several services in disability have been rendered by Government Departments as a programme. However, social problems are experienced by mothers of intellectually disabled children mostly in rural areas in Alice. They face prejudice in their homes and at the same time need to work through their own biases due to socialization, similar to those experienced by disabled women (Lorenzo, 2003). The development of these mothers in caring for their children is crucially important because it will strengthen and support them in doing this.

1.1 Relevance to current legislation in South Africa

The present government of South Africa has given disability and poverty relief priority in the country, drawing strongly on the social model of disability and community-based rehabilitation. The White Paper on the Integrated National Disability Strategy (Office of

the Deputy President, 1997) demonstrates the government's commitment to the equalization of opportunities and the redressing of social injustices towards people with disabilities and their affiliates. Given the legacy of apartheid, this qualitative research is aimed at specifically exploring the experiences of Black mothers of disabled children. It was also hoped that it would be possible to inductively analyse the essence of the lives of these women within the South African context.

1.2 Background to the present study

Community participation forums were used as a means of raising disability awareness and identifying possible participants from the community (Department of Social Development, 2003). These forums enabled the researcher to make contact with parents and caregivers of disabled children and to invite their active engagement in this study.

In 2003, the initial group evolved into a support group for parents with disabled children established by the researcher in collaboration with parents of disabled children from five communities and Disabled Children's Action Group (DICAG) co-coordinators. They were connected to the study by the researcher and to the DICAG which is a non-profit organisation that offers training and support to families and advocates for the rights of disabled children. It was aimed at rendering assistance to parents of disabled children. The group was named uMzamomhle Day Care Centre (in IsiXhosa meaning *Good Efforts*). Thus, the group and their associated activities created *access to* opportunities for parents from the five communities. In reality, the parent support group was comprised of mothers, the key caregivers to children with disabilities, with no input from fathers.

The disability focus of the project continued from 2003 through to 2005 due to increased enlistment of parents. The parent group identified two main areas that they wished to pursue, namely, skills enhancement towards economic empowerment and the active raising of disability awareness within their communities.

1.3 Problem statement

In South Africa, little is known about the effect on mothers of caring for their intellectually disabled children in considering the well being, development and achievement of potential of these children. According to the register in the Social Development Office in Alice, thirty intellectually disabled children are out of school due to their impairment (Department of Social Development, 2004). However, these children have potential and gifts which need to be developed.

The mothers of these children lack the knowledge to care for their children. 20 children are victims of abuse due to the lack of this knowledge; they are exploited and sexually abused (Department of Social Development, 2004). Thus, more needs to be understood about the coping mechanisms of a mother who has a child with intellectual disability.

1.4 Purpose

The purpose of this study was to explore and gain insight into the experiences of mothers caring for their intellectually disabled children within the realm of a parent support group. In order to plan effectively and provide appropriate support to mothers and their disabled children, insight into and an exploration of the mother's perspective is essential because an understanding of what is valued and considered as being meaningful to them will facilitate effective self development of their children. The key feature that differentiated the participants in this study from any other parent of a disabled child was their affiliation to a parent support group.

1.5 Research Aim

The aim of the study is to provide a detailed description of the experience of the effects of caring for an intellectually disabled child on mothers and how they cope with the challenges of the everyday life experiences.

1.6 Objectives

- To gain insight into the roles of mothers with disabled children
- To describe how the presence of the intellectually disabled child affects the family
- To identify the strategies that mothers use to cope with everyday activities
- To determine how mothers could be assisted in providing and facilitating the care and education of their intellectually disabled children

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

In this study, the experiences of mothers of children with an intellectual disability, with specific reference to caring for them, will be explored. This chapter will provide a review of the literature as a background to the current study. Six key issues to be discussed are: firstly, disability and poverty; secondly, the psychological and social impact of disability on mothering; thirdly, the role of women in households; fourthly, the role of religion in gendering as mothers; fifthly, the lack of educational access for intellectually disabled children; sixthly, advocacy by mothers of children with intellectual disability in South Africa.

2.2 Disability and poverty

Literature examining the relationship between poverty and disability indicates that difficulties experienced when providing care for children with disability are exacerbated by poverty. Being disabled is costly and can place a strain on the family (McConkey and O'Toole, 1995; Tiroler, 1995).

Lagerdien (2000) states that the budget strain and time spent caring for, or nursing a disabled individual, can ultimately lead to neglect of needs of other non-disabled members of a poor family. In cases where the role of the caregiver has been imposed on women, their capacity to generate much-needed additional income in impoverished communities is limited (Boylan, 1991). African rural women are said to have triple roles: mothers, social producers and economic producers (Lagerdien, 2000). These triple tasks are physically demanding and time consuming which in turn, impact on their health status.

The successful promotion of social protection depends on fostering the social integration of all groups of people in a secure and fair society, enabling sustainable livelihoods and

working conditions and access to fundamental social services (Barret, 1997). In developmentally impoverished communities, mothers of disabled children have little access to systems of social protection because they are providing special attention to these children.

Tumusani (2000) undertook a research project to understand the experiences of people living in poverty. Thousands of poor people across the world were given an opportunity to share their experiences and needs within their poverty stricken circumstances. The study provides a heightened insight into the lives of poor people. The focus in the study on women, who currently have disabled children and live in poverty, suggested that mothers of disabled children are especially affected by poverty. Tumusani argues that poverty, disability and unemployment exist throughout the world and have a detrimental impact on the level of inclusion in society. Using a materialist analysis to explore this notion, he shows that capitalist development, although not exclusively the only factor responsible for the creation of this triangle (poverty, disability and unemployment) is still having a particular impact on mothers of disabled children as well as on the lives of societies. The mothers as well as all family members are faced with poverty.

Cornieljie (1999) suggests that a public health approach in dealing with disability be adopted. This approach sees health, disability and poverty as interrelated factors, which affect not only disabled people, but also their families. The emphasis on intervention is thus placed on treating the family unit as a whole, not only the disabled person. In so doing, research focusing on understanding mothers with disabled children becomes pertinent, as it is they who are directly involved in the child's development.

2.3 Psychological and emotional impact of mothering

Stone (1999) maintains that caring for children, whether disabled or not, is usually the responsibility of the mother. Culturally speaking mothers are largely responsible for performing domestic and caring roles and fathers for work as heads of the family. She cites an example of a mother who takes care of her deaf child. The father is reported to be

seldom at home and never bothers himself with the disability of his daughter who became deaf at the age of six years. Mothers usually reveal a degree of care, commitment and concern for their child irrespective of their social economic status.

Chinn (1979) highlighted the psychological and emotional reactions of a mother in caring for the intellectually disabled child. A defect in one's child may be interpreted as a defect in one's self, particularly when a mother identifies closely with the child. A mother may anticipate social withdrawal because her chances to socialise are very much limited as she is always paying special attention to her disabled child.

Having a child with an intellectual disability, who grows into adulthood within the family, is one of the most stressful experiences one can endure. Parental reactions to the realization that their child has impairment usually include shock, depression, guilt, anger, sadness and anxiety (Ward and Webster 1993). Individuals handle each of these feelings differently and may stay in certain stages longer. Some mothers perceive the child with a disability as an extension of them and may feel shame. Social reactions may be reflected by economic status, personality traits and marital stability. An initial parent response may be a form of emotional disintegration. This response may evolve into a period of adjustment and later into reorganization of the family's daily life. Some parents cannot cope beyond emotional disintegration. They sometimes decide to give the child for adoption or to place their child in an institution, which is a stressful decision for the family (Chinn, 1979).

The simultaneous experience of love and hatred experienced by mothers towards their children is found to be greatly intensified towards a disabled child (Chinn, 1979). The child's relative lack of achievement and tendency towards disruptive behaviour are likely to increase a mother's frustration. Frustration in turn, generates anger and resentment, which may lead to death wishes for the child and feelings of rejection, typically accompanied by guilt. Inconsistent behaviour, sometimes alternating between rejection and overprotection can be expected (Chinn, 1979).

Chronic feelings of sorrow are to be anticipated as a non-pathological reaction to having a disabled child (Chinn, 1979). Most mothers are disappointed in their child and concerned about their future. Some mothers adopt a “martyr” attitude and sacrifice all personal pleasures for the sake of the child. The child may become the focus of a mother’s total interest, often to the detriment of other family members. Family disruption, including marital conflict, may accompany this pattern. The child may become the focus of mutual blame and criticism by the parents (Chinn, 1979).

Mothers may become acutely sensitive to implied criticism of their intellectually disabled child and may show resentment and belligerence. In extreme cases, mothers deny the existence of the disability, rationalize the child’s shortcomings, and seek professional opinions to substantiate their own contention that there is really nothing wrong with the child (Chinn, 1979).

Chinn (1979) suggests that blame for wrongdoing might be placed elsewhere. To many, the birth of a child with intellectual disability represents wrongdoing. Mothers sometimes follow this line of reasoning, and when they are unable to place blame elsewhere, they turn to themselves. They begin to look for and eventually find something in their lives or their behaviour that may seem to be responsible for the handicapped condition of their child.

Guilt may be in the form of self-recrimination for past wrongs and punishment in the form of the child with the impairment. Guilt may follow more logical lines. It is even possible that the mother, however unintentionally, may be responsible for the condition. Usually, however, guilt is insidious and debilitating. Assuming the blame will not make the impairment disappear, and intense feelings of guilt can erode the mother’s positive self-concept. Professionals working with parents who are experiencing feelings of guilt can help them to channel them into more productive activities (Chinn, 1979).

When the realities have set in and the mothers begin to realize fully what has happened, they may react with grief and mourning (Turmusani, 2000). Grief is a natural reaction to

situations that bring extreme pain and disappointment. We all grieve when we lose something that we cherish and value. The birth of a child with impairment represents a loss of the mother's positive self-image. To the mother, this birth may seem more like a death. In some instances, mothers can react to the birth of a child with death wishes. The role of nurturing a disabled child is embedded in the minds of these mothers and can affect their well being. All these stresses experienced by these mothers may hinder the importance of education for their intellectual disabled children.

The arrival of a new child into a family represents some degree of intrusion with rare exceptions. Prior to the arrival of a new born child, family patterns have usually been established. Parents have to forsake much of their freedom and flexibility. Children often detract from the direct relationship between husband and wife, and the arrival of additional children into the home naturally represents additional and emotional commitment (Chinn, 1975).

2.4 The role of women in households

The literature on the different roles of women indicates that women are engendered into certain roles, of which mothering is but one (Cosslet and Summerfield, 1996). Before exploring the impact of having a child with a disability, one needs to understand the role that gender plays for women. Egalitarian couples share power and responsibility within the household as well as in paid work. The transitional ideology is a combination of the traditional and egalitarian roles. The woman is equally involved in paid employment, but she expects her partner's identity to be based more on paid work (public sphere). Stone (1999) maintains that husbands are breadwinners and also expected to be the heads of the family. Basically, the role of women is to care for the children and maintain the household.

Primeau's (2000) study explored how heterosexual couples divide household work between them in order to sustain the family. She discovered that household work is subdivided between couples based on their gender ideologies. Gender struggles, noted as

inequalities, arose when the different partners had different gender ideologies and thus displayed divergent gender practise. These gender struggles are influenced by one's gender identity. The gender identity is then socially constructed according to the society in which one lives (Barret, 1997). In my study the role of caring a disabled child is attached to mothers and the fathers were free and abandoned their children as their role is only to be head of the family and looking after the cattle's, that is outside the household.

The occupations that women and men choose to engage in are influenced by their gender ideologies (Zuzanek & Mannell, 1993, In Lagardien (2002)). Barret's (1997) work in an African context has indicated that the socio economic climate contributes significantly to the roles and occupations pursued by women. Culturally speaking, women are expected to be carers of the households. African culture stipulates that mothers are responsible for maternal work and this is confirmed even in our belief system and religion.

2.5 The Role of Religion in Gendering Women as Mothers

Child rearing has been described in relation to maternal identity in Biblical text. Religion is said to play a key role in influencing the gender identity of people (Cosslett et. al., 1996). Christianity as a religious order, for example, is based on two models of social organization, namely, egalitarian and patriarchal. The egalitarian approach regards men and women as being equal. The patriarchal approach views men and women within a hierarchical framework with men assuming the ascending role. The latter approach has dominated the world and is still prevalent today. Even though Christianity had elements of an egalitarian prophecy within its teachings, according to Cosslett and Summerfield (1996) an egalitarian model cannot prosper in a society that is patriarchal. The role of religion also stresses the importance of mothers caring for their children and if they fail, they think they are going against Christianity.

Cosslett and Summerfield (1996) differentiate between motherhood as an experience versus motherhood as an institution. Motherhood as an experience refers to the meaning attached to being a mother while motherhood as an institution appears to have been

overtaken by motherhood as an experience. The institutionalisation of motherhood is viewed as oppressive since the nurturing aspect is not valued as work, but as a 'labour of love'. The care of a person with a disability and the sick and the elderly appears to be primarily the role of women.

One such study by Larson (2000) describes how mothers, through a process of orchestration, reflect on their past whilst engaging in family duties. This careful orchestration was aimed at producing a child-sensitive, contingent occupation that is, in turn, reflective of the woman's values of being a good mother.

The role of women as the main caregivers can thus be analysed within a gender perspective framework. From a socio-historical and immediate context, women living in impoverished communities fulfil their role as caregivers and are expected to care for people who are frail, sick and disabled. This care-giving role is clearly a continuation of the institution of motherhood, which stems from societal expectations as well as from the demands of their immediate context (Thomson, 1993; Primeau, 2000). The immediate role of African women living in poverty is that of sustaining their households by ensuring that both they and their families survive (Boylan, 1991). Mothers are regarded as good carers in African culture, while men cannot wash nappies or change them otherwise they are regarded as cowards. Women are also expected to play a significant role in the education of their children irrespective of whether they are disabled children or non-disabled children.

2.6 Lack of education access for intellectually disabled children

According to a research study conducted by Ray (2004) on the needs of mothers of disabled children, she found that mothers of these children usually refer to the problem of disability as an inconvenience, as the situation makes it difficult for them to handle the children. They have difficulty with using public transport to take their children to school. They also experience inconvenience in interacting with teachers. All the mothers felt that the primary difficulty of their children was in communication.

Turmusani (2000) found that mothers of intellectually disabled children believed that their children had difficulty in enunciating the words clearly or putting their thoughts in words. So these children were perceived as an inconvenience because they could not talk with their mothers and the mothers could not respond to whatever they said. They regard taking care of disabled children as an inconvenience because children cannot play with other children or go to school alone, and cannot go on outings. The mothers indicated that they needed support.

Mittler (1985) suggests that teachers and the staff of centres for intellectually disabled children need more knowledge and skills in meeting the needs of their children. They are given very little information about the children's disabilities or about the results of assessments that have been carried out by other professions, e.g. doctors. On the other side, specialist or advisory teachers, who could suggest ways in which a child's needs could be met, rarely visit mothers.

The importance of collaboration between the teachers and mothers of intellectually disabled children is highlighted by Mittler (1985). There is a lack of information about the mother's own child or about alternative ways in which needs of educating or training the intellectual disabled child can be met, in that teachers do not provide mothers with the challenges of the children. Mothers are not given the full information they need nor consulted or given the opportunities to make choices. Their participation concerning the education of their children is too little. Mothers of disabled children feel excluded from discussions and decision-making and are often not involved in the educational programmes being developed by teachers.

Reasons that justify the need for a partnership have been highlighted by Mittler (1985). Firstly, parents and teachers each have information about the child which needs to be shared between the educators and the mothers i.e. information about likes and dislikes, responses to adults and to new demands and situations, moods and dispositions, as well as about achievements and skills at home, in school and other environments. Secondly,

all parents share with teachers, as well as with others, the major tasks of socialisation and of preparing children to take their place in adult society. Parents and teachers have many additional common teaching goals e.g. teaching the child self-care and independence, including self-feeding, dressing and toileting. They are both concerned with helping the child to learn to communicate, and to understand and finally adapt to the demands and expectations of the local community. Thirdly, growth and learning in all children can only be fostered by working closely with the environment in which the child is living.

However, there is no mention of the evidence of the involvement of the mothers during the assessment of their children with disability. This involvement is a challenge, as the teachers should assist in educating disabled children. Lack of education in these children may contribute towards poverty experienced by disabled children.

Lack of opportunity for sexual expression, and lack of education about sexuality and sexual abuse could be regarded as a contributory factor towards the stress experienced by these mothers. In order to reduce the risk of sexual abuse, children with an intellectual disability and their parents require education covering human development, sexuality, appropriate social behaviour and sexual abuse prevention (Giddens, 1993). Intellectually disabled children are found to be vulnerable to sexual abuse, as they cannot identify the perpetrators. These children experienced an abuse of their sexuality. However, many mothers are reluctant to discuss sex with their able children. Therefore, it can be worse with the mother of an intellectually disabled child. Social workers, nurses, community health workers and other professionals should be invited to this centre to take the opportunity to initiate the discussion of this issue with these mothers.

2.7 Advocacy by mothers of children with intellectual disability in South Africa

The changing political climate in South Africa has given rise to a Civil Rights Movement in the disability sectors, creating organisations such as Disabled People of South Africa

(DPSA) and Disabled Children's Action Group (DICAG)¹ who have been actively involved in policy development and advocacy. The establishment of an Office on the Status of Women and an Office on the Status of Disabled People in The Presidency is evidence of the government's commitment to addressing the many injustices that women, children and people with a disability endure.

Boylan (1991) makes mention of the value of parent groups, particularly of mothers publicly expressing the need for additional resources (financial support skills) in order to improve the rehabilitation of disabled children. The needs of mothers of intellectually disabled children are described in a study conducted in the Northern Cape (Ray, 2001). Mothers of intellectually disabled children, who were interviewed, expressed a need to be free of the burden of disability. Most of these mothers are single parents with little earning income. They have to care for several children in addition to their disabled children. There were no grants given to these mothers in the past. They stress a need for a day care centre where these children would be taken during the day. They felt that this would give them a chance to do their housework undisturbed and also give them the opportunity to do casual work to earn money. Mothers expressed the need for education on how to handle and train their children, as it would help their children to develop especially if they can get home care programmes.

The mothers of the intellectually disabled children also expressed a need for support groups where they could meet with other mothers to share their problems and frustrations. They felt a need for support from others in the same situation in order to cope with the stresses and strain of everyday life. Other mothers felt a need for assistive devices such as carts or wheelchairs for their children who could not walk. They had to

¹ DICAG is a cross-disability national organisation of parents of children with disabilities in South Africa. It began life in 1993 as a programme of Disabled People South Africa (DPSA) in response to a growing recognition of the role played by parents in their children's development. In September 1997 DICAG registered as an independent membership-based organisation.

carry their children for a long distance to get to the care centres, which became a problem as the children become older, bigger and heavier to carry.

The study conducted by Ray (1994) further revealed that even with mothering a normal child, problems may arise, but with a disabled child these problems are profound because they have emotional, physical and financial implications. In this way, the experience of parents of disabled children and their children need to be explored. Strategies for their development need to be devised to eliminate the extent of their struggles which can be achieved with the support for mothers by advocacy organisations.

CHAPTER 3: METHODOLOGY

3.1 Method of Inquiry and Design

This particular study was best suited to a qualitative method of inquiry, as it was a topic that needed to be described from the subjective view of the participants in their natural settings. Qualitative research enables the researcher to explore the subjective experiences of participants in natural contexts. The researcher becomes the instrument for data collection. The data is comprised of verbal accounts related by the participant, as well as visual accounts of what the researcher observes.

The study design is based on phenomenology. A phenomenological approach enables the researcher to view the person within their context and experiential time (Moustakas, 1994). Phenomenologists believe that people direct and shape the events that affect them in order to bring meaning to the multiple realities in their lives (De Vos, 1998). In phenomenology, the researcher attempts to illustrate the multiple realities that people hold about a particular phenomenon. The phenomenon in this study is the effect of caring on mothers of intellectually disabled children living in Alice, Eastern Cape and who are affiliated to a parent support group.

3.2 My Research Journey

As a field researcher, I met and worked with the mothers from the parent support groups of uMzamomhle Day Care Centre as part of the Project from Social Development Department. I was appointed as the district co-ordinator in April 2002. I worked in partnership with civil society and service providers. As mentioned previously, the community participatory forum enabled the target group (parents of disabled children) to engage in the research project through sharing their concerns and problems. I worked alongside a few parents who came forward seeking social grants for their children, and together with them, started up a parent support group at uMzamomhle Day Care centre. I went on home visits with a parent (Nozuko) visiting other parents explaining what the

purpose of starting a parent support group was all about. DICAG was also instrumental in facilitating the formation of parent groups. My role with the existing parents was to find twelve to eighteen interested parents or caregivers so that the DICAG co-coordinators could run the necessary workshops to affiliate the parents and caregivers to the organisation.

In November 2004, I was privileged to attend the first mobilisation workshops with the DICAG field co-coordinators in East London. The mobilisation workshops were held to provide parents with information regarding DICAG and inform parents of their rights and their children's rights. Parents were also provided with video footage of DICAG parent groups across South Africa. The videos portrayed true-life stories of parents narrating their lives before and after affiliating themselves with DICAG. The excitement and enthusiasm that emanated from those workshops was amazing. The mothers (at least 36-50 years) were free and willing to relate their stories at the workshops and on the home visits. This participation inspired me. It made me realize that the essence of the lives of these mothers was in the meaning they attributed to their experiences.

The fact that these mothers knew me was an advantage in fostering a trusting relationship with them. I formed part of the recruitment for parents to the parent support groups in these communities and was involved in the parent support group meetings as well as disability awareness activities. The talks became part of the parent support group awareness strategies in their communities and enabled them to recruit more parents. By the end of 2004, I realized that the parent support group activities had become such a focal point in the study that it warranted funding. The application for funds to run the Centre was made to the Department of Social Development in Eastern Cape. In 2005, my workload had trebled, as I was involved in the services rendered to elderly person's centers and parent support group activities. When funding came through from the National Research Foundation in 2005, I decided to appoint a personal assistant, who would focus on carrying my books and assist in pushing the wheelchair, because I am a person with physical disability.

3.3 Gaining Access

Access to uMzamomhle Day Care Centre was gained through the directors of the service organisation who had an existing relationship, trust and good reputation with the mothers of the disabled children themselves. uMzamomhle Day Care Centre is the most significant service organization for intellectually disabled children and their mothers in the identified geographical area.

The introduction of the study to the staff of the Day Care Centre for intellectually disabled children and their mothers was done through appropriate channels. The first channel was the Chairperson of Ntselamanzi Township where the centre is located. Following that, the researcher was introduced to the Director of the centre who in turn introduced the study to, and gained information from, the support group. The researcher negotiated with the directors of the centre for participation in the focus group with selected mothers, prior to introducing the researcher to them.

3.4 Sampling

The parent group was approached and asked if members would be interested in participating in this research study. The researcher used a purposive sample as the selection of participants was based entirely on the judgement of the researcher to choose participants who best met the purpose of the study (De Vos, 1998). To participate in the study, mothers had to be between the ages of 20 and 50 years, be single or married, and must have been in the parent support group for at least one year. Purposeful sampling helped to identify information-rich participants who provided an in-depth understanding about a particular process or a context that was used (Sarantakos, 2000).

A sample of six mothers was selected from a population group of mothers of intellectually disabled children at uMzamomhle Day Care Centre in Alice in the Eastern Cape. Unfortunately one of them could not participate because she was involved in a car

accident. After the participants agreed to be included in the study, the researcher met individually with them to ensure that they met the research criteria.

3.5 Participants' profiles

The names of the participants were changed for purposes of confidentiality. All the mothers had disabled children and were members of a parent support group (refer to Table 1 for more demographic details).

Table 1. Demographic profile of the Participants

Participant	Phumla	Nozuko	Joyce	Nosipho	Fikiswa
Age	42yrs	37yrs	34yrs	36 yrs	50 yrs
Religion	Methodist church	Zion church	Baptist Church	Universal church	Baptist church
Marital Status	Married	Divorced	Unmarried	Married	Unmarried
Employment Status	Unemployed	Part-time	Part-time Domestic Worker	Unemployed	Unemployed
Child's impairment	Intellectual impairment	Intellectual impairment	Intellectual impairment	Cerebral Palsy	Intellectual and physical impairment
Age of child	11 years	16 years	16 years	15 years deceased	18 yrs
Gender of the child	Female	Male	Female	Male	Female
Family composition	Husband, Son (16), Daughters (21, 8)	Sons (13 and 4), Daughters (11 and 8)	Grandmother, Sons (21, 14, 11), sister with niece (3)	Husband, Daughter (4)	Son (26)
Level of Education of Mother	Standard 7	Standard 5	Standard 6	Standard 4	No formal education

3.6 Data Collecting Methods

Data was collected by using semi-structured interviews, participant's observations and focus group discussions.

3.6.1 Semi-Structured Interviews

De Vos (1998) describes semi-structured interviews as the method used by a researcher to collect data which will ensure a detailed picture of a participant's belief about, or perception or account of a topic. This method enabled the researcher to follow up particularly interesting avenues that emerged during the interview and participants were able to give a fuller picture.

Face to face interviews allowed for the clarification and in-depth exploration of complex issues. The participants were made to feel comfortable and at ease (Smith et al, 1995). The researcher prepared main questions that enabled her to begin and guide the conversation (See Appendix 1).

My prolonged relationship with the mothers in the sample did not guarantee that they were able to share the essence of their stories with me. Even though all the mothers cared for disabled children and appeared to have similar experiences, each of their stories was unique. So the researcher had to establish an amicable relationship that made the participant to talk freely.

A series of each interview took 45 to 60 minutes per participant and was conducted over 2 months. The researcher used a semi-structured format for the interviews based on key topics and questions that needed to be explored, (De Vos, 1998). The loose format provided me with the flexibility to explore the participant's thoughts even further and still remain within the framework of the study.

De Vos (1998) suggests that the use of an interview schedule should be prepared for prompting; the researcher ensured that questions were not judgemental. The participants gave permission for the use of a tape recorder during the interview, as it allowed for a full recording so that the researcher could concentrate on how the interview proceeded and its direction (Bailey 1982). Field notes were also used to enable the researcher to sit down immediately after an interview and jot down her impressions of the interview. The notes helped the researcher to remember and explore the process of the interview.

A trial interview was very helpful as the questions were modified to accommodate the educational status of the participants. The interview questions were straightforward and simple, yet enabled the participants to describe their experiences in detail. A similar pattern ran through all the interviews. The interviews were conducted at a time and place most convenient to the participants. Most of the first set of interviews took place at their homes. The procedure for the interviews in Alice was consistent throughout.

The first set of interviews focused on the general life experience of the participant as a woman and mother of a disabled child. These open-ended questions about the participants made it possible for them to relate their life stories from a perspective with which they felt comfortable. This process enabled me to gain insight into the participant's view of themselves. Based on their narratives, I was able to further explore specific areas relating to the outlined above in Chapter One.

I produced a flow diagram as an interview guide for each interview. Refer to the flow Diagram 1 (Appendix 2) for an outline of the first interview guide.

3.6.2 Participant Observation

The purpose of participant observations was to supplement data from the interviews and focus group discussions. An advantage of participant observation is that it offers a wide range of first hand information (Sarantakos, 2000). This method assisted the researcher to

study the behaviour of the participants in the study. Participant observation was conducted during home visits, meetings and mini workshops conducted at uMzamomhle. Field notes were also used to record the salient features of the behaviour. This method was also relevant for this study because the researcher wanted to study in detail the behaviour of mothers of intellectually disabled children.

3.6.3 Focus Group discussions

Focus group discussions were also used in this study as it created a chance of sharing and comparing ideas among the mothers of intellectually disabled children at uMzamomhle Day Care Centre. Kruger (1995) points out those focus group methods are popular with researchers who are concerned with the empowerment of research participants because it allows participants to become an active part of the analysis process. The idea behind this is that the group process can help the participants to express and clarify their views.

De Vos (1998) maintains that focus group discussion is a powerful means of exposing the participant's reality and of investigating behaviour and motivation. Focus groups are especially useful in attempting to understand diversity since they can help one to understand a variety of different experiences. The focus group method was relevant to this study because sensitive topics were discussed. Mothers of intellectually disabled children had an opportunity to understand each other. The group provided mutual support in expressing feelings that were common to all participants.

Three meetings were conducted on Saturdays, starting at 10h00 so that the researcher would not disturb the programmes in the centre. Data was recorded using a tape recorder and field notes with the participant's permission. All participants attended all the meetings but sometimes they were late. Each meeting lasted for one hour so that enough information was shared. Having considered the strength of using the focus group, its limitations were also considered. Focus groups can be quite expensive because the researcher has to prepare a meal for the participants after each meeting. Participants were provided with a bus fare of R10.00 each. Focus groups also create the risk that passive

participants may be unduly influenced or inhibited by active participants. The researcher voiced out that each and every ones ideas are respected. The participation if the group members were further encouraged.

3.6.4 Journaling

The journal entries were used as a means of bracketing (Krefting, 1990). Bracketing develops the rigour of the research study and enables the researcher to explore his or her assumptions and perceptions of the study matter. Thus, the researcher can identify and address biases that may surface by documenting experiences and feelings in field work notes (Holloway and Wheeler, 1996).

I diarised observations in a journal and reflected on what was seen and heard. The recorded information included events, my immediate response to what happened after each interview, any concerns I may have had, and ideas and general thoughts about the research process. An example of an immediate response after an interview would be as follows:

Thinking back I am amazed at how much Nozuko has on her plate, between the kids and work. I've seen how she has grown and become so confident in the last couple of months. There is a desire to acquire more knowledge which I see (September, 2005).

3.7 Data analysis

All data were analysed by the researcher. The transcribed interviews were coded. The aim and objectives of the study formed the framework for the analysis and interpretation of the data. Information that emerged was therefore linked to the objectives.

The researcher labelled audio tapes, bought electricity for the recorder and found a quiet place for note taking. This process enabled her to keep the data intact, complete, organised and accessible. Audio tape for interviews was coloured red and for focus

groups, white, to keep track of dates names, titles and attendance at workshops. The researcher then transcribed the tapes and translated IsiXhosa into English. The aim of translation was to keep the sentence structure and form of expression as close to the original.

These transcripts were subjected to thematic analysis. They were read entirely several times by the researcher to identify meaning of codes. The codes were grouped into sub-categories, which in turn were linked to categories and from these categories three themes emerged. The names of the themes, categories and sub-categories were selected with care to reflect the experience and meaning making of the participants' descriptions. They were allowed to emerge through reading and re-reading the transcripts, which enabled the researcher to be familiar with data in an intimate way. During the reading process, the researcher listed on note cards the data available, checked the minor unnecessary mistakes to make field notes retrievable and cleaned up what seemed unmanageable. Memos in the margins of the field notes were made. This also helped the researcher to piece together patterns defining categories for further data collection. Notes from the participant observation were also used at this point to support the categorisation process.

3. 8 Ensuring rigour

Lincoln & Guba (1985) make a case for four alternative ways to undertake the evaluation of qualitative data. These are credibility, transferability, dependability and conformability. They provide the foundation for demonstrating both trustworthiness and a decision trail.

Feedback and discussion about the research results was clarified (see Appendix 2-5). The researcher explained limitations and benefits. The discussion of issues pertaining to confidentiality was conducted as well as the clarification of any concerns or questions the participants might have had at the time of descriptions.

3.8.1 Credibility

I had the opportunity of a prolonged engagement with the participants as I worked in the community of Alice as a researcher. As a result, I had observed the participants within their context since 2003. The involvement of the Directors of the Centre was valuable. They acted as the group's full-time facilitators and engaged directly with the group in terms of their activities. This involvement enabled me to distance myself from the parent support groups yet remain as an observer and listener. I was also granted permission to act as an observer during certain events. I was actively involved in the group discussions, alongside taking notes. The prolonged engagement, different methods of data collection and peer evaluation (discussions with other colleagues) all helped to increase triangulation. Theoretical triangulation was also made possible through reviewing relevant literature, (Creswell, 1998; Holloway & Wheeler, 1996).

The researcher provided each participant with a summary of their first interview and paraphrased portions in the interview that were unclear (on the tape recording) or needed more explanation. In this way, the participant could verify the information and rectify any misinterpretations. Credibility was further enhanced by my ability to expand on questions within the interview. I could conduct a follow-up interview and re-phrase questions. Further member checking was conducted at the end stage of data analysis to verify the evolution of the themes. I went back to two participants (uMzamomhle Day Care Centre) who were available, to have them comment on the themes, categories and sub-categories. The purpose was to have the participants verify the accuracy of the themes which had evolved and indicate whether they were a true reflection of what was described within the interviews and focus group. Conducting a second interview (two months after the first interview) and member checking enabled me to verify the data.

Member-checked with each participant by presenting the information to her in a verbal summary. Participants were asked to confirm the transcript of their interview to clarify issues and ascertain her perceptions. This helped me note any biases. The member checking entailed clarification with each participant at the start of the second interview.

3.8.2 Transferability

Adequacy and saturation are criteria that ensure rigor in qualitative research. These concepts refer to the amount and richness of data captured (Morse, 1998). Ample data was collected to allow for variation to be accounted for and understood. The time lapse between interviews enabled the participants to reflect and then re-engage in the interview process. The depth of the data reflected the knowledge needed to address the objectives. During the analysis stage the same themes recurred which indicated that saturation of data was achieved.

A thick description evolves out of the data and the context in which the research is based. Such descriptions include detailed accounts of the participants' experiences and sense making of their actions within a situation. The details are about the context in which the participants are situated, events and narratives reflecting the participants' perceptions within a particular context (Holloway and Wheeler, 1996). The transcripts were indeed rich as they provided detailed accounts of events that described the experiences of these mothers with disabled children. The level of in-depth reflection varied between participants and also between the first and second interview as well as within the interviews. The interviews reached saturation level once the researcher realised that the participants had no more new information to share even after allowing them time and maintaining an attitude of listening attention.

3.8.3 Confirmability

Interviews were conducted in IsiXhosa and then translated in English by the researcher. Any misinterpretations were noted in brackets by the researcher and then verified by the respective participants. Once the transcriptions were complete, I cross checked the information against the audio-cassettes.

I also kept a journal in which I reflected on what I observed and thought, as mentioned previously. The observations were recorded in one colour and my perceptions and

decision-making process (process notes) in another. I could thus follow my research journey from beginning to end as I dated each entry. The journal entries enabled me to reflect on immediate responses after an event or interview. I could also revisit entries and note any change in my views and reasons for making process decisions. My journaling thus facilitated a level of reflexivity in my research process (Krefting, 1991).

I communicated with my colleagues conducting research in similar fields of interest at the School of Health Sciences and Rehabilitation in the University of Cape Town. These discussions enabled me to present aspects of my work and ensure a level of objectivity through feedback from them.

3.8.4 Dependability

Dependability (Creswell, 1998, Holloway et al, 1996) was ensured through observation over an extended period and the peer reviews helped me to gain feedback on my analysis of data.

3.9 Ethical considerations

Expectations, conditions and terms of participation (De Poy and Gitlin, 1994) namely, informed verbal consent (see Appendix 4), confidentiality (they were assured that whatever information was discussed in the research would be kept secretive), anonymity (their real names could not be revealed), and freedom to withdraw at anytime, were negotiated with the participants. After the participants were briefed about the purpose of the study, each one of them was asked if she wished to participate in the research study before we proceeded with the interviews. They were assured that everything that they said during the study would be kept confidential and permission would be sought, should there be any need to use the information elsewhere. To ensure anonymity, the names of participants quoted in the study were changed. Participants were informed that they were free to withdraw from the study at any time if they felt uncomfortable about anything in the process.

CHAPTER 4: FINDINGS

The findings presented three themes that emerged from data analysis of the interviews, focused group discussions and observation of participants, namely:

Theme 1: The burden of mothering

Theme 2: From despair to hope

Theme 3: Belonging to a parents support group

The themes reflected the barriers related to the challenges, sadness and burdens experienced by mothers in caring for their intellectually disabled children. They also demonstrated their coping mechanisms and their ability to change their situations. Each theme is subdivided into categories. Supporting quotes are used and translations are given in English. The themes and categories are presented in a tabular form and flow systematically.

4.1 Theme 1: The burden of mothering

THEME	CATEGORIES	CODES
1. The burden of mothering	Suffering in silence	Abandoned by the family Struggling alone Tortures me Staying in hospital alone Neglect by father of child and other family members
	Inadequate Support System	Too heavy to carry Uncertainty in dealing with impairment Learning from each other No skills <i>It's not my fault</i>

	Dealing with cultural beliefs	<i>Washing of the womb</i> Tolerate the insults Female dignity and respect undermined
--	-------------------------------	---

The common theme that emerged was the burden of mothering an intellectually disabled child. The notion that women are the sole carers of the whole family, as well as the intellectually disabled child, constituted the burden of being a mother of a disabled child in rural areas. This burden means that these mothers are unaware of what could be done about the child’s disability. It is an ongoing process that is informed by their values and beliefs related to disability, and challenged by their living environment. All the participants described their confusion in understanding the disability. They are unsure about how to manage their children with an intellectual disability. Participants found that mothering an intellectually disabled child was demanding.

4.1.1 Suffering in silence

Neglect by the father of the child was due to the impairment of the child and can affect the emotions of the mothers of these children. The emotional impact of caring for a disabled child was illustrated by a mother:

What tortures me is the fact that I don't know what to do when my child is sick, I just don't know what to do. Nande has been denied by her father. I don't know where to go and I don't know what to do when Nande is sick. I am all alone with this child. My father is refusing and abusing me for having a relationship with an irresponsible man (Pumla, 8.09.2006).

Initially I was so eager to get a baby boy. I later became frustrated when my husband and my in-laws said that there has never been any mental illness in the family (Nozuko, 08.09.2006).

The fact that these mothers are deserted by the fathers of their children also affected their families. This has a detrimental effect on the family relations. Pumla reflected how she struggled to maintain her child alone:

I am struggling alone. Nande is abandoned by her father without any form of support. There is no food, no money, and I am still waiting for the child grant approval. There is just nothing, nothing, but it is not my fault, it's not my fault! (She emphasised) (Pumla, 17.07.2006).

Nosipho's burden of mothering was more challenging than the other participants as she was caring for a child abandoned by his biological mother as well. The first challenge was to convince her own family, that is, her husband and children, to accept Luyolo as part of their family. This situation created a tension in the whole family as they found it hard to understand why the mother would abandon her own child and why Nosipho should be the one to sacrifice their own happiness by accepting a disabled child. She was constantly accused of paying more attention to Luyolo than her own children, especially the youngest one. It was not easy for her as she had to explain that Luyolo was a child in need of care whereas her other children were able to deal with their day to day challenges alone. Nosipho described that the matter was made worse when Luyolo drowned and died in the local dam:

...I am still worried about the disability of Luyolo. My family is not accepting him yet Luyolo was a child in need of care, my children were reluctant to accept him especially the last born. He kept on saying take him to his mother mom, I don't like him. They kept on saying till Luyolo died. (Nosipho, 17.07.2006).

Data analysis revealed that the mothers of these children were exposed to suffering related to the absence of the child's father:

The most difficult thing that I have been living with is to see my baby suffering. I'm just alone in caring for her. So now I think with things, there's been some exploitation and abuse from my husband on me. I have been staying in the hospital alone. Sometimes a whole month, sleeping on a chair and staying in a hospital watching my baby suffering. My husband left our child uncared for. (Pumla, 17.07.2006)

4.1.2 Inadequate support system

Fikiswa had to focus all her attention on her disabled child whom she could not leave with her own mother, as she could do with the other children. The disabled child was

more challenging to raise than others. Fikiswa used to lock her child up in the house whenever she had to do odd jobs to earn an income:

I had no option rather than locking her in the house. Sikelelwa is too heavy. I cannot manage to carry her on my back for long periods at a time. My mother is too old to carry her (Fikiswa, 17.07.2006).

Joyce's experience was that she was not sure how to deal with a disabled child. After the doctor told her about the condition of the child, she spent lots of money and time on traditional medicines, visiting the sangomas often. Emotionally she was not ready to deal with her child's disability. She thought by going to the traditional healers the child's disability would be cured. Joyce demonstrated her lack of knowledge pertaining to the disability:

I visited many sangoma's trying to find out the cause of the disability and good medicine to change the condition of my child. They charged me R200 for each consultation, but the condition did not improve (Joyce, 17.07.2006).

In Pumla's mind, the frustration is that the person whom she claims to be the father of the child is denying paternity. On the other hand, her own father puts more pressure on her as a result of her not receiving any form of maintenance from the alleged father. She does not know what to do as she did not get any support from her own father and the father of the child. This denial has a detrimental and degrading effect upon her wellbeing:

Truly speaking I had a relationship with one man. Out of our union Nande was born. There is no other man I know except Zwayi. I was honest to him; this means he did not trust me. I don't know why he treats me like this. It's not my fault. I really don't know why I gave birth to a disabled child. It's not Nande's fault, it's not my fault, and it's not my fault! (Pumla, 08.09.2006).

4.1.3 Dealing with cultural beliefs

In Nozuko's family, the birth of a disabled child was associated with "washing of the womb", meaning that her womb was dirty. This belief caused uncertainty as to where to go with the child as Nozuko did not know the cause of her child's disability. Her own father suggested that she goes away with the child, as she was not getting the support

from the child's father. The biological father maintained that there had never been any disabled child in his family; therefore the child could not be his. The cultural adherence in the mother's family of the disabled child had contributed towards the prejudices and stigmas attached to these mothers:

I am being neglected and rejected by my family because of the impairment of my child. My female dignity and respect is undermined. I tolerated the insults imposed on me. I am regarded as a woman with a dirty womb. It's unfair! (Nozuko, 08.09.2006).

Their husbands and boyfriends did not provide important support and co-operation to the mothers when in need, that is a lack of exercising parental responsibilities. Even where the child has a single parent, both parents should share the child rearing and child care. Family expectations were often different even within one culture, as related by Pumla:

In my culture a family is headed by a man, but in my family it is I, a woman, who heads the family and is the breadwinner because I am neglected by my husband (Pumla, 17.07.2006).

Fikiswa also had left her favourite hobby of traditional dancing to look after her son. She described the difficulty associated with motherhood of a disabled child:

The other challenge with me was that I got pregnant from a married man. It was a secret love affair and now I have the disabled child. I kept this child as a secret because of the marital status of the father. As a result I am not getting any kind of support from the father of my child. This was a burden, not only physically and mentally, but also emotionally! I did not know whom to tell about the relationship between myself and the father of my child. I had to suffer in silence. (Fikiswa, 09.07.2006).

4.2 Theme 2: From Despair to Hope

THEME	CATEGORIES	CODES
From despair to hope	Struggling to provide	Feel like a donkey Stupid woman Feel small of myself Blame myself
	Being vulnerable to poverty	Unknown Unable to provide Learning skills of surviving
	Loving your baby	Give him special attention Protect him from being abused Makes me happy
	A spirit of change	Involve the community Change our society Conduct meetings Educate families Rise up We can
	Starting a new life	Providing proper care Hospitalisation of the child Rejuvenated identity

4.2.1 Struggling to provide

The challenge of caring for an intellectually disabled child is emotionally demanding especially for the mothers without the support of their husbands or partners. The mothers identified the lack of support from the fathers of their children and the family as the donkey carrying heavy loads on its back:

...because sometimes I feel like a donkey, I am taking the whole responsibility of raising my disabled child alone; no one is sympathizing on my family. I am regarded as a stupid woman; I am the only one giving care to our child (Nozuko, 08.09.2006).

The feeling of neglect by the father of the child and family members and inadequate emotional support created stress, self blame and low self esteem for many of the mothers. Many mothers revealed that their families had called them by names that destroyed them inside.

...because sometimes I feel like crying, when I hear my brother refer to my child 'you stupid boy, get dressed quickly.... This makes me to blame myself for having a disabled child, and I feel small of myself (Pumla, 17.07.2006).

There was stress related to the perceived inability to change the health status of their children. These mothers experience the stigma and prejudice from the family members. They felt hopeless, as they are unable to provide for their children without support from their fathers. They talked about non-availability of food, clothes and money to buy medical treatment because the fathers of their children deserted them:

I'm the only one who is giving care to our child. She needs special attention. Her diet is expensive as she is dependant on light diet. I have to go to town and Victoria hospital every week to buy her nappies and diet and get treatment for her. I have to pay school fees for other children (Pumla, 17.07.2006).

4.2.2 Being vulnerable to poverty

Another significant category that emerged was the poverty the participants experienced, evident in the previous categories as well. Piece jobs and selling sweets was the only source of income common to these mothers. This state of income maintenance was inadequate for the needs of the intellectually disabled children as it affected the physical and psychological wellbeing of the participants.

So I don't know where to find food and other needs of this child. I don't know where to go. I don't know what to do, what to do (she cried) (Pumla, 07.07.2006).

Mothers in this study mentioned that they were affected by poverty, as they had no chances of getting better paying jobs while they work to get money to make ends meet. This deprivation might jeopardize their health-risk as well as children. Fikiswa talked about the challenges of living without any form of financial support. The participants voiced their frustration as they could not provide other siblings with school needs:

I am unable to pay school fees of my other two children; my other children have no school uniform and provision for lunch. With the grant I pay I am unable to provide my children and support them...The whole family is dependent on the state grant received on behalf of my disabled child (mhhh!) I wonder where can I get money but I won't give up I will struggle caring for my child even if I don't have money I wish to start a business and learn skills of sewing (Joyce,25.09.2006).

Pumla talked of the financial hardship she endures:

I did not know where to go and ask for the money. I did not know what can I cook for my children but now I have learnt new skills of surviving. I know how to plant vegetable and maintain my children (Pumla 17.07.2006).

There was a strong feeling amongst these mothers that they could not abandon their children even if poverty was a challenge to their upbringing. They are also hoping that their burden will become lighter by selling sweets and piece jobs instead of sitting and expecting miracles. The words of these mothers also indicate their eagerness or desire to gain economic empowerment to meet the basic needs of their children through opportunities to access resources. They also feel strongly about providing for the needs for their children. They are frustrated about the hunger they experience with their children and the fact that their children are not being educated, as they need special attention. The stories illustrate the perseverance of the mothers in taking care of their disabled children:

I will continue providing care to my child even if I got no assistance from her father, I will embark on projects in our centre, I won't abandon my child, even if I got no maintenance from my husband (Fikiswa,15.09.2006).

The data revealed that only one mother was not affected by poverty, who appreciated the moral support from her husband.

My husband was always standing by me when I went up and down looking for the cure for my child, although we have no money after his retrenchment from University of Fort Hare (Joyce, 15.09.2006)

As indicated in the previous theme, having a child with a disability has complex, multiple challenges. The needs of a disabled child are amplified within an impoverished environment, placing even more strain on the participants as care givers.

4.2.3 Loving your baby

Despite the fact that the participants experienced inadequate support from their family, they exercised love and care for their disabled children.

I love my child irrespective of his disability, he makes me happy and I laugh when he is singing. I will treat him like any other child. I will give him special attention; I keep him clean every time. He is my child I love him (Nozuko, 09.07.2006).

Nozuko seemed to be frustrated about her child who was abused by other children in her neighbourhood. She related how difficult it was for a child to tolerate teasing by other children. She emphasised how emotionally demanding it was to fight for her child:

Pumezo used to cry when playing with others, I became so worried because they are taking the chance of his disability. (Raising her voice) You must love your baby; you must protect him from being abused by others (Nozuko, 17.07.2006).

4.2.4 A spirit of change

Mother's of disabled children revealed that the community lacks knowledge on disability issues. Hence they feel a spirit of changing the negative attitudes of the community towards the disability of their children. The participants were eager to show a remarkable change in their communities so that all the community members would stop abusing their children.

We have to conduct meetings or render counselling services with our families and tell them about what disability entails. Workshops also need to involve the community at large because there are labels that our children are named.

Sometimes they are called mad. We need to educate the family to stop abusing our children with heavy loads they carry from the local spaza. Committee members don't know what disability means and the tendency is to label our children and that affects us. Yes!!! We can change our society!!! We can! We can! (Pumla, 07.07.2006).

They talked about their developing a sense of change and a renewed sense of hope was evident in their ambitions to see things differently:

I wish I can be trained to be a qualified teacher of disabled children. I was trained by DICAG on advocacy and leadership. I want to rise up. Sky is the limit. I want to be an example to mothers in fighting for the rights of disabled children (Nozuko, 09.07.2006).

4.2.5 Starting a new life

The participants experienced adaptation as women and mothers of disabled children. They gained knowledge on how to start a new life. They now know how to manage and resolve their problems. To have a disabled child was no longer regarded as a curse, but was seen as part of life to be dealt with.

There exists a sense of doing things to develop the situation of these mothers; they indicated that they were eager to participate in their church projects and local projects. But they faced the challenges of paying special attention to their disabled children, which deprived them of chances of involvement in these projects. Being faced with the challenges of caring for their disabled children, they revealed their wish of participating in the development that will improve their situation. A rejuvenated sense of identity was evident:

Ever since I joined a parent support group I have a hope of changing my situation. At Umzanomhle, we meet and share our problems regarding our disabled children. We are all dedicated to embark on projects, (Nozuko, 17.07.2006).

The participants felt rejuvenated and developed through their efforts of involving themselves in a parent's support group. They have a feeling that they will be rewarded for their efforts in joining the support group and sacrificing their happiness for their children:

I identified myself with Zakeu who was unable to see Jesus. He climbs up the tree in order to see Jesus. Jesus slept in his house because of his efforts (Pumla, 09.09.2006).

The findings showed that the mothers found a purpose and fulfilment in life spiritually despite their children's disability. The participants used biblical parables to compare with their situation and changes which happened to them. Through participation in the research and workshops, a sense of hope prevailed. The mothers related that they felt dedicated and devoted to having to manage things on their own. They found strength within their newfound ability to manage things on their own.

The participants voiced that they sacrificed their leisure activities in the interest of their disabled children, but they do not blame themselves, instead they feel proud. Fikiswa talked about her sacrifices:

I stopped attending practices of traditional dance. I used to dance a lot. I had to stop all that. I did not leave my mother with Sikelelwa because of her disability. I just lost everything (Fikiswa, 09.09.2006).

4.3 Theme 3: Belonging to a parents support group

THEME	CATEGORIES	CODE
Belonging to a parents support group	Building a sense of coping	Acquiring new skills Mutual support Being independent
	Empowered by group experiences	Being Independent Volunteering Gives us compassion It helps me

	Feeling reassured	Recognised by my husband Continue attending group meetings Appreciate support <i>I won't give up</i>
	A sense of uBuntu breaks the isolation	Helping each other Sharing ideas Be together

4.3.1 Building a sense of coping

This category reflected the sense of breaking the isolation and stopping the discrimination that mothers of intellectually disabled children endured, as well as acquiring new skills in peer support through belonging to a support group. The participants developed gradually after joining the parent's support group at uMzamomhle Day care centre. They obtained a spirit of being independent in caring for their children. The common feeling amongst them was that they accepted the impairment of their children. Many of their stories reflected the provision of mutual support:

It is important to join a support group for me. There is a real change in my life especially when I meet people with common problems. I feel a real important change in my life; especially I reach out to people, when I struggled. I am still struggling and I belong to a group of mothers having the same problem although it has a little help but it meant a lot to me, (Joyce, 17.09.2006).

The parent's support group afforded opportunities for mothers to be acknowledged, to give and receive help. By helping themselves they were able to help others. Pumla mentioned many things, for instance, the group as a means of socialising, an opportunity to build her own capacity through skills acquisition and a chance to escape her problems. This feeling was true for all the mothers. The participants valued the opportunities they had to meet with other parents and professionals, as it enabled them to share their experiences without hindrances.

It's nice to be in this group. DICAG taught me a lot about intellectual disabled children. I enjoyed a lot of meals in the workshop provided by DICAG. I became so strong when I watch videos, saw the kids and the ways those mothers were talking about them. I must feel so strong to support my child and I am not the only one (Fikiswa, 09.09.2006)

The mothers revealed that they experienced changes after joining the parent support group. They acknowledged that by virtue of belonging to a parent's support group they felt confident because they were participating in the education of their children. They identified themselves as a tool that could be used in the communities to change the mindset and understanding of the concept of disability.

4.3.2 Empowered by group experiences

Although the participants joined the parent support group because of their disabled child, it seems that they valued this opportunity. They remembered their lives before joining the parent's support group. Some of the mothers related the need to join.

Because if it wasn't for Luyolo I wouldn't be where I am today in volunteering and starting a parent support group at uMzamomhle. I feel very proud to be where I am today. I think this group gives me compassion and many things came from it. I want to do something for my community. Before joining this group I was unable to control Luyolo, (Nosipho, 15.07.2006).

Pumla felt that the group provided an opportunity to attend workshops and for her to receive capacity building, such as learning to address an audience about the intellectually disabled, handling a disabled child, and sewing and gardening skills.

It helps you to function and I learn a lot as a person goes through the workshops provided by DICAG and a parent support group, it helps me, because it's almost right (Pumla, 09.09.2006).

The motivation to participate in a parent support group changed the silence and feelings of disempowerment as the mothers became confident and contributed towards the betterment of their community. It also revealed that the parent's support group provided another potential benefit by helping other community members to understand disability.

So support received from this group was seen as an eye opener in understanding their disabled children.

4.3.3 Feeling reassured

Two participants revealed that there seemed to be a sense of appreciation from their family members. Nosipho's husband was very happy to hear that she could write letters and articles on caring for their intellectually disabled children.

When Luyolo was left uncared for by her biological mother I felt very frustrated. I think how am I going to convince my family about the arrival of Luyolo at home, but I am happy to tell you that my husband recognises me as a good carer. He can see the importance of parent support group. He is now praising and encouraging me to continue attending the group meeting. I also appreciate his support (Nosipho, 17.07.2006).

One participant bravely expressed her desire not to depend on her family members in caring for her disabled children:

I am staying with my father and mother after I was told that there is no disability in the generation of my husband... Now I identify myself with an ant carrying a worm...Mpumezo is very heavy. He gained a lot of weight. It is so strenuous to go up and down visiting doctors and checkups carrying him on my back, but I won't give up, he is my child. He is my load even if he is heavy I have to carry him. The child is mine. I can not give any one (Nozuko, 17.07.2006).

4.3.4 A sense of Ubuntu

A sense of solidarity was created as the participants encouraged other mothers of intellectually disabled children to participate in the group activities and to tell their stories. They conducted awareness campaigns in their communities. They worked together through educational talks and mini workshops. Their first target was uMzamomhle: 'Together in excellence' was their motto, illustrating their sense of uBuntu in doing things together, by helping each other.

Ubuntu means help each other through hardships and happy times, I think its good to help others, always be together, helping each other (Fikiswa, 17.07.2006).

Ubuntu (Humanity) is marked by a collective solidarity of the mothers on survival issues. The mothers saw a difference in their situation. While reflecting on their lives, they appeared to have a spirit of being that helped to sustain them:

I value to have someone and in turn being helped by him when it is a good or bad time. It is important to help her back. The communities are sharing ideas with other communities through Imbizo (General meetings), (Joyce, 17.07.2006).

There prevailed a positive self-worth attitude in helping each other within the group of mothers of disabled children. After they had been capacitated by DICAG in caring for intellectually disabled children, they felt helpful about doing well with others. Working together and assisting each other also meant that they were eager to achieve their desired goal.

Three themes were identified in this chapter in an attempt to integrate the difference experiences of mothers of intellectually disabled children from individual to family to community level. Categories were also identified that have a direct impact on the themes. Although themes are presented individually, the reader should bear in mind that there are interconnections as one theme influences and relates to the other. In the following chapter the transitional management will be discussed at length.

CHAPTER 5: DISCUSSION - MANAGING DISABILITY TRANSITIONS

This discussion will integrate the themes from the findings into three sections: Firstly, the effects of caring; secondly the coping strategies; and, thirdly, the (Bridge's 1991) Model of Managing Transitions was used as a framework to show the importance and relevance of parent support groups in generating coping strategies and changes experienced by the mothers in caring for their disabled children. Figure 1 provides an illustration of the relationship between the themes from the findings and how these will be integrated in the discussion.

5.1 Effects Of Caring

In this section the absence of fathers on the families will be discussed and the socio-emotional responses to disability will be explored further.

5.1.1 Absent fathers in families

There has been a common recognition that disability does not only affect the individual children, but impacts on other family members as well. Tirole (1995) maintains that the relationship between disability and poverty indicates that difficulties experienced when providing care for intellectually disabled children are increased by poverty. Being disabled is costly and can place a strain on the family. The theme of the burden of mothering revealed that support from the father was important in caring for any child. These mothers therefore seem to be invisible victims, as they keep quiet about lack of financial maintenance from their husbands. The fact that the fathers neglected their intellectually disabled children caused immense stress for the mothers. The study revealed that other children's needs are neglected due to insufficient finances. Money is always spent on the needs of the disabled children. These mothers appeared to be frustrated about the lack of support for other children. Fathers also ignored the needs of other siblings as well. Thus the involvement of fathers in rearing disabled children is imperative.

Giddens (1993) has developed an analysis of gender differences based on the images adult women and men have of themselves and their attainments. Women define themselves in terms of personal relationships and judge their achievements by reference to the ability to care for others. The position that women traditionally place themselves in relationship to men is that of carer and help mate. But men frequently devalue the qualities developed in this task, and see their own emphasis on individual achievement as the only form of successes. Concern with this relationship on the part of women appears as a weakness rather than strength.

Further suggests that women in comparison to men are more cautious in their moral judgements Giddens (1993). Traditionally women are seen as more caring in comparison to men, and this is shown in their desires not to hurt other people and to follow a stricter moral code. Women view themselves on the basis that they successfully fulfil the needs of others rather than on pride in individual achievement. The role assumed by women in this study has been imposed upon them by society. Mothers of intellectually disabled children were found to be very concerned with how they provide care for their children, as it is regarded as a reflection of being a good mother; taking good care of their disabled children enhances the women's self-worth as good mothers.

Women are primarily concerned with child rearing and maintenance of the home without the assistance of men Giddens (1993). The majority of men do not bear primary responsibility in rearing their children. The initial physical necessity for mothers to give birth to and nurse their children leads easily to the continuing caring and nurturing role which women adopt in our culture. The mothers in my study were socialised to be good mothers at an early stage of their development as they began to define their place within the community in which they resided. This socialisation involved learning about the different roles men and women had in relation to one another. Although men are considered to be more powerful than women, in terms of caring for their disabled children, they were found to have abandoned the family in this study.

Men were absent in the role of caring for their disabled children. They assumed the traditional head of the household position as they were expected to be the main breadwinner. They had the authority to deny their children and fail to support. Mothers of intellectually disabled children indicated that they experienced problems and barriers with rearing their disabled children in the absence of their husbands. The result of this abandonment is the difficulty in paying the medical care required for their children and they missed advice and encouragement typically provided by fathers of the children.

5.1.2 Socio-emotional responses to disability

There is no doubt that the disability of these children impacts on the family (Lorenzo, 2003). A person cannot be separated from their environment. The oppressive unethical practices such as abandonment, lack of care by the family and neglect by their father and stigmas are often enacted in the best interest of these mothers (Oliver and Barnes, 1998). These mothers experienced embarrassment and ridicule for giving birth to disabled children though no fault of their own. *Washing of the womb* is a myth, which means that when giving birth to a disabled child, your womb is unclean. Mothers in this study were emotionally victimised and blamed for the disability of their children, which made them lose their dignity and self respect, and subsequently jeopardised their health and well being. This myth has to be addressed by the professionals in this field. . Some mothers in this study experienced denial due to a lack of knowledge of disability. Other mothers, especially those who were Christian, felt that taking care of an intellectually disabled child was demanding emotionally, but they would just persevere due to their fear of God and love for the child.

The diagnosis of an intellectual disability in a child was found to be an extremely severe psychosocial stressor (Giddens, 1993). This is evident in my study. The mothers showed severe emotional stress that made them vulnerable to illness and caused them to have physical and psychosomatic symptoms. The presence of an intellectually disabled child at home disturbed both the social and intra-familial interactions. These mothers experienced poor social interactions, as one had to sacrifice her traditional dance and hobbies for the

welfare of the disabled child. However, since the stressor could not be changed, it was imperative to change the mother's attitude towards it, to help them cope and to improve social support. For the purpose of counselling, cognitive understanding of both the condition and the nature of the progress of the affected as well as available and assessable support services were essential for these mothers. Giddens (1993) suggested that skills and continued counselling, starting as soon as the diagnosis is made, may identify the vulnerable families and help them to meet the demands of the situation. Professionals need to treat the family holistically.

The mothers in this study internalized guilt and blamed themselves for having a child with an intellectual disability. These mothers revealed that they endured emotional abuse without support from the early stages of their child's development. Again, this made them committed and responsible in caring for their children. Initial denial was a reaction experienced by one of these mothers due to her belief in traditional healers. This belief led her to refuse to accept the reality of the child's disability and close her mind to the child's limitations, and their child was deprived of medical treatment. All in all, this hindered the acceptance of the child's disability by the mother. The fact that some mothers experienced a positive attitude about the disability of their child from their husbands was at least appreciated by the researcher, as they had exhausted all their monies thinking that the disability of their child would be cured. One of the participants was traumatized by the death of the child, but that did not stop her attending a support group. She showed commitment and dedication to the service provided to intellectually disabled children.

Watermeyer (2000) provided a concise introduction on how the psychoanalytic model may usher in a new level and era of thinking surrounding the oppression of disabled people. Psychoanalytic models provide us with the opportunities to examine how ideas and images of disability are experienced emotionally by all of us (Mark, 1999). Disability can invoke feelings of vulnerability and frightening memories in non-disabled people and these unconscious feelings systematically affect the way in which disabled people are treated. These feelings are often directly related to the way in which we try to

defend our unconscious feelings. So this theory provides the researcher with the knowledge to examine how ideas and images of disabilities are experienced emotionally by the fathers, mothers as well as community at large and how these experiences shape the way in which the family and the community treat the mothers of intellectually disabled children. These fathers neglected their families unconsciously because they are affected by the fact that to be a father of disabled child carried a stigma to the society. They are overwhelmed by fearful feelings of being stigmatised and this resulted to disowning their children through using defence mechanism. Their mother regarded them as a burden in caring a disabled child. Mother's experiences left them feeling inferior, ashamed and unlovable and incapable to bear normal children.

Mothers of disabled children became passive recipients of services in the process. In fact they were not given much opportunity to develop their own skills for self reliance, as there is a lack of support from the families because they are neglected by the fathers of these children.

Society further puts more emphasis on perfection and we therefore keep our own imperfection hidden from our conscious awareness and project them on to those people who have been socially constituted as "damaged" (Watermeyer, 2000). By doing this, attention is diverted from our own imperfection. If we can perceive others to more imperfect or dependent than ourselves, and maintain this in the eyes of society, then we feel good about ourselves and so continue to "push down" our own anxiety and feelings of inadequacy. It can therefore be argued that fathers of disabled children treat these mothers and their children as "dustbin of disavowal" (Shakespeare, 1994). He maintains that Psycho-analysis captures this predicament of a dustbin into which we throw our unwanted feelings and hence disavowed characteristics. These characteristics then become culturally cemented to disabled people.

5.2 Coping Strategies

Mechanisms to tackle poverty through participation and redefining a disability identity will be discussed here.

5.2.1 Tackling poverty through participation

The participants in this study were chosen in order to gather data from the narration of their experiences, which was regarded as a powerful tool enabling them to break their social isolation, remove the stigma of disability and stop discrimination of the mothers as well as their intellectually disabled children. The stories of these women revealed that their confidence was restored after forming the parent support group at uMzamomhle Day Care Centre. The effect of the parent support group was that it provided these mothers with an opportunity to manage the transitions from the time they became aware of their children's impairments, up until they became involved in the parent support group, which gave them relief through sharing ideas. Parent support groups at uMzamomhle are now very well attended and have a stimulation effect which is encouraged as this assists the mothers to cope effectively with their children. These resources could be regarded as enabling factors because they help these mothers to manage their situation and to reach a state of equilibrium, to the benefit of both the mother and the child. The findings confirmed that the strength of training for the mothers to advocate for their children's rights was warranted.

The needs of other children can be regarded as a precipitating factor that causes these mothers to join a parent support group where they are empowered to start income generating projects. This action put them on a path towards self-actualisation. All the participants shared a common concern to succeed in caring for the intellectually disabled children and providing them with their basic needs, although they struggled under stressful situations to meet these needs. The income they obtained from selling proved to be insufficient for their needs as well as their families. The findings revealed that these mothers have little access to systems of social protection because they provide special

attention to their disabled children. Chances of getting better paid jobs are very limited for them as they are alone in rearing their disabled children. As mentioned earlier, fathers are absent during these ups and downs. Mothers revealed that the only source of income was disability grant and a care dependant grant they receive in respect of these children. This grant was found to be insufficient for the mothers' and their children's wellbeing as it does not meet their basic needs. Practitioners from Social Development need to address these mothers in respect to other social grants so that they could be assessed with a view to alleviating the pressures of poverty.

Kaplan (1999) maintains that there are many forms of poverty, economic poverty being one of these. Max Neef (1991) found that human poverties occurred if any one or more of the nine fundamental needs were not satisfied. His theory of Human Scale Development focuses on the understanding of people-centred development practice. The mothers in my study indicated that they had very limited opportunities for further education, employment and leisure because of their duties as caregivers. Parents of intellectually disabled children are recognized as a vulnerable group as they care for their children. Boylan (1991) supported this notion when considering the fact that mothers are unable to generate income as they are always responsible for caring for the disabled children. The term 'vulnerable people' was used to describe people who were disadvantaged because of poverty, were living in a high-risk environment, suffered from social bias and were parents caring for an intellectually disabled child. They were undermined and excluded within their own community (Office of the Deputy President, 1997). Most of these mothers were single parents and their husbands neglected them after having the disabled child. The perception was that their experience is that of internalised struggle and oppression that can result in various types of negative approaches to the situation. uMzamomhle Day Care Centre is perceived as an important satisfier of the mother's human needs for identity, creation and freedom and for the human needs of subsistence, understanding and participation as they accessed resources including jobs. These mothers also had some respite from caring thus meeting the human need for idleness or rest. They also felt a sense of belonging being affiliated to DICAG. The fact that these mothers initiated this centre of their own accord was very much appreciated. It also showed their

eagerness to participate in programmes addressing the hardships they experience as mothers of disabled children. Social workers need to pay visits such centres consistently with the purpose of conducting awareness campaigns to address these mothers on their rights as well as those of their children. That will enable them to be well informed about the importance of speaking out and reporting the failure of their husbands to maintain their children and access other opportunities.

Lorenzo (2003) reported findings from a participatory action research study focused on the development needs of women with disabilities in Khayelitsha, Cape Town. The analysis of the women's stories revealed their human needs for identity, affection and protection. The study further revealed that if disabled women could be assisted to become active, competent participants in their own development, they would overcome feelings of isolation and dependency. She also asserted that the identification and removal of barriers to the social integration and economic dependence of disabled women would have a positive influence on their families as well as the community they live in. This study found a similar case with the participants, as they were actively involved in vegetable gardens and awareness campaigns to educate their families and communities at large about disability.

In considering participation of individuals and communities in human development in South Africa, Taylor (2000) recognizes that the poor may not have the same capacity as active and informed citizens or organized formations, in decision-making at every level of society. It is in this context that the challenges for social action to change the attitudes and approaches to disability seem more daunting.

5.2.2 Redefining a disability identity

The social model of disability makes an important contribution to understanding disability. Disability is understood as a social and developmental issue rather than a medical one as it makes an important distinction between impairment and disability. Impairment refers to an individual's biological condition; while disability denotes the

collective economic, political, and cultural disadvantage encountered by people with impairment. The social model moves beyond personal limitations that impaired individuals may face, to social restrictions imposed by an unthinking society (Thomson, 1993). In this study one can regard that the exposure of these mothers to parent support groups and workshops provided by DICAG equipped them with the difference between impairment and disability and they are now regarding disability as a developmental issue. The findings revealed that mothers of intellectually disabled children recognised the value of programs organised by DICAG and social development. These programmes contributed to fostering their hope and development of self-confidence. Lagerdien (2000) also found that DICAG was appreciated as an agent of change evidenced by the involvement of the mothers of intellectually disabled children. The mother's contribution in a supporting role to promote the wellbeing of mothers and their children was recognised. The mothers revealed that they are no longer ashamed of themselves as being mothers of disabled children. They felt they are like other mothers who have able-bodied children.

Mothers of intellectually disabled children were found to be confused about the knowledge of impairment and disability. Oliver (1998) pointed out that the society is confused by medical and social approaches in understanding disability. He maintains that these approaches compete with each other. The participants were found to be nurturing their children in a society that devalues and medicalizes the lives of disabled people, but this also provides the backdrop for local activities of the disability rights movement. It is, therefore, important for the mothers of intellectually disabled children to understand their children and define disability in relation to these structural and societal barriers. They need to find their way among these competing models, and how they define their own children in relation to disability. Such redefining would also enable these mothers to know disability at length and the intervention programmes needed by disabled children. The programmes would enable the mothers to take care of their children, as identified in this study. They were involved with the stakeholders in the Day Care Centre in rendering different services required by disabled children.

All the women in the study had grown up believing that impairment was abnormal and the consequence of a woman's poor choice. In interaction with physicians, mothers of intellectually disabled children often encountered the medical model in the form of labelling the child. Giddens (1993) suggested that when a mother hears that her child is diagnosed with an intellectual disability she argues that her child has been mislabelled. They accused the doctor of giving a wrong story. This experience was the same in my study as one of the participants visited many traditional healers looking for a cure for her child and spent a lot of money. Other mothers experienced neglect by their husbands and became victims of poverty. The findings of this study revealed that these mothers were isolated, discriminated and stigmatised because of their disabled children. The opportunities of being exposed in support groups and mini workshops were regarded as a powerful tool in breaking the social isolation most women experienced subsequent to the disability of their disabled children, similar to Lorenzo's (2003) study of disabled women.

In the context of the mother's experiences, diversity could be used to deepen an understanding of disability amongst these mothers. Its main aim is to work towards an environment where people can be respected, accepted and comfortable with each other despite their differences (Whyte and Ingstad, 1998). Mothers of these children deserve to be treated in a fair way. More democratic opportunities for all need to be created, in order to normalise power relations by questioning the ways in which power operates by shifting focus to the provision of privileged, rather than looking at the position of disadvantaged and being outside the norm. The husbands of these mothers normalised the tendency of abusing their families, maintaining that they all have the power of staying away from caring for the children. Questioning the power relations, as I endeavoured to illustrate in the findings, could result in a deeper understanding of disability within these mothers. It would enable them to properly care for their children. There is no difference between the mother of a disabled child and non-disabled child. They only differ in terms of providing care to the child with a disability who needs different attention.

The above knowledge will assist professionals to deliver effective services to the mothers of disabled children so that they can make their children independent citizens of tomorrow. There is a great need for mothers of disabled children to join with professionals in formulating policy and to work towards its implementation. In agreement with Thomson (1993), the researcher suggests that other professionals should change their attitudes. Professionals in this field need to encourage these mothers to be involved in policy making so that the rights of their children can be considered.

5.3 Managing Disability Transitions

Bridges' (1991) conceptual model on transition processes focuses on making change in human organisations. Although the themes of this study were not deduced from Bridges conceptual model, the model helped to reveal how the themes were linked to each other. The following diagram illustrates the trends of managing disability transitions.

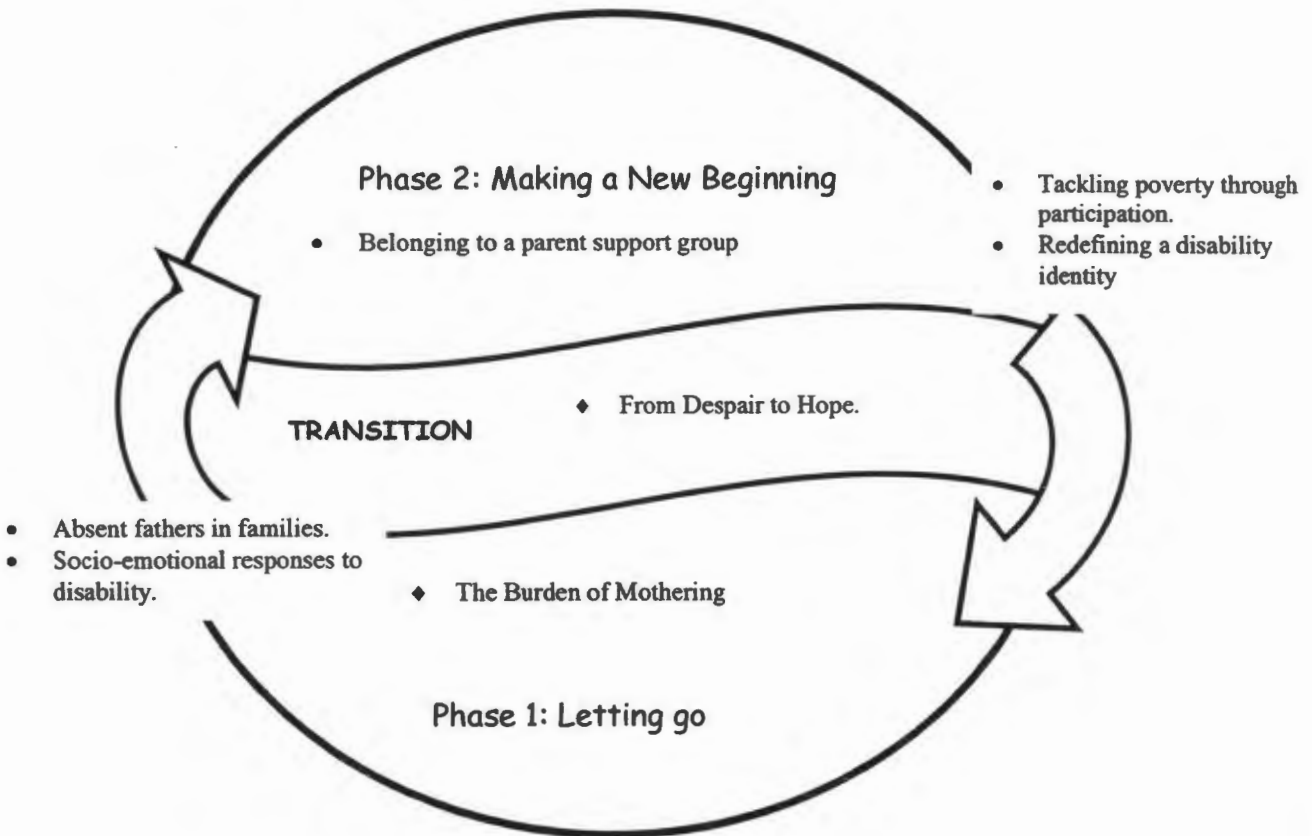


Figure 5.3: Managing disability transitions

The trend of these themes could be compared with transitions experienced when coping with a traumatic event within a specific context. The researcher found Bridges' approach to be relevant to this study, even though his organisational context was very different, as he managed transitions while working at California University.

Bridges (1991:56) defines "transition as the psychological processes people go through to come to terms with new situations". He maintains that the change is external and transition is internal. Unless transition occurs, change will not work. People have to re-orientate themselves psychologically if the situational difference is going to work. New arrangements must be understood if we are to be ready for the change. Transition depends on letting go of the old reality and identity you had before the change took place. Managing transition addresses the fact that people have to embrace new situations and carry out the corresponding change.

In managing transition, Bridges' (1991) model involves the simple process of helping people through two important phases, firstly, **letting go of the old ways** and old identity people had. This phase is an ending, and the time when you need to help people to deal with their losses. In my study this shows that these mothers acquired skills of handling their disabled children when they were exposed to the parent support groups and attended workshops provided by DICAG. The second phase involves coming out of the transition and **making a new beginning**. This change happens when people develop a new identity, experience new energy, and discover the new sense of purpose that makes the change begin to work. Because transition is a process in which people unplug from an old world and plug into a new world, we can say that transition starts with an ending and finishes with a beginning. This transition was the case in the mothers of disabled children who had to forget their old traumatic experiences from their relatives and communities and adjust to new changes of caring for their children. They also got support through the transition by joining a parent support group and tackling the poverty through participation in income generation projects (See Figure 5.1). Lorenzo (2003, 2005) found that disabled

women experienced inward changes, which then led to outward changes occurring as they engaged in advocacy and awareness campaigns. In her study, the disabled women were found to create a network of action spaces as a strategy to overcome the barriers to opportunities for socio-economic and political development.

CHAPTER 6: CONCLUSION

6.1 Conclusions of the Study

The experiences shared in this study point to the fact that mothers of intellectually disabled children have needs to be met such as moral support, financial maintenance from their husband and services from different stakeholders. The findings reflected that the mothers, as well as the children need to be protected from abuses within their families and their communities. This protection is essential for their self worth and healthy emotional development. Many of the stories in the study showed how important it was for mothers of intellectually disabled children to receive psycho-social support in relation to their everyday life experiences. Poverty has left these mothers feeling vulnerable and dependent as their sense of security and means of survival remains tenuous.

The mothers had managed to perform their caring roles through all the challenges they faced. They have carried the burden of raising their children with dignity and worth. This way of thinking is typical of African women in general as they see the challenge of caring for their children as nothing but God's command and society's expectation of them (Giddens, 1993). In South Africa, there are several policies as well as a number of mechanisms to challenge legislature, but the mothers in this study do not participate in policymaking decisions due to their level of education and inaccessibility of relevant resources. Although these mothers struggle to care for their children, they cope effectively although they lack the understanding of disability. Coping under poverty is very strenuous and this proves the dedication and perseverance which is needed for the caring of a disabled child. The role of the carer is seen to involve a multiplicity of skills, including handling the emotions of others and smoothing tension between family members.

Giddens, (1993) found that mothers of disabled children often experience social isolation as the informal support network activities available to non disabled children were not necessary available to disabled children. This experience is the same with the mothers at

uMzamomhle day care centre. Mothers from this centre came from low income families and joined parent support groups because they lived on limited budgets and therefore were not able to buy into practical sources of help and diversion for themselves and their children. The absence of fathers in the upbringing of disabled children was of particular concern as this worsened the poverty situation in the family and deepened the disempowerment linked to the mother's of disabled children.

The experience shared in this study show that mothers of intellectually disabled children have needs to be met. Services must meet these needs, for example, capacity building. Their children need to be protected from abuse within the family and the community. Also, they need protection from attitudinal discrimination within their homes and communities. This protection is essential in terms of self-worth and healthy emotional development. Most of the stories in this study show how important it is for mothers of intellectually disabled children to receive psycho-social support in relation to the daily discrimination they experience.

6.2 Limitations of the Study

The researcher was familiar with the participants and this may have influenced their responses – eliciting a response bias. She constantly reminded herself that she had to maintain an objective attitude all the time. She openly talked about her personal interest in the study with her supervisors.

Participants may have responded in a favourable manner on occasions so as not to represent themselves in a bad light to the researcher during the interviews. However, the researcher worked on establishing a trusting relationship in which they could respond freely. This trust was possible through prolonged engagement. During the interviews, she acknowledged what they said by responding in a non-judgemental manner, thus fostering a climate of trust.

Mothers related to the researcher's experience and vice-versa. Some of the comments made by the researcher may also be influenced by the researcher's personal experiences as a disabled person. Thus, the reflective journal was a means of ensuring that the mothers' voices were heard.

6.3 Recommendations

The research endeavour has several outcomes benefiting various stakeholders and role players in the fields of disability, social development, poverty relief, gender equality, and community development. For example:

1. Mothers of children with a disability were able to voice their opinions in a meaningful and non threatening way, which facilitated a process of change on an individual, family and community level. The learning gained from this process can be used to support further the development of parent support groups for mothers and their disabled children
2. Principles (as indicated in the benefits and values ascribed to being affiliated to a parent support group) can inform current practices of professionals, policy makers and DPO's (Disabled People Organisations). The incorporation of these principles into policy development and professional practice can support the further empowerment and capacity building of the mothers of disabled children.
3. For needs to be met, service providers in the Eastern Cape Province must be made aware of them through this study. The findings will help them to shape the services they provide to the intellectually disabled children and their families. The dissemination of the findings and recommendations of the study will influence the service providers to involve the rural communities, but especially the mothers of intellectually disabled children. This will be done through presentations of the research to the relevant stakeholders in the government departments of education, health and social welfare.
4. Family therapy and counselling needs to be organised to provide guidance and support on how to handle their disabled children.

6.4 Areas for further research

- The specific contributing factors that facilitate a process of empowerment within parent support groups, with a specific focus on an African perspective on empowerment in relation to the caring of disabled children in this study, should be examined.
- More details are required to explore what would sustain a parent support group in the long run in terms of resources required e.g. financial support, professionals, organisational and technical skills required.
- What a parent support group could offer fathers of disabled children and how it might alleviate the difficulties they experience in parenting a disabled child should be explored.
- Further research needs to be conducted to explore the differences amongst mothers in terms of mothering and womanhood. Single mothers of a disabled child are exposed to stigmatisation more than married mothers and the tendency is abandonment of their children with their families. At the same time, the married mothers are accused of caring about their heredity and as a result, neglecting the disabled child. These myths need to be explored and addressed for the betterment of the mothers of intellectually disabled children.
- Provision of education of disabled children also needs to be explored.

REFERENCES

- Bailey, K.D. (1982). *Methods of Social Research, (3rd ed.)*. London: Collier Macmillan.
- Barret, H.R (1997). Women, Occupational and health in Rural Africa: Adaptation to a changing socio-economic climate. *Journal Sciences*, 4(3), 1993-105.
- Boylan, E. (1991). *Women and Disability*. London: Zed Books Limited.
- Bridges, W. (1991). *Managing Transitions*. London: Addison-Wesley Publishing Company Incorporated.
- Chinn, P.C. (1979). *Mental Retardation: A life cycle approach, P.L (Ed)*. London: Sage Publications.
- Coleridge, P. (1993). *Disability, Liberation and Development*. Oxford: Oxfam Publications.
- Cornielje, H. (1999). *Towards a Public Health Approach*. Philadelphia: Open University Press.
- Cosslet, T. A. E. & P. Summerfield. (1996): *Women, Power and Resistance: An Introduction to Women's Studies*. Philadelphia: Open University Press.
- Creswell (1994). *Research design: Qualitative and Quantitative approaches*: Thousand Oaks: Sage.
- De Poy, E. & Gitlin, L.N. (1994). *Introduction to Research: Multi Strategies for health and Human Services*. MO: Mosbey.
- De Vos, A.S. (1998). *Research at Grassroots, for the social science and human services professions (2nd Ed)*. Pretoria: Van Schaik Publishers.
- DICAG (1998). *DICAG's Role in improving situation of children with disabilities in South Africa*. Background Document: Cape Town.
- DICAG (2000) *Parent Empowerment on the move. Together we can make it works*. Cape Town.
- Giddens A, (1993). *Sociology (2nd Edition)*. Oxford University.
- Harro, B. (2000). The cycle of socialization. In M. Adams, W. J. Bluemfeld, R. Casteneda, H.W. Hackman, M.L. Peters, & X. Zuniga, *Readings for Diversity and Social Justice*. New York: Routledge.

- Holloway, I. & Wheeler, S. (1996). *Qualitative research for Nurses*. Oxford: Blackwell Science.
- Kaplan, A. (1999). *NGLS Development Dossier: The development of capacity*. Geneva: UN Non - Governmental liaison Service.
- Krefting, L. (1991). Rigor in qualitative Research: the assessment of trustworthiness. *American Journal of Occupation Therapy*, 45 (3), pp. 214-222.
- Kruger S, (1995) *Focus group: a practical guide for applied research (3rd ed)*. Thousands Oaks: Sage
- Lagerdien, K. (2000). Exploring the meaning and experience of women with disabled children leaving in Ocean View and Masiphumelele. Unpublished Thesis for a Masters in Sciences in Occupational Therapy, Faculty of Health Sciences, University of Cape Town.
- Larson, E.A. (2000). The orchestrian of occupation: The dance of mothers. *American Journal of Occupation Therapy*, 54(3), pp. 269-280.
- Lincoln & Guba, E. (1985). *Naturalistic Enquiry*. London: Sage Applications.
- Lorenzo, T. (2003) No African Renaissance Without Disabled Women: A Communal Approach To Human Development in Cape Town South Africa. *Disability and Society* 18 No 6 October p.113-120.
- Lorenzo, T. (2005) 'We don't see ourselves as different': A Web of possibilities for disabled women. Unpublished PhD, Department of Public Health, University of Cape Town.
- Mark, D. (1999). *Disability: Contronsial Debates and Psycho-social perspective*. London: Route Ledge.
- Max-Neef, M. A. (1991). *Human scale development: conception, applications and further reflections*. London: The Ape Press.
- Mittler, P. (1985). *Working together: guidelines for collaboration between Professionals and Parents of children and young people with disabilities, guides for special education* No2 London: UNESCO.
- McConkey, R. & O'Toole, B. (1995). *Innovations in developing countries for people with disabilities*. England: Lisieux Publications.
- Morse, J.M. (1998). *Designing funded qualitative research in Strategies of qualitative inquiry*. San Francisco: Sage Publications.
- Moustakas, C. (1994). *Phenomenological Research Methods*. London: Sage Publications

- Office of the Deputy President. (1997). *White Paper on the Integrated National Disability Strategy*. RSA government Rustler Press: Western Cape.
- Oliver, M. and Barnes, C. (1998). *Disabled People and Social Policy*. London: Addison Wesley Longman Limited.
- Primeau, L.A. (2000). 'Household work: When Gender Ideologies and Practices Interact', *Journal of Occupational Science*, 7 (3), pp. 118-127.
- Ray, M.A. (2004). *The study of phenomenology: critical issues in Qualitative research methods*. Thousands Oak: Sage.
- Sarantakos, S. (2000). *Social Research*. Sydney: Macmillan.
- Shakespeare, T. (1994). Cultural Representation of Disabled People: Dust bin for disavowal. *Disability & Society* 9, 283-299.
- Smith, J.A., Harre, R. & Van Langehoven, L. (1995). *Rethinking methods in psychology*. London: Sage.
- Stone, E. (1999). *Disability and development*. Leeds: Disability Press.
- Social Development Department (2004). *Annual Report*. Eastern Cape Government.
- Thomson, P. (1993). *Course for concern: What directors of Social Services think about the Impact of the changes to the independent living fund*. London: Sage
- Turmusani, M. (2000). *The economic needs of disabled people in Jordan: from Personal to the political Perspective*. Jordan: Jordan Press.
- Tiroler, G. (1995). 'Learning about the links'. *CBR News*, 21, (99), pp. 4-5.
- Ward, E.J & Webster, L.M. (1993). *Working with parents of young children with disabilities*. San Diego: Singular Publishing Group Incorporated.
- Watermeyer, B. (2000). *Psychoanalysis & Disability: An exploration of the utility of psychoanalytic methods & analysis in the interrogation of Social responses to impairment*. Unpublished Masters in Art (Clinical psychology) Department of Psychology, University of Cape Town.
- Whyte, S.R. & Ingstad, B. (1998). 'Help from people with disabilities: do cultural differences matter?' *World Health Forum* 19, pp 42-6.
- Zuzanek, J. & Mannell, R (1993). Gender variations in the weekly rhythms of daily behaviour and experiences. *Journal of Occupational Science*, 1 (1), pp. 25-37.

APPENDIX 1

Flow Diagram 1: Interview guide for the first interview

INTRODUCTORY EXPLANATION



How would you describe yourself?
How do you see yourself?
If someone were to ask you – who are you ___ what would you say?



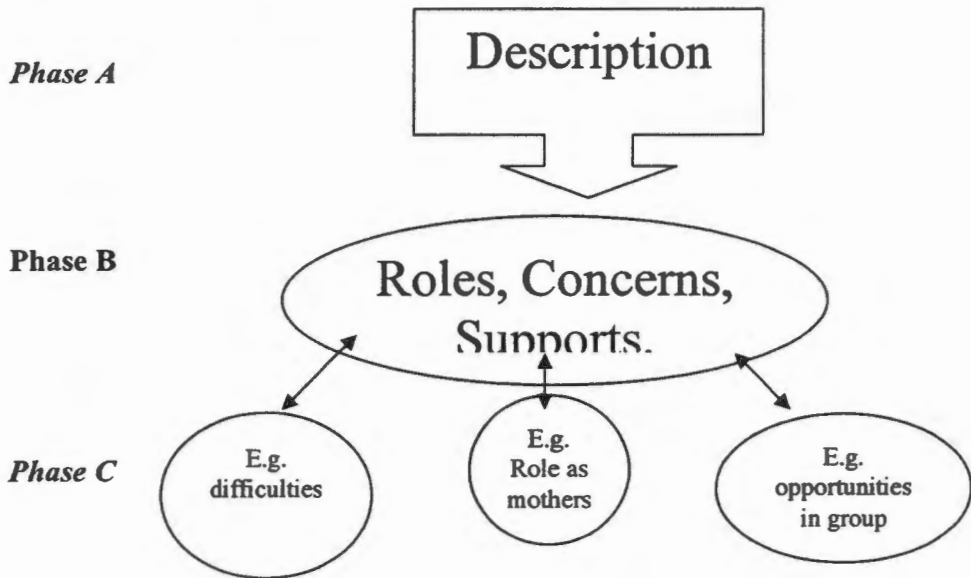
You have spoken quite a bit about your daughter/son who is disabled as you described yourself. Do you think that having a child with a disability influences the woman you are?



Tell me more about ___ (e.g. the parent support group)
What does that mean to you?
(All cues responded were guided by objectives.)

I conducted a second interview with six participants (from uMzamoMhle Day Care Centre). The format for the second set of interviews was based on the specific circumstances of the participant's narrative. Thus, the second set of interviews evolved from the first interview, enabling further member checking yet staying within the experiences of the mothers of disabled children. The questions for the second-phase interviews were related directly to the affiliation and involvement of the parent support groups. The questions posed were more participant-specific. I continued to use a flow chart diagram (refer to Diagram 2) as an interview guide, but included shorthand notes on specific issues that either were to be clarified or explained future.

Flow Diagram 2: Interview Guide for stage 2



The second interview began with a reflection and clarification of the content of the first interview (Phase A, diagram 2). This enabled member checking. Phase B and C (Diagram 2) prompted me to explore and gain more insight around their roles, concerns, supports, and opportunities for development and a perspective on the parent support groups. The format of the flow diagram was consistent for each interview, but the shorthand notes in Phase C (Diagram 2) were participant specific, for example exploring issues around group cohesion: are they a group? Why? What does being a group mean? What do they mean by Ubuntu?

APPENDIX 2

Interview Schedule

1. How do you think having a child with a disability has influenced the woman you are?
2. How do you cope with the responsibility of caring for a disabled child?
3. What effect has your disabled child had on your family?
4. What effect does your disabled child have on your family and community?
5. What challenges do you face in rearing a disabled child?

Imibuzo ecwangciselwe imfunalwazi

1. Ingaba ucinga ukuba nomntwana okhubazeke ngengqondo kuya kuchaphazela ukuba unexanduva lokuba nguMama?
2. Ulunyamezele njani uxanduva lokukhulisa lo mntwana?
3. Ubukho balo mntwana kuyichaphazela njani usapho lwakho?
4. Ingaba abahlali bachaphazeleke njani bubukho balo mntwana?
5. Mingeni mini ojongene nayo ekukhuliseni umntwana wakho okhubazekileyo?

APPENDIX 3

Consent Form

I, -----hereby agree to participate in this research study of my own free will. I am aware that all data will be kept confidential as no names will be mentioned in the transcription, analysis and publication of information. Participants are aware that all interviews will be tape recorded and transcribed. The researcher will not disclose the identity of the participants at any one stage of the research process. Participants are aware that the content of the interviews will be discussed during peer briefing and consultation with the researcher's supervisors. The researcher acknowledges that the participant is free to withdraw from the study at any point.

Consent confirmed by:

Participant:

Acknowledged by

Researcher: NOTHANDATHU M. GARA

APPENDIX 4

Verbal Consent Form

I, hereby agree to participate in a research study conducted by the University of Cape Town in M Phil in Disability Studies which will be carried out by Nothandathu Gara.

I agree to answer questions about various experiences of caring for an intellectually disabled child.

I am aware that I have the right to refuse to participate and can withdraw at anytime I feel the need.

Circle yes if you wish to participate in this study.

Yes

Circle no if you do not wish to participate in the study

No

Ifomu yokuzibophelela

Mna, _____
Ndiyavuma ukuthatha inxaxheba kule mfunalwazi ngokokuthanda kwam. Ndiyayazi ukuba lonke ulwazi ngam lukhuselekile kwaye akuzukusetye-nziswa magama abantu kuyo yonke into ebhaliweyo, xa kucazululwa naxa kubhalwa olulwazi. Abathatha inxaxhe-ba bayayazi ukuba iimpendulo ziza kurekhodishwa kwaye zimanyelwe ngumntu wangaphandle. Umntu owenza imfunalwazi akayi kuthetha ngamagama nagaliphi na iixesha ngesithuba salemfunalwazi. Abathatha inxaxheba bayayazi ulwazi kuzakuxoxwangalo xa kukho indibano nomtu ophethe abenza imfunalwazi.

Isigqibo sivunywe ngu: _____

Othatha inxaxheba

Yaziwa ngu: _____

Owenzisa imfunalwazi: Nothandathu M. GARA

APPENDIX 5

Information Sheet

Dear Mothers

I am Nothandathu Monica Gara, a student studying the M Phil in a Disability Studies programme at the University of Cape Town. I would like to conduct a research study with mothers of intellectually disabled children at Mzamomhle Day Care Centre. The purpose of the study is to gain an insight into the impact on mothers who care for their intellectually disabled children and to advance an understanding of this in relation to their ability to care for and train their children.

The main aim is to provide a detailed description of the impact that caring for a disabled child has on their mothers and how they cope with circumstances through the everyday things they do with and for their children.

You have been selected to participate in the study. Questions will be asked in Xhosa. Your name will not be used in any report. Consider so, what you say will remain confidential. The answers you give will not affect what happens at your centre in any way.

Should you feel uncomfortable with answering any question, you can tell the researcher or discontinue the interview.

You will not miss work. I will ask your manager when would be the best time to ensure this. The information provided will be used in a research report and maybe in a journal.

Thanking you in anticipation,

Signed

Nothandathu Monica Gara

APPENDIX 6

Definition of fundamental human needs

Identity	The need to feel that in yourself, that you are worth something, that you have something to offer
Affection	The sense that you are appreciated, accepted, loved the need to have close friends or people that you love and who love you.
Protection	The need to feel safe, secure; not scared that you are in danger.
Subsistence	The need for food, shelter, water-the things commonly referred to as basic needs, without which a person can die.
Understanding	The need to understand what is going on around you as well as the need to be understood by others.
Creation	The need to be creative, to make things, invent use your own ideas and imagination
Participation	The need to be part of what is happening, to belong to something, to take part in decisions that affect you: the need not to be isolated or ignored.
Idleness	The need to rest, reflect, relax, take time out, play, do nothing.
Freedom	The need to be free and not restricted: free to make your own choices and not have everything said and decided for you