

**EXPLORING THE MEANING AND EXPERIENCES OF WOMEN
WITH DISABLED CHILDREN LIVING IN OCEAN VIEW AND
MASIPHUMELELE**

**A DISSERTATION SUBMITTED IN PARTIAL FULFILLMENT OF
A MASTERS DEGREE IN OCCUPATIONAL THERAPY**

**At the
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A study conducted by

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ABSTRACT

This phenomenological study captures the experiences of women with disabled children living in Ocean View and Masiphumelele. Each community has a parent support group namely, Changing Outlook and Siyazama.

Aim: To explore the meaning of experiences of women who have disabled children, who are affiliated to a parent support group and who live within impoverished communities.

Methodology: Nine semi-structured interview were conducted. Interviews were tape-recorded, transcribed by an external source then analysed thematically.

Findings & Conclusion: The study yielded five themes. The parent support groups have been an opportunity and catalyst for the women's empowerment process through their increased hopefulness.

CHAPTER 1

1.1 Introduction

The current study explored the experiences of women with disabled children living in impoverished communities. The inspiration for this topic evolved out of a project, "Rehabilitation within the District Health System", initiated by Professor Ruth Watson in the Department of Occupational Therapy at the University of Cape Town (1999). This project focused on rehabilitation through occupational therapy; disability issues were closely associated with this topic. Health Systems Trust funded the Rehabilitation project, (Watson, 1999). The fieldwork was based in Ocean View and Masiphumelele, two peri-urban suburbs located in the South Peninsula District of Cape Town. Ocean View is a predominantly Coloured community with a population of 34 000 and an unemployment rate of 70%, whilst Masiphumelele, is a predominantly Black settlement has a population of 15-20 000 with an even higher unemployment rate. (Valley Development Project, annual report, 2000).

Watson's (1999) project took a "bottom-up" needs approach to address the occupational therapy rehabilitation needs of clients at a district or primary level. "Forum Theatre", (Baol, 1985) was used as means of raising disability awareness and identifying possible participants from the community (Eliason, 1998; Watson, 1999). The "forum theatre" productions enabled the researchers to make contact with parents and caregivers of disabled children and to invite their active engagement in the project. The initial group evolved into a support group for parents with disabled children. They were connected to the researchers (Professor Watson and myself) and to the Disabled Children's Action Group (DiCAG). DiCAG is a of the non- profit organisation that offers training and support to families and advocates for the rights of disabled children.

At the end of 2001 there were two parent support groups. I established the parent support groups in collaboration with a parent from each community and DiCAG co-ordinators. The parent support groups were developed with the aim

of rendering assistance to parents of disabled children. The Masiphumelele group was named Siyazama (We are trying) and the Ocean View group, Outlook. Thus, these groups and their associated activities created access to opportunities for parents from the two communities. In reality, the parent support groups were primarily comprised of women. Women are the key caregivers to children with disabilities in Ocean View and Masiphumelele. Mothers, sisters, aunts and grandmothers formed and continue to form the foundation of the parent support groups.

The Rehabilitation and Disability focus of the project continued in 2001 through 2002 due to increased enlistment of parents. The parent groups identified two main areas that they wished to pursue; inter-alia skills enhancement towards economic empowerment (for Siyazama) and the active raising of disability awareness (for Outlook) within their communities. Funding was awarded by the National Research Foundation to document this means of self-help amongst parents of disabled children. The study reported in this thesis was performed at the same time as the above mentioned research project. I focussed specifically on the experiences of individuals within parent support groups where as the main research project tracked the progress and activities of the entire parent support group.

1.2 Purpose

The purpose of this study was to record and gain insight into the lives of women with disabled children, both as a particular phenomenon and during the time that they were engaged in a process of personal development (as described above). The study explored the experiences of women with 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 required. This will facilitate understanding of what is valued and considered as being meaningful to them. The key feature that differentiates

the participants in this study from any other parent of a disabled child was their affiliation to a parent support group.

There is a paucity of research in South Africa that focuses on the plight of these "invisible victims" yet they, the parents/mothers, form the cornerstone and key to the development of children with a disability, (Boukhari in Abu-Habib, 1997). Exploring the mother's experiences is the empirical basis from which principles can be derived, which in turn, could inform policy and professional intervention with respect to factors that impede or support the development of these women.

1.3 Aim of the study:

The aim of this study is to explore the meaning of experiences of women who have disabled children, who are affiliated to a parent support group and who live within impoverished communities.

1.4 Objectives:

1. To ascertain what it means to be a woman and mother of a child with a disability in Ocean View and Masiphumelele.
2. To gain insight into the roles of women with disabled children.
3. To note the shifts and changes in meaning over time as expressed by the women.
4. To gain the women's perspective on the parent support groups and associated activities.
5. To explore, with the input of the women, factors which hinder and support their personal development and growth in and outside the support group.

1.5 Literature review

The role of women in society and the influences of gender and religion is explored in relation to identity. Furthermore, the gender identities of women with disabled children who are challenged by impoverished circumstances are discussed. Lastly, the value of self-help and support groups as a means of community development is highlighted along with the process of empowerment and transition.

The role of women

The literature on the different roles of women indicates that women are “gendered” into certain roles, of which mothering is but one, (Lawler in Cosslett, Easten and Summerfield, 1996). Before exploring the impact of having a disabled child, one needs to understand the role that gender plays in women and mothers.

Gender ideology refers to the perception of womanhood, manhood and marital status. Traditional ideology sees the woman as having less power in the relationship with her main identity based within the household; whilst the man assumes his main identity within paid employment, (Dalley, Bowlby, 1953 and Leach, 1979 in Beattie et al, 1993,). The egalitarian couple share power and responsibility within household tasks and 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) than on the household (private sphere).

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 the couples based on their gender ideologies and resultant gender practices. Gender struggles, noted as inequalities, arose when the different partners had different gender ideologies and thus displayed divergent gender practices. Household duties and family obligations have been found to magnify gender inequalities as women tended

to have more household tasks compared to men, a factor which compounded the gender struggles experienced by women. (Zuzanek and Mannell, 1993). These gender struggles are influenced by one's gender identity. This gender identity is then socially constructed according to the society in which one lives, (McWhannell and Blair in Jones, 1998).

Zuzanek et al (1993) illustrated the influence of gender identity on occupational engagement. The occupations that women and men choose to engage in are influenced by their gender ideologies. However, this is not the only determinant. 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.

The Role of Religion in Gendering Women as Mothers

Child rearing has been described in relation to maternal identity in Biblical text and Christian art, (Rogers in Beattie et al, 1993). Religion is said to play a key role in influencing the gender identity of people, (Rogers in Beattie et al, 1993, Sawyer in 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 Sawyer (cited in Cosslett, et al, 1996) an egalitarian model cannot prosper in a society that is patriarchal.

Motherhood

Feminists, such as Rich (in Lawler in Cosslett et al, 1996) differentiate between motherhood as an 'experience', versus motherhood as an 'institution'. Motherhood as an experience refers to the meanings attached to being a mother, whilst motherhood as an institution is socially constructed. According to Rich (Ibid) motherhood as an experience appears to have been overtaken by motherhood as an institution. The male dominated social organization

view the innate ability to nurture children and elderly dependants unconditionally and unselfishly as 'natural' process for women, and therefore not work. This institutionalization of motherhood is viewed as oppressive since the nurturing aspect is not valued as work but a "labour of love", (Lawler in Cosslett et al, 1996).

Caring for children, a person with a disability, the sick and the elderly appears to be the role of women primarily. Research has also been conducted on understanding the meaning of occupations that men and women are engaged in, (Zuzanek and Mannell, 1993; Larson, 2000 and Primeau, 2000). One such study by Larson (2000) focused on women with children who have special needs. Larson (2000) describes how mothers, through a process of orchestration, reflect on their past whilst engaging in the present, and planning future occupations for themselves and their families. This careful orchestration was aimed at producing child-sensitive, contingent occupations that are, 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, the women living in impoverished communities fulfill their roles as caregivers and are expected to care for the frail, sick and disabled. This is clearly the continuation of the institution of motherhood. The care-giving role stems from societal expectations as well as from the demands of their immediate context, (Thompson, 1993 in Primeau, 2000). The immediate context of African women living in poverty is that of sustaining their households by ensuring that both they and their families survive, (Boylan, 1991).

Poverty and Disability

Literature examining the relationship between poverty and disability indicate that difficulties experienced when providing care for disabled children are exacerbated by poverty. Being disabled is costly and can place a strain on the family, (McConkey and O'Toole, 1995; Tiroler, 1995 and Oliver and Barnes, 1998). The budget strain and time spent caring for or nursing a

disabled individual ultimately leads to some sort of neglect of the needs of other non-disabled members of a poor family. In cases where the role of the main caregiver has been imposed on women, generating much needed additional income in impoverished communities is difficult, (Boylan, 1991). African rural women are said to have triple roles: mothers, social producers and economic producers, (Barrett, 1997). These triple tasks are physically demanding and time consuming which, in turn, impact on their health status.

One of the core principles of the United Nation's policy on social development of communities includes the promotion of systems of social protection, (wbln0018.worldbank.org). The success of promotion of such 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. In developmentally impoverished communities, mothers of disabled children have little access to the systems of social protection as described above.

Cornielje (1999) and Khan (1998) suggest that a public health approach in dealing with disability be adopted. This approach recognizes that health, disability and poverty are interrelated; factors which affect not only disabled people, but their families as well. The emphasis of interventions is thus placed on treating the family unit as a whole, not only the disabled person. In so doing research focussing on understanding mothers with disabled children is pertinent as it is they who are directly involved in the child's development.

Darbyshire (1995) describes the paradigm shift of Appleton and Mincham's expert model to the consumer rights and social system network model of parent partnerships. The latter models have an emphasis on empowerment whereby health and social professionals are no longer key experts, but where they enter the relationship as a facilitator. The role as facilitator is more concerned with enhancing parent involvement, participation and empowerment by working with and understanding where parents are coming from. These concepts are supported by the work of Ward and Webster, (1993). This shift entails a partnership in which both parties are equally

involved. Gaining insight into the life of the parents is thus important. Research indicates that there is a growing trend on the part of health and social professionals to build partnerships, not only with people with disabilities, but their families and caregivers as well, (Cornielje, 1999; Khan, 1998; McConkey and O'Toole, 1995; Tiroler, 1995).

The Power of Self-help

Self-help groups aim to provide support and educational information to members who share a common life problem. The purpose of self-help groups is to facilitate personal and or societal change, (Wilson, 1986; Adomson in Townsend, 1996; Kurtz, 1997; Gidron et al and Checkoway et al in Powell, 1998. Professionals in their capacity as consultants have traditionally facilitated support groups, as opposed to self-help groups, (Wilson, 1986). Membership for either group is voluntary. Self-help and support groups usually form part of a bigger formal organization, (Checkoway et al in Powell, 1998 and Wilson, 1986).

Self-help and Empowerment

Empowerment is a critical factor in self-help groups, (Gidron et al, 1998). Gidron et al (1998) defined empowerment as a process through which a person gains strength or mastery, thus enabling the person to engage in activities that were previously deemed unattainable. Feminists describe the empowerment approach as the ability to increase the capacity of women so that they are able to "improve their own strength and self-reliance through bottom-up mobilisation around practical gender needs", (Moser in Hedman et al, 1996, 15). Both definitions illustrate empowerment as the ability in people to bring about change and regain control over their lives by the choices they make in what they do. Empowerment occurs when people are able to portray mutual respect, ensure hope and build trust in themselves and others, (Adomson et al, 1990 in Townsend, 1996). Further more Nelson and Wright (1997, 137), describe empowerment as "an individual's right to choose the services that will best suit their particular circumstances".

Rissell (1994) takes it a step further and differentiates between levels of empowerment; namely, psychological empowerment and community empowerment. The psychological empowerment is more at an individual level and the community empowerment at a socio-political level. Psychological empowerment focuses strongly on personal development by enhancing self-esteem and self-efficacy (Bandura, 1982 in Rissell, 1994).

The transition process model (Bridges, 1991) describes an individual's change process as a result of a traumatic event. It is sub-divided into eight stages. The stages are as follows: routine, change event, decline, letting go, confusion/creativity, illumination/vision, renewal and new routine. Each stage is weighted against a level of productivity or mood. The stages are not linear. The process indicated in this model is dynamic, thus one may re-enter a stage and emerge at a higher or lower level of productivity. The transition process model depicts how a traumatic change or event alters one's usual routine and leads to a decline in mood and productivity. After stage three and four (decline and letting go), stage five follows which is a state of confusion, of going back and forth up and down. Creativity can emerge out of the confusion (stage five) as well. As the individual looks at better ways of coping, there appears to be an illumination and development of a vision of the future (stage six). This enlightenment or sense of renewal (stage 7) involves the adaptation of routines and old behaviours. At the stage of renewal, there is an increased level of independence with a new sense of self and is considered to be a good time for projects and teams, the start of new routines (stage eight).

Self-help for Parents of Disabled Children in South Africa

The changing political climate in South Africa has given rise to civil movements in the disability sector. Disabled People Organisations such as DPSA (Disabled People South Africa) and DiCAG (Disabled Children's Action Group) have been actively involved in the disability movement in South Africa. The establishment of the Office on the Status of Women and an Office on the Status of Disabled Persons as well as a National Plan of Action for Children is

evidence of the government's commitment to address the many injustices that women, children and people with a disability endure.

DiCAG is a national self-help group with a very strong advocacy component. It comprised mainly of parents with disabled children in South Africa. DiCAG's role as an organization is focused on promoting equal opportunities for children with disabilities and empowering their parents in the process. The right to self-representation of parents through the organization is one of the core principles of DiCAG. The word parent (in parent support groups) eludes one to think that men as fathers, caregiver or guardians are equally involved. However women as mothers and caregivers are the main driving force in the establishment and running of parent support groups. Boylan (1991) makes mention of the value of parent groups, particularly of mothers publicly expressing the need for additional resources (financial, community support, skills) in order to improve the rehabilitation of disabled children.

A recent study conducted by Meyer, et al (2000), in South Africa focussed on identifying the needs of mothers of disabled children so that "something can be done for them" by professionals, (ibid, page 7). This study aimed to explore the participants' aspirations, hopes and dreams and to identify injustices, discrimination and experiences of the participants as women and not only as mothers. The World Bank undertook a research project to understand the experiences of people living in poverty (<http://www.worldbank.org/povert/data/trends.index.h>, 13/05/00 at 20.10).

Thousands of poor people across the world were given an opportunity to share their experiences and needs within their poverty stricken circumstances. The outcome of the World Bank study was heightened insight into the lives of poor people. Similarly, the current study endeavoured to listen to women who have disabled children and live in poverty.

CHAPTER 2

2.1 Method of Inquiry

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 researcher then analyses the data inductively and “describes a process that is expressive and persuasive in language”, (Creswell, 1998, 14).

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. Few research studies have been conducted in South Africa that describes what the experiences of women with disabled children who are affiliated to support groups and live in impoverished communities is. Meyer et al (2000) as cited previously is one that explores issues pertaining to women with disabled children living in a South African context.

2.2 Study design

2.2.1 Why phenomenology

The study design is based on phenomenology. A phenomenological approach enables the researcher to view the person within their context and experiential time. Phenomonologists believe that people direct and shape the events that affect them in order to bring meaning to the multiple realities in their lives, (Becker, 1992). In phenomenology, the researcher attempts to illustrate the multiple realities that people hold about a particular phenomenon (Moustakas, 1994). The phenomenon in this study is the experiences of women with disabled children living in Ocean View and Masiphumelele who are affiliated to a parent support group.

2.2.2 My Research Journey

As a field researcher, I met and worked with the women from the parent support groups of both Ocean View and Masiphumelele in 2000 as part of the Rehabilitation Project funded by Health Systems Trust (refer to Introduction for more detail). I was appointed as the key field researcher in February 2000. I worked in partnership with civil society and service providers. The community and service providers of the area helped me identify the focus area and sample, as children with disabilities and their parents and caregivers or guardians. As mentioned previously (page 4), the forum theatre productions enabled the target group (parents and caregivers of disabled children) to engage in the research project through sharing their concerns and problems. I worked alongside a few parents who came forward after the plays, and together with them started up a parent support group in Ocean View and Masiphumelele. I went on home visits with a parent (Anne from Ocean View and Hannah in Masiphumelele) visiting other parents and caregivers explaining what the purpose of starting a parent support group was all about. DiCAG was also instrumental in facilitating the formation of the parent groups. All I needed to do with the existing parents was to find ten to fifteen 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 September 2000, I was privileged to attend their first mobilisation workshops with the DiCAG field co-coordinators. The mobilisation workshops were held to provide parents with information regarding DiCAG and inform parents of their rights and their children's. 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 women (at least 12-15 parents and caregivers from each community) were so free and willing to relate their stories at the workshops and on the home visits. This inspired me. It made me realize that the essence of the lives of these women was in the

meaning they attributed to their experiences. Phenomenology thus seemed to be the best methodology to further explore these meanings.

The fact that these women 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 each community and was involved in the parent support group meetings for the first six months as well as disability awareness activities. The plays became part of the parent support group awareness strategies in their communities and enabled them to recruit more parents. By the end of 2000, Professor Watson and I realised that the parent support group activities had become such a focal point in the study that it warranted separate funding. In 2001, my workload had trebled, as I was involved in the rehabilitation project and parent support group activities, which had grown into a project on its own. When funding came through from the National Research Foundation in 2001 we decided to appoint a second research assistant who would focus on the parent support group activities. I was keen to continue my masters dissertation on the experiences of these women who were affiliated to one of these parent support groups. The Principle Investigator (P.I.) and I agreed that a second researcher would focus on the group activities. My involvement would be limited to focusing on the individual experiences of at least four of the women all of whom I was familiar with.

2.2.3 My Identity as a Researcher

I am an occupational therapist and became involved in research through the Rehabilitation project, (Watson, 1999). I was stationed at the Learners with Special Education Needs School in Ocean View where I also came across parents and caregivers. In Ocean View, I was familiar with the dialect, religious and cultural nuances of the community and this enabled me to access the community easily. The fact that I am a Muslim woman and Coloured enabled me to be aware of some of the community entry principles. For example, it is rude to be visiting a Muslim family you do not know over a prayer time. In Masiphumelele I was not familiar with the language (Xhosa) and all the cultural and religious norms. Here I depended a lot on my Xhosa speaking colleagues (such as the social worker and community health

workers) that worked in the community and on parents who I had met through the plays. My journaling proved to be most beneficial in this regard as a bracketing tool since I could document what I saw, heard, thought and felt.

2.2.4 Observation

Observation proved to be most helpful to confirm the findings and often highlighted contradictions, or yielded new revelations. I attended various activities organized by the parent support groups in my capacity as an observer. These activities included, plays that were conducted by parents at schools and in the community to raise disability awareness, portfolio training run by DiCAG for the parent support groups, a DiCAG conference and a fund raising event by the Ocean View Parent Support Group. I worked in the community of Ocean View and Masiphumelele as a researcher (Health Systems Trust Project – Occupational Therapy Rehabilitation at a district level) from 2000. This enabled me to observe the women in their natural contexts before and after the interviews. Observation as a source of data collection added to the “thickness” of the context descriptions as well as insight into the lives of the participants. It also provided as a means of identifying and bracketing out and making biases explicit.

2.2.5 Researcher's Journal

The journal entries were used as a means of bracketing, (Holloway and Wheeler, 1996). Bracketing develops the rigour of the research study and enables the researcher to explore his or her assumptions and perceptions on 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 the observations (2.2.3) 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, or 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 Anne 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 in her, is it the life long learner in her?"

The reflection in and on action (Schon, 1991) in my journal helped me to unravel my own perceptions of the issues at hand, such as motherhood, womanhood, disability and poverty. An example of this was an entry documenting my thoughts and perceptions after the first set of interviews of the gendering of women in Ocean View and Masiphumelele. In this entry I began to reflect on the biases I may have had on the influence of religion and the role of the church in the lives of these women and me. A journal extract from this includes; *"Religion plays an important role in gendering these women...certain expectations of what women should do and why, how women should behave and dress ... I think these expectations stem from culture, religion and politics. What influences my thinking here?"*

2.2.6 The Interviews

My prolonged relationship with the women in the sample, did not guarantee that they could share the essence of their stories with me. Even though all the women cared for disabled children and appeared to have similar experiences, their stories were unique.

Initially, I considered conducting free attitude interviews, but soon realized that this required a level of sophistication and expertise as an interviewer. Likewise, the interviewee needed to be intellectually and emotionally insightful. Language was also an important barrier that could stifle a free attitude interview for Xhosa-speaking participants. I opted for in-depth semi-structured interviews as this provided me with the opportunity to work within a framework and still promote the opportunity for individuality to prevail with each participant.

2.2.7 Use of an interpreter

I chose an interpreter from Masiphumelele who was fluent in English and Xhosa. The interpreter was not familiar with the participants but had lived in Masiphumelele all her life. I met with the interpreter before the interviews and explained to her what the purpose of the study was and established her willingness to assisting me. Issues pertaining to confidentiality were discussed with the interpreter and once she agreed to partake consent form was signed stipulating our agreement, (refer to appendix 6). Before each interview, I reminded the interpreter of the procedure we would follow and reiterated that she had to translate directly and not convey her own meanings of what she heard. During the interviews, I sat opposite the interpreter beside the participant and posed the question directly at the participant. The interpreter then translated the question to the participant. The participant responded in Xhosa and the interpreter would then translate back to me. The duration of the interviews per participants varied between one and half to two

2.3 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 stability and community-based rehabilitation. The Integrated National Disability Strategy is clear proof of the government's commitment to the equalization of opportunities and the redressing of social injustices towards people with disabilities and their affiliates, (RSA Government, 1997). Given the legacy of apartheid, this qualitative research is aimed at specifically exploring the experiences of Black women with disabled children, who are living in poverty. 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.

2.4 The Participants

2.4.1 Participant selection: The study population comprised of women with disabled children who had affiliated themselves with the parent support groups in Ocean View and Masiphumelele. The sample was homogenous as

all the women have disabled children and was members of a parent support group. The parent groups were approached and asked if members would be interested in participating in this research study. Once potential participants stepped forward, the researcher met individually with them to ensure that they met the research criteria. (Refer to Table 1 for more demographic details.) I also discussed issues pertaining to confidentiality and clarified any concerns or questions they may have had at the time.

2.4.2 Criteria for participant selection:

- ◆ Participants had to be the biological mother of a child with a disability and affiliated to a parent support group (in Ocean View or Masiphumelele).
- ◆ Participants had to be residents of either Ocean View or Masiphumelele.
- ◆ Participants needed to be willing and available to share their experiences.
- ◆ Four participants had to be conversant in English and or Afrikaans and that are willing to relate their stories were selected from Ocean View and Masiphumelele parent support groups.

In Masiphumelele, the two participants who met the criteria were quite willing to share the experiences, but preferred to speak in their mother tongue, Xhosa. The participants were aware of the language barrier and agreed to have an interpreter present. (An interpreter from the community of Masiphumelele was used to assist during the interviews with participants who were more conversant in Xhosa.)

Table 1. Demographic profile of the Participants

Participant/Mother	Anne	Safia	Joy	Hannah	Makhazi
Community	Ocean View	Ocean View	Ocean View	Masiphumelele	Masiphumelele
Age	31yrs	37yrs	34yrs	36 yrs	64 yrs
Languages spoken	English/ Afrikaans	English/ Afrikaans	English/ Afrikaans	Xhosa/ Afrikaans	Xhosa/ Afrikaans
Religion	Christianity	Islam	Christianity	Christianity	Christianity
Marital Status	Married, previously divorced	Divorced	Unmarried and living with Partner	Married	Widow
Employment Status	Unemployed/ Part-time Nurse Aid	Part-time Teacher Aid	Part-time Domestic Worker	Unemployed Informal Worker	Unemployed
Child's impairment	Epilepsy	Learning Disorder	Cerebral Palsy Visually and hearing impaired	Cerebral Palsy	Behavioural Disorder
Age of child	9 years	12 years	9years	6 years	26 yrs
Gender	Male	Female	Female	Female	Male
Family members in household	Husband, Son (16 years), Daughters (21years, 8 years)	Sons (13 and 4 years), Daughters (11 and 8 years)	Grandmother, Sons (21 years, 14 years, 11 years), sister with niece (3years)	Husband, Daughter (4 years)	Son (26yrs)
Level of Education of Mother	Standard 6	Standard 5	Standard six	Standard 4	No formal education

The demographic profile indicates that most of the participants (except for one born in 1936) were born between the 1950's and 1960's, a time when apartheid reigned supreme. Black women, in general, were mostly disadvantaged, more so the women who lived in rural areas before relocating to Cape Town. Education was an area in which they were deprived due to the oppressive system they were born into. The 70's and 80's were turbulent times for our country, characterising major uprisings by Black youth. These were the decades in which four participants received their formal education.

2.4.3 Gaining access

Given that the study took place within the context of the research already explained, and that the researcher had previously established her bone fides with the participants and in the community, no additional measures other than ethical considerations were needed. In Ocean View, three mothers were prepared to participate. All three women met the research criteria. To ensure fairness within the selection process, the researcher approached the women from Ocean View and asked if anyone was prepared to act as participant in the trial interview. The purpose of the trial interview was to determine whether the research questions could be easily understood and interpreted by the participant. The participant who agreed to the trial interview was aware of the conditions and was prepared to participate in only the one interview. The trial interview was information rich and for this reason was incorporated into the analysis and findings.

Finding participants was not problematic. When I approached the parent support groups to request help, three women from each group volunteered. In Ocean View, one out of the three was willing to be part of the trial interview only. In Masiphumelele, I had three women who volunteered. My choice of two was based on the availability of the candidates. The third woman declined voluntarily and offered the opportunity to the other two women with no regret. All participants signed a consent form on the day of their first interview (refer to Appendix 2-4).

2.5 Data Collection

2.5.1 The Interview Process

A series of two semi-structured interviews per participant was conducted over 3-4 months, (refer to Appendix 5 for a detailed account). I used a semi-structured format for the interviews based on key topics and questions that needed to be explored, (Mason, 1996). 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. 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 explore 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 except for one participant in Masiphumelele who had no electricity. The interview was thus conducted at her sister's home since we needed electricity for the tape recorder. The procedure for the interviews in Masiphumelele and Ocean View 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 enabled me to gain insight into the participants' view of themselves. Based on their narratives, I was able to further explore specific areas relating to the research objectives as outlined above in Chapter One.

I produced a flow diagram as an interview guide for each interview. The key questions were linked to the aim of the study and the objectives. I responded to the participant's cues during each interview. This response was guided by the objectives of the study. This enabled the participants to elaborate on key issues, which provided me with more information. Refer to the flow diagram 1 for an outline of the first interview guide.

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 is ____ what would you say?



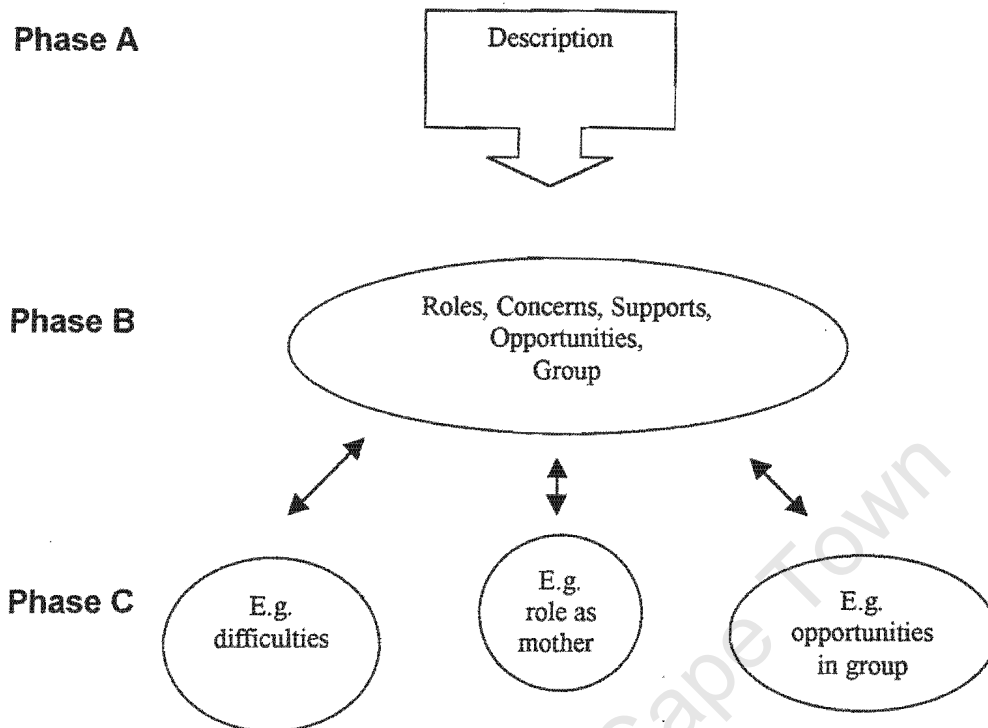
You've spoken quite a bit about your daughter/son who is disabled as you described who you are. Do you think that having a child with a disability influences the women you are?



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

I conducted a second interview with four of the participants (two from Ocean View and two from Masiphumelele). 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 woman. The questions for the second-phase interviews were directly related 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 be clarified or elaborated on.

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. The Phase B and C (Diagram 2) prompted me to explore and gain more insight around their roles, concerns, supports, and opportunities for development, and perspective on the parent support groups. The format of the flow diagram was consistent for each interview but the short-hand 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?

2.6 Ensuring rigor

Guba and Lincoln (1985) make a case for four alternative ways to undertake the evaluation of qualitative data. These are credibility, transferability,

dependability and confirmability. They provide the foundation for demonstrating both trustworthiness and a decision trail.

Measures of Credibility

I had the opportunity of prolonged engagement with the participants as I worked in the community of Ocean View and Masiphumelele as a researcher. As a result, I had observed the participants within their context ever since 2000.

The involvement of a second research assistant was valuable. The second researcher thus acted as the group's full-time facilitator and engaged directly with the group in terms of their activities. This enabled me to distance myself from the parent support groups yet remain as an observer. I remained stationed in the community for the duration of the research. My key contribution to the main project (refer to page 5) was to conduct the interviews with the participants. I was also granted permission to act as an observer during certain events. The prolonged engagement, different methods of data collection and peer evaluation (discussions with the second researcher and the P.I.) all helped to increase triangulation.

Conducting a second interview (three to four months after the first interview) and member checking enabled me to verify the data. The member checking entailed clarifying with each participant at the start of the second interview any issues that had to be clarified from the first interview. 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 and the fact that I could conduct a follow-up interview and rephrase questions.

Adequacy and saturation are criteria that ensures rigor in qualitative research. It refers to the amount and richness of data captured, (Morse, 1998). Ample data needs to be collected to allow for variation to be accounted for and understood. The transcripts were on average of 12-13 pages per interview. 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 it provided detailed accounts of events that describe the experiences of these women 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.

Measures of Confirmability

Interviews were transcribed and typed by an outside source. The transcriber was made aware of the confidentiality issues and agreed to sign a consent form to abide within the ethical considerations (refer to appendix 7). Interviews conducted in Masiphumelele were transcribed and translated directly into English. Any misinterpretations were noted in brackets by the transcriber and then verified by the respective participant's and the interpreter. Once the transcriptions were complete, I cross checked the information against the audio-cassettes and 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 ensure that the data was

captured correctly. The data was then analysed with the aid of the NVIVO Software Package.

I briefed the interpreter before the interviews and reflected with her after each interview so as to clarify issues and ascertain her perceptions. This helped me note any biases that the interpreter may have had.

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 attended several peer-briefing sessions with colleagues conducting research in similar fields of interest at the School of Health Sciences and Rehabilitation of the University of Cape Town. These meetings enabled me to present aspects of my work and ensure a level of objectivity through feedback from them. The peer-briefing sessions occurred during the protocol, data collection and data analysis stages. There were six sessions all together. During the data analysis phase, the feedback was specific to my method of coding and evolution of categories and themes.

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 (Ocean View and Masiphumelele) 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

Measures of Dependability

Dependability (Cresswell, 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.

Triangulation was ensured through peer-briefing, member checking and participant observation. Theoretical triangulation was also made possible through reviewing relevant literature, (Cresswell, 1998, Holloway et al, 1996).

Measures of Transferability

Audit trail is carefully documented in the methodology section of this report which captures critical decisions made. Transferability was further ensured through thick description.

2.7 Analysis

Analysis of findings occurred in two stages. In the first stage of analysis, the transcribed interviews were open coded with the aid of the Nudist Vivo (NVIVO) Software Package. The aim and objectives of the study formed the framework for the analysis and interpretation of the data. Furthermore, the interview guide was framed within the overall aim and objectives of the study. Information that emerged linked to the objectives.

The codes were grouped into sub-categories, which in turn were linked to categories and from these categories the 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.

Stage two of the analysis involved looking at the data pertaining to each participant within and across each theme. This enabled me to locate each woman within each theme. At this stage I revisited the literature to look at what parallels could be drawn with previously cited work. Bridges (1991)

conceptual model on transition process matched well with the themes of this study and how the themes were linked to each other. These themes were not pre-determined by Bridges (1991) conceptual model. However, the trend of these themes could be compared with the transition experienced when coping with a traumatic event within a specific context as in Bridges (1991) model. The model depicted in Diagram 3, page 85 illustrates the link between the themes.

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CHAPTER 3

Results

The themes describing the experiences of each of the participants are captured in tabular form, refer to Tables 2, 3, 4, 5, 6. Each theme is sub-divided into categories and sub-categories. The essence of each of the themes, as well as the sub-categories, is substantiated with supporting quotes. All quotes have been placed in **bold** font and translations to English (from Afrikaans) are in *italics*. The themes and categories flow systematically. Sub-categories are linked to categories in order of appearance (in the tables) and discussed in this manner. Sub-headings are used to indicate categories.

3.1 Theme 1: Creating a Life Puzzle

The puzzle refers to the women's understanding of what constitutes the meaning of being a woman. Configuring this identity as a woman is an ongoing process, which is informed by the their values and beliefs and challenged by the living environment.

Table 2: Thematic Representation of Theme 1

THEMES	CATEGORIES	SUB-CATERGORIES
1. Creating a life puzzle	Values and beliefs	• I believe • Valuing family support • Taking good care • My privacy • Faith in God
	Interplay between the woman and her environment	• Familial and cultural expectations of a

		woman • Earning a living
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Safia uses the term “puzzle” metaphorically in her narrative. Here she describes how she makes sense of her life by seeing the puzzle as a symbol.

Safia: “Dis soos ’n puzzle, en al die pieces lê so rond en jy moet probeer om die pieces by mekaar te sit, en as jy klaar is, dan sien jy die ‘picture’ en hoe dit moet lyk. En jy moet alleen sikkêl. As jy nie weet hoe moet die picture lyk nie, moet jy jou kop gebruik om die picture uit te figure.

“As time went on, I took my time to put the pieces together, in other words, I didn’t rush it, I took my time and now the puzzle is nicely in place. So like I said about the puzzle, especially where he is concerned, it must now first fall into place, and when the puzzle is complete, then we can see what is what.”

Values & Beliefs

This category describes what the women value and believes in. It includes elements of their perception of motherhood and womanhood as well as their religious views, all of which gave them the power to take charge of their lives.

Anne believed that she needed to take charge of her life and not allow her problems to control her. She had an internal locus of control when reflecting on her life experience with her children and husband. On the other hand, Anne acknowledged how the environment shaped the lives of her children. She was therefore adamant that she would remain positive and be a role model for her children:-

Anne: “I would just then describe myself as simple and down-to-earth and not allow problems to like, sort of get me down and interfere with who I am. Due to Nathaniel’s illness, I think that made me more careful in life of forgetting about the children and seeing to my own needs. I said “Yes, you’ve got to be a positive person, in what we are busy doing.” If you are not positive, you are not going to achieve anything

and because you've got to be positive...And therefore positive parents make for positive kids."

Safia also appeared to have that internal locus of control but admitted that the environmental press complicated matters:-

Safia: "But I don't care what impression people have of me, as long as I know the truth and what is really going on. Now what I've experienced is that you are put on this earth for a reason, and sometimes that reason is clear to you but then you get people who will try and manipulate you or try conk up some lies."

Joy related the temporal nature of having a severely disabled child as well as trying to make a difference by providing support and encouragement to other parents within the group. This indicates that Joy's own value and beliefs enabled her to motivate others to take charge of their lives:-

Joy: "If I had to leave the earth, two days after she got sick and she will be seven on the 4th July. Why, I don't think there's time anymore to give up. I would like people to support me as well and where my children is concerned and I'm a single parent because my mother isn't always gonna be there. You know, you must keep on encouraging and that's how you will build up this group. And people will put their pride in their pockets and will say that they also have a child like that, I also have the same problem. And that is where I think is where we supporting each other, especially in the community. I mean, you first have to start with your family but sometimes you have to reach out because you family is stubborn."

Taking good care also meant looking out for the child's best interest by teaching them independent life skills. Also, protecting them from harm, as with Safia having to reprimand a neighbour for acting inappropriately was necessary. The care included the need to be observant and seek medical intervention when appropriate:-

Safia: “ Anyway wat sy drie jaar oud raak en toe vat ek haar na Red Cross. Ek begin nou to worry raak oor Sameerah. Hulle vra “Hoekom?” Toe sê ek “Die kind is drie. Die kind kan nie is lank op haar nappie, nie soos my ander kinders nie.” Nee kyk, by agt maande praat die kinders al sentences, al my kinders maar met Sameerah is net a difference.”

Safia: ” Anyway when she was three years old, I became more worried and took her to Red Cross Hospital. When asked why, I told them she is three and has been too long on a nappy compared to my other children, who by eight months, were talking in full sentences but not Sameerah, there’s just something different with her.”

All the women considered family support as important and this helped ground the women’s values and beliefs.

Makhazi: “Family support and a peaceful household – What I mean is that you as a family must always be united, you must not allow the second or third person to come in between, ‘cause that make you fight a lot. I believe you need to help each other, always be together, helping each other.”

Anne indicated that her children’s positive feedback motivated her to continue with the endeavours of the support group. She narrated what her children told her when she spoke about her involvement in the parent support group.

Anne: “ and then they, my children say, ‘you a clever mommy, we have a clever mummy!’”.

The women from Ocean View spoke of various reasons why confidentiality (privacy) was so important to them. The need for privacy was related to wanting to be respected within the community, like any other person and not to be judged. The “history of disempowerment”, to be explored further within the socio-historical context of childhood, is interwoven with the need for privacy as some women were stripped of their dignity due to an abusive

upbringing (more fully described in the themes that follow). Although the Ocean View women speak of the need for privacy, they did share very selectively. Safia continues by indicating why privacy is important and what the implications have been for her as a woman:-

Safia: "Daarom is dit dat as ek in die straat in loop dan moet die mense vir my aankyk soos 'n gewone persoon en nie as 'n 'shame' nie, and that is why I keep all my things to myself."

Safia: "When I walk in the street, I want people to treat me like an ordinary person. I don't want to be pitied. This is why I keep everything to myself."

In another story Anne related how a particularly bad experience in a woman's church group made her wary of self-disclosure due to the risk of being judged. (Related in Theme 4A)

The women's religious and spiritual beliefs formed an integral part of their identity. Faith in a God and prayer helped the women to persevere and deal with difficult issues. Their ability to take control was thus further enhanced by their religious convictions. Safia turned to her Maker whenever she was in distress. She found solace in sitting on her moesalah (prayer mat) and making duah (praying).

Safia: "Ek het maar altyd vir Allah gevra om my te help want as ek help nodig het, dan, "Ja Allah, help vir my." Daai was die enigste woorde wat uit my mond uit kom en so met die koedrat van Allah het ek al die swaarste dinge deur gemaak. Toe al wat ek gedoen het is sit op my moeslah en huil. Ek was so van kleins af om vir Allah te vra vir help en vir my die krag te gee om die next ding te tackle, to try to solve it."

"I always asked Allah to help and guide me when I was in need. "Oh Allah, help me!" Those were the only words that came out of my mouth and with the mercy and blessings of Allah I managed to endure many hardships. All I did was sit on my moesalah (prayer mat) and cry. I've been that since a child already, asking Allah to help me and give me the strength to face the next challenge and to solve it."

The women's identities were constituted partly by their value and belief systems but were influenced by feedback from the environment as well.

The interplay between the environment and the woman

The women described their family's expectations of being a woman and the influence of their culture. These expectations shaped who they were as women and affected the activities and occupations they pursued. Family expectations were often different even within one culture, as related by Safia:-

Safia: "In ons se familie is die man nie, die man is wel die breadwinner, maar in my familie was ek die breadwinner. Ons het agt kinders en van daai agt kinders was ek die breadwinner. En my familie en sy familie, they, hulle het nie a high thinking van 'n boy nie. Hulle verwag dat eendag as daai vrou 'n man vat sy moet kan goed huis skoonmaak; sy moet kan mooi haar kindertjies leer, sy moet kan goed huis skoon maak; sy moet kan goed kos maak, sy moet kan koek bak. Nou weer van my familie weer, wat hulle verwag van 'n meisie kind is, sy moet baie stervy wies, sy moet at all times 'dressy' lyk,"

Safia: "In my family, the man's the breadwinner. But in our family I was the breadwinner. We were eight kids, His family had no high expectation of boys. They expect one day when he gets married, his wife has to clean the house, look after the children, clean the house properly, cook and bake. My family expected women to be "stirvy" (prim and proper) and be smartly dressed at all times.

Hannah and Makhazi shared similar experiences of a traditional role of Black women. The deprivation that these two women endured were evident in their descriptions of growing up in a rural area and living in poverty.

The sub-category, "Earning a living" was intertwined with familial and cultural expectations of being a woman. Hannah related how women back then, in the rural area where she came from, worked on farms for a measly amount of R10-R12/day, and then gave their earnings over to their family. Safia, Joy

and Makhazi related similar stories of having to work from an early age to help support the family. The women were workers in their teens and even though education was an aspiration, it too was inevitably seen as a luxury.

Hannah: "Women were working and getting paid about R10 or R12 in the fields, packing potatoes. And at the end of the month they would give the money to their families. The problem was that our school ended with Standard six. So to carry on you had to go to Port Elizabeth, Cape Town or East London, then parents would say "No" to that. They wouldn't let their kids leave home. "What if they get lost?""

Makhazi: "My parents wanted us to go to school, but it was up to us if we wanted to be teachers, nurses, doctors or anything else. But they also didn't have money to take us to school. But I never went to school. I had to look after sheep and cattle."

The most common need for work was to economically sustain the families.

Anne: "I believe that the work I'm in should be a calling and not a matter of money making. You've got to work to earn money. Working part-time is to help support my family and also, if I hadn't to work part-time, then it would have been a bigger struggle than what it is right now. That's why I have to work part-time, you know. Keep the family going financially."

Not all the women experienced this level of job satisfaction. Joy worked in a factory for many years where she was given added responsibilities that boosted her self-esteem. When Joy had Melanie, her worker role was compromised, and it disappeared completely when the factory closed down. She eventually found work as a domestic worker after many months of job hunting. Makhazi is unemployed and assisted by her son's disability grant. Hannah sells sweets at a school to contribute financially to her family's survival. All the women had hopes and dreams of become a professional of one kind or another. Their dreams were challenged by the context in which they lived and in rearing a child with a disability. The women have

nevertheless remained hopeful as they continue their journey of self-discovery and hence their understanding of their life puzzle.

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3.2 Theme 2: Looking At Things Differently & Standing Firm in Yourself

Looking at things differently concerns the women's reflection on and meaning-making of the events in their lives. The turning point for them was the realisation that they had developed the courage to speak.

Table 3: Thematic Representation of Theme 2

THEMES	CATEGORIES	SUB-CATERGORIES
2. Looking at things differently and standing firm in yourself	The environment we live in	• History of disempowerment • I'm satisfied
	Speaking with courage	• Breaking the silence

Anne illustrates her "reflection on action", (Schonn, 1991) when describing this "looking at things differently" means it brought about a sense of rejuvenation and renewed hope for her:

Anne: "And if you change your view or perspective, if you look at things differently, as if you are looking at it for the very first time, the difference would come."

This ties in with Joy's meaning making of "Standing firm in yourself".

Joy: "For me, here, you must continue where you started. It's a matter of standing firm in you and believing that things come right. Because if things could come right there, then why can't it come right here. I feel if you don't, if you're not much educated, you need to understand that I'm also just learning."

Joy highlights her belief in being hopeful. She is explicit about the process involved in trying to change things and acknowledge that she is still learning and to acquire the skills to develop herself.

The environment we live in

This category describes the socio-historical context of the women's childhood and current life situation. The previous apartheid regime segregated South Africans into specific geographic locations. Resources were allocated within these locations according to race. The resultant impact on South Africans, more specifically on non-Whites was poverty and deprivation in all forms. Thus, the socio-historical context highlights poverty-related issues of the past that impacted negatively on access to opportunities such as formal learning within educational institutions.

All the women spoke of the difficult circumstances in which they grew up and what they had to endure. These experiences have had a lasting impact on their lives. Poverty is a common factor to all the women. The women's stories conveyed a strong message of their will to persevere and survive. A deep sense of gratitude for that which they do have also prevailed.

Safia: "At least we got a roof over our head to protect us from the wind and rain".

Joy, Anne and Safia had verbally and physically abusive fathers. The experiences varied from alcohol abuse (Joy's father) to emotional and physical abuse (Anne's stepfather, Safia's father). The impact of the abuse had a lasting affect on Joy, Safia and Anne. They noted how compliant their mothers were when relating to the abusive males. Anne, Joy and Safia's impressions of parent-role figures were marred from an early age.

Safia's father neglected to fulfil the family's basic financial needs whilst she grew up. Consequently, retaining her dignity and self-respect within the community was very important to her as a woman.

Safia: “Ja, it is, because when I walk in the street I don’t want people to look at me and say ‘shame’. I don’t like that because I had that as a child. Want ons het nooit klere in die huis gehad nie en as ons na ons se familie gaan kuier, dan sê hulle, “Hier kom Nur se kinders, shame.” Want dit was my pa se responsibility om agter ons te kyk, nie die familie s’n.”

Safia: “...we never had clothing in our house and when we visited family they would say – agghh shame here comes Nur’s children. It was my father’s responsibility to take care of us not the family’s.”

The embarrassment and shame related to the abuse has influenced Safia’s and others perception of herself. It directly shaped her expectations of a mother and wife, and her ability to successfully fulfill these roles. The fact that Safia’s mother had to undertake a demeaning worker-role to see to the needs of her family angered her (Safia), and reinforced the perceptions she had of being a wife and mother:-

Safia: “Dit was unfair because why my ma het by die scrap yard gewerk om geld te kry vir kos, toe dink ek dat dis unfair dat ons moet ‘hand-me-downs’ dra en somtyds sonder kos gaan.”

Safia: “ This was unfair. My mother worked at the scrap yard to earn money to buy food. SO I thought, this is unfair, why should we wear ‘hand-me-down’ clothing and go without food?”

The participants lives reflected some of their mothers’ experiences. The “history of disempowerment” appears cyclical as the participants were subject to similar acts of discrimination as were their own mothers. All the women, except Makhazi, left school early to work and contribute to the family. Makhazi did not attend school and tended to cattle from an early age like her mother did before her. Hannah’s experiences were similar to Makhazi’s:-

Hannah: “I dropped out in standard six, my parents didn’t mind and were not educated themselves. So they didn’t worry. This was in Tsitsikama, and it also was a long distance to school. I did have

uniform, but it was not full, at times I would walk barefoot to school. So when I dropped out nobody said anything, because they didn't have money. We were in the worst rural area."

All the participants had limited opportunities for further education, which posed a hindrance in their lives, especially as workers. Education was considered important for the women now (narrated in Theme 5), as it could serve as a means to alleviate their poverty. Despite the immense poverty the women endured, they conveyed their gratification for that which they do have, as expressed by Anne and Joy:-

Anne: "I guess in the country we live and even if I have to move in any other country, there will be financial problems always. Even if you have to be rich or whatever, there's always financial problems. So I'm satisfied with what I've got and the little I have."

Joy: " Financially bietjies - dit gaan swaar. Its all things that I must accept."

The participants spent their formative years during the apartheid era, where speaking out against injustice was met with violence and trauma. They witnessed their mother's silence for fear of retribution by the perpetrators of abuse. It takes courage to stand up, be "firm in yourself" and speak out. As the women reflected on their past and current situation, the courage to speak appeared to emanate from the opportunities presented in the environment e.g. the DiCAG workshop, within the parent support group, on home visits, public addresses and the interviews themselves.

Speaking with courage

The courage to speak evolved from the liberation the participants found within the parent support groups they were affiliated to. Traumatic experiences from the past silenced many of the women as they reflected and "looked at things differently". However, they stood firm in themselves and found the courage to open up, break the silence and share their experiences within the non-

threatening environment of the parent support group. Joy related the similarities between the parent support group and the research interviews conducted:-

Joy: "I don't think there is much more that I can say, besides thank you for the interview. I think that you are the first person to whom I spoke out to and I don't think there is anyone else I spoke to like this. Because sometimes you must choose what people to speak to because you can't just speak to any person. The interview itself shows you that there are people who listen. And it also gives you the courage to speak out your mind, but not necessarily your personal life - but like the main problems or similar problems that parents have. Sometimes you have something on your heart that you want to talk about, and feel more open to talk about it in the group where you know there are people who are listening. And they can give you advice and encouragement."

The participant's values and beliefs enabled them to speak out and empower themselves over time by becoming more self-confident. Their value and belief systems reinforced their self-identity.

3.3 Theme 3: The onus of living with a disabled child for me and my family

Table 4: Thematic Representation of Theme 3

THEMES	CATEGORIES	SUB-CATERGORIES
3. The onus of living with a disabled child for me and my family	Living with and Loving my disabled child Emotional & financial cost to the woman and the family	• Loving our special children • It's demanding on me, the mother • Everyone's contribution • Target of discrimination • Dealing with negative feelings • Ambivalence • Sense of helplessness • Consequences of professional information • I got sick myself • It is costly

Living with and loving my disabled child

This category describes the complex discourse act of loving and living with a disabled child. The participants described the love for the disabled child with physical gestures. This physical manifestation of love was interwoven with the demanding nature placed on the women in caring for a child with a

disability. The assistance the women received from people helped ease the burden of care and indicated how others also cared for and loved the disabled child. However, the individuals who provided this very assistance at times discriminated against the disabled child as well as the mother. This highlights the paradox of love versus burden of care in rearing a child with a disability for the participants as caregivers.

Anne beautifully portrays the meaning of loving a child with a disability:-

Anne: "Our children are our joy and our hope. That is just two things. They keep us prayerful and peaceful, you know. They also take away our tears with laughter because there is so many times that, that happens that you just that makes you just laugh. Keeps you happy, keeps you confident. Makes you want to go on, so there's actually in that way this is what makes them special ... not mad, but special."

The community members of Ocean View had stigmatised children with disabilities in the neighbourhood by referring to them as "mal kinders" or "mad children". Anne thus reiterates that her views of children with disabilities are seen in a positive light as she describes them to be "special" and "not mad".

Other descriptions of love include:-

Hannah: "I must love her, not more, but I must love her. Because she can't do anything for herself and God will punish me if I don't take good care of her, because I know that she can't do anything for herself."

When asked what advice Makhazi would give to other women with disabled children to help them learn to cope, this is what she had to offer:-

Makhazi: "I would say to you that God gave you this disabled child, you must take very good care of him; clean him, feed him or just do

everything. For everyone around the community would love this child for who he is, for he is clean and you have taken good care of him."

This love and nurturing are closely associated with gaining acceptance from society and God, which is sought through these physical manifestations of love. Nurturing a child with a disability is particularly demanding on the woman, as she is the main caregiver. It requires much patience on her side, as the women describe. The demands are not only physically strenuous but emotionally exhausting too. (This reflects the sub-category, 'It's demanding on me, the mother')

Anne: " Having a child like Nathaniel maybe makes a difference. I guess there's many other parents that sits with kids like him. At times it's difficult and at times it's very tough, it's tiring, it's exhausting. You got to see to your house you got to see to Nathaniel."

Safia related how strenuous it was for her in the beginning caring for her daughter:-

Safia: " Dit was eers in die begin baie strain maar, ek het geleer om te cope. Ek kan nêrens gegaan met Sameerah nie because Sameerah het at all times vuilgemaak in haar nappy."

Safia: "In the beginning it was very strenuous but I learnt to cope. I could not go anywhere with Sameerah because she dirtied herself in her nappy.."

Hannah related how tiring it was caring for a child who cried up to nine hours day. Hannah emphasised how emotionally demanding nurturing a child with a disability is:-

Hannah: "The baby used to cry eight to nine hours a day. She would start like at nine o'clock in the evening till in the morning, then start again at afternoon one to five."

Hannah: "You must love your baby. You'll feel tired because she depending on you more. But even if you are tired you must feed the baby, bath the baby."

The dependent nature of having a severely disabled child was reiterated with what Joy had to say:-

Joy: "She's going to be at all times dependent on me - so, Okay, from there I came to understand that you know, I must accept it and my life must go on. But now I still - up to now - my life didn't go on like it was before."

The physical demands placed on the mother are most obvious when she has to carry the disabled child around because mobility aids and transport are not readily available. Limited access to mobility aids and transport acts as a severe limitation for the women who have children that are severely physically disabled.

Joy: " I must carry her everywhere. On the other hand, I'm making...I'm making hell of a plans that I can get something that's comfortable for her and I didn't get that far."

Both Joy and Hannah spoke to me of their anguish at having to use public transport with their disabled children on visits to Red Cross and False Bay Hospitals. A trip to the hospital meant taking a day off work. They described spending an average of eleven hours preparing, with being seen or not and commuting to and fro from hospital.

Everyone made reference to the help they received with caring for their disabled child. The assistance came from family, friends, spiritual leaders, neighbours, professionals and strangers. The participants described in loving terms how they felt about their disabled children. Family, neighbour and friends supported the participants in various ways when it came to caring for the disabled child, e.g. providing food or babysitting.

Hannah, Makhazi and Joy sought guidance from religious institutions as a means of obtaining help with their disabled children.

Hannah: "I went to Woodstock church where I always go, and told the pastor that I am not happy about my child, she is always crying and he asked me if I trust God. And I said yes I do. He then told me to go home with my child and she'll never cry again, when I get home she is going to sleep peacefully, she'll never cry like she used to. Ever since she never cried again."

The advice Hannah received from the family left her feeling a bit frustrated as she tried indicating that whatever was said was something that she had already taken heed of. Thus the perpetual advice-giving from people also made it emotionally demanding on the participants.

Hannah: " They talked. My family and my in-laws would say I should find an OT or any therapist that could help her sit on her own. But I was trying that."

Neighbourly support for the participants included practical help and advice to encourage the women, and let them know there are people out there who are willing to assist.

Hannah: "The neighbour would say God will help you and give you strength to do. She (the neighbour) would take her, and the baby will be fine. All the talks will help a lot. That makes me very happy because sometimes I would have a problem or want to do something that is not good or I've got a problem and I don't know how to solve it then they would support me - that makes me very happy because I don't know what to do sometimes."

Joy's previous employer was as supportive when Melanie was very ill:-

Joy: "I used to say today to my supervisor, "Tomorrow I must go to Red Cross Hospital and I won't be able to come in late" or so." She tell me, "No it's fine." "

Support from the church congregation was just as important.

Makhazi: "They are fine with him. At first they did not understand him then I tried to explain to them that he was disabled. Every time when they go to the church, they pick him up."

The disabled child and the mother were victims of unfair discrimination at various stages of their lives. The disabled child still remained a target for discrimination by the very family, neighbours, friends and strangers who supported them.

Safia described going to various school institutions, "the creche, Marine skool, 'die Madressa', Fish Hoek School Clinic" and meeting with unfair discrimination towards her disabled daughter. The discrimination came in a number of ways for Safia; she was either told they could not help her or else they mocked her daughter.

Safia: "Sy't met die vuil maak van haar panty in die hoek laat staan tot 5 o' clock wanneer ek haar kom haal. Dan loop sy nog. Dan sal hulle se, "oooo, die kind het vuil gemaak." Dan se hulle "Oooo dat girl stinks." Niemand wil om haar gewies het want die hele creche se dingis was gewies "Dat girl stinks! Sameerah stinks. She always p* in her panty""**

"Because she soiled her panty, she was expected to stand in the corner and wait till 5 o'clock when I fetched her. Even then she would still walk. Then they would tell me; "She dirtied her panty". They would then say; "oooh that girl stinks". Nobody wanted to be around her because people at the creche maintained; "That girl stink, Sameerah stinks. She always dirties her panty!"

Anne and Safia spoke about family members commenting about their child but directing the comments at them, as the mothers.

Safia related how her husband swore and shouted at Sameerah for taking too long as they were about to go out.

He said: "Jy's so veel jaar oud, jy's onnooslik! Kyk die anders, jou broers en susters. Hulle's daai ouderdom en jy kan nie eens die reg doen nie and jy kan nie eens daai reg doen nie. Kan jy nie fokken reg kom nie!"

"You so old! You are stupid! Look at the other children and your brothers and sisters. They are that age and you can't even do this right or that right. Can't you fucking come right!"

The blame the participant felt as a mother was as a result of the disabled child's actions which was reiterated in what Makhazi said:-

"In the Transkei it was difficult because sometimes the child go out and do something and they think "Eh! Its Makhazi do not look after the child because he is doing that to them," whereas it is not so."

Safia spoke of an incident whereby a neighbour had touched Sameerah's breasts and intimidated her. Sameerah informed Safia immediately. Safia confronted the neighbour, a man, who lived close by, in public. The neighbour denied the incident ever happened. To his and the rest of the neighbourhood's surprise, Sameerah spoke out loud and related exactly what he did and said. The assumption this neighbour and many others made was that Sameerah could not speak or understand what was happening around her.

Safia: "Boeta Doltjie, het Boeta Doltjie aan Sameerah se têtê gevat?"

Safia: "Uncle Doltjie have you touched Sameerah's breasts?"

The Emotional and Financial Cost to the Woman and the Family

Coming to terms with the disability meant recognizing and dealing with the emotional and financial costs incurred by the participants and their families. The emotional cost to the participants and their families related to an ongoing need for acceptance. The participants constantly had to re-evaluate and accept the disabled child within the family. This acceptance was not always easy for the women and their families. The category, "My disabled child" relates to the feelings and experiences of having a disabled child. Having a child with a disability impacted directly on the emotional and financial cost to the women and their families.

When the participants first discovered that their child would be disabled, it brought on feelings of guilt, blame and anger. The participant's feelings of acceptance, guilt and blame were all enmeshed. They admitted to not being able to accept that their child was disabled in the beginning because their first-born children were "normal".

Anne: "I couldn't handle him just getting sick out of the blue like this and you know up and down to the hospitals. I blamed myself and how I found out I wasn't to blame and how I learnt to deal with it. Maybe it was due to being too fat and there wasn't space for Nathaniel to grow inside of me and the fat inside me was squashing. Maybe I didn't eat healthily enough, you know, things like that. I couldn't handle it because Nathaniel wasn't born with a disability."

Joy's story indicated the difficulty many women face in having to accept that their child is disabled. It appeared more difficult in the beginning, but with time the acceptance became easier.

Joy: "The Fri- the Saturday when she started going into a fit, they admitted her - I had to stay there. I had to think of my other children at home. It wasn't a nice experience from the beginning when she fell ill. When she fell ill - can I - OK I don't mind if it's on tape. I didn't accept the illness in the beginning because it was for me, it was so - life in a

difference because my boys weren't sick. Her sickness was - It really put me down from everything. Ja, it was a tough experience, but now like, the time went on, so I came to realise that I must accept that Melanie's disabled."

Makhazi acknowledged that she only discovered her son was disabled at age ten. She then continues with advice to other women with disabled children on accepting the child.

Makhazi: "At the age 10 years - we couldn't see before that the child was disabled. In Transkei we couldn't see that the child was disabled, we couldn't take him to doctors there because there is no care there. They would only say he is a 'psycho' and do nothing. I feel that other women must help you, must support you and not laugh at you. This is not your fault. The child must be accepted and within the family and she must feel that she is loved, because what causes kids to go around and do all wrong things is the feeling inside that "I am not loved, I am not accepted, so what's the point of staying in this house?"

Thinking back to the birth of her child, Hannah revealed some painful memories. These are memories she wishes to forget. Hannah cried bitterly when talking about the birth and remembering when the doctor told her Nonzuzu was disabled.

Hannah: "I wasn't sure whether its my fault or what, because while I was giving birth, nurses were shouting "Hey you need to push this baby now", and I was feeling pain of labour plus of being swollen the whole body. So I couldn't do it properly. It was difficult. Oh! What a day. I am trying to forget about the day I gave birth, because the pain I felt wasn't the normal pain of giving birth."

Hannah made it clear what it meant in having to accept Nonzuzu by saying "If she is hungry or if she crying or even if I am tired I must just find time to give her. Whatever the problem she has because she can't do anything

for herself. Nonzuzu must also feel that my mother loves me the way I am. The way I treat her - Nonzuzu could see that she is accepted the way she is and Nonzuzu knows that she belongs here."

Sibling rivalry was rife when it came to sharing with the disabled child. Anne pointed out how she constantly had to be fair and "spend equal, quality time with all her children" as the siblings would tell her that she was giving Nathaniel more attention and had to see to their needs too. Hannah emphatically stated that she did not love Nonzuzu more than her other children but did so equally.

The ambivalence the women endured refers to current and past experiences concerning the disabled child. The past experiences related to understanding whether the disability was as a direct result of something the women did wrong. Anne mentions the turmoil of not knowing whether or not it was her fault that Nathaniel took ill (as mentioned in the previously sub-category, 'It's demanding on me the mother', page 46 and under the 'Emotional and financial cost to the woman and family' on page 51). The rest of the women echo these sentiments.

Hannah: "I wasn't sure whether it's my fault or what, I don't know where it came from."

This uncertainty also relates to making decisions regarding improving the child's current state of health, for example, giving consent to have the disabled child undergo an operation without being certain of the outcome. The responsibility of making an informed choice and without the father's moral support, proved demanding on Joy and left her feeling helpless.

Joy: "A woman said to me, I mustn't have the op. Because she told me of this other lady's child who also had a spine problem but could still walk, but then after the operation the child couldn't walk anymore. Now you see, I'm torn in the middle, I dunno! Ya, if I'm gonna make the right

decision or not, after the six months, I dunno what am I gonna do. Now that is where my brain seems to be working overtime again..."

The ambivalence of making a decision regarding the operation also meant that Joy relived her previous experiences of the many hours spent with Melanie in hospital at the beginning. Time with Melanie in hospital meant time off work and no pay. Thus the ambivalence not only had an emotional cost but a financial implication as well.

The acceptance by fathers as portrayed by the participants was inconsistent. Makhazi's husband died when her son was only a few months old and at that stage she had no idea her son would be disabled. All the women agreed that the biological fathers had great difficulty in coming to terms with the child's disability.

The response from Sameerah's father was not always positive. In the beginning, her father was actually verbally abusive. Safia relates a time when they were still married and a family outing was arranged. Sameerah got excited, started kicking her legs and took her time to get done. This infuriated Sameerah's father and he lashed out at her. Safia came to Sameerah's rescue and reprimanded her husband. A verbal fight broke out and the family outing was called off. The entire family thus bore the brunt.

Safia: "Dan sal ek sê, "Hoekom onnodig skreeu jy?" En dan is die hele ding deurmekaar en dan skel ek en hy en dan gaan ons nie uit nie. "

'I would tell him: Why are you screaming at her unnecessarily and then everything's up side down because now we land up arguing and then we don't go out.'

Anne spoke of Nathaniel's stepfather with much pride but never mentioned Nathaniel's biological father.

Anne: "My husband could of have so many stable jobs if we could have been financially better off as what we are today. It wasn't like for

Nathanial's illness. He had to keep on supporting me and his not even Nathanial's real father. He's Nathanial's stepfather for that matter. And he's sacrificed so much and such a lot of himself."

Hannah said her husband did support her financially and would also take care of Nonzuzu when she was tired.

Hannah: "He was around. At Nonzuzu's birth he was working. But when we came to Cape Town he helped out. I can't say he didn't help a lot, because he was working. When he came back from work he would say I can go to bed and he take care of the baby. And he would give money when I wanted to go to doctors and church."

The acceptance appeared to be an ongoing issue for several fathers. Hannah revealed how her husband disclosed his feelings of helplessness in not being able to give Nonzuzu the physical capacity to do things independently. Seeing Nonzuzu was a constant reminder to him that the disability was permanent.

Hannah: "He told me that he is hurting. How he wish that she could sit and be able to feed herself. She mustn't depend like at least she must do something."

Joy spoke about having to be strong within herself and acknowledge that Melanie's biological father was not ready to give her the emotional support she needed. She adopted dual parenting roles like Anne and Safia who were divorced and Makhazi who was widowed shared similar experiences.

Joy: "So I had to be mother and father."

Joy spoke of needing practical support from Melanie's biological father to assist with feeding but even that was difficult for him to deal with. She explained how he at one stage tried to feed her through the tube but became nervous and immediately called for her to take over.

Joy: "I would have just wanted - like help and support, but I accept that he can't take it because I - I actually made myself strong to accept."

Joy continued to explain in the interview how she believed that Melanie's biological father would come to terms with the disability as she did, and that it would take time. She acknowledged that the 'transport support' was there for her and Melanie to from Red Cross Hospital but only when he was in town and available.

Joy: " But I'm sure that father will also get there where I got, 'cause I also felt like that in the beginning and I was wrong."

All five participants related their experiences of having to come to terms with having a child with a disability at various stages of their lives. It appeared to be an ongoing process whereby the women came to new realisations about having a child with a disability whether it was at the time of the birth, or when a medical professional informed them of the child's status (reflected in the subcategory, 'Consequences of Professional information' in the paragraphs below). Talking at the interview made the women think back and reflect on how it was in the beginning. This was not easy for any of them.

Joy experienced a series of incidents with medical personnel in and around Ocean View that left her feeling disillusioned with the services offered. The consequence of this was that each time something went terribly wrong with Melanie they landed up at Red Cross Hospital. Red Cross Hospital was their salvation.

Joy: "No, up until today - I'll be honest with you. Up 'til today, I believe if Melanie get sick, I don't worry with these doctors here. OK, I do go to the house doctors, but I don't worry with this hospital - I go straight - even if I must pay R100 - I go straight to Red Cross Hospital. I go straight to Red Cross Hospital because they at least there they tell you

immediately what's wrong, or if they can't tell you, they ask - they refer to another doctor."

Joy felt more reassured receiving medical care for Melanie at Red Cross Hospital. The doctors Joy became acquainted with at Red Cross Hospital took an interest in what she had to say as a mother. The interest and belief in her opinion was an important factor that fostered trust in the institute.

Hannah's experiences with medical personnel in Masiphumelele were more positive. The advice Hannah received at the Nomzamo clinic helped her seek medical expertise at Red Cross Hospital.

Hannah: "I took the baby to the clinic here the other day. The nurse in the clinic said this baby is not Okay, and I must take her to Red Cross because at the age of three months, four months at least, she must balance."

It was at ten years after Nathaniel took ill that Anne discovered more about his condition. A genetic doctor connected to school health provided her with some of the answers she was looking for in order to come to terms with the disability. The consequence was that Anne felt reassured that she was not to blame for Nathaniel's disability.

Anne: "I was starting to think all things and stuff and then the genetic doctor told me "There's nothing that you could have done that would have had a different effect on him." ...Probably be just the same."

This sense of helplessness is linked to the "Ambivalence and Consequence of Professional Information". Joy explained how helpless she was at the beginning in trying to manage Melanie's illness. She was never assured of herself that as a mother that she was doing the right thing in terms of caring for Melanie. Because of her bad experiences at the local health authorities in Ocean View with Melanie, she was very reluctant to seek advice there adding

to her uncertainty of knowing exactly what to do for Melanie when Melanie started fitting so badly.

Joy: "She used to fit. Melanie use to fit the whole day, the whole day! I used to sit there, helpless - didn't know what to do."

Caring for the disabled child took its toll on the participant's physical and mental health. Hannah, Anne and Safia described how they became depressed and required medical attention when they heard about their child's disability. The travelling between and from hospitals was expensive and tiring for the participants.

Hannah: "I was tired of changing the hospitals, from Princess Alice, to Red Cross, to find that when the baby was now fine, I got sick myself."

On the day I interviewed Hannah, I met up with her coming from the doctor. She said the doctor recommended she rest her body because the pain experienced was related to stress. A month after my interview with Joy, she also took ill and her doctor suggested a similar course of action: take it easy and rest. Time off sick for the women meant no pay and placed strain on their ability to care for the disabled child and the rest of the family.

Professionals informing or not informing the women of their children's status, that is, "disabled or not", proved to be stressful. The haziness of the diagnosis and prognosis affected the women and their families emotionally and financially. Emotionally, it was the stress factor. Financially, it was costly travelling to and fro, as it meant paid working days were lost for the participants and their male partners. Anne explains how her third husband, Nathaniel's stepfather, lost job after job because he had to support her (Refer to quote on page 54-55).

3.4 Theme 4: The Parent Support Group as an Agent of Change

The participants described what it meant to be affiliated to the parent support group and the impact it had on their lives and their families' lives. They also explained the impact the parent group had on the community and what the benefits are of belonging to the group are. As indicated in the previous theme, having a child with a disability is a challenge. The needs of a disabled child are personified within an impoverished environment, placing even more strain on the participants as caregivers. This a common issue which each woman share in their respective parent support group.

University of Cape Town

Table 5: Thematic Representation of Theme 4

THEMES	CATEGORIES	SUB-CATERGORIES
4. The parent support group as an agent of change	Motivation to participate	• My childhood experiences • The Family's interest • Group experiences
	What it means to me	• Feeling reassured • Impact of self-help • It's ongoing • Scope of opportunities • Camaraderie • Sense of Ubuntu • Feeling complete
	A changed person	• People notice • A different husband and kids
	Group dynamics	• Internal conflict • Lack of leadership • Lack of resources

Motivation to Participate

Even though Anne was the only participant who verbalized that Nathaniel was the reason she joined the parent support group, it can be inferred that the motivation applied to all the other participants as well.

Anne: "Because if it wasn't for Nathaniel I wouldn't be where I am today in volunteering and starting a parent support group here in Ocean view."

Thinking back on life before the parent support group, some of the women related their original need to become involved in a parent support group and their motivation to continue.

Anne: "Being reared by a stepfather, and being pushed around and shunted constantly, I guess I built a wall around myself in dreaming away, just fantasizing and so forth. I think that that is where the compassion and things mostly came from, 'cause I wanted, I wanted to change things and in time I could be my own person. I said I always want to put something back to the community, that as a childhood thing already."

She continues:-

Anne: "I think I always needed something to do for others and I don't talk about helping one person or two persons. Even if I can just help one or two in this. I know I can help a lot of people in just by raising awareness towards in this way, and you know maybe not 100%, even it is just 40% of people who will just take note of the awareness raising."

Safia spoke about an abusive father and the effect this had on her family. She was physically abused by her father and so too Anne by her stepfather.

Safia: "Growing up was difficult because my father was abusive, we were eight children and he hit us all."

She became self-sufficient at a very young age, but she acknowledges the importance of parental figures in a child's life. She wanted to make a difference in her children's lives by not reliving the past and by adopting a positive outlook in life. The opportunity to join a parent support group provided her with the chance she needed to make a difference.

Safia: "Daarom sê ek, "'n Ma en pa speel 'n groot rol in 'n kind se lewe," en van wat ek 'ge-experience' het, as 'n ma en pa se lewe nie reg loop nie dan 'affect' dit die kind se lewe. Want dit het ons almal se lewe 'ge-effect' because why, ons is almal slim but because of my pa het verkeerd geloop toe het dit vir ons 'ge-effect', you understand, but nou ek kannie sit en terug dink van die past nie want ek het vier kinders en ek moet na die future kyk, you understand, it 'n hele thing that you must go through but Algamdoerillah ek maak dit because I'm positive."

Safia: "That's why I say, a mother plays a huge role in the child's life. I experienced it. If parents lives are not running smoothly, it affects the child's life. It affected all our lines. We were intelligent but because of my father, he went astray, it affected all of our lives. But now I can't dwell on the past because I've got children and I need to consider their future. It's a whole thing you gave to go through but Algamdulillah (all praise and thanks to Allah) I can manage, I'm positive."

Joy recalls being very scared of her father when he was in that state and scared to talk out against him when he hit her mother.

Joy: "My father, he use to drink and there was a time when he use to hit my mother. We were scared of my father because we knew if he came home drunk we would get hiding for stupid reasons and then be sent to bed without food."

Since Joy was a teenage mother as well, she did not feel standing up to him would be wise as she was dependent on the family for a place to live. The silence and feelings of disempowerment changed over the years as her

confidence grew. The parent support group provided a space for the participants to voice their opinions and promote empowerment. Joy's rough childhood, fear-filled silence and disempowerment provided a backdrop to join a support group that promotes support and liberates the voices of women.

Joy: "I mean, we are people who keep quiet and that why things go backwards. I know we all got our pride, but, I think the world that we live in today, we can't afford to keep quiet."

All the participants grew up in immense poverty that inhibited them from making choices about their future prospects. The parent support group provided them with opportunities for personal growth and development. One of the key objectives identified at a DiCAG workshop (28/07/00) within the parent support group was economic empowerment. The women were motivated to carry on within their groups, as they wanted to provide more lucrative opportunities for their children and themselves - opportunities that they were deprived of as children themselves.

The family's interest in the women's activities in the group served as a motivating factor in continuing their mission. Hannah's husband would take the time to listen to her talk about Siyazama. Safia's mother could not believe that she wrote an article in their newsletter, Making a Difference. The praise Safia received from her mother served as motivating factor. Anne described how excited her children and husband were to hear from her whenever she returned from a parent group activity. This excitement motivated her to carry on with what she set out to do. She aptly described the motivational influence of family support. Hannah's husband also took the time to listen to her shared stories about activities within Siyazama.

Anne: "Family support is important because without family support I don't think we will have that energy. It can be all in your mind, all in your fantasy world so to say, but without your family support, you could so easily just sit back and relax. So it is important, it's vital to have your family's support even though they don't go out themselves and go out

with you and say this and that and that. But inside your house they support you."

Past experiences in other groups, positive and negative, motivated the participants to contribute to and engage in their respective parent support groups. Anne related a particularly bad experience with a women's church group that left her feeling too scared and vulnerable to self-disclose at the risk of being judged. She eventually left that group in search of another.

Anne: "The others were all sitting and having tea and whatever. Now they discuss one another's problems. And they'll say every time she came back with the same thing because she does this, because of that you know, and that was the point when I never wanted to open up. And that was the reason why I moved from the one church to the other church to maybe seek for a difference to seek for something to seek for something - starting a parent support group for Ocean View and the disabled and you know ."

Joy belonged to a parent support group at the Deaf Child Centre and attended meetings regularly. The group at the Deaf Child Centre only stayed together until the children turned a year old, thereafter the group dissolved. The positive experiences related to that group motivated her to join the Ocean View Parent Support group.

Joy: " I mean from the previous support group that I belonged to, it was also for twelve months, I learned a lot there, and there was a lot of encouragement because I could also encourage."

Makhazi belongs to a pensioners group as well. The positive experiences in this group serve as motivation for her to join Siyazama.

Makhazi: " It's a good thing. It's their future being a human being. You don't know everything, but meeting with people, sharing different ideas, you learn a lot."

The participants also spoke of positive experiences within their parent groups that strengthened their motivation.

Makhazi: "We haven't started yet, but we still talk about it at the "Mothers with Disabled Children Group" and we feel that we must do it. It's the right thing to do."

Joy: "The group is doing well. We quite strong for four mothers who are fighting so. I think we are strong because there is a lot of people who is coming back to us."

What it means to me

This category describes what the support group means to the women from their perspective. Feeling reassured involved discovering other parents who were in similar or even worse off situations who could empathise.

Joy: "There is support somehow or another. Now I'm not, not actually alone, I'm not standing alone. There was a change in my life, meeting people there with the same needs."

Hannah: " They would be able to support each other and learn that I am not the only one on this stake, there are other babies' and mothers' lives involved."

Makhazi: "I felt so strong when I found out that I am not the only one with a disabled child. At least with everyone's problems you don't feel sorry for yourself because you are not the only one."

The parent support groups afforded opportunities for women to be acknowledged to give and receive help. By helping themselves they were able to help others as well. Anne related what helping herself and others "sitting in the same position" meant through the parent support group. The parent support group was thus the medium for facilitating self-help. Anne

even thought of her affiliation to the group as a calling, like her work as a nurse-aid.

Anne: "A calling! Yes, yes it's part of the same thing because I'll still be helping others and in the same way I'll be helping myself and also helping others. While we are talking, people learn from me as I learn from them. So as long as I have the love and happiness to share with my family - my family to share with me. And so in that way I know exactly the work I'm doing for others and not just for myself, for my children, but for others."

Safia spoke of a number of things; for instance, the group as a means of socializing, an opportunity to build her own capacity through skill acquisition, and a chance to get out of a problem filled environment. Most importantly, it meant feeling needed for the expertise she had as a woman with a disabled child. This was true for all the other women as well.

Safia: " The parents support group is there for you to "mingle", mingle your social life because I mean we go out places, we do courses together, we go here, we go there, and it gets me out of that "bedoempigheid" 'crowded feeling, feeling overwhelmed', "gekoestugheid" van my huis or wherever I sit and worry. That's also what the support group has taught me, to be in control and not to lose my cool. It makes me feel that I am needed somewhere even though I know I am needed 100% by my children. But I mean a person also needs to feel needed somewhere else, it makes you feel what your aim is and it helps you."

Joy: "So this support group, I feel is important to have, for me. It was a real change in my life, especially I could reach out to people, when I struggled. And I'm still struggling and I got help, although it was a little help but it meant a lot to me. And I can tell people if you struggling in a way and I can help. Even if I just make a phone call and to ask if there's

a different need to what I experience, so I feel this group we must still learn a lot, I say “we” because I know its not only me....”

As parent support group in Masiphumelele was not as established but Makhazi and Hannah spoke of the potential benefits their group could have as well.

Makhazi: “I felt so strong when I find out that I am not the only one with a disabled child. I also feel that the community and other mothers could go and confront that particular person, to stop doing whatever she is doing. I don't know if the kid is getting any support from that. Even others like you (interviewer) could come and help out that hard case.”

Hannah: “What I mean is that if the mother is not right, maybe the mother she get sometimes tired in such a way that she just ignore the baby, she doesn't cook, wash for the baby or maybe the way she treats her baby is just not good enough, because she is disabled. She doesn't understand what is going on in her life as well so them as mothers could come and talk and support and advise.”

The women also derived meaning from the temporal nature of the group and the potential impact it could have on the broader community. This was described as “ongoing” and reflected in the subcategory, “It's ongoing”.

Anne: “By helping themselves, helping others, so it is an ongoing thing. It's not just a day thing and then it's gone tomorrow, it's ongoing. Because one happy community could actually go out and share with other communities and you could only try can't we? And we know nothing is that simple and we can only try and keep on doing it.”

Opportunities to meet other parents and professionals and to share their experiences proved to be very valuable to the participants. The opportunities were that which DiCAG afforded them and that which the participants generated as a result of the main research project.

All the women spoke with fond memories of the mobilisation workshop DiCAG ran at the Days Inn Hotel in Cape Town (August 2000). The trip itself from their community was an adventure. Several of the participants stepped into a four star hotel for the first time in their lives. That opportunity epitomized "Feeling reassured" as they watched videos of women with disabled children living in rural areas. These were all female members of DiCAG striving towards raising disability awareness and empowering themselves economically.

Makhazi: "I knew I was going to learn a lot about their disabled children. Now I don't want to talk about the food, there was a lot of meat! I felt strong when I watched the video, saw the kids and the way those mothers were talking about them. I must take what ever it is to support the child I'm not the only one. It encouraged me when I saw that video how they were treated."

Meeting professionals from overseas at a DiCAG seminar was really exciting for the participants.

Anne: "This guy of Sweden was quite impressed by what came up there, you see, and parents were ask about, were asking me questions about this and that whatever and you know so what I say-what I am glad about is that something is busy happening, something is busy."

Safia felt that the group enabled her to attend courses and build her own capacity. Capacity building included opportunities such as performing their plays in public and making speeches.

Safia: "It helps you function and I learn a lot as a person goes through the situation courses of the parents support group, and it helps me, because its almost like "my regte (right) hand"."

Hannah, like many of the other participants, saw the group as a potential to generate an income that could help to sustain their lives as well as that of their families.

Hannah: "Maybe if we can get together we can get a sponsor, or start sewing, or do gardening at least within the community. They could even use my house and keep the children around, but for sure they need something to help their husbands as well. And also my husband was not working in February and March."

The two participants from Masiphumelele shared the same understanding of what Ubuntu meant to them personally.

Makhazi: "That could make me a mother with a good heart, if something might happen to those family. I might go and give them support the way they did to me with my child. Ubuntu means helping each other through difficult times and happy times, it doesn't really matter if you were together, supporting each other. I believe you need to help each other, always be together, helping each other."

Hannah: "If someone could help me whether it is good time or bad times, and I must also help her back- it's Ubuntu."

However, they differed in opinion as to whether Siyazama shared a sense of Ubuntu.

Makhazi: "Within the group they do have Ubuntu, because whenever they are meeting at 9 o'clock, even if you are late they don't question you and also if they must go and remind you in your house, they don't speak to you in a bad language."

Hannah: "I feel that within the group they don't have Ubuntu because they don't attend meetings they always see, they don't care what's going on within the group."

I asked Hannah what could rekindle the sense of Ubuntu for Siyazama, she responded:-

Hannah: "If they could meet again, being all the mothers of disabled children (the group) and try to explain to each other what does Ubuntu mean. Because now I could see that I don't attend the meeting, that's not fair to other group members, so starting the group afresh I think they need to put some rules."

In contrast to the parent support group members in Ocean View developed a feeling of camaraderie as they did more things together. A sense of solidarity was being created as the participants went on home visits to inform other parents of the group and to listen to many sad stories. What was phenomenal was that these participants found the courage and strength to assist other needy parents wherever possible. They were keen on taking what they knew to other communities and worked together at it through their drama performances, newsletters and even radio interviews. Their first target community was Ocean View, to help bring about "A difference in Ocean View".

Joy: "I believe we can make a difference here in Ocean View."

Anne: "One happy community, sharing with other communities."

Besides fostering as sense of camaraderie, Anne also spoke of 'Feeling complete':-

Anne: "Starting with this parent support group already gave me a sense of completion and whole and achieving something. Even at that time I

only started out in a little way. Feeling complete now means to me that if I should die at this very moment or at any time, I die happy. Feeling happy I did something, even if I just started it out, I did something to help others and starting to helping something in my own community.”

A changed person

The category refers to positive changes the participants see in themselves. This is reinforced by feedback from other people. Anne also noted a change in her husband and children.

Anne describes the changes she has undergone ever since being affiliated to DiCAG and the initiation of the OV Parent Support Group.

Anne: “ Ever since I'm in this DiCAG business, awakening my interest in doing something, that this is actually what I wanted to do. Because in that very day, sitting there in one of their seminars, the first time actually something happened to me and I can't explain it. It was, there was excitement inside of me. When I got home I was completely a changed person. I was thinking different, I was talking different, I was doing things differently and I wasn't the same - I just wasn't the same. It makes me feel good because it's a change, it's not feeling burdened.”

The women have also noticed changes in others, as depicted by Joy:-

Joy: “Ja, so, the group is doing well, we quite strong for four mothers who are fighting so, I think we are strong because there is a lot of people who is coming back to us, like the farmer and the skipper who said he'll give the children a free ride.”

Anne was the only participant who verbalized seeing a difference in her husband and children, and attributed it to a spin-off from her involvement in the parent support group. The other participants did not name it as such but mentioned it in their narratives events, which illustrate noticing a difference in certain family members.

Anne: "While we are talking, people learn from me as I learn from them, and that is the way of sharing. A household is different and the kids are more happy, I'm happy, my husband's happy. We've got major financial problems and even that can't dampen us 'cause we feel like eating sandwiches even if it's just butter and black coffee there that night. At least the children's happy, my husband is happy, I'm happy, you know. And before it was like everyone sulking and there's never nothing, there's never - but now it's like there's just this funny, different atmosphere."

Group dynamics

Group dynamics included the difficulties the participants experienced within their groups. The internal conflict the groups experienced could be attributed to the lack of communication between group members.

Joy: "I don't see anything wrong with this group. Like I said, we still fresh and we need to learn each others ways, some how or other. There is still no proper communication between us."

Joy did admit noticing a lack of representation of parents of children with severe disabilities:-

Joy: " Sometimes you also can't fit into this group because I discovered I'm a lot for the other – special parents. They more for this school and then for the special care side...when they talk about working for disabled children they seem to fit in more with the ones who can't walk or talk. But the children at this school can walk and talk and there's some who can write, so if I can get more parents from the special care then maybe it will make a difference."

Hannah explained why she lost interest in the group:-

Hannah: "I lost interest with Siyazama group. I haven't been to the group for a long time. When I was there they would talk about something but it doesn't work out whenever they talk about something. They don't conclude, they don't put it into practice so now I feel that I just want to get out of the group."

She continued by saying that although the group embarked upon a sewing project, sewing did not interest her. Something else did:-

Hannah: "There are two or three people interested in sewing within the group so what could motivate them to want to sew? For my side, I am not interested (in sewing) not at all. I don't know about others - my idea is to buy stuff and sell it. Buy it in bulk and sell it whatever price they decide on. I feel it is not organised, because other mothers will come and others just decide not to come when they feel like."

Makhazi tried figuring out why the group attendance was so poor and commitment so low. She provided some of her own reasons of what the possible problems could be attributed to:-

Makhazi: "She doesn't know what can be done, maybe they expect someone to fetch them at their homes. She says Lydia offered her space at the back for planting, she even ordered manure, they never planted, they never came. She doesn't know why they didn't start. Maybe it's because it's not yet clear, so it's difficult for people to commit themselves. Due to laziness people do not show up."

The Masiphumelele parent support group, as mentioned previously, was not well established and lacked group cohesion. One of the main contributing factors to the group not thriving was the lack of consistent leadership. Makhazi acknowledged the role Lydia, another group member, played in leading the group. However, the leadership role was compromised by Lydia's duties within another group and thus Makhazi felt the group required a leader.

Makhazi: "Someone to help Lydia so that they can see what more else to proceed with their processes. Yes, they do need a leader, even if that person won't have to come everyday cause Lydia would sometimes be there. But she is very busy because she is attending all the meetings. She must be in the hall, she must be with them so it's not possible for her to help them but she is trying."

For Anne, the chairperson of the group in Ocean View, it was not about not being a leader but more about the skills required to be able to fulfil the role and deal with the organisational dynamics within the group. During my observations, I noted Anne seeking advice on experiencing difficulty managing the group conflict. At times she relayed wanting to leave but after seeking advice would build the courage to return to the group and try again.

The lack of resources was problematic for both groups. Participants from Ocean View and Masiphumelele spoke of the need to have money to get the group going to where they wanted to be.

Hannah: "The problem with their group is they don't have money. They need money but because they don't have money that's why maybe is not working out."

Joy: "Its not a fun money-making thing. I told them that, that the finance must be there and can't also work without money."

Makhazi spoke of needing expert assistance to help the women sew professionally and requiring land space to start a food garden:-

Makhazi: "She is saying that they would be very much happy if someone could come and help out so that they can compete with others (in sewing). There is no problem for them sewing and doing gardening, if they could get enough space."

3.5 Theme 5: Being Hopeful

As the women 'Looked at things differently' whilst reflecting on their lives, there appeared to be a spiritual domain that helped to sustain them. An element of hope and belief that things will be better triumphed as the participants reflected on having a child with a disability and the role of the parent support group. The reflections on the children and group were juxtaposed against the poverty the participants have endured since childhood.

Table 6: Thematic Representation of Theme 5

THEMES	CATEGORIES	SUB-CATERGORIES
5. Being hopeful	Adapting to changes	• Starting a new life • It's all on me - I learn to cope • Enabling factors • The reason He gave me a disabled child
	Enabling dreams	• Unfulfilled childhood dreams • Dreams for my children and me • A successful Parent Support Group

Anne: "Be hopeful, always be hopeful because there is hope and there is light at the end of the tunnel."

Hannah: "You must always have hope if your baby is disabled."

Safia: "Dan dink ek, hoekom moet ek deur die gaan? Gee my die 'strength' om daar deur te gaan, as ek wiet daar is 'n 'light at the end of the tunnel'. Dan sal ek deur dit gaan maar kanallah! Don't let me go through this 'til the day I die, you understand, but to know there is a rainbow at the end of the tunnel then that gives me strength to go through it, you understand. Nou die parent support en almal daai gee my die 'strength' om alles daai deur te gaan. En die werk wat ek nou het, you understand, because se maar nou ek het nie gewerk nie, en ek het nie die parent support group gehad nie, of nie by die meetings attend nie, dan sal ek nie al die 'stress' kon 'gehandle' nie, because then I won't be able to go out or visit my friends, or take the kinders out to the beach, you understand."

"I think to myself, why do I have to go through all this? Give me the strength to endure this. If I knew there was light at the end of the tunnel, I will go through this. But kanallah (please), don't let me go through this still the day I die, you understand. But to know there is a rainbow at the end of the tunnel, then that gives me the strength to go through it, you understand. Now the parent support group and all that gives me the strength to go through all this. And my work. Say for instance, if I did not have work or the parent support group or did not attend meetings, then I would not have been able to handle all this stress. Because then I won't be able to go out or visit my friends or take the children out to the beach, you understand."

The renewed sense of hope coincided with reflections of the past and current situations, and the realisations of their (the participants) inherent ability to adapt to change.

Adapting to Changes

This category describes the adaptation that the participants experienced as women and mothers of disabled children. The process of adaptation was not linear for any of the participants.

This sub-category, 'Starting a new life' reflects how the participants came to understand where they fitted in the world and how managing and resolving problems was like starting a new life. Thus, having a child with a disability was not regarded as an additional problem for the women, but was seen as part of normal life that had to be dealt with.

Safia spoke of all the hardships she had to endure with her ex-husband in addition to their financial difficulties. She had coped thus far, and this helped her see that having a child with a disability was in fact manageable. This illustrates Safia's inherent abilities to cope and adapt to change, with stress giving her the strength to manage any issue with Sameerah.

Safia: "Nou is Giem sinne weg. Die huis is nou klaar, ons kan aan gaan soos ons nou hier aangaan so lank dit net ons. Die wind en reën ons kan nou gekeur word but nou is die 'major stress' wat op my was is af. Nou is Sameerah se stress op my but I don't feel it."

Safia: "Giem's stuff is off me. The house is paid for and built and we can carry on as is. The can be protected from the wind and rain. All the major stress is off me, only Sameerah's stress but I don't feel it."

Joy, in her reflections, acknowledged that her activities and routines changed since Melanie became disabled. She realised that in trying to find her place in the world, she made choices. These choices had obviously shaped the direction her life took, but she gained a sense of control knowing that she could determine her destiny through hope and enabling dreams.

Joy: "And so I lost track of everything. I was active everywhere but when she fell ill I thought no, ja it was like starting a new life. You know, I had to change things - I didn't like for instance my activities outside my

pleasure – my pleasures - now like ballroom dancing, I use to dance a lot. I had to leave all that. Not that I - it was necessary, because just that I thought I didn't want to leave my mother all the time with her and find people to take care of her, and its thereby I just thought ag, leave everything. I just lost everything, lost track with all this children and I'm not blaming the children. I blame myself.”

The participants reflected on all the responsibility they took and how they derived hope out of their eagerness to learn how they coped and believed that God had ordained their path. The participants' ability to adapt to change was based on past experiences with which they had coped. Their religious convictions gave them the inner strength and hope to deal with whatever the Almighty had predestined for them.

The women related how they felt completely responsible for having to manage everything on their own, yet found strength within that ability to be self-sufficient.

Joy: “I mean from the beginning I was self supportive with all my children, and it didn't keep me back in any way as my responsibilities as a mother to my kids.”

Safia: “Algamdoelillah (All thanks to Allah), I'm coping much better than what I did before and I'm more relaxed. Because the last time you spoke to me, there was more "sea water" around me than what there is now because the "waters" were rough and stormy compared to now. Well, I had to accept the fact I had a child like Sameerah, and if I tried to treat her equally like the others then I would be giving myself lots of stress. I can cope with it.”

“Giem bakklei nog altyd oor die 'child-support' want hy will nie die R600 betaal vir sy vier kinders nie. Maar ek kry whatever hy kan gee dan mean dit dat ek moet nou meerder gee en daai cause ook stress want al die skuld, die klere, die kos en al daai le nou op my skouers. Ek gaan

nie allow dat daai moet vir my 'down in life bring nie', I learn by it everyday, I learn how to cope with it."

Safia: "Giem's still fighting over maintenance money for the kids. He does not want to pay R600 for his four kids. I get whatever I can but that means more stress 'cause I have to worry about money for food, clothes – all that on my shoulders. I can't allow that o get me down in life, I learn by it everyday, I learn how to cope with it."

Hannah: "If she is sick no one is gonna look after Nonzuzu. Not that there are no friends around me but I want to do it myself."

Another enabling factor, were the women's spiritual and religious meanings they attached to having a disabled child, which helped them to cope and adapt to changes positively.

Makhazi: " The reason that God give you this child, he wants to know how you are going to feel about this child. Are you going to take good care of him? But if you don't, He is going to give you the worse punishment. The worse from this child. May be something you won't cope with for the rest of your life."

Hannah: "You must be strong, and don't lose hope. You must always have hope if your baby is disabled. If she got sick, within five minutes she might be dead. But if you have hope, you become strong and the baby come right."

Factors enabling hope were those that made it easier to raise a child with a disability, as well as the participant's expectations of their community.

Makhazi spoke about practical things that women with disabled children require to help make things easier for them. She insisted that women with disabled children should get grants as the money would help take care of the child's basic needs. However, her appeal to government was to increase the

grant allowance as the cost of living had increased and the money often does not last the entire month. Makhazi also mentioned how community kitchens or food garden projects could help alleviate the starvation in Masiphumelele. Finally, transport was seen by all women as a necessary commodity. Makhazi stated that there were no specialised educational facilities for disabled children in Masiphumelele. Therefore children had to travel and required transport.

Hannah explained what she needed to keep herself and Nonzuzu happy.

Hannah: "What make me more happy is to find her child that she is happy. What could make me happy is to have everything to support Nonzuzu. Nonzuzu mustn't suffer. Enough money to support Nonzuzu maybe if I am sick or she need something, she must get it immediately. I don't want her to suffer or to need something I might not be able to give it to her. And to be always healthy."

Joy spoke about her need for moral support from Melanie's father.

Joy: "If there can be a father, ok let's not speak about him, but say if I was married, I would have the chance to second a decision or discuss it, then maybe it would have been different. Then I won't sit with the decision or problem alone."

Expectations from the community were about respect and dignity, not only to them as women but towards their disabled children as well.

Makhazi: "The mother of normal kids must not get upset with the child or mother. They must try to help just to explain to the child what you are doing is not right and to come to the mother. And maybe if you could treat the child like this a bit of normal life. I feel that other women must help you, must support you and not laugh at you. This is not your fault."

Enabling Dreams

The women spoke of lost dreams, many of which were attributed to the environment they grew up in (Socio-historical context of childhood/ History of disempowerment). The dreams can be considered as forming part of the "light at the end of the tunnel". The women have actively worked on trying to make some of their dreams a reality.

Safia, Hannah, Joy, Anne and Makhazi all dreamt of becoming professionals but due the context in which they lived, their dreams were not fulfilled.

Safia: "Ja, daai was my problem gewies, ek het aanhoudent 'ge-relive' the past, soos my pa getrek het. 'Cause hoe kan ek sê, ek het hoe drome gehad, en because my pa was so abusive, ek konnie daai drome experience nie. So daai was my dream, om 'n madrasa teacher te word, enige teacher te word, om met kinders te werk. En 'n airhostess en 'n nurse. Nou daai tyd moet jy mos qualifications gehad het. Ek het high aims gehad which my pa konnie vir ons gegee het nie want hy het nie ons se toekoms voorgesien nie. That's why ek try om my kinders 'n toekoms te gee en ek weet ek kan dit vir hulle gee."

Safia: " Yes, that was my problem, I kept reliving the past as my father moved. How do I put it, I had dreams but my father was abusive therefore I could not experience those dreams. My dream was to become a Moslem school teacher, any teacher, to work with kids. And an airhostess and a nurse. I had high aims but my father could not assist because he never planned for our futures. That's why I try hard to give my children a future which I never had."

Hannah: "When I was young I wished that I would be educated and be wealthy, get married, and have children. I never thought I would drop out and suffer the way I did. I wanted to be a teacher or a nurse."

Joy: "I used to say, a teacher, but I never reached there."

The participants shared some of the dreams they had for their children and themselves now, which originated out of a desire to compensate for unfulfilled dreams.

Safia: “Daarom toe Abduragmaan vir my se hy will standard ses los, skool los en gaan werk, toe se ek “NO! jy gaan in daai skool bly want die main aim is education en daai is baie important”.”

Safia: ' That's why when Abduraghmaan told me he wants to drop out of standard six to work, I told him, "NO! You will complete your schooling. Education is the main aim. It's important."

Joy: “Well, I hope one day my children can look up to me and maybe I can sit back if they can see all the things that I do for them. That's what I'm hoping for.”

Safia's dream of becoming a teacher has partially been fulfilled as she started as a sessional teacher aid at the Learners with Special Educational Needs School in Ocean View. This opportunity evolved from Safia's involvement with the parent support group.

Safia: “Dan wou ek 'n teacher geword het, 'n madrasa teacher, but nou at least kry ek dit reg hier, alhoewel dit is maar whatever, but at least ek werk met klein kinders.”

Safia: " I wanted to become a teacher, a Moslem school teacher, but now I'm at least achieving something by working with children."

A successful parent support group meant achieving solidarity and striving towards economic empowerment for all of the women.

Anne describes what her dreams are for the parent support group:-

Anne: “I do have hopes and dreams of taking much further - being very busy and even at the end of the day I should stop my part-time job. Just go into doing, just this. I'll be happy in doing just this.”

The participants from both communities were keen on involving more fathers in the parent support groups.

Joy: “Fathers are slap. You try to get them there, but they are very slap. I think they more shy than the mothers are and not shy. I'm sure there's something else that's keeping the fathers back. I don't know what language to use to get the fathers here, so I don't know. Ja, uh, that's my next aim for this group; to get more men involved because that's also means of support. I know that if we stand together we can make a difference.”

Group success was also about expanding the membership and acting as role models to the community, as Makhazi explained:-

Makhazi: “ We haven't started yet, but we still talk about it at the "mothers with disabled children group" and we feel that we must do it. It's the right thing to do. I wish that if Siyazama could succeed and be a good example so that more people, disabled kids could join to make it work and worth it for them.”

The participants from both groups agreed on the need to get financial support to accomplish their dreams for the groups. Hannah made several suggestions of how to revive Siyazama:-

Hannah: “I would love them to meet again and start a group again and share ideas and get advices and help each other, because now that she's lost interest of going there, but if they could meet again and form a big group maybe all the mothers to come and decide on what must be done and how to go about it. And going back to the point of money, if they could reunite again, I feel they must pay money to buy stuff, because every time they go to follow a meeting after the meeting they always talk. We are wasting our time, we don't have money we are just talking and talking but there's nothing going on. If they could have that

money, I am also volunteering that I could sell stuff in my house. I told them before if you want to sell something I can help out. If they could meet again and work out something put it into process that would give me more interest to go to the group. After the meeting when I come home I could tell my husband - explain what's going on, because now there's nothing much to tell, this is happening this is not happening."

The participants in Ocean View conducted home visits to inform parents of the support group. The Ocean View women agreed that the visits were productive, and that they needed to maintain such a level of personal contact. Joy said that the home visits would serve as a means to motivate parents to attend the support group. She also thought that the group somehow needed to alleviate the needs of parents who lived in absolute poverty.

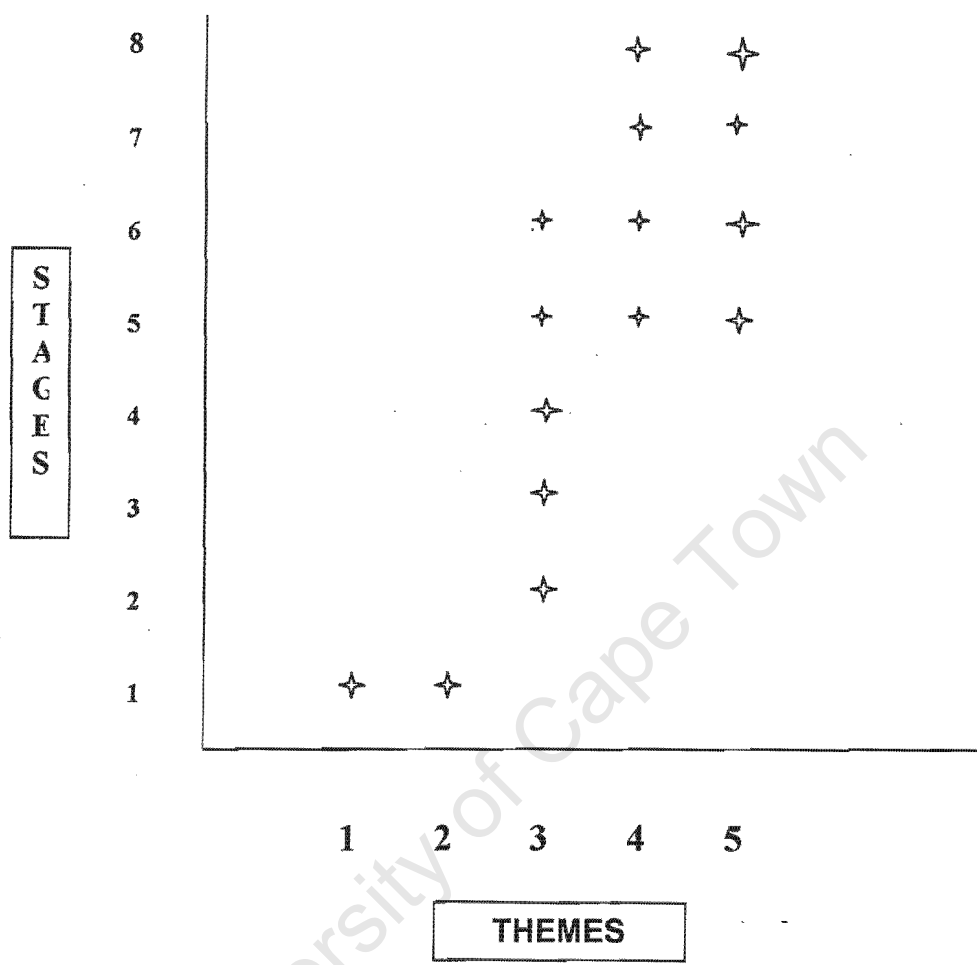
Joy: "Nou moet 'n mens nou elke week nou "hello" se vir julle mense, dan sal julle nou nader kom. Now that's also how you get people to understand what you doing and what you busy with and what the support group stands for. You belong to a group and you should say if you don't have food for this week or if there is anyone who can give me half a dozen eggs and loaf of bread. We must aim for success."

Joy also mentioned needing to work on their communication skills to help deal with some of the group dynamics.

Joy: "To communicate for one another, and if there is a problem to sort it out in a decent way. I mean we're adults, sort it properly and don't bear grudges because that's not going to build the group and make the group strong."

Results hereafter have been interpreted and represented within Bridges' (1991) conceptual framework.

Diagram 3: Graph depicting the interception between the Themes and Stages of the Transition Process model (Bridges, 1991).



Refer to Appendix 8 (page 128) for a tabular version of the themes versus the stages of transition by Bridges (1991)

Notes: Each theme reflected a passage through time. The various stages of Bridges (1991), transition process model can be paralleled with the themes that have evolved in this study. Stage 1 (routine as usual) of Bridges' (1991) model (refer to page 12) is similar to theme 1 and 2. These themes describe the constant, routine life of the women. The richness of the women's usual routines served as the foundation of their transition process. Their sense of hopefulness was fostered as they developed from children to teenagers to adults. As they reflected on past events in their lives, they derived at new meanings in their life and gradually became empowered

by developing the courage to speak out. (Refer to results section, page 42-43). Their values and beliefs enabled them to speak out and empower themselves over time by becoming more self-confident. Their value and belief systems reinforced their self-identity.

All the participants have narrated that the discovery of their child's disability changed their lives significantly as reflected in theme 3. This major change event disrupted their usual routine – comparable to stage 2, Change Event (Bridges, 1991).

The decline and letting go (stages 3 and 4, Bridges, 1991; see page 12), is highlighted in the stories that the women reveal about living and loving their disabled child (refer to Theme 3). Most importantly this involves dealing with the acceptance of the disrupted routine as a result of the change event. (refer to results section page 45, theme 3, category: Living with and loving my disabled child). The element of being hopeful is reflected in the women's spirituality and meaning making related to having a disabled child. Their religious convictions that is, their faith in God and prayer enabled them to persevere and adapt in times of hardship (reflected in theme 1, category 1: Values and Beliefs). This highlights that an inter-relationship exists between the themes. This relationship indicates that the themes in this study are not as linear as the stages described by Bridges (1991).

The ambivalence which the women refer to in Theme 3 can also be linked to the confusion stage of Bridges' (1991) model (that is, stage 5). The women revealed incidents how they adapted to change when they were faced with new challenges with their disabled children.

Theme 4 and 5 links to the creativity and vision stages, (Bridges, 1991). The women had chosen to become involved in a parent support group within their own community. Their motivation to participate in a parent support group (Refer to theme 4) is the creative means in which they began to develop a vision of their future in which they would bring about significant changes in their lives and within their families and their community.

The sense of renewal (Bridges, 1991) is supported by theme 2, (Looking at things differently, category: Speaking with courage), in which the women reflect on what their lives were like before the major change event. This involves letting go of past meanings and having the creative spark to channel the consequences. Deriving at new meanings brings about a "sense of renewal" during their involvement with the parent support group. The parent support group introduced a set of new routines for the participants as they were engaged in new activities. This rejuvenated their spirits and contributed to their sense of being hopeful as reflected in theme 5. The experience of becoming hopeful during their involvement with the parent support group influenced the meaning they assigned to their experiences (as reflected in themes 1, 2, 3,4 and 5). Hopefulness emerged as both an ongoing process (Theme 5, category: Enabling dreams) and as an outcome of change (Theme 5, category: Adapting to changes) within the parent support group. This hopefulness was affected by the environmental demands or constraints.

The following chapter discusses the relationship between the process of identity formation, gender identification, the role of the parent support groups and empowerment. All the themes impacted on the women's identity building. In the discussion that follows, key elements of the conceptual model are integrated.

CHAPTER 4

4.1 Discussion

The discussion brings together key issues from the findings and draws on literature stated previously. The key issues include understanding how identity develops and what influences the development of these women's identity. The women's identity shaped the present roles they assumed. These roles are explored and discussed here within the particular context of having a child with a disability. Furthermore, matters pertaining to parent support groups are explored in relation to the development of the women's identity and experiences of empowerment and hopefulness.

The Process of Identity Building

The participants' process of identity-building evolved in a unique way and was formed within their own time and space. Their (women with disabled children) personal narratives influenced this process of identity building. According to Christiansen, (1999) life-stories are a validation of our identity. The interpretation of life-stories fosters a better sense of who we are. The interview process captured but only a snapshot of the participant's time and space. The women in this study narrated aspects of their life-stories during the interviews. The women's life-stories revealed who they were and what they had become as members of a parent support group (refer to findings, theme 4, category 2 and 3). Indeed, there are many other components of the women's lives that were not explored (such as dealing with the dangers within their communities) but are acknowledged to exist.

Christiansen (1999) describes identity as a means by which people derive meaning from their lives through engaging in occupations. He also maintains that identity is influenced by interpersonal relationships. Occupations create meaning and maintain an individual's identity in life. The puzzle (Theme 1) was used as a symbol to describe the participants' identities as women with disabled children. The symbolism attached to constructing the puzzle and reconfiguring it varied between the women in this study. Each piece of the

puzzle represented that which constituted each woman's identity. Identity construction is a multifaceted process. The variables described below illustrate the complexity of this process.

The women's value and belief systems were strengthened over time. This contributed to their unfolding process of identity formation. Butler (cited in Levy in Willard and Spackman, 1988) indicates that the search for identity is a life-long process. Their values and beliefs represented who they were and what they had become at the time study was conducted. These values and beliefs not only concerned their perceptions of motherhood but of their womanhood as well. The women's value and belief systems were influenced by various factors within their environment including their socio-historical context in which they grew up, their own lived experiences and perceptions of civil society. These factors will be explored further.

Identity and Context: A Socio-historical perspective

The women's formative years were riddled with poverty and many social problems. Poverty placed limitations on the women's occupational opportunities throughout their lives and ultimately determined their occupational choices. The participants shared their childhood dreams and made it quite clear that they were not realised. They attributed this to their poverty stricken circumstances. This forced them to make sacrifices in their life decisions. The environmental press was exacerbated for each woman as she responded to the demands of rearing her disabled child. This again influenced the nature and frequency of the occupations she engaged in.

The apartheid regime deprived women, particularly Black women living in rural areas, of their civil rights by denying them access to opportunities that could enhance their personal growth and development. This was clearly evident with the participants in this study. The women from Masiphumelele spent their childhood years in rural areas. The geographical location disadvantaged them from gaining access to essential commodities such as education. The Ocean View women experienced a different kind of deprivation, which forced them to deal with other social issues, such as over-

crowding and minimal wage income. One factor remained common to both sets of women in this study that is, they were forced into child labour to help the family to survive financially. By sixteen years old all of the women were working full time, just as their mothers did in the previous generation.

Being Engendered

Social rules determine how boys and girls are socialised into a particular society, (McWhannell and Blair in Jones, 1998). Gender identity is socially constructed and is specific to a particular society, culture and historical context. Gender and the contexts in which people reside in are interrelated and thus needs to be explained in relation to one another. The following discussion outlines the relationship between gender and context.

An impression of motherhood and womanhood was established in the women's formative years. Childhood memories were related with joy and sadness. Theorists such as Ruble (1983 in Christiansen, 1999) maintain that identity is influenced by social relationships established in childhood, and shaped as children mature. Adrienne Rich, the North American feminist, supports the idea that motherhood is socially organised but that there are historical and cultural differences. Rich (1990) professes that motherhood as an institution is socially organised, is overshadowed by men and thus oppresses women, (in Lawler in Cosslett et al, 1996). The institution of motherhood equates a woman's identity with maternity. In turn, maternal work has come to define the entire identity of women even though it may or may not be a temporary aspect of her life. Rich (1990 in Lawler in Cosslett et al, 1996) suggests that because of this association, a woman's maternal work is reduced to a 'natural' part of her identity. "Nurturance, patience and the rest are not valued (or paid for) because it is considered 'only natural' that women should care selflessly and unconditionally, not only for children, but for adult men also." (Lawler in Cosslett et al, 1996, 154).

During adolescence and adulthood, identity continues to be influenced by social factors. These factors created multiple levels of challenges for women with disabled children. This included contributing to their family's economic

viability during adolescence or being married by early adulthood and becoming mother's to a disabled child.

The gendered division of labour that the women were exposed to and the discrimination they endured as women with disabled children contributed to their identity formation. The women's perceptions of themselves were clearly influenced by familial and societal expectations to engage in traditional paid employment as well as to conduct themselves appropriately as the primary caregiver to a disabled child. Erikson (1968) and Baulmeister (1988) indicated that the focus in adolescence is on consolidating values, interpersonal traits and preferences, whereas in adulthood the concerns are more about aspiring to become a certain person accepted by society, (Erikson, 1968 and Baulmeister, 1988 in Christiansen, 1999). Being accepted by society was not only meaningful to the women themselves, but to their disabled children as well. It was important for the women to be acknowledged within their community. This acknowledgement enabled the women to feel good about who they were. Hence, the women were keen to build on who they had become.

Identity building that is socially acceptable enhances a person's sense of well-being, (Christiansen, 1999). The developmental theorists referred to above describe the growth of humans as linear, which evolves in phases. The women in this study did not fit such a linear model. Their stories revealed a jump between adolescence and adulthood compared to the smooth transition theorists suggest. (Refer to page 37, where the participants describe their life as teenage workers).

The Reality of the Roles Women Assume

Barrett (1997) found that rural African women have triple roles within their key role of sustaining families and communities, as cited previously in the literature review (see page 9). All the women in this study depicted the roles of women in a stereotyped, traditional sense; that of nurturing children, tending to domestic duties and being forced to leave school early to help support the family financially. The women in this study grew up learning

about being a woman as they began to define their place within the community in which they resided. This involved learning about the different roles men and women had in relation to one another.

This is the case in Ocean View where participants were more explicit in their descriptions of what was expected of women and men within their culture and community. Men played a dominant role in the community and assumed the traditional head of the household position, as they were expected to be the main breadwinners. The women at the time were expected to adopt a key role in the domestic or private domain. They were tending to the household and nurturing children and sick relatives. Despite these expectations, this was not the case for two participants in Ocean View. They narrated stories of their own mothers going out to seek paid employment in order to sustain the family economically in the absence of a male breadwinner.

The Ocean View women were born out of an urbanised generation. They lived in the city and were exposed to the industrialisation of life. The women from Masiphumelele have a rural heritage. These participants were exposed to very harsh environmental conditions in which subsistence farming, for example, formed an important part of their daily life. They witnessed how their own mothers were forced to endure manual labour in the fields and still tend to household duties. As children, the participants from Masiphumelele adopted similar roles and tasks to their own mothers. However they were confronted with having to adapt to an urbanised way of life when they moved to the city in search of health advice for their disabled child and seeking paid employment. This adaptation involved assuming roles and tasks, which were unfamiliar and distinctly different from before.

The survival strategies were different for both sets of women although they shared the same purpose, of ensuring the survival of their family. The women's impressions of what was expected of them were communicated to them from a very young age - to ensure that the family survives before pursuing their own needs. This ensured that their respective communities perceived them as 'good mothers'.

An eclectic gender perspective enables one to analyse the above scenario at multiple levels. The manner in which the women's experiences within their immediate environments generated specific gendered roles is explained below, (Thomson, 1993 in Primeau, 2000). Thomson (1993 in Primeau, 2000, 121) provides an organisational framework that links the four levels of analysis, namely: "the broader socio-historical context, the immediate context, inter-actional processes, and individual outcomes". The immediate context or environment impacted directly on the women's gender identity. Feelings, behaviours and beliefs are shaped by everyday circumstances and happenings.

Ruddick (1990 in Stone in Cosslett et al, 1996) maintained that maternal work is more than just emotional, intuitive and a physically-based activity and is in fact disciplined, rational and reflective. Maternal work aids the development of people, which all adults can be engaged in irrespective of whether they are male or female. Maternal thinking underlies maternal work and is comprised of preservation of the child's life, facilitating the growth of children and ensuring that children are reared in a way that enables them to be socially acceptable. The women in this study have illustrated in their narratives the discipline, rational and reflective thinking required in rearing a child with a disability. They have indicated that their disabled children's lives were worth fighting for to ensure that they, too, should be accepted within society. (Refer to Theme 3 for examples such as page 45 for quotes by Anne and Hannah; page 45-46 for a quote by Makhazi).

The women's upbringing did not allow for maternal work to be embraced by men. The occupations the participants' saw men engage in from a young age were typical of the public domain. The Ocean View women witnessed men engaging in paid employment in the industrial setting. The women from Masiphumelele saw men migrate from subsistence farming towards an industrial urban life. The gendered division of labour was intensified by industrialisation. These Western notions placed women in the private or domestic sphere in the key role as nurturer, emotionally sensitive and

domestically bound. Men's roles were viewed by Stone (in Cosslett et al, 1996) as rational, independent and economically productive in the public sphere. The context in which the women lived determined the type of occupations they engaged, in which in turn, was influenced by their gender identity, (Dunn, Brown and McGuigan, 1994).

When the women in this study related their current situation, the roles they assumed were similar to that of the previous generation of women. The women had the role of nurturer and worker. The added responsibility was that of being the main caregiver to a child with a disability. The Ocean View women also assumed the breadwinner-role within their family nucleus. The triple roles placed enormous strain on the women. Many parents of disabled children have begun documenting their experiences in rearing a child with a disability. By sharing their experiences, parents of disabled children are attempting to expand this global network of support. One such parent is Jennifer Simpson who acknowledges the joys and difficulties of parenting a child with a disability. Simpson admits that being told that "your child is disabled" is not easy and that the rearing of a disabled child hereafter is even less easy as the volume of work is "bigger, louder and more compelling", (http://www.empowermentzone.com/par_dsb.txt, 01/08/22 at 01.58).

Culturally the women from Ocean View and Masiphumelele were very different. Communal living has different connotations for the participants. Privacy was more of a concern for the Ocean View women as they equated it with respect and acknowledgement. An invasion of privacy by the community in which they resided was interpreted as a deprivation of their civil liberties. The participants had a great need to be acknowledged and respected as equal members of society and not to be looked upon with shame. Having a child with a disability exacerbated the discrimination they endured as women living within an impoverished environment. This in turn affected their perception of self-worth. The environmental pressure resulted in the constant reconfiguration of the women's identity.

As the women reflected on their past and current situations, they began to re-interpret the events in their life. Larson (2000) described this phenomenon as "perspective-shifting". "Perspective-shifting" is described in terms of a process. It illustrates how individuals shape the direction of their future by understanding their past through reflecting on who they were and what they did and what they have gained. For the women in this study, this meant reflecting on their poverty-stricken lives as far back as they could remember. Poverty remained a common factor for all the women in this study. It had a significant impact on their lives as women with disabled children. The women were faced with a daily challenge to survive and creating innovative ways of fostering the development of their family and themselves.

The role of women as caregivers, particularly for the mothers, are imposed to a large extent by cultural, religious and societal expectations, (Boylan, 1991). This impacts on the women's choice making which is further restricted by poverty, as she is unable to generate an income. The women's current living conditions still indicate immense poverty, yet they were modest according to their descriptions, and related a deep sense of gratitude for that which they do have.

The Woman's Role as Primary Caregiver

The gendering of women does not permit them to relinquish responsibility in caring for their families and children, particularly children with a disability. However it 'allows' for the absence of caring for the masculine set. Why is that? The ideology of familism is constructed on the basis of a nuclear family, with the man being head of the household and main breadwinner, and the woman tending to the domestic and nurturing aspects, (Dalley in Beattie et al, 1993). Familism operates as a principle of social organisation at the domestic and public level within society. Women are predominantly placed in the private sphere, tending to domestic duties, and men to the public sphere with a key role as breadwinner overseeing to the family economically. Theorists such as Bowlby (1953) and Leach (1979 cited in Dalley in Beattie et al, 1993) have supported this gendered division, favouring the domestic carer role of women, and suggesting that children will suffer if separated too early from

their mothers. This unfair division of labour shifts the responsibility away from the man as father, onto the woman as mother and caregiver, holding her ultimately responsible and accountable for the outcome of child-rearing. Men thus gain economic power over women in the public sphere and domestic sphere on the foundation of such an ideology. The women in this study experienced the remnants of such an ideology. The reality for them is that many of their children's biological fathers are absent in their lives. Three of the biological fathers were not supporting their disabled children financially. Three of the women in this study adopted dual-parenting roles defying the 'rules' of the private and public sphere. They were the breadwinners and soul providers for their disabled children. The environment in which they lived contributed significantly to their choice making as occupational beings.

Literature has indicated "child rearing and its evaluation are always the product of person-in-culture" and that "our understandings can not help but tell us about ourselves", (Rogers in Beattie, Gott, Jones and Sidell, 1993, 164). We arrive at a sense of who we are by evaluating the social world. The self and the sense of self are themselves socially constructed. The mothers of disabled children have been referred to as the "invisible victims" as they are subject to the same oppression and discrimination their disabled children endure (Boukhari in Abu-Habib, 1997, 36). These mothers' opportunities for further education, employment and leisure pursuits have been limited because of their duties in being a caregiver requires of them, (Boylan, 1991; Abu-Habib, 1997; Whyte and Ingstad, 1998, Meyer and Moagis, 2000).

The women's religious convictions gave them the strength to be able to manage difficult tasks in their lives. Their religious beliefs underpinned their perceptions of being a woman and mother. God and prayer form an integral part of their lives. All the women believed that God would not give them that which they are not able to cope with.

The identity building evolved into a strategy on how to survive and be safe within an impoverished community for a woman with a disabled child. The survival and safety constituents are parallel to those of maternal thinking,

namely the preservation of life and facilitation of growth of a child to ensure social acceptability. All of this relates to the notion of 'good mothering'. The puzzle as a symbol represents the women's constant negotiation for survival amidst the poverty they live in together with their disabled children. This negotiation is further challenged by the need to maintain relationships with family and others. The strategies for survival witnessed and learnt in the women's formative years came from observing their own mothers.

The Heightened Gendered Implication for a Woman with a Disabled Child

The gendering of a woman with a disabled child is more intense. The expectations of these women have been personified as reflected in their stories. Women of disabled children have a heightened sense of awareness about being a good mother. According to a study conducted by Larson (2000), mothers of disabled children were found to be very conscious of how they engaged with their disabled children, as it was a reflection of being a good mother. Thus "mothering a child with special needs required additional skills, knowledge and organisation", (Larson, 2000, 273). The skills refer to being able to manage a child with special needs; the knowledge refers to information about the child's disability and the organisation involves managing a daily routine. A positive outcome of mothering is closely related to the woman's subjective well-being and hence the perception of being a "good mother". Christiansen (1999) further states that people derive meaning from feelings of self-worth, which is achieved through the approval of others. The participants valued the positive reinforcement received from family, friends and the community about their ability to be a good mother. Being viewed as a good mother by others, enhanced the women's self-worth. (Refer to Theme 1, second category, page 34, a quote by Anne.)

The Complex Discourse Act of Loving a Disabled Child

The internalised guilt and blame associated with having a child with a disability is linked to the deep sense of obligation to take good care of the disabled child, as the participants felt completely responsible for the well being of the child. Nurturing a child with a disability placed physical and

emotional demands on the woman as caregiver and on the family. The love and affection was portrayed in physical manifestations, which appeared to be the easiest part of caring for a child with a disability. Loving your child and taking good care of him/her meant carrying out physical tasks that proved the affection. In so doing, there would be a visible outcome that society could note. The women thus received verbal feedback, which helped to reinforce the notion of being a "good mother". A concept noted by Mead (in Christiansen, 1999) is symbolic interactionism, the main premise of which is that the individual and society are interdependent.

The demands and need for assistance by the women as caregivers, presented itself in various forms. These numerous demands placed strain on the roles the women adopted in life. Several of the women had triple roles: - mother, wife/partner and breadwinner. The biological fathers had more difficulty coming to terms with their child's disability and did not appear to have played an active role in rearing the child yet society granted them a concession. Unlike, the women who were gendered in such a way whereby they were expected to cope and be strong thereby not forsaking the parental role. The participants were viewed within their community as having to bear the entire responsibility for the disabled child. The societal pressure, including that from the family, held the women responsible and accountable for the child's well-being.

The women's acceptance of their disabled child emerged at various stages in the child's life. Each incident, positive or negative in the child's life, forced the woman into a reflective state, reconfiguring their acceptance, their feelings towards their disabled child and about themselves as mothers. All the women named the discovery of the child's disability as one of the most taxing incidents, which spear-headed the direction their lives took. The interviews allowed for space to reflect and re-accept the outcome of their lives, gaining new insights into who they were and what they had become. Simpson (http://www.empowermentzone.com/par_dsb.txt, 01/08/22 at 01.58), indicated to parents of disabled children that the grieving process, as depicted by theorists and professionals, is in reality not a linear model. She admitted

that the course of her feelings in coming to terms with her child's disability was in fact not linear. There were times in her life where she cycled between anger and denial when confronted with a new decision that would affect her child's well being. Even though Simpson has lived through a decade of accepting her son's disability, there are occasions when feelings of grief are evoked. The women in this study narrated many incidents, which reflect the sentiments of Simpson. The conceptual model reflects a process, which is not linear. This meant that the participants' experiences were influenced by the environmental context at the time and their mean-making. (Refer to end of results section).

Sacrifices, Changes, Adaptation

The women acknowledged changes in their occupational patterns as their disabled children grew up. The burden of care placed on the women in rearing a child with a disability intensified the role strains in the public (as a worker) and private (as a caregiver and housewife) domains. Poverty only compounded the issues the women had to face up to. The disabled child's well-being determined the extent and choice of occupational engagement for the women, be it at work or home. The women sacrificed certain activities that they may have enjoyed or wanted to pursue in favour of their disabled children's needs at the time. The dual-parenting roles certain women assumed complicated matters even further.

The women's past experiences of surviving times of disempowerment enabled them to adapt to the ever-changing circumstances of raising a child with a disability. They constantly adapted to the changing needs of their disabled children. This manifested during incidents that were embraced with joy and turmoil simultaneously. Larson (2000) described the embrace of paradox as key times when mothers were at a disjuncture of experiencing happiness and despair during significant points in the life of their disabled child. Thus during a key incident, (like attending school, deciding on a type of surgery) these women have had to renegotiate negative feelings which again indicates that their experiences are not linear.

Constructive adaptation was attributed to two major factors; namely, family support and financial assistance from the state in the form of a grant. Family support enabled the women to pursue occupations such as paid employment as a relative was prepared to take care of the disabled child during that time. This helped to alleviate the burden of care placed on the woman. The assistance and interest shown by family towards the child with the disability served as positive reinforcement for the women in this study. Financial aid from the state helped to alleviate the financial strain for three women. Tending to the needs of a disabled child is exorbitant. Without financial aid, the difficulties in rearing a child with a disability is exacerbated for the women as related in this study.

The women's religious beliefs and spirituality were intertwined and remained a source of strength to remain hopeful about the future. They remained hopeful about the future and the ability to cope with a disabled child. All the women believed that their Creator would not have given them something that they would not be able to cope with. Thus a child with a disability was seen as worth fighting for. These children gave the women happiness, love and brought them closer to God. Their faith in a God was tested on discovering the child had a disability and each mayhem hereafter. Larson's (2000) finding supports this notion. These women found meaning in faith, which helped them in turn to "embrace the paradoxical joy and pain of parenting a child with a disability". The women's faith in God enabled them to love and live with a disabled child amidst all the difficulties and challenges they faced.

In summary, the gendered implications for women with disabled children are the exacerbation of their roles and duties within the domestic sphere. The demands placed by society on women with disabled children are heavy. Women with disabled children tend to sacrifice themselves in silence, in return for the affirmation of their worth from society. The research findings have indicated that having a disabled child inhibited the women from pursuing occupations they desired. Poverty freezes them even further.

The Parent Support Group – As an Agent of Change

The women joined their respective parent support group for various reasons. Even though only one woman verbally stated that the main reason for joining the group was their disabled child, it can be inferred that this was common to all the women. They sought support from a group that could empathise with their experiences as a parent of a disabled child.

The fundamental difference between self-help and support groups lies in the outcome of the group, (Wilson, 1986). Self-help groups are aimed at providing support and educational information to its members who share a common life problem, (Gidron, Guterman and Hartman, 1998) to facilitate change through an educational and supportive medium. The purpose of support groups is purely to offer emotional support. The two parent support groups developed quite differently from the start. Initially both groups were focused on providing emotional support to each other. At a later stage, the groups decided to embark on an advocacy campaign within their communities to raise disability awareness, market themselves and to try and gain recognition for both the needs they and their disabled children had. The stories related by the women indicated the direction in which the groups grew. The women from Masiphumelele wanted more than emotional support out of Siyazama and needed to engage in self-help economic activities to bring about change in their financial situations. Siyazama evolved from a support group to a self-help group. The women in Ocean View focussed more on enhancing the emotional support aspect of Outlook parent support group.

The philosophy of self-help groups is supported by Gidron et al (1998) who maintained that the purpose is to provide space for people in which they are acknowledged and supported and this helps to counter the culture of silence. Critics such as Mantell et al (1976) and Ringler et al in Gidron et al (1998) have conveyed their concern about the quality and nature of emotional support at self-help groups in the absence of trained professionals. Hardly any of the women alluded to the role the researcher played within the groups, nor any other professional who may have sat in on meetings. From a methodological point, it could not have been explored in great detail through

direct probing. The Entrepreneurship Development Institute (EDI) in India, have also compiled programmes that focus on organisational and technical skills in building the capacity of women entrepreneurs. The main premise of EDI was to develop an entrepreneur trainer-motivator (ETI), (www.ediindia.org/CFT.htm). The ETI's role was to train, motivate and guide other women entrepreneurs, thus following a group and population approach. By investing in human capital within India, more women could be reached. For the parent support groups in Ocean View and Masiphumelele, the research assistant acted as facilitator to help guide and motivate the women. More research needs to be conducted to explore with the women how significant a role the facilitator plays, especially if professionally trained.

Boylan (1991) speaks of the value of parent groups, particularly mothers speaking out in public, expressing their opinions on inadequate rehabilitation services and the need to become more proactive. In addition, women as caregivers have expressed a need for recognition through community support, financial help and skills to be able to effectively care for the disabled child/adult as they have been ignored for too long. Parent support groups are avenues through which parents could fulfil their needs and build themselves up. Outlook and Siyazama served as a stepping-stone for the women to fulfil unmet needs as parents, mothers and women. These benefits of being affiliated to a parent support group are described below.

Linking the Parent Support Group and the Women's Identity Formation

Competency achieved in occupational engagement contributes to identity shaping, (Christiansen, 1999). The parent support groups afforded the women several opportunities to engage in occupations that enabled them to do, to be and to reflect within the group. A person's new identity in later life is said to be derived from discovering new uses for what has been learnt during previous years, and from developing innovative means of coming to terms with reality, (Aiken in Levy in Willard and Spackman, 1988). The participants in this study have used their respective parent support groups as a new way of coming to terms with their reality – being a woman with a disabled child

living in an impoverished community. Being affiliated to a parent support group was not about finding a solution but about sharing experiences and looking at other opportunities for the women.

The participants' self-worth was tainted by a society, which did not ultimately value them as women with disabled children. The women exhibited an internal desire to be acknowledged and affirmed as a good mother. The parent support groups and DiCAG provided them with some salvation to regain their sense of self-worth and remain hopeful to the possibilities for change towards an enhanced quality of life for themselves and their families including their disabled children. Hence the women found it meaningful to be affiliated to a parent support group and DiCAG.

The Benefits and Values Ascribed to a Parent Support Group

The mobilisation workshop facilitated by DiCAG appeared to have a profound impact on the women. The workshop brought about a sense of group cohesion within each parent support group gathering. It set a precedent whereby the parents were motivated to become more empowered as they were acknowledged and recognised as worthy human beings who were entitled to equal rights. The women gradually became informed about the rights of their disabled children. The workshop was a powerful advocacy tool in which the sharing of experiences and mutual support was high on the agenda.

The parent support group served as an outlet for the women to be acknowledged, heard and emotionally supported as a parent of a disabled child. It presented an opportunity to share stories in a safe environment where they were not judged for what they had experienced as a parent of a disabled child. (Refer to Theme 4, the second category, What it means to me, for example on page 65-66 for quotes by Anne, Safia, Joy and Makhazi). The recognition the women received not just as mothers of disabled children but as women with needs, along with the affirmation received within the group, enhanced their self-worth and empowered them to seek further opportunities for personal growth and development.

The parent groups were comprised mainly of women (as mentioned previously); yet the name parent support alludes to equal gender representation. Several women acknowledged unequal balance of parenting as the biological fathers negated their responsibilities towards their disabled child mainly because they could not come to terms with the disability. The sharing of stories was symbolic to all the women, as the society in which they were gendered did not allow space for women to be heard and affirmed. Thus, talking about concerns and problems defied the conventions of their society in which women were expected to be subservient, not complain, but remain silent. This open communication was thus perceived as an act of weakness on the side of the woman, "who could not cope on her own". The silence the participants knew and observed dated back to their own mothers who were discriminated against. The participants and many of the other women who joined the parent support groups thus rebelled against a system of oppression and silence by having the courage to speak out. The women were familiar with disempowerment as they, too, experienced it in their lives. All of the participants were victims of discrimination. However, they chose not to assume the "victimic", (Polkinghorne, 1996) role and instead these traumatic childhood experiences served as motivation to bring about life changes. The parent support group made a significant contribution towards developing the women's ability to gain the strength to speak out to others in the community in their advocacy campaigns.

The changes that the women experienced impacted on their families' lives as well, (Refer to page 72 for a quote by Anne). According to Antonovsky, (1979 in Christiansen, 1999) individuals with a sense of coherence see their lives as understandable, meaningful and manageable and are thus able to cope more effectively with sudden life changes. The affiliation to a parent support group and a mother body organisation such as DiCAG also afforded the women many opportunities to empower themselves through skill acquisition and knowledge. The skills and knowledge acquired helped the women to develop their inner resources and strengthen their survival strategies. The mutual sharing, advice-giving and assistance within the

parent groups helped build on the women's self-confidence to be able to face more challenges in times of adversity.

Based on the narratives of the women, the two groups experienced a sense of group cohesion in different forms. The women from Masiphumelele had varied perceptions as to whether their group did in fact experience a sense of Ubuntu, as the group struggled to form an identity and lacked consistent leadership. Building a sense of cohesion continued for both groups as it determined their existence and sustainability. The difficulty in forming group cohesion contributed to the conflicting perspectives of the Masiphumelele women regarding the viability of their group, Siyazama. What remained apparent for both groups was the discrepancy between meeting personal versus collective group needs. Individual needs as expressed by certain participants were not always in line with the group's needs, which proved to be detrimental to the survival of the group. The organisational dynamics within the groups related to poor communication, power struggles and limited skills to manage tasks, all issues identified as important for the group. Thus the success of a parent support group according to the women was dependent on several factors. These factors included resources, financial support and technical support, which were considered important to ensure that the groups could be sustained in the long run. Strong leadership was necessary to help co-ordinate the group. Enhancement of communication skills was imperative to help group members deal with organisational dynamics.

Both groups struggled to maintain and increase their group membership. Literature has indicated that groups cannot continue to exist without new members and that existing members cannot benefit without regular attendance, (Luke et al, 1993, Kurtz et al, 1995, Gidron et al in Powell et al, 1995 in Wilson, 1986). These parent support groups promote the principles of community development such as the active engagement of community members for the upliftment of not only themselves but also others within the community, (Refer to Results section, Theme 4 page 65, 66, 67, 69, 70 and

71). However, it illustrates an approach that can be paralleled with Women in Development (WID), (Moser in Hedman et al, 1996)

The greatest criticism of women in development in the 1960's was that it isolated women from the mainstream of development. By the mid-1970's, the empowerment approach evolved to shift the focus away from women to gender in development, (Moser in Hedman et al, 1996). The support groups did not evolve as a microcosm of their communities, in fact, it only highlighted the gender disparities – poor representation by men. The reality for most of the women was that the males were indeed invisible partners in fostering the growth and development of their disabled children (as discussed previously). So it seems almost obvious that the male membership would be low. However, the women recognized the need to include more men in the groups.

Nonetheless, the women acknowledged the transformation in their being and becoming as empowered women with disabled children. The transformation can be equated with the women's personal growth and development during this process of empowerment through the parent support group. Projects in India have supported self-help groups as fostering empowerment. "Self Help Groups (SHG's) of women in India have been recognised as an effective strategy for the empowerment of women in rural as well as urban areas: bringing women together from all spheres of life to fight for their rights or a cause", (<http://wed.nic.in/webs/Ignou1.htm>). The affirmation the women experienced came from family members, group members itself, and the broader community. A clear indication of the value attached to being affiliated to their parent support group, (refer to page 71 for a quote by Joy and Anne as examples to illustrate this value). The women's self-efficacy was enhanced and this motivated them to continue with the endeavours of the respective parent support groups.

The Road Less Travelled

Siyazama and Outlook experienced difficulties and confusion in trying to unify their group of parents with disabled children. This difficulty and confusion related to understanding the organisational dynamics and needing the skills to

be able to manage the process. This indicates that parents themselves needed capacity building. They required technical skills to be able to manage the process. Research conducted in India around community development amongst a group of village women has indicated that much emphasis was placed on initiating entrepreneurship programmes as way of empowering the women, with hardly any effort made to focus on technical and organisational skills, to ensure that they could manage and sustain the programmes. Many of these projects form part of the United Nations Development Project (UNDP). The UNDP defines Human Resource Development (HRD) as a process within an organisational context in which human capabilities are continuously fostered, (<http://www.manage.gov.in>).

Being hopeful has to be understood in the context of the women's life stories. These stories are complex, like the configuration of their identity. The parent support group contributed to the feelings of hope in the women through the opportunities it afforded them.

Being Hopeful

Yalom (1995 in Wilson, 1997) identified eleven therapeutic factors in psychotherapy groups which are also found in self-help and support groups, one of which is the instillation of hope. Research conducted by Kurtz (1979) and Rappaport, 1993 in Wilson, 1997) on the story-telling activity in self-help groups has supported the importance of instilling hope. So too have the interviews conducted in this study facilitated a subconscious revelation of instilling hope in the women through their own narratives. The instillation of hope can thus be argued to be a product of the methodology as well as an outcome of being affiliated to a parent support group.

Although none of the women had the opportunity to complete their formal education and fulfil the vocational dreams. The women's optimism about the future, and belief in the survival of the human spirit in times of adversity, motivated the women to try and provide growth and development opportunities for their children in the form of education. Indirectly, the opportunities afforded the women through the affiliation with the parent

support groups' and DiCAG would develop the women and in turn benefit their children.

The women's religious convictions sustained their hopefulness. Freire (1985) viewed hope as key contributor to the process of empowerment. The women experienced an increase in hopefulness through their involvement with the parent support groups. Thus, the parent support groups offered the opportunity for an increased sense of hopefulness and empowerment.

Individual and Collective Empowerment

Gidron et al, (1998) and Moser in Hedman et al, (1996) illustrated empowerment as the ability of people to bring about change and regain control over their lives by the choices they make in what they do. Empowerment develops when people are able to portray mutual respect, ensure hope and build trust in themselves and others, (Adomson et al, 1990 in Townsend, 1996). The parent support groups in this study were safe havens where the women felt free to share their experiences and learn from each other in a trusting and mutual respectful environment.

The women in Ocean View related the benefits of the parent support groups in relation to activities that brought about an increase in self-esteem and self-efficacy. This can be equated with Rissell's (1994) psychological empowerment. Becoming psychologically empowered, enhanced their own identity. The women in Masiphumelele felt that the spirit of Ubuntu was not sufficiently displayed and thus the sense of community and need for collective action was considered more important in relation to individual pursuits for success. This collective action may be likened to the process of Community empowerment described by Rissell, (1994).

The transition process model (Bridges, 1991) yields an increase in productivity as the individual progresses from each stage but does not necessarily relate to empowerment. However, from the findings (comparing Bridges stages, 1991, to themes 1-5) it is clear that the women experienced an increase sense of hopefulness. The women developed a renewed sense

of hope since being affiliated to a support group. As empowerment is based on a philosophy of hope (Freire, 1985), the women in this study became empowered as they experienced an increase in hopefulness through the parent support group. This empowerment could not have been present without the women's prior experiences and what they had become. The women felt more confident to deal with the reality of an unpredictable future when they experience a greater sense of hope. This fuelled their empowerment.

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4.2 Conclusion

Women have been gendered through internal and external influences and pressures. The socio-historical context, the process of being engendered, and the role strains of having a child with a disability, formed part of the external environments in which women have to manage their lives. These factors also had major influences on the perceptions of their own self-worth.

Programmes with a GID (Gender in Development) approach suggest the need to address the entire social system and the impact that macro-economic policies have on both men and women. In South Africa, we have several policies at our disposal as well as a number of mechanisms to challenge existing legislature. The reality for most South Africans who live in poverty is the constant negotiation for survival. The level of inequity is high and access to resources is limited to one's socio-economic status. Exercising one's right as a citizen means firstly being aware of this and then understanding what it means. For women with disabled children living in poverty, the factors which fuel disempowerment are omnipresent, but the possibility of change and becoming empowered is possible. The women in this study revealed how they managed to overcome the adversity of poverty as victors in the process of living meaningful lives with disabled children.

The parent support groups have been an opportunity within the community that acted as a catalyst for the empowerment process of the women. This had a positive impact on the lives of their families. Such alternative practices of service delivery, like the formalisation of parent support groups, need to be sought that would help and facilitate the empowerment of people coping with disabled children. Professionals could thus act as facilitators and consultants in such a process during which the affected community ultimately remains responsible for their own empowerment. Self-help parent groups are examples of how resources might be mobilised and effectively utilised to empower not only individuals, but affect the community as well. Realistically, there are not enough professionals in South Africa to assist everyone on an

individual level. The traditional approach of professional 'doing for' clients fosters a culture of dependency.

Understanding the challenges that are posed by the formation gender identity and its impact on the empowerment process is of paramount importance. Further research in this area would contribute to this understanding.

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CHAPTER 5

5.1 Recommendations

(a) The research endeavoured has several outcomes benefiting various stakeholders and role players in the field of disability, poverty relief, gender equality, community and social development. For example:

- Mothers of children with a disability were able to voice their opinions in a meaningful way, which could facilitate a process of change on an individual, community and societal level.
- Principles (as indicated in the benefits values ascribed to being affiliated to a parent support group, page 103) were derived at that can inform current practices of professionals, policy makers and DPO's (Disabled People Organisations).
- It has elicited new avenues for research development for instance; disability, culture and indigenous knowledge systems; the infiltration of the West on mothers of children with a disability in Africa and an African perspective on the empowerment of women.

(b) Further research could explore:

- The specific contributing factors that facilitate a process of empowerment within self-help groups
- More details required to explore what would sustain the groups in the long run in terms of resources required e.g. financial support, organisational and technical skills required.
- An African perspective on empowerment in relation to self-help groups like the parent support groups in this study.
- Quantitative methodologies to gain evidence that supports the viability of self-help groups.
- The cultural influences, which hinder and help group cohesion in a support and self-help group.

- What a self-help parent group could offer men with disabled children and how it may alleviate the difficulties they experience in parenting a disabled child.
- The contributions and impact of a researcher as professional in the self-help groups.

Where are the men, the fathers, what are they going through? An area of contradiction in reality and in literature, that role of fathers in caring and nurturing for children or sick relatives may or may not be fostered within a particular society. Areas to explored are; how would one support fathers, why they do not come to the group, how do you help these fathers?

(c) Areas of complexity

Further research needs to be conducted to explore the differences amongst women in terms of mothering and womanhood.

(d) Program and Policy related issues to consider

In order for development programmes to succeed, one would need to enhance community partnerships in the project planning stage, (www.dinf.ne.jp). There are various factors that influence the sustainability of projects. Lessons learnt from community-based rehabilitation programmes in developing countries such as India have highlighted such factors as the organisation as a whole, leadership, management, policies and finances, (www.dinf.ne.jp). We could also learn from developed countries like the United States, who experienced difficulties with the implementation of their Individual Educational Program (IEP) for children with learning difficulties. The IEP was a policy, which was developed, but the application down to local level was fraught with problems, as it did not have clear goals and objectives. Nor was there a clear link between the policy goals and programs. Getting parents to amend the policy was as problematic as they felt intimidated by the terminology used and were not sufficiently familiar with the processes involved to bring about change, (Gallagher in Zigler, Kagan and Hall, 1996). Thus parent involvement at the planning phase of projects and policy formation is imperative. Parents need to be informed in advance of the

procedures in order for them to contribute in a meaningful way. Literacy is another aspect, which needs to be considered when involving parents. Parents are disadvantaged from making meaningful contributions unless they are equipped with the necessary skills.

5.2 Limitations of the Study

- ❖ Interviewer was familiar with participants and this may have influenced their responses – eliciting a response bias. As mentioned previously, (chapter 2), the involvement of a second research assistant enabled me to distance myself from the parent support groups yet remain a participant observer. I remained stationed in the community for the duration of the research. Conducting a second interviews (three to four months after the first interview) and member checking enabled me to verify the data.
- ❖ Participants may have responded in a favourable manner on occasion so as not to represent themselves in a bad light to the interviewer/researcher. However, I worked on establishing a trusting relationship in which, they could respond freely. This was possible through the prolonged engagement. During the interviews I acknowledged what they said by responding in a non-judgemental manner thus fostering a climate of trust.
- ❖ The interpreter may have been slightly biased within the interview. However, I ensured that I briefed her before the interviews and reflected with her after each interview so as to clarify issues and ascertain the perceptions. The transcriber, who was an outside source, fluent in Xhosa and English, highlighted missing words and discrepancies in brackets in the transcripts. Thus I could then go back to the respective client and interpreter to clarify the information, (previously discussed in Chapter 2).

References

- Baol, A. (1985). Theatre of the oppressed, Theatre communication group, New York
- Barrett, H.R. (1997). Women, Occupational and Health in Rural Africa: Adaptation to a Changing Socio-economic climate. Journal of Occupational Science, 4 (3), 93-105.
- Beattie, A., Gott, M., Jones, L. and Sidwell M. (1993). Health and Well-being. London: Macmillan Press limited.
- Becker, C.S (1992). Living and Relating. , California : Sage Publications.
- Boukhari, H. (1997). 'Invisible victims: working with mothers of children with disabilities', in Gender and Disability, ed L. Abu-Habib, London: Oxfam, pp 136.
- Boylan, E. (1991). Women and Disability. Care-givers: In the shadow of disability. London: Zed Books Limited.
- Bridges, W. (1991). Managing Transitions. London: Addison-Wesley Publising Company Incorporated.
- Butler in Levy LL: Late adulthood (Section 3) in Willard and Spackman (1988): Occupational Therapy (7th edition) JB Lippincott Company: Philadelphia.
- Checkoway, B., Cesler, M.A & Blum, S. (1998). 'Self-care, self-help and community care for health', in Work with self-help, Powell, B. NASW Press, London, pp 267-278.
- Christiansen, C.H. (1999). 'The 1999 Eleanor Clark Slagle Lecture. Defining lives: Occupation as Identity: An essay on competence, coherence, and the

creation of meaning'. American Journal of Occupational Therapy, 53 (6), pp 547-558.

Cosslett, T. A. Easton, & P. Summerfield. (1996): Women, Power and Resistance: An Introduction to Women's Studies. Philadelphia: Open University Press

Cornielje, H. (2000). Towards a Public Health Approach

Cresswell, J.H. (1998). Qualitative Inquiry and Research Design: Choosing among Five Traditions. London: Sage Publications.

Dalley, G. (1993). 'Heath and well-being. Familist ideology and possessive individualism' in Health and Well-being. Beattie, A., Gott, M., Jones, L. and Sidwell M London: Macmillan Press limited.

Darbyshire, P. (1995). 'Empowering parents of children with special needs'. Nursing Times, 9:91 (32), pp .

DiCAG, (1998). DiCAG's role in improving the situation of children with disabilities in South Africa: Background Document.

DICAG, (2000), Parent Empowerment on the Move. Together we can make it Work. Cape Town: Norlen House.

Eliason, R.B. (1998). 'The "Bottom-up" approach to health planning'. Contact, April-May, pp3-15.

Freire, P. (1985). The politics of education: Culture, power, and liberation. South Hadley, Dallas: MA: Bergin and Garvey.

Gallagher, J.J. (1996). 'Policy Development and Implementation for Children with Disabilities'. in Children, families and Government Preparing for the 21st

Century. eds. E.F. Zigler, S.L. Kagan & N.W. Hall, Cambridge University Press: Cambridge, pp 171-187.

Gidron, B., Guterman, N.B., and Hartman, H. (1998). 'Participation in self-help groups and empowerment among parents of the mentally ill in Israel', in Work with self-help, Powell, B. NASW Press: London, pp 267-278.

Guba EG Lincoln YS (1989): Fourth Generation Evaluation, Newbury park: Sage

Hagerdorn, R. (1995). Occupational Therapy Perspectives and Processes. Edinburgh: Churchill Livingstone, pp 147-298

Hedman, B., Perucci, F. and Sundstrom, H. (1994). Engendering Statistics. A tool for Change. Sweden: Statistika Publications Limited, pp 15

Khan, N.Z. (1998). ' Best resource use for disabled children'. World Health Forum, 19, pp 47-52.

Krefting, L. (1991). Rigor in Qualitative Research: The Assessment of Trustworthiness. American Journal of Occupational Therapy, 45 (3), pp 214-222.

Kurtz, L.F. (1997). Self-help and Support Groups: A Handbook for Practitioners, London: Sage Publications.

Larson, E.A. (2000). ' The Orchestration of Occupation: The Dance of Mothers', American Journal of Occupational Therapy, 54 (3), 269-280.

Lawler, S. (1996). 'Motherhood and identity', in Women, Power and Resistance: An Introduction to Women's Studies, eds. T. Cosslett, A. Easton, & P. Summerfield, Philadelphia: Open University Press, pp 154

Mason, J. (1996). Qualitative researching. London: Sage Publications.

McConkey, R. and O'Toole, B. (1995). Innovations in developing countries for people with disabilities. England: Lisieux Publications.

McWhannell, D. and Blair S.E.E. (1998). Sex, Gender and Feminism in Sociology and Occupational Therapy: An integrative approach, Jones, D. Edinburgh: Churchill Livingstone.

Meyer, C. and Moagis, S. (2000). Determining priority needs of mothers with disabled children in Winterfeldt. South African Journal of Occupational Therapy, 30 (2), pp 7-11.

Morse, J.M. (1998). Designing funded qualitative research in Strategies of qualitative inquiry, Denzin and Lincoln (Eds.), San Francisco: Sage Publications.

Moustakas, C. (1994). Phenomenological Research Methods. London: Sage Publications

Nelson, N. and Wright, S. (1997). Power and Participatory Development. Theory and Practise. London: Intermediate Publications, pp 134

Oliver, M. and Barnes, C. (1998). Disabled People and Social Policy, London: Addison Wesley Longman Limited.

Polkinghorne, D.E. (1996). Transformative narrative: from victimic to agentic life plots, American Journal of Occupational Therapy, 50 (4), pp 299-305

Primeau, L.A. (2000). 'Household work: When Gender Ideologies and Practices Interact', Journal of Occupational Science, 7 (3), pp 118-127.

Office of the Deputy President, RSA Government (1997). White paper on the Integrated National Disability Strategy.

Rissell, C. (1994). Empowerment: the holy grail of health promotion? Health Promotion International, 9 (1), pp 39-47.

Roger, R.S. (1993). The social construction of child-rearing. (Chapter 17) in Health and Well-being, Beattie, A., Gott, M., Jones, L. and Sidwell M. (1993). Health and Well-being. London: Macmillan Press limited, pp 164

Sawyer, D. (1996). 'The Church: equality or patriarchy?' in Women, Power and Resistance: An Introduction to Women's Studies eds. T. Cosslett, A. Easton, & P. Summerfield, Philadelphia: Open University Press.

Schon, D.A. (1991): The Reflective Turn: Case Studies In and On Educational Practice, New York: Teachers Press, Columbia University

Stone, C. (1996). Gender values and identity: Carol Gilligan's work on women's moral development, in Women, Power and Resistance: An Introduction to Women's Studies, Cosslett, T., Easton, A., and Summerfield, P. Philadelphia: Open University Press.

Tiroler, G. (1995). ' Learning about the links'. CBR News, 21, (99), pp 4-5.

Townsend, E. (1996). ' Institutional ethnography: A Method for Showing How the Context Shapes Practice'. Occupational Journal of Research, 16 (3), pp 179-199.

Ward, E.J & Webster, L.M. (1993). Working with parents of young children with disabilities. San Diego: Singular Publishing Group Incorporated.

Watson, R. (1999). Rehabilitation and Disability (unpublished report).

Whyte, S.R. & Ingstad, B. (1998). 'Help from people with disabilities: do cultural differences matter?', World Health Forum, 19, pp 42-6.

Willard and Spackman (1988). Occupational Therapy (7th edition)
Philadelphia: JB Lippincott Company.

Wilson, J. (1986). Self-help groups. Getting started – keeping going. London:
Longman.

Zuzanek, J. and Mannell, R (1993). ' Gender variations in the weekly rhythms
of daily behaviour and experiences', Journal of Occupational Science, 1 (1),
pp 25-37.

Internet references

Simpson J: How to be a good parent of a child with cerebral palsy or parent's
rights, (Online), Available: http://www.empowermentzone.com/par_dsb.txt
(01/08/22 at 01.58).

The World Bank – Social Development. Principle and Good Practices in
Social Policy, (Online), Available: <http://wbi0018.worldbank.org/essd/essd.n>
(08/06/00 at 12.30).

World Bank – Poverty trends and voices of the poor, (Online), Available:
<http://www.worldbank.org/povert/data/trends.index.h>
(13/05/00 at 20.10).

World Program of Action Concerning Disabled Persons, Objective,
Background and Concepts, (Online), Available:
<http://www.un.org/esacodev/enable/diswp002.htm>
(30/05/00 at 10.30).

APPENDIX 1

Definitions

Development – “a gradual unfolding or growth”, (Chambers concise 20th century dictionary, 261)

Environment – “The sociocultural environment, e.g. people, social structures, beliefs, values: and the physical environment – non-human organic and inorganic features; human constructs and artefacts.” (Hagerdorn, 1995, 298).

Impoverished

- living in poverty

Poverty

– “ ‘relative’ poor in relation to the average standard of living in their country and when they lack the goods and services needed to live a fulfilling life in that society’ or

- “ ‘absolute’ when people are so poor that they lack enough of the basic goods and services needed to live at a minimum standard”, (Tiroler, 1995)

Rehabilitation – The combined and co-ordinated use of medical, social, educational and vocational measures for training or retraining the individual to the highest possible level of functional ability. (WHO in Hagedorn, 1995, 143)

APPENDIX 2

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: Kashifa Lagerdien nee Abrahams

Date:

Funded by NRF

APPENDIX 3

Ifomu yokuziibphelela

Mna, _____

Neliyavuma ukuthatha inxaxheba kule mfunalwazi ngokokuthanda kwam. Ndiyayazi ukuba lonke ulwazi ngam lukuselekile kwaye akuzukusetye-nziswa magama abantu kuyo yonkeinto ebbhaliweyo, xa kuxazululwa naxa kubhalwa olulwazi. Abathatha inxaxheba bayayazi ukuba iimpendulo ziza kurekhodishwa kwaye zimanyelwe ngumntu wangaphandle. Umntu owenza imfunalwazi akayi kuthetha nagamagama nagaliphi na iixesha ngesithuba salemfunalwazi. Abathatha inxaxheba bayayazi ulwazi kuzakuxoxwangalo xa kukho indibano nomtu ophethe abenza imfunalwazi.

Isigqibo sivunywe ngu: _____

Othatha inxaxheba

Yaziwa ngu: _____

Owenza imfunalwazi: Kashifa Lagerdien nee Abrahams

Umhla: _____

APPENDIX 4

Permisie Form

Ek, _____

Erken dat ek beried is om deel te neem aan hierdie navorsings projek. Ek is bewus dat alle data konfidensieel sal bly weens die feit dat geen name bekend gemaak sal word in die transkripsie, analiese of publisering van die inligting. Deelnemers is bewus dat alle onderhoude op band opgeneem sal word en deur 'n eksterne persoon transkripeer sal word. Die navorser sal nie die identiteit van enige deelnemers op enige stadium van die projek openbaar nie. Deelnemers is bewus dat die inhoud van die onderhoud bespreek sal word gedurende "peer briefing" en konsultasie met die navorser se toesighouer. Die navorser erken dat die deelnemer is vry om op enige tydstip van die projek te kan onttrek.

Toestemming van

Deelnemer

Navorser

Datum: _____

APPENDIX 5

Time line of Interviews Conducted

PARTICIPANT	INTERVIEW	DATE	DURATION
ANNE	1 (TRIAL)	5 MARCH 00	2 HRS
JOY	1	24 MARCH 00	2 HRS
SAFIA	1	18 APRIL 00	2 HRS
MAKHAZI	1	19 APRIL 00	1.5 HRS
HANNAH	1	19 APRIL 00	1.5 HRS
MAKHAZI	2	14 JUNE 00	1.5 HRS
HANNAH	2	14 JUNE 00	1.5 HRS
SAFIA	2	21 JUNE 00	2 HRS
JOY	2	27 JUNE 00	2 HRS

APPENDIX 6

Consent form: Interpreter

I, _____, hereby agree to partake in a research study conducted by Kashifa Lagerdien. I am aware of the issues related to confidentiality and am prepared to abide by them. I agree to respect the privacy of the participants and conduct myself in an appropriate manner. I agree to translate what the participants say in an honest, clear and non—bias manner.

Interpreter

Kashifa Lagerdien

Date:

APPENDIX 7

Consent form: Transcriber

I, _____, hereby agree to partake in a research study conducted by Kashifa Lagerdien. I am aware of the issues related to confidentiality and am prepared to abide by them. I agree to respect the privacy of the participants and conduct myself in an appropriate manner. To note any discrepancies or omissions in brackets.

Transcriber

Kashifa Lagerdien

Date:

University of Cape Town

APPENDIX 8

Diagram 4: Table depicting the Themes versus the Stages of the Transition Process model (Bridges, 1991)

STAGES OF THE TRANSITION PROCESS MODEL (BRIDGES, 1991)	THEME 1	THEME 2	THEME 3	THEME 4	THEME 5
STAGE 1 ROUTINE AS USUAL	✓	✓			
STAGE 2 CHANGE EVENT			✓		
STAGE 3 DECLINE			✓		
STAGE 4 LETTING GO			✓		
STAGE 5 CONFUSION CREATVITY			✓	✓	✓
STAGE 6 VISION			✓	✓	✓
STAGE 7 SENSE OF RENEWAL				✓	✓
STAGE 8 NEW ROUTINE				✓	✓