Exploring factors that inhibit the Outlook Parent Support Group from achieving their stated goals

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A dissertation submitted in partial fulfillment of a **Masters degree in Occupational Therapy** in the Division of Occupational Therapy, School of Health and Rehabilitation Science, Faculty of Health Science, University of Cape Town

March 2005

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Declaration

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

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Abstract

This study explored the factors that hindered the women of the Outlook Parent Support Group from achieving their stated goals.

The literature review discusses the relationship between poverty and disability and its impact on the identity and occupations of carers of disabled children. Furthermore it explores self-help and support groups as tools for self-empowerment as well as the role of professionals within these groups.

The action research design created opportunity for collaboration between the researcher and the participants, thereby, encouraging participants to share in the control and decision-making within the research process. Data was generated through a series of eight focus group sessions over a period of seven months.

The study yielded three themes, 'Tensions with becoming a self-help group", 'I versus We' and 'The process'. The study found that the women from OPSG experienced missed opportunities, multiple roles, negative habitual behaviour and time poverty as consequences of their socio-political and socio-cultural environment. This negatively impacted on the success of achievement of self-help goals.

It concluded by urging parent groups to identify strategies to overcome the root courses of their difficulties and not only on the consequences there of.

Acknowledgements

To the women of the OPSG. Thank you for the tea, all the food and for allowing me to share your lives for two years. Without you this would not have been possible.

To my supervisors, Roshan Galvaan and Professor Julia Mekwa. Your knowledge, guidance and perseverance helped me immensely. I feel very privileged to have had you as supervisors. Roshan you helped me cope with some very difficult times. Your encouragement, support and weeks and weeks of reading made this thesis possible. Shukran.

To Theresa Lorenzo for being there to share this passion and for being available whenever I needed you.

To Professor Doris Khalil, Pat Mayers and Madeleine Duncan for patiently answering hundreds of questions.

To all my colleagues from the Division of Occupational Therapy. Thank you for giving me the space to complete this research.

To my family and friends. Thank you for carrying me these last few months. Thank you for making decisions for me and allowing me to focus by taking care of the little things.

To Hanske Flieringa who sat next to me on so many occasions forcing me to work. Thank you for helping me find the right words.

To my Creator who actually did everything. Shukran.

DEFINITION OF TERMS

Impairment

"The loss and/or abnormality of mental, emotional, physiological, or anatomical structure or function: this term includes all losses or abnormalities, not just those attributable to the initial pathophysiology, and also includes pain as a limiting experience" (Christiansen and Baum, 1997: 597).

Disability

"The inability or limitation in performing socially defined activities and roles expected of individuals within a social and physical environment as a result of internal or external factors and their interplay" (Christiansen and Baum, 1997: 597).

Within this study the researcher interchange the terms; *'people with disability'* and '*disabled people*'. Both terms are acceptable in literature.

Poor people

The researcher chose to use the term 'poor people' when referring to people living in impoverished communities. This is inline with present literature on poverty (Barberton, Blake and Kotzé, 1998).

Support functions

For a definition of a 'support group', please see literature review. Within this study this participants defined 'support functions' as including, giving support, listening, giving advice where needed.

Self-help functions

For a definition of a 'self-help group', please see literature review. Within this study this participants defined 'self-help functions' as including, awareness raising, advocacy and liaising with the community, including community organizations and services, in order to bring about social change.

CHAPTER 1

Introduction

This study explores the various factors that inhibit the Outlook Parent Support Group from achieving their stated goals as a support and self-help group within Ocean View community. Motivation for the study evolved out of the need for group members, consisting of women carers with disabled children, to understand the difficulties that they experience as a collective.

In 2001 the Division of Occupational Therapy at the University of Cape Town commenced a two-year research project (funded by the National Research Foundation) involving mothers/carers of disabled children. The researchers, Ruth Watson and Kashiefa Lagerdien, worked in the impoverished community of Ocean View. This peri-urban Southern Peninsula suburb is about 64 kilometers south of Cape Town. The community is predominantly coloured with a population of 34 000 and an unemployment rate of 70%, (Valley Development Project, Annual Report, 2000). Housing in Ocean View consists of a variety of formal brick structures. Often houses have informal attachments of zinc and wood structures to accommodate the large numbers of people that reside there. It is poorly served by transport and lacking in industry.

The purpose of this research project was to create an opportunity for mothers/carers of disabled children to form a group to develop themselves, so that they could help others in similar positions to themselves (Watson and Lagerdien, NRF Project Proposal, 2001). Women with disabled children, who expressed an interest in exploring the problems that they experienced as mothers and primary carers of disabled children participated in the research. These women formed a parent support group and identified raising awareness about disability as their area of focus (Lagerdien, 2002). They called their group the Outlook Parent Support Group (OPSG).

The research process enabled the OPSG to develop as a support and self-help group and to identify and work towards their goals. They affiliated themselves with the Disabled Children's Action Group (DICAG). This brought them into contact with other mothers/carers of disabled children, gave them access to training in disability issues and facilitated awareness of the rights of their disabled children. Their interests and needs dictated the group's activities. Their goals were set around and activities included empowering themselves to establish a support group, advocating for the rights of their children, raising awareness about disability issues within the community and personal development according to individual interests and ability.

The OPSG as a collective had been on anti-bias training and wrote a group constitution. Members completed courses, such as computer literacy, learner's and driver's licence courses. Despite the progress that the group made in certain areas, they identified that they were having difficulties attaining their group goals that they had set for themselves. These difficulties inhibited their effectiveness as a support and self-help group.

Access to the group

The researcher became involved with the group in October 2002, when Ruth Watson and Kashiefa Lagerdien approached her. They identified that the OPSG's members were experiencing interpersonal conflict within the group. According to them, the interpersonal conflict impacted on the group's ability to function effectively. The researcher, experienced in conflict resolution, was asked to intervene by facilitating conflict management sessions with the group. Two sessions addressing conflict management took place. It was during these sessions that the group expressed the need to understand the cause of the conflict and what was preventing them from progressing. However, it also became evident that conflict was but one factor inhibiting the achievement of their goals. The group expressed a need to explore further. This informed the aim and objectives of this study.

Rationale for the study

Carers of disabled children should be amongst the main advocates for the rights of their children. They are, however, often marginalised within communities (Boukhari, 1997) and this contributes to their disempowerment.

If carers, as a collective, are to effectively advocate and contribute to the development of their community, they need to overcome factors that inhibit them from reaching their stated goals.

The women from the Outlook Parent Support Group were already engaged in a process of promoting growth. This study identified the underlying issues that inhibited them from achieving their goals of advocacy, community development, group and personal development. Through collaboratively exploring these inhibiting factors, the group would develop more insight into the causes and consequences of these factors thus strengthening them as a group.

Identifying the causes and consequences of these inhibiting factors would enable the group to overcome these factors and reach their potential so that they can work cohesively, while continuing with their other activities and thereby sustain and improve their own lives, those of their children and their community.

Aim of this study

This study explored the potential barriers inhibiting the Outlook Parent Support Group from reaching their stated goals.

Objectives of this study

- To identify, describe and understand what the factors are that inhibit the group's functioning.
- To identify, describe and understand how these factors inhibit the group's functioning.
- To identify, describe and understand what the consequences of these inhibiting factors are for the group's functioning.

CHAPTER 2 LITERATURE REVIEW

"Marginalized and occupational deprived people are at a disadvantage when their limited stock of knowledge and skills is challenged by the realities of life, and more so if they are simultaneously confronted by additional difficulties, such as the care of a disabled child" (Watson and Lagerdien, 2004: 103).

This chapter highlights the plight of primary carers of disabled children. The primary carers are often women and mothers. Factors impacting on the carer's self-identity and occupational development are discussed. Furthermore, the relationship between poverty and disability and its impact on the identity and occupations of carers of disabled children, is explored. Lastly self-help and support groups as tools for self-empowerment as well as the role of professionals within these groups are investigated.

2.1. Poverty and disability

The description and definition of poverty has received much attention globally (Tiroler, 1995; Wilson and Ramphele, 1989; Giddens, 2001). Tiroler (1995) identifies poverty as the lack of:

- the ability to influence
- power
- information
- resources

Poverty does not refer to only the lack of income. The consequences of poverty are that it limits the opportunities to have control over and make basic decisions about one's life. Poverty is commonly divided into:

- **Relative poverty** –"When people are poor in relation to the average standard of living and when they lack the goods and services needed to live a fulfilling life in that society"(Tiroler, 1995: 4).
- **Absolute poverty** – "when people are so poor that they lack enough of the basic goods and services needed to live a minimal standard life"(Tiroler, 1995: 4).

Both types of poverty are common in South Africa but "absolute" poverty is more common according to the Poverty and Inequality in South Africa Summary Report (Inter-Ministerial Committee for Poverty and Inequality, 1998).

Hancock (1986) links poverty to health by defining poverty as an environmental condition that combines various, if not all of the major environmental obstacles to attaining health. These environmental obstacles, for example: lack of food, a safe living environment, basic health care and education, can all influence health negatively and can lead to disabilities (Tiroler, 1995). Thus, disabilities are caused or exacerbated by environmental obstacles that influence health, so much so that one could say that poverty exacerbates disability. This means that poor people or poor people with impairments can become further disabled due to their poor living conditions. For example, a poor person with mobility impairment may not have the means to acquire a wheelchair. This could cause them to be isolated from others within the community or unable to physically access much needed services. Even if they are able to access a wheelchair, with the inferior roads infrastructure and scarce public transport for people with disabilities, they are still isolated and marginalised.

On the other hand, disability can also exacerbate poverty, as it is more difficult for people with disabilities to obtain employment, education and accessible medical care. This is due to the fact that disabled people face a set of inter-connected barriers that prevent ultimate economic self-reliance (Disabled People of South Africa, 2001). These barriers include fears, myths and stereotyping about the inabilities of disabled people. They compound the lack of access to resources of daily life that are available to able-bodied people, which in turn leads to disabled people lacking power, information, the ability to influence, resources and access to opportunities to fulfill basic needs. Disabled children living under these circumstances frequently grow up believing that their disability is a burden to their families and "perceive themselves to be worthless" (ODP, 1997: 5)

Influenced by the South African constitution, the countries national health policies are attempting to incorporate principles of democracy, social justice, human rights and equity to redress past inequalities (Duncan, Buchanan, Lorenzo, 2005). For this reason the White Paper on Integrated National Disability Strategy (INDS) (ODP, 1997) identify various vulnerable groups that has been marginilised in the past. Disabled women and children, particularly black women and children, a two such groups. The INDS (ODP, 1997) urges role-players to give special attention to understanding and addressing problems, which has lead to the vulnerability of these groups.

2.2. Impact of disability on families/ carers

Disability leaves families living in poverty with disabled family members even more disadvantaged. Research indicates that difficulties experienced when providing care for disabled people are exacerbated by poverty (Tiroler, 1995; McConkey and O'Toole, 1995). As there are limited opportunities available for disabled people, disability can be costly and place a strain on family resources, (McConkey and O'Toole, 1995; Tiroler, 1995 and Oliver and Barnes, 1998). In South Africa more that 80% of black children with disabilities live in impoverished communities with poor access to health care services, educational facilities, social services and other early childhood development opportunities (ODP, 1997). Traditionally, it becomes the family's responsibility to care for the disabled person and to compensate for the lack of opportunities. This means that the carers of disabled children have to work harder to obtain all that they need for their children (Read, 2000). For example, if a child cannot go to school or day-care due to disability, a family member commonly either has to stays at home to care for the child or make special arrangement for transport of the child to a special school. Consequently the unmet financial demands and time spent caring for or nursing a disabled child can ultimately lead to neglect of the physical, emotional and developmental needs of other non-disabled members of the family, especially the primary caregiver, who in the majority of cases is the mother (Read, 2000).

The time consuming role of caring (which can last for many years and sometimes for the rest of the carers' lives) (Read, 2000) dictates the carers' schedule, limits their activities and curtails opportunities for their development. According to McKeown, Porter-Armstrong and Baxter (2003), the effect of providing care decreases the quality of life for carers. This is caused by the daily frequency and tasks of caring. The carers tend to ignore their own needs. This, in turn, impacts negatively on their physical, emotional and social well-being.

The needs of carers are also often ignored by society. Boylan (1991:64) states that carers are in the "shadow of disability". Carers can be isolated by the attitude of the community toward disability as well as by their time consuming role as a carers. According to the Disabled Children Action Group (DICAG) an estimated 98% of mother of disabled children, living in rural environments are unemployed, semi or illiterate, ostracized by the community, abandoned by their partners and extended families (ODP, 1997).

The role of women, particularly mothers as carers, is imposed largely by cultural, religious and societal expectations (Lagerdien, 2002; Miers, 2002; Nicholson, 1994; Wilcock, 1998; Boylan, 1991). This impacts on the woman's decision-making, which is further restricted by poverty, as she does not have time to generate an income or to participate in activities that lead to self-development. Barret (1997) further emphasises this when he says that sub–Saharan African women have triple roles: those of mother, social producer and economic provider. If these women spend the bulk of their time caring for their disabled child they will neglect their other roles. This leads to a loss of control over their own circumstances, which can lead to their becoming powerless.

Freire (1973 as cited in Albertyn, 2000) argues that powerlessness causes people to lose their ability to make decisions, leaving them at the mercy of others. Albertyn (2000) takes this further by suggesting that powerlessness can cause distrust, pessimism, hopelessness, self-blame, feelings of inferiority, dependency and lack of faith that one can change one's circumstances and result in alienation. The sense of powerlessness influences interpersonal relationships and one's ability to be goal oriented and to perform, initiate and complete tasks.

This sense of powerlessness is especially applicable to women living in poverty who are carers of disabled children. The amount of time and energy they spend on their disabled children limits their opportunities to direct and have control over their own lives. The problem of neglecting their physical, emotional and social well-being is aggravated and further disempowers them (Read 2000).

Albertyn (2000) argues that it is important that we identify the causes of powerlessness before we find solutions to it. This raises the question: What renders women carers of disabled children powerless? Based on the assumption that insight will provide impetus for change, it is essential for women carers to understanding the implications of this, as it would enable them to look at possible solutions in order to meet their needs and thereby empower themselves.

2.3. Empowerment through self-help and support groups

The purpose of a support group is to offer knowledge, emotional and sometimes physical support to members. In her study Lagerdien (2002:103) found that 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".

Self-help groups consist of individuals who share similar problems, concerns or circumstances (Wituk, Stepherd, Slavich, Warren, Meissen, 2000). Members aim to provide emotional and physical support to one another and act as a vehicle for members to learn from and share with each other. Members learn to cope better with their situation, they discover strategies to improve their conditions and to help others, while helping themselves (Wituk, *et al.*, 2000). According to the discourse literature, the ultimate purpose of self-help groups is to facilitate personal and societal change, (Wilson, 1986; Adamsen in Townsend, 1996; Kurtz, 1997; Gidron *et al.,* 1998 and Checkoway *et al.*, 1998).

According to Smith, Gabard, Dale and Drucker (1994), some aspects of parent support groups overlap with self-help groups. Wilson (1986), however, states that the fundamental difference between self-help and support groups lies in the outcome of the group. The outcomes of support groups focus solely on support and building knowledge to benefit the individual within the group, while self-help groups not only focus on the individual, but also have both individual and societal empowerment as outcomes (Lagerdien, 2002).

In both types of groups (support and self-help groups), individual problems are turned into common ground (Adamsen, 2002), which can lead to members of the group experiencing feelings of 'being normal'. Group sessions provide an opportunity for members to receive understanding and support from other members. It also provides an opportunity for them to form new relationships, which could decrease their sense of loneliness and isolation, caused by the role of caring for a disabled family member (Adamsen, 2002). This together with an increased opportunity to network, increased knowledge and coping skills as well as feelings of "being normal" and being supported and listened to, can all lead to an increase in self-esteem for carers (Adamsen, 2002). Consequently it can shift members of groups from being victims to being agents of change in their own lives and those around them.

Although there are many benefits to attending groups, groups are often poorly attended (Smith *et al.*, 1994) or are only in existence for a limited time. Various reasons for this are cited. Gidron, Guterman and Hartman (1990) suggest that people, living in poverty, may be too preoccupied with basic survival to participate in support or self-help groups. Smith *et al.* (1994) conducted a survey in which 45 families were asked whether they attend parent support groups, why they attend and which factors encourage attendance. Smith *et al.* (1994) reported that the main reason cited for not attending meetings anymore was that members felt that they no longer needed it. Many parents felt that they started to attend the group to meet other parents and for emotional support and knowledge. After they had an opportunity to fulfill these needs, they no longer desired to attend the groups.

Lagerdien (2002) explored the meaning and experiences of women with disabled children living in Ocean View and Masiphumelele. She found that there was a discrepancy between meeting personal goals versus collective group goals within these groups. This discrepancy proved to be detrimental to the group's success. Most of the women came into the group wanting individual benefits and this impacted on their ability to work and think as a collective thus, impacting on the perceived success of the group and being successful as a group. Lagerdien (2002) also found that organisational dynamics related to power struggles, poor communication, limited skills to manage tasks as well as the fact that the group was struggling to maintain and increase membership impacted on the effectiveness of the groups.

These studies all offer different reasons why self-help or support groups are not always successful. Wituk *et al.* (2000) urge researchers to explore and understand self-help groups better and to investigate why some groups are able to function as a group for longer periods. Access to such information could assist groups that are growing to become more empowered.

2.4. The role of professionals within self-help and support groups – The controversy

The basic principles of self-help groups in general are summarised as: reciprocity, the notion of self-help through helping others and the absence of professionals and anti-bureaucratic organisational forms (Adamsen, 2002; Wituk *et al.*, 2000). This study singles out the principle of "absence of professional and anti-bureaucratic organisational forms" for further discussion as they raise major debates in the literature.

Recent literature reflects an increase of professional involvement within self-help groups, which is at odds with the principle of "absence of professionals" (Adamsen and Rasmussen, 2001; Adamsen, 2002). The absence of professionals was regarded as crucial in the standard perceptions and definition of self-help groups (Adamsen, 2002). It was felt that the term "self-help" is the core principle here and that by helping themselves, group members are empowering themselves and controlling their own development. This was reiterated by Weissbourd and Kagan (1989:25) who took exception to leadership by professionals and stated that "the role of the authoritative professionals no longer fits in a program where parents are respected as developing adults, as advocates on their own behalf, and as the most significant influence in their children's lives".

Professionals have ideas about what people may need in certain situations. They have knowledge and skills that they offer and are experienced in knowing how to identify particular problems and how to find solutions. A good facilitator should, however, always try to create a situation where group members can empower themselves (Hope and Timmel, 1984) and should be very vigilant of not making decisions and solving problems for the group. As group facilitators, professionals are not always successful in sharing their expertise.

There are many arguments for the inclusion of professionals in self-help groups. For example, Smith *et al.* (1994), whose study was discussed earlier, pointed out that when education is the primary objective, professionals are needed for their knowledge and skills in specific areas. They also said that "support" would be more constructive if professionals guide the group process and control the group dynamics (Smith *et al.*, 1994). When looking at arguments for and against professional involvement both have their merits. The question that should be asked is: What do group members think of professional involvement?

Research studies about professional involvement (Adamson *et al.,* 1992; Banks, Crossman, Poel and Stewart, 1997 and Toro, Zimmerman, Seidman, Reischl, Rappaport, Luke and Roberts, 1988) report that a significant portion of self-help group members wants professional involvement. It is the type and nature of involvement that they are more concerned about. Many group members argue for professionals to have an indirect consultation and referral role and not to automatically assume the leadership position. They feel that the group should belong to the members and that one of the members should lead the group. This was also in line with literature that argued for the absence of or limited input from professionals in self-help groups.

The discussion about professional involvement extends beyond evaluating their role. In their article about partnerships between health professionals and self-help groups Banks *et al.* (1997) summarise the tensions and barriers to partnerships between groups and professionals as: communication barriers; confusion about each others' roles and role ambiguity; language differences between professionals and group members; time available (group members feel that professionals have limited time available); funding barriers; created dependency; control/ power/ monopoly; attitudes and perceived beliefs about each other; skills deficiency; ideological differences and conflicts as well as differences in knowledge and levels of awareness. These tensions can contribute to groups not being as functional as they could be.

In the new millennium the changes that are taking place within the areas of self-help and support groups, will result in a new conceptualisation of these groups that will be reflected in a developing practice that welcomes professional involvement (Adamsen, 2002). By doing this, however, it needs to be ensured that opportunities for members to empower themselves are not jeopardised.

CHAPTER 3 METHODOLOGY

This chapter describes the research method of inquiry and design. It explores, in detail, reasons for these choices within occupational therapy and community dimensions. Furthermore it introduces the participants and the researcher and explores the research process that was followed. It concludes by reflecting on techniques that were used to ensure trustworthiness of the research study.

3. METHOD OF INQUIRY

3.1. Research approach

A **qualitative research** approach was chosen for this study, as this method is able to provide a comprehensive overview of the context under study, from the perspective and understanding of the participants. Principle to this method is that the research takes place in a natural context and that it "interprets the phenomena in terms of the meaning people bring to it" (Denzin and Lincoln, 1994: 2). As an occupational therapist, the researcher found that she was comfortable with this method as it fitted with the values, beliefs and language of her profession.

When defining 'enabling occupation', a central theme for occupational therapy, the Canadian Association of Occupational Therapy, states that as occupational therapists we have to "collaborate with people to choose, organise and perform occupations which are meaningful in a given environment" (1997:30). Comparing this definition with that of qualitative research, highlights strong similarities between the two. Both advocate for the perspective of the person and stress the importance of meaning that the person attaches to their actions and behaviour. This is essential in understanding human behaviour (Cook, 2001).

In occupational therapy as in qualitative research we try to understand the behaviour instead of predicting the behaviour. We recognise that the person (participant) is an expert of his or her own situation and behavior (Cook, 2001). This makes it imperative that the person's perspective is central to occupational therapy and research. The qualitative research method used in this project, enabled women with disabled children, to bring their perspectives to the situation, thereby validating the importance of their perspectives. This can be empowering for a population of women who are often marginalised.

3.2 Research design

The study design was that of **Action Research** (AR). There is an argument for research to reflect social relevance and to be conducted in a "manner, which facilitates processes and outcomes which are empowering for its participants"

(Price and Kuipers, 2000: 55). There is also an argument for the importance of participants being involved in identifying the need for research and setting the research agenda themselves (Price and Kuipers, 2000; Barlow and Harrison, 1996). Action research (AR) has emerged as a method of choice for researchers who align themselves with these arguments. As the participants themselves identified the need for this study, AR was chosen as the most appropriate method to achieve the aims and objectives of this study.

In a literature survey that was completed in 1997 where 29 articles on action research, spanning over a 25-year period, were reviewed, the focus of action research was found to be 'change' and 'reflection'. Checkland (1999) reiterated this when he said that the essence of AR is about change and how to achieve it. He added that the focus of AR is the practical concerns of people in a problematic situation. Price and Kuipers (2000) take these definitions further by saying that AR is a research approach that encourages collaborative action in a social setting within a research framework. The key assumption for this method is that; people in a specific setting can solve their own problems by studying their own behaviour, attitudes, knowledge and beliefs (Patton, 1990, Lindsey, Stajduhar and McGuinness, 2001). This shifts the power relationships between the researcher and the participants that exist in traditional research methodology.

Darbyshire (1995) describes the paradigm shift from the expert model to the consumer rights and social system network model of partnerships. The latter models have an emphasis on empowerment whereby professionals are no longer key experts, but act as facilitators or moderators (Then, 1996; Smith, 1995). Participants are viewed as part of the panel of experts. This perspective matches the concept of AR in that research is done with participants, not on them (Lindsey, Sheilds and Stajduhar, 1999).

Sung Sil (1995: 5) states that a collaborative process within research brings isolated people together around common needs and validates their experiences as the foundation for understanding and critical reflection. It also presents the knowledge and experience of the researcher as additional information upon which to critically reflect. Lastly, it contextualises what was previously classified as personal and individual problems and weaknesses so as to link such personal experiences to political realities. All of these factors contribute towards making AR an empowering process.

The research process is a cycle of critical reflection. Participants reflect on what has already happened in order to look at future action. The process therefore alternates between action and reflection. By participating in this process, a better understanding of the situation develops. (Action Research website, cited on 18/01/2005).

AR was the most appropriate method for this study for a number of reasons. Firstly, AR was chosen because it is participatory (Price and Kuipers, 2000). Self-help groups, by definition, are very concerned with empowerment of participants and democratic decision-making. This makes them very suspicious of traditional research methods, where the researcher maintains control of the process (Gray, Fitch, Davis, 2000). It is argued that traditional methods of research may alter the nature of the self-help group and the results of the research may then be meaningless (Tebes and Kraemer, 1991). A research approach like AR, was relevant as participants shared in the control and decision-making about the research process.

Secondly, AR was chosen because it is a suitable approach where the goals of the research are to problem-solve and to improve (Price and Kuipers, 2000). The group identified that they had hindrances that they needed to overcome. The process of action-reflection provided an opportunity to investigate these hindrances. This in turn could assist in overcoming these hindrances.

Thirdly, AR is suitable in a community context and accommodates empowerment frameworks (Price and Kuipers, 2000). This support and self-help parent group is active in a community context. Research done in a community setting should be iterative, participatory, practically and socially oriented. (Price and Kuipers, 2000). AR satisfied all these requirements.

3.3 The researcher

There is a strong correlation between the researcher's background and that of the participants. The researcher is a female in her thirties, Muslim, coloured (as then classified in South Africa) and an occupational therapist. She also comes from and still resides in a low socio-economic suburb of Cape Town. Neither of her parents completed their secondary education and both were factory workers. Her mother, who only completed grade seven, worked full-time in a clothing factory for 35 years of her life. At nights she had to come home to the job of mother and wife. Working at the clothing factory and working at home, were two demanding roles, which arguably were the equivalent of two full-time jobs.

The researcher's parents grew up in an impoverished environment during the height of apartheid. This situation denied them access to opportunities that could have enhanced their quality of life, personal growth and development. For example, they were denied access to quality education and the choice of living conditions. Although the researcher only lived through the last two decades of apartheid, she was able to see the impact that this regime had had and continues to have on the lives of her family and others in her community. This background aided her in better understanding the participants' culture, beliefs and situation better. It also aided in building the trust that allowed her to become a member of the group sessions.

The fact that the researcher speaks the Cape Town dialect of Afrikaans that is also spoken in Ocean View meant that all the participants in the group could understand her and vice versa.

The dual role of researcher and group facilitator

Within the focus groups the researcher had the dual roles of group facilitator and researcher. As a group facilitator, the researcher followed the role as described in literature (Then, 1996; Smith, 1995). This was to set the tone of the discussion, encourage participation of all members and expression of ideas and solutions. She also had to maintain a balance in her roles as leader and participant, facilitate interaction amongst members, validate and acknowledge contributions, keep discussion focused, clarify, summarise and bring closure when needed. It was important that she constantly had to remember to allow the participants to perform any of these roles before she did so. This was to prevent them becoming dependent on her as a facilitator. In the first meeting she made it clear to the group that she saw them as the experts of their own situation and that she was only there to facilitate the research process, to participate in the process and for the group to utilise her skills and knowledge as a tool if needed.

3.4. The participants

3.4.1. Sampling

Convenience sampling (Mc Millan and Schucher, 2001) was used to identify participants. This sampling strategy, which is also referred to as available sampling, "involves choosing readily available people" (Brink, 1996: 140) for the study. The OPSG as a collective expressed their interest to address the identified research problem (see '*Access to group*': 3). As this was a pre-exiting parent support group, all the members were elected to be part of the study.

The study participants consisted of women from Ocean View, who are mothers of children with various disabilities. This study focused on the Outlook Parent Support Group, which consisted of seven group members at the beginning of the research process and five women at the end of the process. As this group is very small and known in the community, the researcher is hesitant to give specific demographical information about individual members as she feels that it might identify them and thereby breech confidentiality. However, taking into consideration that some group demographics are necessary in order to judge transferability of the results, a general description of the demographics of the group and a profile of each individual member will be given. This profile will not contain identifiable specifics. Information about members' backgrounds and behaviour in the group will be offered. The researcher took these written profiles back to the group to ensure trustworthiness.

Two of the members left the group during the research period. One member left after the first group session. She was not a mother but a great-aunt of a disabled child. She left as she found employment and this impacted on her ability to attend meetings. The second member left after the third group session as she had a baby and subsequently moved out of the area. She only attended two sessions, as she missed the first group. Only profiles of the members that completed the research project are included.

3.4.2. Demographic profile of the group

Group size	At start of research: 7 At end of research: 5
Sex	All females
Age	1 member was in her mid 20s while the rest of the members were between mid 30s and mid 50s.
Level of education	One member had Matric but no further education; all the others did not finish primary and/or secondary schooling. One member is presently busy

	completing her matriculation.
Marital status	1 member is single, but living with a long-term partner. 1 member is divorce. 3 members are married.
Employment	• Laundress for a navy residential complex • Teachers aid • Char • Sewing instructor at a local adult education facility • Part-time admin clerk at a local church
Child's impairment	Includes intellectual impairment, cerebral palsy, visual and hearing impairment and learning disorder

The participants grew up in and are still living in a relative impoverished community. They have lived through the oppression of the apartheid regime. As indicated in this table, it impacted on the level of education, which in turn impacted on their employment opportunities. As discussed in the literature review, living in an impoverished community, during the apartheid era, impacted on opportunities available to them as women and limited their ability to have control over their own lives and development.

The group had a set meeting time for Thursday evenings, in the garage of one of the members. However, these meetings were often irregular.

3.4.3. Profiles of individual members

The actual names of the participants have been replaced by pseudonyms to ensure confidentiality.

Aniesa

Aniesa is often very quiet. She talks very little unless directly addressed. Even then her answers are short and often non-committal. She always appears as if she is listening attentively.

She had a very strict Islamic upbringing. She was not allowed to voice her opinion as a child. She felt that she had to keep quiet and agree with others. She did not always agree with others, but felt that she did not have a choice in the matter. When she got married, her married life followed the same pattern. She felt that she still could not voice her opinion.

Shahieda

She was usually very busy playing the caring role. For group sessions, she always prepared lots of food without asking anybody to contribute financially. She would check to make sure everyone had enough and was comfortable. During discussions of sensitive issues, she would often contribute while trying to be very diplomatic.

Her parents were strict and would dictate what she should do. She had to do what they said without questioning.

Initially life with her husband was just as difficult. Many times she thought of giving up but she felt that she had to be strong for her child. She grew up understanding that you have to think about others before you think about yourself. She also expressed a belief that you have to sort out your own problems, but feels that you cannot always do it yourself. Sometimes you just have to keep quiet and be strong. Things will get better. Her belief in religion is strong and she believes that God will not give you a problem if God did not think that you could handle it. She said that she learnt to be patient and be positive and wait, as these problems cannot go on forever. She shared openly within the group.

Joan

Joan was very talkative during sessions. She often dominated the discussions and, at times, came across as though she was not listening to other members. This could have been due to her pre-occupation with her problems. She often spoke directly with the facilitator. Her comments were always relevant to the discussion. She could be very direct. In the first meeting she appeared as if she needed to ventilate and needed support.

According to Joan, she had a difficult life. Her mother was a good support and since her death, Joan missed her support tremendously. Life has taught her not to be dependent on others since they can let you down. She felt that she needed to have control over her own life. She said that one way of doing this was to do things yourself. She also said that the group taught her to use support from others. She wanted to be in control of decisions that affected her own life.

She felt strongly that the group should have been more active as a self-help and advocacy group. They should have focused less on their own development and more on the development of the community.

Juwaya

Juwaya was very talkative in sessions. She offered support readily to other members and often linked it to her own situation. She was often very concerned about how others interpreted her behaviour. She came across as caring and interactive but often giving advice and being prescriptive.

She was abused as a child. She provided her mother and siblings with emotional support while growing up. She became the main breadwinner and decision-maker for the family after her father passed away. She felt that the family was her responsibility and that she could not let them down. She had to make decisions alone. When her husband left her, she was responsible for her children once again. Again she is the main breadwinner and decision-maker for the family. She is used to making decisions for other people without having the benefit of being able to discuss these with them. She learnt to rely heavily on herself and her God. She is also very religious.

During the research period, Juwaya was completing her secondary education. This made it difficult for her to attend group meetings regularly, as she had classes four nights a week. This caused conflict between her and Joan as Joan felt that Juwaya should finish studying now and start working in the group.

Juwaya struggled to make ends meet at home. She often spoke about how she did not always have food at home for her children for breakfast in the mornings.

Sanna

Sanna did not often speak in the group, but always indicated non-verbally that she was listening. Her input was often very concrete and relevant. The researcher sometimes had to explain concepts to her in simpler language. As the research progressed and the depth of reflection increased, her voluntary input became less as she had difficulties understanding the abstract process.

Her grandparents raised Sanna. Her mother had to work and could not look after her. She never finished her primary education as she struggled at school. Her grandparents both died when she was about 15 years old. Sanna was left to look after three of her younger cousins whom her grandparents were also raising. She had to find work and worked as a general cleaner at a hospital. Later she worked as a domestic worker. She often spoke about “die wit mense” (the white people) and how difficult her life was when she was working for them.

She abused alcohol during her younger years, but decided to stop for the sake of her children. She is a devout Christian.

Her husband abuses drugs and often has affairs with other women. These trends upset her often and she needed to vent her feelings about the situation. She felt comfortable talking in the group about her problems.

3.5. The group’s journey prior to this study

As indicated in the introduction, the group was established in 2001 through a research project initiated by the occupational therapy division of the University of Cape Town. Kashiefa Lagerdien, the researcher that collaborated with the parents to start the group, was involved in the OPSG during 2001 and 2002. She only withdrew from the group early in 2003. Although the group had elected a management committee, which consisted of members, the researcher was often seen as an important member of the group as well as a motivator, by the members.

3.6. Research Process

3.6.1. Data collection

Focus group sessions and journaling by the facilitator were used as tools for data collection.

3.6.1.a. Focus groups

Focus groups are defined as a group interview that aims to "capitalise on the interaction that occurs within the group" (Seale and Barnard, 1998: 24). These groups are an opportunity for large amounts of data to be collected and give participants an opportunity to build on each others' responses thus taking discussion and meaning to a deeper level (Steward and Shamdasani, 1990).

All participants understood both English and Afrikaans although some preferred to speak in Afrikaans, hence focus groups were facilitated in a Cape Town dialect of Afrikaans. Participants were free to use the language of their choice. The researcher was well conversant with both languages.

A total of eight sessions were conducted with the focus group. The first three focus group meetings were held two weeks apart. This was done in order to familiarise participants with the research process. After the third meeting the participants were given the choice of deciding how often they wanted to meet and when this would take place. They decided to have monthly meetings. The researcher made it clear that these meetings would not take the place of their regular meeting.

During the first session the participants were asked to list the goals that they identified for the year (see Appendix 1 for this list). These goals were used as an initial point of entry into discussions. The agenda for the first session included: introductions, obtaining consent for the research as well as to audio-record the sessions, deciding on goals for this session and follow-up sessions and the process to achieve these goals. The agenda also included discussion about the goals that the Outlook Parent Support Group wanted to achieve for the year, scheduling and drawing up a group contract.

The agendas for the other sessions were as follows:

Table 1: Outline of agenda for sessions

Sessions	**Agenda for session**
Session 2	• Reflection on session one. • Verifying information gained in session one. • Verbal consent. • Discussing how far they are in achieving goals as set. • What has prevented them from achieving

	what they set out to achieve. • What they want to achieve by the next session.
Session 3	• Reflection on session two. • Verifying information gained in session two and reflecting on this information. • Verbal consent. • Discussing how far they are in achieving goals as set. • What has prevented them from achieving what they set out to achieve. • Reflecting on norms and problems in the organisation and how does this contribute to the prevention of achieving goals. • What changes need to be made. • What they want to achieve by the next session as a group. • Reflecting on the group process.
Session 4	• Reflection on session three. • Verifying information gained in session three and reflecting on this information. • Verbal consent.

	• Discussing how far they are in achieving goals as set. • What has prevented them from achieving what they set out to achieve. • Reflecting on personalities, past and present identities of self and others and how these contribute to their interaction in the group. • What changes need to be made. • What they want to achieve by the next session as a group. • Reflecting on the group process.
Session 5 This was a short session, as one of the member's children was in the group and he had difficulties staying silent for an extended time.	• Reflection on session four. • Verifying information gained in session four and reflecting on this information. • Verbal consent. • Discussing how far they are in achieving goals as set. • Reflecting on specific problems that arose while they were planning an event. • What has prevented them from achieving what they set out to achieve. • Drawing up the agenda for the next

	session. - Reflecting on the group process.
Session 6	- Reflection on session five. - Verifying information gained in session five and reflecting on this information. Also reflected on achievements of group. - Verbal consent. - Evaluation on how far they are in achieving goals as set. - What has contributed to achievement of goals and what has prevented them from achieving what they set out to achieve. Here we reflected on practical and both interpersonal and intra-personal factors that impacted on their abilities to achieve goals - What changes need to be made. - What do they want to achieve by the next session as a group. - Reflecting on the group process.
Session 7	- Reflection on session six.

	• Verifying information gained in session six and reflecting on this information. Also reflected on achievements of group. • Verbal consent. • Evaluation how far they are in achieving goals as set. • What has contributed to achievement of goals and what has prevented them from achieving what they set out to achieve. Again we reflected on practical and both interpersonal and intra-personal factors that impacted on their abilities to achieve goals. • What changes need to be made. What procedures need to be put in place? • What do they want to achieve by the next session as a group. • Reflecting on the group process. • Discussion of termination.
Session 8	• Reflection on session seven • Verifying information gained in session seven and reflecting on this information. Also reflected on achievements of group

	goals. • Verbal consent. • Evaluation on how far they are in achieving goals as set. • Summary of outcomes of previous sessions. • Summary of the process that we have experiences. • Summary of changes and procedures that has been decided on. • Way forward. • Termination.

Group process

Although it appears as if each session followed a set agenda, the agenda was applied to different situations and problems every week. Within each session the group followed the action research cycle (Stringer, 1996) of 'look', 'think' and 'act' once the initial problem had been identified. The cycle was repeated as often as needed.

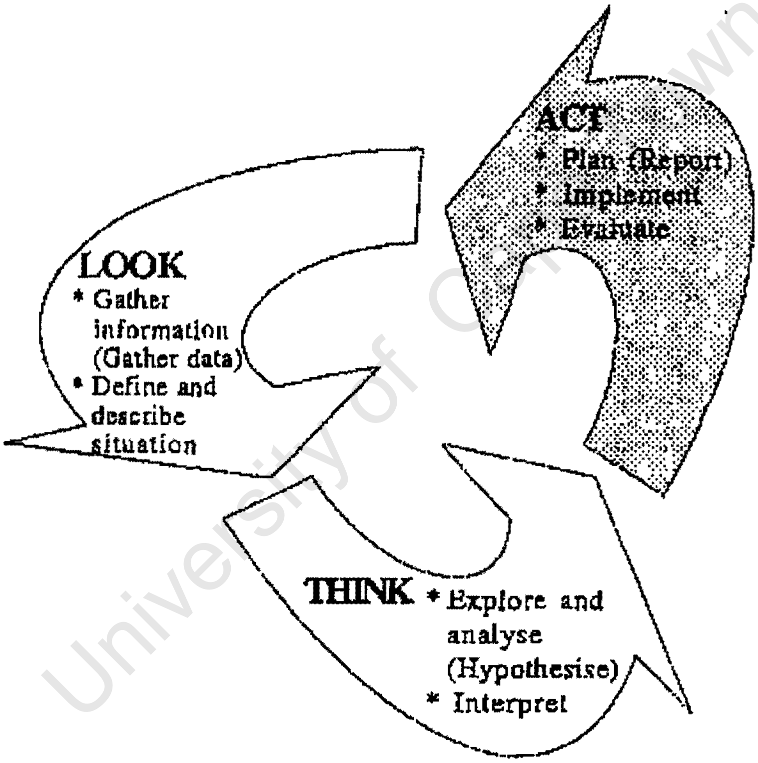

Figure 1: The action research cycle (based on Stringer, 1996) in Price and Kuiper, 2000.

At the end of each session, the group would decide on a goal to work on until the next session. For example, one goal was: To make other parents with disabled children aware of the existence of the OPSG by visiting them at their homes. At the start of the next session, achievement of this goal was evaluated. As this goal was not achieved, reasons for not achieving the goal were reflected on and analysed. Following this reflection the group would try to identify how these hindrances could be overcome by looking at what changes needed to be made in terms of their actions and what procedures they needed to put in place. They then decided what they wanted to achieve as a group by the next session.

As the group facilitator, the researcher had to downgrade her input by guiding less and giving the group the opportunity to follow the process more independently. As the group proceeded, there was less need for probing. The level of discussion was also graded from identification of concrete problems (for example: We are not meeting enough) to underlying problems (for example, not coming to meetings because members had different priorities (See Theme 2).

The physical structure of the focus group changed from a formal circle to sitting around a table having tea while we discussed. The change happened after the researcher felt that the group were looking too often to her to facilitate and did not interact enough with each other. Their actions were also very stilted in the sessions due to their being unfamiliar with the situation. This changed for the better with the change in structure, as tea was a more familiar situation for them.

3.6.1.b. Journaling

After each session, the researcher wrote down her feelings and experiences of the group in a journal. This was done as a means of bracketing, (Holloway and Wheeler, 1996). Through bracketing the rigor of the research study was developed and it enabled the researcher to explore her assumptions and perceptions on the study matter. Through this she was able to identify and address biases that surfaced, evaluate her own role as a researcher and group moderator (Holloway and Wheeler, 1996). This was found to be very beneficial and it was through the process of journaling that the researcher realised that she was not maintaining a balance between her roles as participant and facilitator. This led to her changing the structure of the sessions, thereby giving members more opportunity for member-to-member interaction.

Consideration was given to asking participants to journal, however, from previous experience with the group, the researcher was of the opinion that the participants would not be comfortable with this. The group appeared to have a verbal culture. The participants were more comfortable to talk about issues than to write them down. This could be due to the various levels of literacy in the group.

3.7. Analysis of data

After the audio-recordings were transcribed, the researcher listened to them while reading the transcription. This ensured accuracy of transcription. This also gave her the opportunity to read each session as a whole. This was the first stage of analysis.

Huberman and Miles (as cited by Creswell, 1998: 142) state that data analysis should be custom-built and choreographed for a specific study and not "off the shelf". Bearing this in mind, Strauss and Corbin's (1990) guidelines for analysis were selected to guide the analysis process, as the researcher found that their methodology, although structured, was general enough to guide a novice researcher in doing inductive analysis for the first time.

In AR, data analysis is a continuous process. The researcher, therefore, selected to do the analysis in two stages.

3.7.1. Stage one

After each focus group meeting the researcher would listen to the audiotapes at least twice and made notes as she listened. A content analysis was performed on the information gained. Special attention would be given to issues around group process and outcomes for the session, as well as the aim and objectives of the research. This information was taken back to the group during the next session for members to check and to use the information as the point of departure for discussions in the next session.

3.7.2. Stage two

Each group meeting was transcribed verbatim. The transcriptions were micro analysed (Strauss and Corbin, 1990) and open coded with the aid of the Nudist Vivo (NVIVO) Software Package. The aim and objectives of the study were used as the framework for the analysis and interpretation of the data. The codes were grouped into sub-categories, which in turn were linked to categories. From these categories themes were identified. Three (available) members of the OPSG, verified the accuracy of these categories and themes to ensure that these were a true reflection of how the participants perceived the problems.

3.8. Rigor

Lincoln and Guba (as cited in Gliner 1994) suggest that "trustworthiness" is more appropriate in a naturalistic setting of qualitative research methods than "validity" and "reliability", as it is more in line with the objectives of qualitative research.

Lincoln and Guba (1985) state that the criteria to judge trustworthiness in a research project are credibility, transferability, dependability and confirmability.

Trustworthiness was establish through:

3.8.1. Credibility

Prior to the start of the research project, the researcher was involved with the OPSG for a year. The group members were familiar with her. The eight focus group sessions took place over a span of seven months. This and the fact that each focus group session lasted for a minimum of one and a half hours gave the researcher the opportunity to be engaged with the group for a prolonged time. Credibility was enhanced by this prolonged engagement.

Reflection on the previous session was included in each session. This provided an opportunity for member-checking as participants had an opportunity to verify information and rectify any misinterpretations. Reflecting on the previous session also acted as an initiator to the next round of discussion, which allowed for continuity and the opportunity to delve deeper. Member-checking contributed to enhancing the credibility of this study.

Member-checking was also performed after the categories and themes were identified (see 3.7.2.).

Peer debriefing opportunities included regular meetings between the researcher and her supervisors. It also included a presentation to the postgraduate students in Research Methods Module II, of the Division of Occupational Therapy.

Theoretical triangulation was made possible through the review of relevant literature (Cresswell, 1998).

A transcriber from an organisation affiliated to the Department of Languages at the University of Western Cape, who was familiar with the language of the participants, transcribed the group sessions. Being affiliated to an academic institution, the transcriber also had an understanding of the ethical obligations of confidentiality that needed to be adhered to. The transcriber indicated if there were any sections that she could not make out. At these times, the researcher and the transcriber would both listen to the tapes together. After tapes were transcribed, the researcher listened to the tapes again while reading the transcription notes. This helped eliminate mistakes made by the transcriber and contributed to the credibility of the information gained.

Reflexivity "refers to the assessment of the influence of the investigator's own background, perceptions and interests on the qualitative research process" (Ruby, 1980: in Krefting, 1991:218). Through keeping a personal research journal and field journal, the researcher was able to assess and reflect on the effects that her personal history, habits and biases had on the study. By journaling personal thoughts and feelings about the research process, questions and problems, she became aware of biases and preconceived assumptions she had about the group, the research and her roles. (Krefting, 1991).

3.8.2. Confirmability

Confirmability is to ensure that the results are an accurate reflection of the participants' experiences and opinions and not the outcomes of biases of the researcher (Holloway, 1997). A time line is provided to contribute towards confirmability, see appendix 4.

3.8.3. Dependability

Dependability of the research process is reflected in a detailed audit trail. This would demonstrate an accurate and consistent research process (Guba and Lincoln, 1985). An audit trail is documented in the methodology section of this chapter.

Morse (1998) argues that adequacy and saturation of data are important criteria to ensure rigor in qualitative research. It is essential to collect ample data to allow for variations to be accounted for and understood. By group six it was evident that data saturation was achieved as the same set of data was generated over and over. The group, however, elected to complete the eight sessions to ensure proper closure. The transcripts were an average of 70 pages per focus group session. Group members had a minimum of two weeks between each session to reflect on the previous session. During the stage two analysis process (see 3.7.2) themes recurred, indicating saturation of data.

3.8.4. Transferability

A dense description of the group context, methods and outline followed was documented in the first few sections of this chapter. In doing so, other researchers would be able to assess how applicable the findings might be in their context (Lincoln and Guba, 1985).

3.9. Ethical considerations

Meyer (1993) queries the usefulness of informed consent in AR. She argues that AR is an evolving process that develops with time and is strongly influenced by participants. Therefore, the exact form that the AR study will take is not fully known to the researcher at the beginning of the process. The participants, therefore, have to agree to the process even though they do not know how it will evolve (Meyer, 1993). Informed consent in AR needs to be an ongoing process that the participants and researcher re-negotiate every time there is a change in the process or when the study takes on a new dimension.

Within this study the researcher obtained informed written consent after the process had been explained to the participants. The consent form was reviewed and accepted by the participants. This was done during the first meeting. Consent forms were available in both English and Afrikaans. (See Appendices 2 and 3). Subsequent consent was obtained verbally every time the group met.

The researcher ensured that the participants understood that they were free to withdraw at any time during the study without any negative consequences. Two of the participants did withdraw from the sessions. This was not due to the research, but due to personal reasons (see section 3.4.).

The boundaries for confidentiality were set by the participants and strictly adhered to. This was negotiated with the participants during the first group meeting and was included in the group contract.

Through the research process the participants shared equally in the decision-making about the direction the process would take. This ensured not only ownership of the process but also ownership of the results. The participants could use the results to benefit themselves.

CHAPTER 4 RESULTS

The study yielded three themes, 'Tensions with becoming a self-help group', 'I versus We' and 'The process'. Themes 1 and 2 describe the hindrances the women are experiencing. Theme 3 describes the gains they achieved trough the research process. The essence of each of the themes, as well as the categories, is corroborated with supporting quotes. All quotes have been placed in bold font and translated to English.

Theme 1: Tensions with becoming a self-help group

Table 2: Thematic Representation of Theme 1

Categories	**Sub-categories**	**Codes**
4.1.1. Internalised expectations as nurturer	Support function is priority and familiar Self-help functions are different	The group listens and supports Mothers are carers It is different to do things for a whole community
4.1.2. Disorganisation	Planning is not happening Things are not happening as expected	Not meeting regularly That's not what was decided on Should not have done it like that Procedures were not followed Decisions are never finalised/made
4.1.3. Confidence in the functions of a self-help group	Facilitator used: • As motivator • To network Lacking experience in role and tasks	We waited for her to call meetings She knew what to do She was connected Still learning about self-help and advocacy Needed facilitation to make decisions and problem-solve (Observation: Waiting for facilitator to facilitate overcoming of problems and not taking the initiative to overcome these issues.)

Theme 1: The tensions with becoming a self-help group

This theme describes the difficulties that the participants experienced during the process of transition from a support group to a self-help group and tries to identify why they experienced difficulties with this process.

The Ocean View Parent Support group has easily adapted to functioning as a support group. Many members were caring by nature. They were able to listen to each other, share personal problems and offered advice easily.

The group experienced difficulties having to combine the support functions with functions that were more inherent to a self-help group. For example, they would spend a full meeting giving support to a member that was having personal difficulties and would neglect to plan for awareness-raising campaigns around disability. Although the group has successfully performed some self-help functions (for example, having an information table on disability at the Navy's festival), they had difficulties achieving goals related to these functions, for example, finding the time to do a talk at the local community health centre.

When asked how the participants understood the self-help function of the group, they agreed that it was about helping yourself to help others that were in the same situation as you. Self-help functions, for them, were ultimately about working towards inclusion of disabled people into the community. This would only be possible if the community understood disability. They stated that functions of self-help groups included advocacy as well as awareness-raising about disability and the needs of the disabled people.

Aniesa: ***"It is like working for the rights of the disabled in Ocean View...om na meetings toe te gaan om oor disability te praat. Soes by die kliniek of soe. Om sieker te maak dat osse kinnes oek kry."***
["It is like working for the rights of the disabled in Ocean View...to go to meetings to talk about disability. Like at the clinic and so. To ensure that our children also get."]

Juwaya: ***"Ja...to involve them...in die community..."***
["Yes...to involve them...in the community..."]

Joan: ***"Die community call die bus wat die disabled kinnes ry die mal bus. Ons werk daaran om sieker te maak die community wiet die kinnes issie mallie...maa disabled...I want them have to understand the difference. Imagine jy kannie loeppie nou sê almal jy is mal. Wat doen daai aan `n mens? Ek kan soe kwaad raak. Ek mean..."***
["The community calls the bus that transports the disabled children the mad bus. We are working at it to ensure that the community knows that the children are not mad...but disabled... I want them to understand the difference. Imagine you cannot walk now everyone says that you are mad. What does it do to a person? It makes me so angry. I mean..."]

For participants to be successful at awareness raising and advocacy, they felt that they needed to be more active in the community and represent mothers with disabled children on various community structures and forums.

Shahieda: ***"Ons moet talks doen...soe maak mens die public aware about disability. Ons moet die anner organisations oek aware maak van disability."***
["We need to do (public) talks...that is how you make the public aware about disability. We also have to make other organisations aware of disability."]

The "self-help function" was one of the reasons that the group was initially established, as the women felt that it was important to develop their community. By raising awareness in the community about disability and helping other parents who were in the same situation, they not only contribute to the development of the community, but also ultimately improve the situation for themselves and their own children.

Shahieda: ***"Ons as maas wiet wat gedoen moet wort."***
["We as mothers know what needs to be done." (Referring to what needs to be done in the community)]

4.1.1. Internalised expectations as nurturer

As a support group, the participants felt that the group was very successful. Participants spoke of how the group listened to them and helped them with problems. They found the discussions about their children's disabilities beneficial and felt that they learnt from other group members about disability and coping with and handling a child with a disability.

Joan: ***"Die groep het vir my gehelp om vir Kim (her disabled daughter) te accept en te cope met al haa disability. Die group het oek geluister toe ek problems gehad het met my broer."***
["The group helped me to accept Kim (her disabled daughter) and to cope with her disability. The group also listened when I had problems with my brother."]

Juwaya: ***"Die group het baie vir my gedoen. Veral in die begin het hulle na my geluister en advice gegee. Net om te dink dat ons almal die selfde problems het, het my al kla lat bietter voel."***
["The group helped me a lot. Especially in the beginning they listened to me. Just to think that we all had the same problems already made me feel better."]

Shahieda: ***"Ek het aannie begin oek net soe gestruggle met Faheema (her disabled daughter). Ek net baie gesukkel. Soe ek wiet hoe jy gevoel het. Ek kan darem vir jou `n bietjie advice gie."***
["I also struggled with Faheema (her daughter) at the beginning. I struggled a lot. So I know how you felt. I was able to give you a little advice."]

Most members saw the support function as priority. On three different occasions during the research process, individual group members spoke about a personal problem that they were experiencing at that time. All the group members would then jump in to support the particular member. This process often took a significant amount of time during the meeting. This was found to be the norm in the group as many members felt that support issues needed to be addressed before issues like advocacy. The need for support was always viewed as being urgent. This is elaborated on further in Theme 2.

Shahieda: ***"Nee, dit is goed as `n mens soe praat oor jou problems. Daai is hoekom ons hier is. Om te leiste. Die anne goed kan wag."***
["No, it is good if a person talks about their problems. That is why we are here. To listen. The other things can wait."]

Participants were very caring towards each other. The participants internalised the caring role that the predominantly coloured community in Ocean View held of women and especially mothers. Men were expected to be the providers (will be elaborated on in Theme 2). The participants grew up understanding that it is their role as women to care for others.

Shahieda: ***"Ons moet `n chairperson en `n secretary het om meetings te run en on te help om die group te run."***
["We must have a chairperson and a secretary to run the meetings and to help run the group."]

Their assumptions and beliefs around a self-help group was that it was more formal in contrast to a support group. A management structure needed to be in place, with a chairperson, secretary and a treasurer. The group needs to be good in organising events, liaising and networking with other organisations and addressing groups of people. Although they thought that they were learning about and were becoming more efficient in these tasks, problems usually arose when they had to work together as a group. They found that although they plan and organise daily in their lives, it differs from planning and organising for communities or other people. This role, therefore, does not come naturally.

Shahieda: ***"Kashiefa (previous researcher) het ons gehelp on te wiet wat aangaan, met wie on te praat.." ..."Sy het gehelp...ons hettie altyd gewiet hoe en waar nie. Ons lee mos nog."***
["Kashiefa (previous researcher) helped us to know what is happening and who to talked to."..."She helped ...we did not always know what or where. We are still learning."]

4.1.2. Disorganisation

The group identified that they had difficulties achieving their goals. One of the main reasons, that they directly and indirectly verbalised, was that ***"...planning is not happening".***

On further analysis, it emerged that this was partly due to the infrequent meetings. Although they had set regular meeting dates, many meetings were cancelled due to poor attendance. Fewer meetings meant that there were fewer opportunities to plan or co-ordinate their activities. This presented a barrier to the group's functioning and ability to achieve goals that they had identified for themselves.

Shahieda: ***"Is het nie gewerk nie, wan niemand van ons het gewiet wat die anner een doen nie. As ons net daa oor kon gepraat het in `n meeting."***
["It did not work out because nobody knew what the other one was doing. If we could only discuss it in a meeting."]

Joan: ***"Ons het al soe baie meetings geset on daai te discuss, maa elke kee wort die meeting gecancel."***
["We have set so many meetings to discuss it, but every time it was cancelled."]

The group highlighted similar examples where the consequences of not meeting were negative.

Joan: ***"If we only knew that we had to talk to each other we would not have had this... big mess with us running around the day before the launch."***

The group identified that not meeting regularly, limited their ability to communicate with each other. They felt that they would have been more effective if they liaised with each other, which would happen during regular meetings. Not doing this, they felt, caused a great deal of anxiety and could lead to failure.

The group had a set meeting time of Thursday evenings, but attendance was often poor. Consequently it impacted on their ability to execute goals that they had set for themselves. For example, one of their goals was to visit other parents with disabled children in Ocean View and invite them to join the group. An increase in membership, they believed, would ensure that they were more effective as a self-help group, as it would mean more people to help with self-help tasks.

Shahieda: ***"Ons kon nooit gaan visit nie, want die een keer was dit net ek en Joan hie en die annerkeer was Sanna oek by. Ons was te min om dit te doen. Ons kon oek nie begin het nie, want die anners was nie hier soe dat ons kon decide wie waa gaan visits doen nie."***

["We could never go on the visits because the one time it was only me and Joan and the other time Sanna was also there. We were too few to do it (the visits). We could also not start the visits because the others were not here so that we could decide who will do what visits."]

There were usually about two or three out of the five members present at any planned meeting. Members felt that they could not have an official meeting because decisions could only be taken if all the members were present. They understood a group or committee as a body that plans and functions only when all members were present. This assumption hindered the group's ability to be effective as a self-help group.

Sanna: ***"En toe sê ons, ons moet ons werk kom doen, maar ons het nooit soe vêr gekom nie, because as ons...daars nooit....almal is nooit hierso nie."***

["And we said that we should do our work, but we never got that far because we ...were never...everyone is never here."]

They did not achieve the goals of visiting other parents, because they never actually met as a full group to plan the visits in detail.

Another consequence of their poor attendance was the matter of writing a constitution. The group was informed by a funding organisation that their existing constitution was of poor quality and incomplete. They felt that this poor quality constitution hindered them from successfully accessing funding.

Not having a working constitution also decreased their recognition by other community organisations as a legitimate organisation. It also prevented them from belonging to certain community forums, applying for their own fundraising number or to apply for funding from for example, Community Chest. The group felt strongly that this made them non-effective as a self-help group. They thus saw writing a new constitution as a priority.

Joan: ***"I spoke to Charles at the Development Trust, nê. Toe vra ek vir hom 'What do you need to become a member of the Development Trust?'"..."toe sê hy `n constitution en nog vier ann goed. Toe sê ek 'Wait and stop at constitution'. We cannot become a member this year."*** ["I spoke to Charles at the Development Trust. I asked him 'What do you need to become a member of the Development Trust?'"..."...so he said a constitution and four other things. So I said 'Wait and stop at constitution'. We cannot become a member this year."]

However, this goal was never achieved during the research period, as there were never sufficient members in the special meetings set aside for this task.

Shahieda: ***"So she said she spoke to Juwaya and Juwaya said that two people can't do the constitution. But we trying to arrange meetings all the time and they don't...either they don't come or then something crops up."***

The researcher reflected that a constitution is a group document, but that writing out a constitution does not have to be a group effort. In response to this the group stated that a group discussion about the content of a new constitution was first needed before that task could be allocated to individuals to be completed.

The participants identified the second barrier to being organised, as **"things are not happening as expected."**

Here the group spoke about members not following the procedures that the group, as a collective, had decided on. This often led to outcomes that were not expected or delays in outcomes that prevented the group from achieving what they had set out to do.

Joan: **"She did not do what we said we need to do. We said that only ... sestien parents moet genooi word...maa sy het sommer vir almal gesê dat hulle kan saam gaan."**
["She did not do what we said we need to do. We said that only...sixteen parents should be invited...but she told everyone that they can go with."]

A specific member did not follow through on what the group had decided because she was not at the meeting. Although she was informed about the task that was allocated to her during the meeting, she did not fully understand the task. Consequently, this meant that too many parents were invited to the launch, forcing many of the group members to take the train to the venue for the launch, so that the excess parents could take the arranged transport.

The group did not confront her when they found out about her actions. They complained about it at length during a meeting where, again, she was absent. Thereafter they proceeded to brainstorm possible solutions of how they would get everyone to attend the meetings. They avoided this conflict situation by not addressing it directly. This tendency is discussed in further detail in the third theme.

The third barrier to being organised and able to work together effectively as a group was that **"We do not make decisions".** Here the group spoke about discussions that they often had about action plans or future goals, but could not always agree on an action plan.

Juwaya: ***"We talk about having a public event, maa ons kannie decide of dit `n march of `n meeting moet wies nie. Naa `n lang discussion het ons eintlik decide om `n meeting te het."***
["We talked about having a public event, but we could not decide whether it should be a march or a public meeting. After a long discussion we eventually agreed to have a meeting."]

This inability to make decisions or the delay in making decisions, they agreed, was partly due to their meeting irregularly as a group. When they did meet, they had so many issues to discuss. Consequently they could not spend sufficient time on any given point.

Another reason for them not being able to make decisions was that different people had different opinions about specific issues. Often certain group members felt so strongly about an issue that they could not see or would not accept another's point of view. This happened regularly between two members. As they were two dominant people, this impacted not only on the group process, but also on the group task at hand. Other members often felt that they either have to choose sides or stop the discussion at that point to preserve the peace.

Their poor confidence in their capacity to make effective decisions and to solve problems, contributed to the difficulties they had in fulfilling the self-help group functions. Through the research process the group improved their ability to identify problems. They did, however, struggle with the stage of solving the problems.

Researcher fieldwork notes: third focus group meeting: ***"It was almost as if they where looking at me to actually facilitate overcoming these issues and not them taking initiative to find solutions for the problems. They can identify the problem, but do not look at the solution for it."***

They relied on a facilitator/ researcher to assist them through the problem-solving process. This could be because they saw the outside researcher/

facilitators as 'experts'. It may also be that they were not experienced in the skill of problem- solving as a group. Members of the group admitted that they used the previous researcher as a problem-solver. They justify these actions by saying that she was "**clever**" and had experience with **"these kind of things".**

(See Joan's quote on page 67)

4.1.3. Confidence in the functions of a self-help group

According to Joan, the previous researcher always phoned to say ***"Kom, daar is `n meeting this Thursday and I am coming through."*** ["Come there is a meeting this Thursday and I am coming through."] All the members would then make a special effort to attend this meeting.

Shahieda: ***"Kashiefa het altyd onsse meetings attend. Almal het altyd getry omit te maak."***

["Kashiefa always attended our meetings. We all tried to make it. (the meetings)"]

They felt that she was coming from far, so they could not disappoint her. The group used her presence as an external motivation to attend the meetings. When she withdrew from the group, they had to rely on other external motivators or internal motivators to urge their attendance. Members started to easily give in to external pressures, which often prevented them from attending meetings.

Juwaya: ***"Ek was soe moeg, I just could not make it early that morning. Ek sal sieker nie soe gemaak it as Kashiefa gekommi vi die meeting nie."***
[I was so tired that I could not make it early that morning. I might not have done that if Kashiefa attended the meeting."]

The group also often relied on the facilitator to link them with other organisations. On her withdrawal from the group, this impacted on their ability to network with other organisations.

Shahieda***: "Sy het die contacts gehad. Is maa deur haa, want kyk die mense uhm…uhm…laat wiet als vir haa…inform vi haa. Nou kom sy terug dan se sy 'Ek het die fax gekry en iemand het vir my gesê van die. Ons gaan die doen en dit doen".***
["She had the contacts. It is through her, because, look the people uhm…uhm…inform her about everything. Then she comes back to us and says 'I got this fax and someone said this. This is what we are going to do."]

They felt less informed about community events or about the various opportunities that they could utilise. They acknowledged that she had experience and knowledge and stated that they would defer to her opinions often. Juwaya said that sometimes a member will give an opinion and the facilitator would come back and ask ***"Don't you think that you should do it this way?"*** The member frequently agreed that the facilitator's suggestion was the better option. Shahieda admitted that, at times, she would come up with suggestions that the previous facilitator had not thought of, but she would not voice it as she was afraid that she would be perceived by the facilitator as 'forward'. When the facilitator withdrew, members had to rely on their own opinions and judgment.

Joan: **"...but maybe we relied too much on our facilitator and we were suppose to take it, we were suppose to solve it ourselves."**

The members recognised the benefits of having the previous facilitator in the group and said that as a group, they would not have been where they were now, without her input. They did, however, add that they now could do their own thing and learn to function independently as a group.

Shahieda: ***"That's why I say. They here, but here to give us more info. Dit gaan daarom.*** [It is about that.] **They've got a lot of information where to go to. We didn't know about going to uhm... for help to other clinics..."**

This expectation and the subsequent behaviour also became evident during the research process. The researcher realised that the group expected her to lead the group and to facilitate the problem-solving processes. They would often ask the researcher for her opinion when decisions or interpretations needed to be made. They asked her to help improve their constitution. The researcher had to reflect the questions and discussion back to them in order to maintain the role of researcher (see quote by the researcher under 4.1.2.).

The group did not have a great deal of experience associated with self-help tasks and functions (see 4.1.1). Therefore, they agreed that they might not be as confident in their roles and functions within a self-help group. This could be one of the reasons why they tended to lean so heavily on the previous researcher. Although the previous researcher did not see herself as their leader and organiser, the group revealed that this was how they perceived her.

Theme 2: “I” versus “We”

Table 3: Thematic Representation of Theme 2

Category	Sub-Categories	Codes
4.2.1. Many priorities, too little time	Children Work and studies	Not meeting regularly as a group Cannot make the meetings So many things to do Missing opportunities for development of the group and the community
4.2.2. Disjuncture between individual goals and group and/or community goals	Support takes priority over self-help and advocacy functions Priority of personal need Not enough time to focus on group priorities	That is why we are hereto listen Life situations lead to a need for support The community might need advocacy, but group members need support Want to obtain skills that develop self It is important to develop self Cannot come to meetings due to class. We’ve got too many courses and trainings

4.2.3. Limited group and community change	Habitual behaviour Development of community does not always take place	In the habit of doing things in a certain way No change in behaviour Do as they always did, therefore, get what they always got Knowledge is not being used Knowledge is not being shared

Theme 2: “I” versus “We”

This theme described the tensions between personal responsibilities, habits and goals and the participants' ability to successfully perform tasks and responsibilities of a self-help group.

Participants believed that there was a need for a parent support group and a self-help group in Ocean View. They were of the opinion that much work was needed in the community to ensure that all the children, including the disabled children are properly cared for. They understood that the Outlook Parent Support Group had the potential to play a key role in ensuring that this happens. The tensions arose when their personal responsibilities, habits and goals hindered their ability to work effectively within the group. This, in turn, impacted on their ability to do the work needed in the community.

4.2.1. Many priorities too little time

The participants had many responsibilities and had little spare time. They were mothers who each had a disabled child. They were or had been, wives. They were responsible for the running of their own household and were also employed in the formal sector. One member of the group was studying and all of them endeavour to work within the group.

Shahieda: ***"Fazlin (navorser) wiet dat ons is maa almal maas. Ons moet alles doen....want alles is mos osse responsibility. Fazlin wiet mos in ons communities issit soe."***

["Fazlin *(researcher)* knows that we are all mothers. We have to do everything...because everything is our responsibility. Fazlin knows it is so in our community."]

The multitasks that they had to perform, limited their ability to attend groups and accept additional tasks that could contribute to the success of the group.

Juwaya: ***"Die kinnes en die studies hou my soe besag, I hardly have time for anything else. Maa Mrs. Minton wiet mos dat ek studies het, daarom is ek nie by die meetings nie."***

["The children and the studies keep me busy, I hardly have time for anything else. But Mrs. Minton knows that I have studies (and) that is why I cannot attend meetings."]

For Juwaya, not being at meetings, meant that she was not always informed about what was happening within the group. It also meant that the group did not receive regular feedback about the tasks that she was supposed to complete or meetings that she was supposed to attend on behalf of the group. Her family and studies were her priority, making it difficult for her to be a fully active, contributing member of the group.

The participants' children were always priority for them. If they fell ill, the participants would not attend group meetings. Although some of the participants had a support system to help with the care and supervision of their disabled child, the main responsibility would still fall solely on the mother to care for the child. When the child was ill, it was the mother who usually had to stay home to look after the child. Even leaving a child for a short time was viewed as a problem because many of the children had special needs, which made it difficult for them to be left with carers or other family members especially when they were ill. This was in part due to the role expectations of women in Ocean View (see 4.1.1. Internalised expectations as nurturer).

Joan: "Nee, ek kan vir hulle vra om na haa te kyk. Ek trust hulle. Hulle is carers by die skool. Maa ek kan mossie elke kee vra nie. Especially nou met die shunt. Ek kyk maa self."
["No, I can ask them to look after her. I trust them. They are carers at the school. But I cannot ask every time. Especially now with the shunt. I look after her myself."]

The two participants who were single parents expressed that they had little support with their children. If they wanted to go out, they needed to find a child minder who was willing to look after the child for little or no money, because they did not have the financial resources. They then either opted to bring the child with them or did not come to the meeting. For example, Joan's mother was her main support system. She passed away shortly before the start of the research project. This meant that besides grieving for her mother, Joan also had to adapt to looking after Kim (her disabled daughter) alone. The problems she was experiencing, sometimes caused her to be late or to miss meetings altogether. There were some community members who offered to look after her daughter, but because her daughter had multiple disabilities, it was difficult for her to trust anyone to look after her daughter. She had to carefully select an appropriate carer for her child. Such a carer was not always available or Joan did not always feel comfortable to ask them to care for Kim.

Joan: "No problem, ek kan hulle vra, maa ek kan hulle nie elke kee vra nie. Al sê hulle is ok."

["No problem, I can ask them, but I do not want to ask them every time. Even if they said it was ok *(to do so).*"]

Kim (Joan's daughter) is diagnosed with cerebral palsy and she has a visual and hearing impairment. She cannot do anything for herself and needs constant care. There was a person in the community that Joan trusted enough to look after Kim, but with the insertion of the shunt, she did not feel comfortable to leave Kim for long periods.

Joan: ***"Kim has the shunt in her head." "I had no one to baby-sit Kim and I did not want to take her out of the house so soon after her operation. So I could not make the Thursday."***

Joan also told the group about her home situation where her brother often brought his friends into the house to smoke substances.

Joan: ***"I cannot leave Kim in the house alone met daai dagga koppe. Hulle kan ienage iets doen aan haar."***

["I cannot leave Kim alone in the house with people that smoke dagga. They can do anything to her (when they are under the influence)."]

Joan was adjusting to looking after her daughter on her own, therefore, discussion pertaining to children was very relevant to her. She often contributed when it was discussed. The other members agreed that their children's health came first as well.

As all the participants live in relative poverty (Tiroler, 1995: 4), they found it essential to work in order to support or help support the family. The entire group, besides Joan, worked full-time. Joan worked part-time at a church. Working impacted on their contributions to the OPSG. When the participants came from work, they had to come home to the full-time job of mother and wife.

Juwaya***: "Die kinnes, die werk, die huis en op daai is daa noggie studies. Daa is min tyd vir ienage iets annes."***

["The children, the work, the house and added to that the studies. There is little time for anything else."]

The participants were aware of the opportunities available to the OPSG. However, they could not capitalise on these.

Shahieda: ***"Daarom sê ek hierso is baie opportunities vir ons, maar nog `n ding wat vir ons afhou, ons werk almal."***

["That is why I say, here are a lot of opportunities for us, but another thing that prevents us, is that we all work."]

Juwaya: "Die sersant by die police stasie het gesê hulle ken ons. Hulle ken die mammies, maa ons kom nooit na hulle toe om vir help tevra nie."

["The sergeant at the police station said that they know us. They know the mommies, but we never come to them to ask for help."]

They had to ensure that the family is fed and the house is cleaned, leaving them with little time or energy for anything else. The two worker roles (at work and at home) were time consuming and impacted on their ability to do work in the group like visiting of other parents or attending community meetings. The support function can be done in their regular sessions in the evenings, but self-help tasks, which include liaison with other organisations, visits to other parents and talks in the community could not always be fitted in their busy schedule.

Shahieda***: "Ons kan soe baie doen, maa ons werk...ons werk."***

["We can do so much, but we are working...we are working."]

Shahieda: ***"Die sister by die clinic het al baie vi ons geinvite om daa met die patients the praat in die waiting room oor ons en wat ons doen. Maa ons kom nooit soe ver nie."***

["The sister at the clinic has invited us many times to come and speak to the patients in the waiting room about what we do and us. But we never get that far."]

Participants revealed that working also limited the possibilities to liaise with other organisations in Ocean View or to make use of developing opportunities like workshops. Many community meetings and workshops took place during working hours. Members either had to take leave from work on those days or miss the meetings and workshops. Due to their poor financial situations, they could not afford to miss work regularly, and often had to forgo attending the meetings.

Their absence from community meetings and non-participation in public talks, impacted negatively on their contribution to the community's development. The knowledge that they gained through attending workshops was not always transferred to others within the community as they had limited opportunity for this.

Since Joan worked part-time, she had more time available to care for Kim and to be available for the group. Her frustration with other group members was evident during focus group sessions. She became irritated when tasks were not completed and was often the one that wanted the group to be more active in terms of advocacy. Joan assumed the responsibility for the day to day running around for the group. Shahieda shared this frustration with her.

Shahieda: ***"Ons het nog meeste uitgegaan on te gaan leer. Ons het nog nie eintlik baie gedoen nie."***
["We have gone on courses the most. We have not actually done a lot (in terms of self-help)."]

4.2.2. The disjuncture between individual needs and group goals

Many of the participants' lives were such that they were confronted with negotiating its challenges daily. Examples of these included Joan being involved in a legal battle with her brother regarding ownership of the house that their mother had left for Joan after her death. This was a difficult time for her. Juwaya had four children, was completing her secondary schooling and a child caring course at the same time. Another example was when Sanna decided to ask her husband to leave their house. During these times the participants used the group as a means of support. On three separate occasions during the focus group sessions, individuals needed the group's support to be able to cope with their life situations. The group sessions were used to allow them to share their feelings and gain support. Discussions and planning of self-help tasks were put on hold during those meetings. The group expressed that the "support functions" needed to take priority. This left the researcher wondering how often this happened.

Shahieda: ***"Nee, dit is goed as 'n mens soe praat oor jou problems. Daai is hoekom ons hier is. Om te leiste. Die anne goed kan wag."***

["No, it is good if a person talk about their problems. That is why we are here. To listen. The other things can wait."]

Priority of personal needs influenced the participants' motivation to focus on collaborative self-help goals.

Sanna: ***"Maa ek wil hê die groep moet my help. Ek wil weer skool gan. Aanskool"***

["I want the group to help me. I want to go to school again. Night school."]

Many participants expressed self-development as the goals to achieve for that year. For example, Sanna wanted to complete her secondary education and obtain her driver's license. Juwaya also wanted to matriculate and complete a home-carer's course. They had difficulty connecting with the development of the group. Only Joan and Shahieda felt that there needed to be more of a focus on the development of the community.

Shahieda: ***"My verlange is wee dat die kinnes oppie straat dat hulle oppie skool moet kom. Daas bie kinnes wat hier in die ronte loep...wat oppie straat is en wattie daa kan kom nie en ons moet...ons moet biedjie daa aan werk as 'n groep om vir hulle in te kry."***

["I yearn for the children that are on the street to get to school. There are a lot of children that walk around ...that are on the street and cannot get there (to the school) we have to...we have to work a little on that as a group to get them in."]

During the group's existence, three members had obtained their learner's licence, one would matriculate that year and all of them had the opportunity to attend various educational and self-developing courses. According to Joan and Shahieda, it is now time that they stop developing themselves and start developing the community. They stressed that part of the role of the group should be "***to work within the community***". They felt that this role had been delayed until some participants had developed themselves.

Joan: ***"...there is people"..."that goes on all this training, but then they don't go out and, and...and...uhm...you know...and go out like to do things*** (referring to self-help tasks).***"***

Although participants agreed with her, some of them were in the middle of courses or studies. They could not take the time out to be more active in groups. All the participants, however, acknowledged that it is essential that they are at least partially empowered at an individual level, before creating opportunities for others to empower themselves. They saw all the courses that they have attend as a means to develop themselves and thereby empowering themselves.

Juwaya: ***"Ek moet eers die skool kla maak, dan het ek mee tyd vir goet. Om te werk innie group. En ek sal dan better kan werk innie group."***
["I first have to finish school then I will have more time for things, to work in the group. And I will be able to work better in the group."]

4.2.3. Limited group and community change

Up until now the main focus of a number of the group's activities had been on empowering themselves through learning skills and knowledge. Not all of the training that members had has focused on developing individuals; some had also been to develop the capacity of the management of the group, while another had been on training for community development. However, members felt that although they have the training, they often did not implement this training in the community.

Shahieda: ***"Ja, ons het anti-bias gedoen...maa wat nou? Ek wiet nou van anti-bias...maa wie annes in die community wiet daa van?"***
["Yes, we did anti-bias (training)...but what now? I know about anti-bias...but who else in the community does?"]

As discussed under "Introduction to participants" (Chapter 3), members' individual habits and behaviour are influenced by their past identities.

Joan: ***"Aniesa is `n muis. Sy sê niks nie, maa ons wiet ons moet haa opinion vra."***

["Aniesa is a mouse. She does not say anything, but we know that we are supposed to ask her opinion."]

Aniesa grew up in a household where it was believed that children should be seen and not heard. She was never allowed to express her opinion. When she got married the situation did not change. She is now the quiet one in the group only speaking when she is directly addressed. She is still in the habit of not volunteering her opinion. Although she understood the impact her quietness had on the group, she had difficulties changing this behaviour to enhance her verbal participation in the group. In a move to create an opportunity for her to develop herself, the group elected her to be their chairperson. They hoped that this move would force her to be more verbally involved in the group. As group leader she did not always push the group to make decisions or plan tasks as needed.

Juwaya: ***"Ek was altyd die een wat na my familie moes gekyk het. Even toe ek nog jonk was. Ek moet sterk gewies het vir hulle. Hulle het ge-ekspect dat ek hulle problems moet solve."***

["I was always the one that had to look after the family. Even when I was young. I had to be strong for them. They expected that I had to solve all their problems."]

Juwaya had become the breadwinner and main carer of her family after her father left the family and after her husband left her. This impacted on her style of doing things. She often made decisions that affected the group without consulting the group. This led to disapproval of her behaviour and conflict within the group, especially between her and some members.

Joan: ***"Sy moet dit met ons gediscuss het. Sy moettie haa eie decisions maakkie. It maak alles net deemekaa."***
["She must discuss it with us. She must not make her own decisions. It messes everything up."]

Juwaya often became defensive when the group confronted her about this behaviour. She felt threatened and responded aggressively, despite having training. One incident where she became defensive in a conflict situation, the researcher encouraged her to reflect on her behaviour.

Researcher: ***"Now I know you had anti-bias training, you had conflict management training and you had problem-solving training. What just happen? Why did you react in that way?"***

Juwaya: ***"And I feel like uhm...I was the wrong doer here..."***

Juwaya felt that the group was accusing her. This caused her to feel threatened and she became defensive. Without thinking about her training, Juwaya went back to her habitual method of handling conflict, that is, she became defensive, aggressive or passive-aggressive. Similar incidences were observed with other participants. Although they had the knowledge of how to handle a conflict situation, participants did not always implement this knowledge within the group situation. This could be due to the fact that they did not have the skills to implement the knowledge or the skills to change existing habitual behaviour. The gain in knowledge was not always accompanied by a change in behaviour.

It is not only the implementation of the knowledge on self that was an issue, it was also the transfer of knowledge and skills to the community of Ocean View. Carrying over the skills and knowledge that the participants acquired seldom went further than the group. The participants did little advocacy and awareness-raising in the community due to the problems that the group were experiencing in terms of self-help tasks (as discussed in Theme 1). This limited their opportunity to share knowledge with the community. The knowledge they gained in courses like anti-bias training, conflict management and disability awareness training was not always being transferred to the broader community.

Joan: ***"Ons is meer...we've got too much courses and trainings..."***

["We are more... we've got too many courses and trainings..."]

Shahieda: ***"Ons het nog meeste uitgegaan on te gaan leer. Ons het nog nie eintlik baie gedoen nie. Daarom kennie baie mense vi onssie."***

["We have gone on courses the most. We have not actually done a lot. That is why not many people know us."]

Theme 3: The process

Table 4: Thematic Representation of Theme 3

Category	Sub-category	Codes
4.3.1. Creating opportunities for learning	Comfort zone to talk and try out new ideas, behaviours and processes Learning about self	Open time Comfortable to talk Building up strength and courage to speak within the group
4.3.2. Progressing towards support and self-help roles	Increase depth in understanding Increase in confidence and abilities	Can plan a task with guidance Prompting decreased Can identify underlying problems with guidance Able to identify solution in hindsight

Theme 3: The process

This theme describes the women's experiences of the research process.

4.3.1. Creating opportunities for learning

Researcher: ***"...you guys talked a lot within this group. What made it different? Why was it easy to talk?"***

Aniesa: ***"We feel comfortable."***

Shahieda: ***"Ons moet lankal soe gepraat het."***
["We should have been talking like this before."]

As the group became familiar with the format of the focus group meetings, they became more comfortable within the group. This impacted positively on their participation in the group sessions. Their interaction within the group increased and they started to initiate discussions themselves. The researcher had to prompt less to encourage all participants to be involved in the discussions. This increased familiarity with the group process and also led to a degree of comfort between participants in the group. Consequently they became less defensive and were not afraid to be honest and verbalise their own mistakes within the sessions.

Joan: ***"Let's be honest with each other. Ons was slap.*** *[We were slack.]* ***That is why things was not happening."***

Verbalising the barriers to successful functioning allowed participants the opportunity to take ownership of the problems and made it easier to look at possible solutions. This openness and honesty was not only towards the researcher, but also towards each other. It gave them the confidence to broach subjects they avoided before. For example, they spoke about the constitution that was of poor quality and incomplete. Initially they spoke about the person that helped them draw up the constitution, stating that maybe she did not know how to do it. As time progressed they began to look at their own input and the fact that they did not ensure that the constitution is relevant to them.

Shahieda: ***"We just accepted dat sy wiet wat sy doen. We never checked."*** ["We just accepted that she knew what she was doing. We never checked."]

According to participants, the group did not look at the constitution after it was written to see if it was appropriate for them. They did not re-read it or consider implementing it practically. They moved from blaming someone to looking at their own behaviour within the research process. They also shifted to being able to understand that they have control over their own situation and progress and that they have to be actively involved. This included evaluating their own input if they wanted to be successful.

Joan: ***"...but maybe we relied too much on our facilitator..."***

Instead of only saying that they do not know all the contact people of the different organisations, they were able to look at why they do not know (this was in response to the quote in Theme 2). The group was able to realise that they relied on the previous facilitator and researcher to network on behalf of the group.

As they became familiar with the reflection process and comfortable with reflecting in each others' company, their reflection skills became more in-depth, honest and less defensive.

Another benefit of the research group process was that participants appreciated that they were able to guide the discussion. They saw the focus group sessions as an opportunity to discuss any group or personal issue that impacted on their lives and, therefore, on their group participation. This was especially valuable to participants when they started discussing conflict between group members, a subject that they had been avoiding for almost a year.

Shahieda: ***"Thank you Fazlin (researcher) for giving us open time. Die was nou al `n problem vi lank. Ons kom net nooit soe ver on dit uit te sortie."***
["Thank you Fazlin *(researcher)* for giving us open time. This has been a problem for a long time. We just never get around to sorting it out."]

Reflection time created the space to consider and understand their own behaviour, the behaviour of others in the group as well as their collective behaviour. They saw this as an opportunity to develop the self and the group.

Joan: **"I must say thank you for this...sessions, because actually I'm building up my strength and courage to say what I want to say."**

4.3.2. Progressing towards support and self-help roles

On evaluation of the process that the group had experienced during the research process, it became evident that positive progress was made. They made particular progress towards achieving initial small goals that they set for themselves. For example, they identified that they wanted more parents in Ocean View to know about the OPSG. This would ensure that more parents are supported and would increase the membership of the group. In response to this need, they were able to plan a public meeting for other parents with disabled children in Ocean View. The progress that they made was not only in "what they were doing" but also mainly in "how they were doing it". As they become more effective in the "how", they also become more effective in the "what".

They improved their method of doing things by becoming more proficient in identifying underlying problems. This made it easier for the group to find appropriate solutions with minimal prompting from the researcher. For example, when they first identified the need to increase membership and ensure that more parents are supported, they planned to do home visits. These home visits did not take place (refer to Theme 1: 59).

Researcher: ***"Hoekom het die visits nie plaas gevind nie…nie gehappen nie?"***
["Why did the home visits not happen?"]

Shahieda: ***"...because ons kannie gemeet hettit as `n groupie."***
["…because we could not meet as a group."]

Researcher: ***"Why could you not meet?"***

Shahieda: ***"mmm.....ons kannie by mekaar gekom hettie...die een study…die anne een moet die doen en soe. Amal was biesag."***
["mmm…we could not meet…the one is studying…the other one do that. Everyone is busy."]

Juwaya: ***"Ja…we do not have time...jy wiet…too many things to do…ek wiet daais nie `n excuse sie. "***
["Yes…we do not have time…you know…too many things to do…I know that is not an excuse."]

Researcher: ***"So are you saying dat dit `n tyd problem is?"***
["So are you saying that it was a problem of time?"]

Shahieda: ***"Ja...ek dink soe...maa issit that we do not have time to meet of dat onssie tyd het om visit tie?"***
["Yes...I think so...but is it that we do not have time to meet or is it that we do not have time to visit?"]

Joan: ***"Issit tie al twee nie? Ek dink it is."***
["Is it not both? I think it is."]

Researcher: ***"So if it is both. Will visits work?"***

Joan: ***"Yes it can but maybe kan ons kyk na `n public event. Dan slaan ons baie vlieë dood met een klap."***
["Yes it can but maybe we need to look at a public event. Then we kill many flies with one blow."]

The group progressed from just knowing that visits were not taking place to a deeper understanding of why the visits were not taking place. Consequently they were able to come up with an alternative solution that was more appropriate and manageable for them.

Another area in which progress was evident was in the prompting needed from the researcher. As discussed in the first category of this theme, the prompting and guidance needed from the facilitator became less as the group progressed. Initially she needed to suggest alternative solutions for problems and facilitate the group to decide on the best alternative. Later in the process the group was able to come up with concrete solutions themselves. These responses illustrate that the participants were starting to reason independently.

Shahieda: ***"We could also have gone to her home to check whether she got the right info…you know."***

Joan was able to find a solution for the problem that they were experiencing in terms of not being able to plan the proposed home visits to other parents in the community. What was evident was that the solutions were often only for very concrete problems or it was very individually focused. As we pursued this matter she was even able to identify a more efficient solution for the problem.

Joan: ***"I will make time even if it... I have to say for people...I mean, even if it's two parents I visit on one night."***

The group's progress could be due to the fact that the members were becoming more confident in their ability to solve problems and to make decisions.

Juwaya: ***"O...daai is nogal a good idea Joan…"***
["O…that is a good idea Joan…"]

Joan: ***"Ja…`n boer maak `n plan...maa ons coloured is gebore met een."***
["Yes…a white person makes a plan…but a coloured is born with one."]

It could also be because they were gaining knowledge about the processes of problem-solving and were becoming more familiar with using this process within the context of the group and Ocean View. What is, however, evident is that the process of action-reflection that was followed throughout this research process gave members opportunities for both.

Researcher's reflective journal, meeting 6***: "I am doing less in the groups in terms of prompting. They are coming up with solutions themselves. The solutions are still very concrete and, at times, superficial...but it is still progress. We must be doing something right."***

Initially the group planned to do individual home visits. Only a few of these visits took place, as the group could never finalise the action plan for this task. During evaluation of this by the group, they identified that not meeting and the limited time that members had available, prevented them from achieving this goal. They were, therefore, able to come up with the alternative solution of having a public meeting. This solution meant less work for them and because it was a once-off event, it was also less time consuming. The public meeting took place after the seventh focus group and was decided on and planned outside of the focus group meetings. This indicated to the researcher that participants internalised the information gained during the focus group meetings and were able to apply some of the lessons learnt without prompting. This illustrated that a move, from just talking to action, was taking place.

Researcher***: "Ses maande het dit gevat om tot by 'n punt te kom waar julle 'n meeting maak om julle membership te increase. Hoekom nou? Wat het gebeur dat julle nou decide on dit eindelik te doen?"***
["Six months it took to get to a point for you to plan a meeting to increase your membership. Why now? What happened to make you decide to do it now?"]

Joan***: "Ons het net soma decide. Ons voel nou ons kan dit doen. Ons het nou mee confidence en wiet nou 'n bietjie hoe."***
["We just decided. We feel now that we can do it. We now have more confidence and now know a little how (to do it)."]

This research process gave members an opportunity to become more proficient in identifying and understanding underlying hindrances. It enabled them to find more appropriate solutions to overcome these hindrances. The research process made it possible for participants to ***"build up their strengths"*** and develop knowledge, skills and confidence to function within a group and as a group. It also allowed them to move towards achieving some of the goals that they had set for themselves.

CHAPTER 5 DISCUSSION

Through their group membership, the women of the Outlook Parent Support Group became conscious of and gained deeper insight into the socio-cultural realities that influenced their lives. The most profound influence was the impact of living with a disabled child within an impoverished coloured community. They came to realise that they had the capacity to transform their reality (Watson and Lagerdien, 2004) and thus create a better life for themselves and their children (Watson and Lagerdien, 2004). This, according to Watson and Lagerdien (2004), is the essence of empowerment.

However, their awakened realisations did not ensure the sustainability of transforming the realities of their own situations. This impacted negatively on their ability to initiate and sustain change at a community level. Although the group did partake in some awareness-raising activities, they had difficulty achieving their stated goals of focusing on developing the community and improving conditions, especially for the children, within the community. The question that this research project attempts to answer is: Why did the women from OPSG have difficulty achieving these goals?

One of the reasons for these difficulties was the difference between support and self-help groups. A significant finding that evolved out of the research is that the group struggled to achieve goals inherent to a self-help group and not a support group. As stated in the literature review (see Chapter 2), the main difference between support groups and self-help groups lies within the outcomes of these groups (Wilson, 1986). Outcomes of support groups focus solely on support and the building of knowledge to benefit the individual within the group. Self-help groups not only focus on individual empowerment, but also on societal empowerment (Lagerdien, 2002). The nature of the group and its outcomes determine the group tasks. Support groups centre around support functions that are performed in a regular meeting or between group members as necessary. This makes 'support tasks' and 'support goals' easier for the group to perform.

Self-help groups, on the other hand, involve tasks that include awareness-raising and advocacy. Performing these tasks require members to liaise with other community organisations, plan and execute public events and transfer knowledge and skills to the community, where appropriate (see Theme 1).

As part of this research the women of the OPSG acknowledged the need for both support and self-help groups for themselves and other parents with disabled children in Ocean View. They did, however, express that they were more comfortable and confident with performing the functions of a support group rather than that of a self-help group. 'Who they are' and 'what they had to do' made it easier for them to be a support group, but created tension with becoming a self-help group.

5.1. The occupation of self-help

The American Occupational Therapy Association (AOTA) defines occupation as "...the ordinary and familiar things that people do every day" (1995:1015). Within their position paper on occupation, the AOTA stated that this simple definition "reflects, but understates the multidimensional and complex nature of daily occupation" (1995:1015). They look at the task and the person only and do not reflect on other influences on occupation.

Clark, Parham, Carlson, Frank, Jackson, Pierce, Wolfe and Zemke (1991: 301) address occupation within a somewhat more multi dimensional context by defining it as "...chunks of daily activities that can be named in the lexicon of [the] culture". This is more in line with Kielhofner's description, which states that human occupation is "...doing culturally meaningful work, play or daily living tasks in the stream of time and in the context of one's physical and social world" (1995: 3). These definitions highlight the fact that there is more to occupation than only a task that people engage in and suggest that context plays a major role.

Occupational behaviour is defined as the "set of responses which allow the individual to maintain role competence" (Christiansen and Baum, 1997: 600). This "set of responses" or behaviour usually has some socially agreed upon function and is performed according to a socially accepted code of norms. This means that society and/ or the context define how a person should behave within a given role or while engaging in occupations.

It is, therefore, safe to say that occupational behaviour is not only influenced by the individual's skills and abilities but also by contextual cues and features that support their performances or that press for a certain performance (Dunn, Brown and McGuigan, 1994; Kielhofner and Forsyth, 1997). Consequently the person, the environment and the nature of the task shape occupational behaviour.

Christiansen (1999) states that occupation and occupational behaviour are key to creating and maintaining a person's identity and he goes further by adding that the identity is shaped by the meaning people derive in their lives through engaging in occupations. Thus, if society can shape occupations and occupational behaviour, it stands to reason that it can also contribute in shaping identity.

The identity of the women from OPSG was influenced by social-historical and socio-economic factors within their context. The women's 'being' (Wilcock, 1998b) that is, their individual identities, occupational behaviour and habits, were influenced and is still being influenced by the social environment. Compounded by their present engendered roles as women, these influences created missed opportunities for development and empowerment, multiple roles and time poverty. Consequently, this impacted on their 'doing' (Wilcock, 1998b) by decreasing their ability to be successful within their individual and collective roles in a self-help group. In turn their ability to 'become' successful (Wilcock, 1998b) in their personal and collective capacity and to achieve the goals they had set for themselves decreased.

5.2. Being disadvantaged through the cycle of deprivation

According to Chambers (1983) communities or individuals within communities are disadvantaged by poverty, inadequate resources and discrimination, for example, racial discrimination based on apartheid. Individuals, within communities, can be disadvantaged by social attitudes and traditions. For example, women in Ocean View are marginalised by their gender identity. Reasons for and consequences of being disadvantaged will be elaborated on later in this chapter.

Being disadvantaged within a community can make women living in an impoverished community poorer than men living in the same community (Chambers, 1983). The women of the OPSG grew up and are still living in an impoverished community. Within Ocean View, they are still marginalised despite the fact that South African legislation has changed to ensure equity of all citizens (Constitution of the Republic of South Africa, 1996). The main difference is that they now have to deal with the *legacy* of the apartheid regime and not with apartheid itself, that is, have to deal with the legacy of being underdeveloped and living in an impoverished environment.

Whatever the reasons are for people being disadvantaged or deprived, the consequences are often the same. Chambers (1983) categorised the consequences of deprivation into five clusters, namely, powerlessness (see Chapter 2), vulnerability, physical weakness, poverty and isolation. These clusters are interlocked "like a web to trap people in their deprivation" (1983: 112) (See Figure 2). Linking the five clusters in the deprivation cycle can give rise to twenty possible relationships. To discuss each of these relationships in-depth is beyond the scope of this thesis. What is significant to this discussion is that, firstly, when investigating these relationships it is evident that the different clusters can be 'causes' and 'effects' of one another. For example, isolation sustains poverty whereas vulnerability is a consequence of isolation. Secondly, all five clusters are applicable to the women's lives, indicating that they are still caught in the deprivation trap.

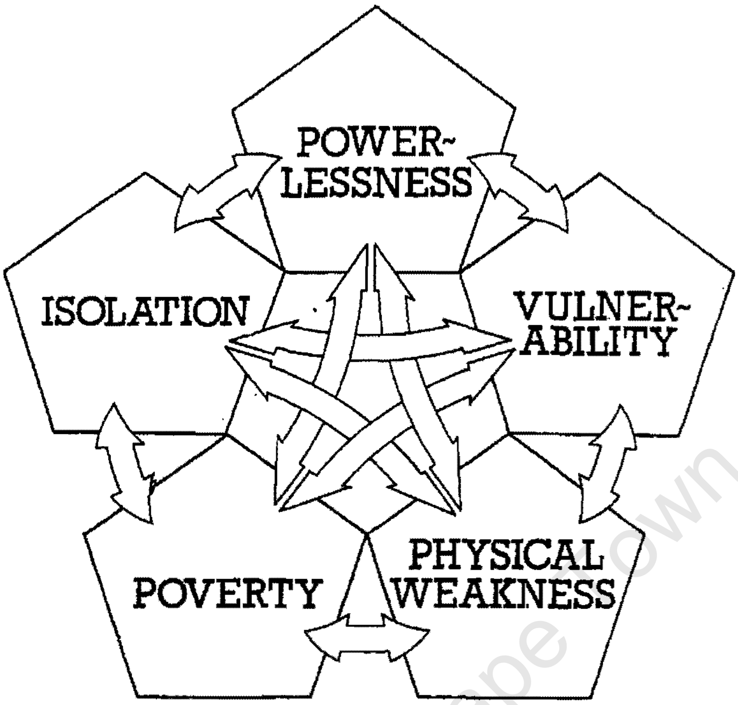

Figure 2: The deprivation trap (adopted from Chambers, 1983)

5.3. The legacy of missed opportunities, multiple roles, habitual behaviour and time poverty

The women from the OPSG were disadvantaged by socio-cultural (engendered roles as women), political (apartheid) and economical (poverty) influences, thus leaving them caught in the deprivation cycle. These influences created feelings of powerlessness. It isolated them and made them vulnerable. The legacy of these influences compounded by caring for a disabled child, continues to affect the women's abilities and behaviour. It causes them to miss opportunities to develop themselves and demand that they independently bear the burden of the numerous roles allocated to them in the community (see Figure 3). The women were left with too many responsibilities and very little time and resources to deal with these responsibilities. The women were forced to form personal habits as a means of coping with the situation. To understand how these influences impacted on their ability to perform self-help tasks, we need to look at these influences more closely. The following discussion explores the socio-cultural, political and economic influences that impacted on the women's identity, development and behaviour. It proceeds to explore and discuss the impact of caring for a disabled child. Furthermore, it looks at the women's behaviour in more detail, and discusses the impact of the above influences on habit formation and how this still affects their behaviour.

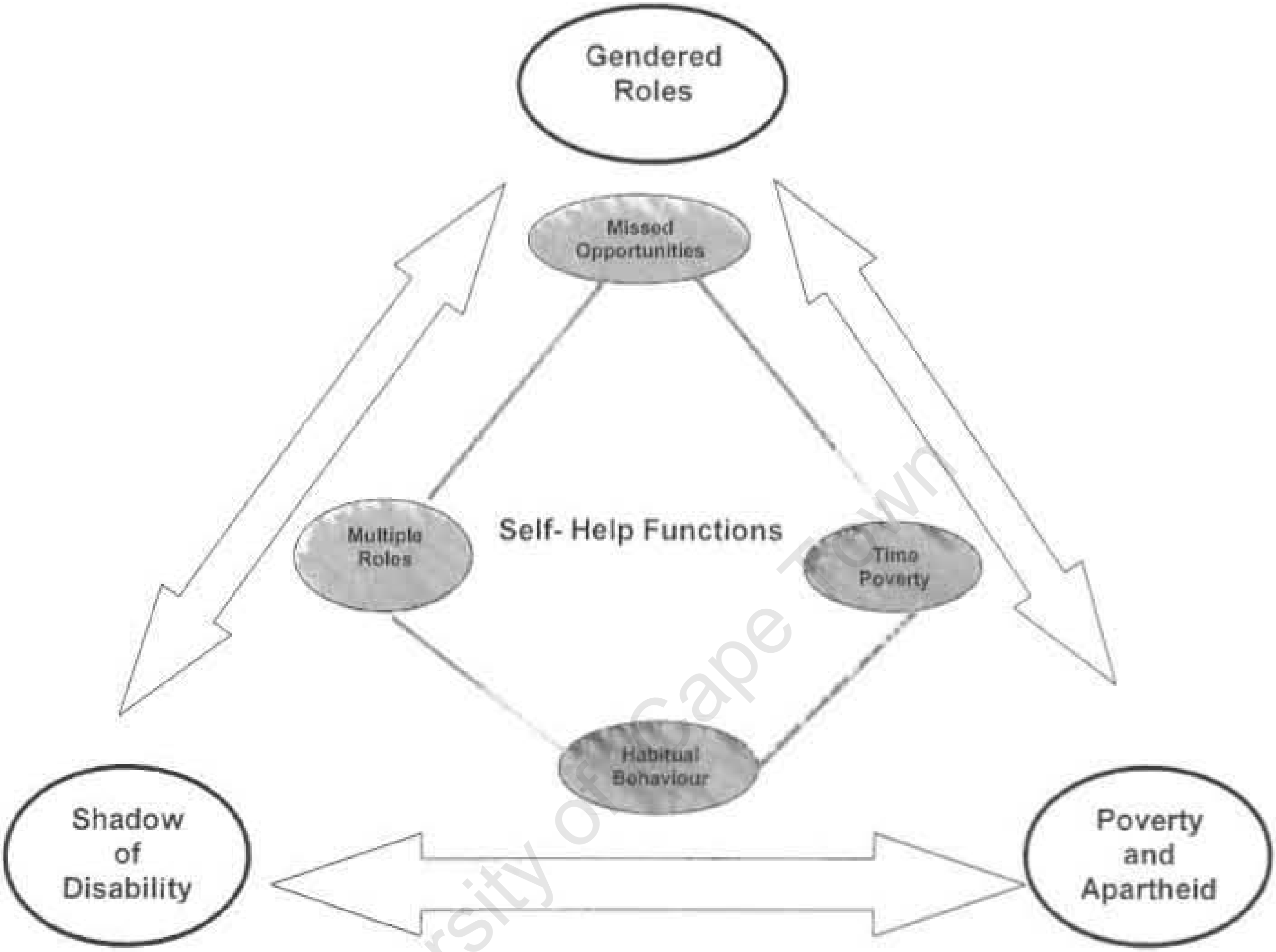

Figure 3: Sustaining the deprivation trap

This study proposes that the women from the OPSG were and still are being deprived and disadvantaged by poverty, gender discrimination and their role of mothering a disabled child. The consequences of these influences are missed opportunities, multiple tasks, time poverty and habitual behaviour. All of these consequences limit their ability to be successful in performing self-help functions. Within Figure 3, the outer circle represents the root problems and the inner circle represents the consequences of these root problems. The root causes that influence each other, causes the consequences and impact on the women's ability to perform self-help functions.

5.4. Consequences of poverty and apartheid

Two significant influences on the lives of the women of OPSG during their formative years were poverty (see literature review) and the legacy of apartheid. According to Barberton, Blake and Kotze (1998: 4) "colonial and apartheid regimes used 'democratic' institutions, the rule of law and the state bureaucracy to sanction and facilitate the exploitation and impoverishment of millions of people". It is, therefore, safe to say that apartheid, directly and indirectly caused and contributed towards the impoverished situation that many South Africans, including the women of the OPSG, find themselves in. Due to the discrimination that they had to endure, they were afforded fewer opportunities that could have benefited them later in life. For example, they had less access to adequate living conditions, educational and employment opportunities and ultimately occupational choices. Many of the women in the OPSG were forced to leave school to help their families financially and all of them have been working ever since. This caused them to miss various educational and development opportunities.

For the women, growing up in an impoverished environment during the apartheid era left them vulnerable to the humiliation of dependency and powerlessness (Chambers, 1983; Watson and Fourie, 2004) as they had few choices in life. It isolated them from resources, services and opportunities (Chambers, 1983) and caused unrealised childhood dreams due to the circumstances they had to endure (Lagerdien, 2002). They were forced to make difficult decisions and many personal sacrifices to ensure the well-being of their families.

Being powerless (see Chapter 2) causes people to lose their ability to make decisions, leaving them at the mercy of others (Freire, 1973 as cited in Albertyn, 2000). Powerlessness also impacts on intrapersonal and interpersonal relationships, thus causing distrust, pessimism, hopelessness, self-blame, feelings of inferiority, difficulties with taking initiative, dependency and lack of faith in one's own skills and ability to change one's circumstances (Albertyn, 2000; McColl *et al.*, 2000). These consequences can negatively limit one's ability to be goal oriented and as well as being able to perform, initiate and complete tasks. The women of the OPSG exhibited many of these symptoms of powerlessness. This limited their ability to successfully perform tasks needed for self-help functions.

Barberton (1998: 253) found that "...poor people often do not have the kinds of resources, particularly skills and information, that are needed to address many of the problems they face", which makes it difficult for them to bring about social change. Within an organisational context like a self-help group, this lack of appropriate skills diminishes the efficiency and effectiveness of organisational initiatives and often jeopardises the sustainability of these initiatives (Barberton, 1998). The lack of skills can also cause dependence by the organisations on outside 'help' (Barberton, 1998). According to Barberton (1998) this can lead to the collapse of the organisation on withdrawal of the assistance. The members from the OPSG identified the need for a self-help group within their community, but were not fully familiar and confident with the tasks and responsibilities of a self-help group. This made it difficult for them to perform these tasks (see Themes 1 and 2) independently. They often looked to the previous group facilitator as 'the expert' to help and assist them (see Theme 1) with networking, planning and decision-making around awareness-raising and advocacy tasks. On her withdrawal, it was more difficult for them to perform these functions effectively. Therefore, they struggled to achieve their goal. This raises the question: Was the group adequately prepared and ready for her withdrawal? According to the previous facilitator of the OPSG (Watson and Lagerdien, 2004) she followed a situational leadership approach (shaping of expert opinions as experiences) as opposed to a directive leadership approach (giving orders). Despite this approach, the OPSG members still leaned heavily on her, thus impacting negatively on their ability to fully develop themselves. This raises additional questions of: At what point is a group of marginalised women, who established a group with the help of an outside facilitator, adequately prepared to facilitate the group themselves? Would an 'expert facilitator' be more equipped to facilitate the process of achievement of goals within a self-help group?

From this study it was not possible to get a sense of how professional involvement had helped or hindered the development of the OPSG as a collective, as there were no professionals or experienced facilitators involved with the group, during the time of the research.

They did not only have difficulty with the roles, responsibilities and leadership of self-help, but also with the skills required for the success of a self-help group, for example, decision-making, problem-solving and conflict management as a collective (see Theme 1). It is the researcher's opinion that the group members could have obtaining information on for example the roles and responsibilities within a self-help group without the help of a facilitator. However skills, for example decision-making and problem solving, are more difficult to gain without the facilitation of an experienced facilitator. Group members often found it easier to problem-solve in their own lives, but more difficult to do this as a group (see Theme 1). As a group, they also had difficulties making decisions around self-help issues and with planning or coordinating the implementation of these tasks. Firstly, this was due to their limited knowledge and skills around self-help issues. Secondly, they believed that discussions and decisions should be a group effort, which was difficult to do as they seldom met as a full group (see Theme 2). This belief and need to making decisions in a group could be due to members needing the security of conformity of the group (Freire, 1974). The legacy of powerlessness, which included limited confidence in own skills, made them hesitant to make decisions without the collective. They needed the whole group present to spread the responsibility for making the correct decisions. Barberton (1998) identified this as a common problem and urged trainers to ensure that training did not focus around organisational needs only, but also around needs of the members.

According to Barberton (1998) it is difficult for poor people to initiate programmes aimed at improving their situations, because this usually requires an investment of time, energy or money. When poor people are working hard at surviving they often do not have excess time, energy or resources left to devote to organisational activities (Meer, 1998). The multiple roles (see Themes 1 and 2) that the women from the OPSG had, left them with little time and energy to perform functions that were needed for the success of a self-help group (see Theme 2). Barberton (1998: 258) named this phenomenon ‘time poverty’. People in impoverished communities simply cannot afford to neglect their basic survival. If having to choose between working to help support the family and attending a workshop, the women do not have much of a choice. Their children, families and work were their main priorities and all their time and energies were spent on tasks around the survival of their families and themselves (see Themes 1 and 2). Consequently, they missed opportunities to contribute to social change in their community.

5.5. Gender oppression and multiple roles

As women, the members of the OPSG were deprived of opportunities to develop themselves. This, as well as the multiple responsibilities (see Theme 2) that they as women were allocated, impacted on the their ability to perform self-help functions. It also contributed to the time poverty (Barberton, 1998) that they experienced, that is, the time available to perform self-help functions (see Theme 2). The following discussion will examine why the women were allocated these tasks and look in depth at the relationship between gender and the context that the women live in.

The concept of gender is seen as a cultural expression associated with the biological categories of male and females (Miers, 2002; Nicholson, 1994; Wilcock, 1998a). Due to a woman's childbearing abilities, she is traditionally allocated the responsibilities closer to home that is caring for the children and gathering food and firewood. Other characteristics attributed to women by society, due to the maternal role, are those of nurturing, interdependency, being family focused and protective of other's well-being (Miers, 2002). Men, on the other hand, were free to roam around. They are, therefore, socialised into the role of hunters and providers (Wilcock, 1998a).

Gender is used in almost all societies for social stratification (Giddens, 2001). Men's roles are usually valued higher than those of women (Giddens, 2001;

Hope and Timmel, 1999). This means that men, as the providers, assume a superior position of power, wealth and prestige, which gives them, increased access to opportunities for development and success. Women, on the other hand, traditionally, have an inferior role and are classified as dependent or interdependent on the man. Due to their roles and inferior position, they are robbed of those opportunities that are afforded to males. This makes them vulnerable to be caught in the deprivation trap (Chambers, 1983). In their dependent position, they are powerless to control their situation. They are isolated from opportunities for development and vulnerable to being under developed, overworked and under appreciated.

Rich (1990) suggests that motherhood, as an institution, is also socially constructed and that society has equated motherhood and a woman's identity with maternity (Lagerdien, 2002). This maternity or 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" (Lagerdien, 2002: 90). It is seen as a natural part of her identity (Rich, 1990). Due to this, Rich (1990) further suggests that it is considered only natural that women should unconditionally and selflessly care for not only children but also adult males.

The impoverished conditions in which they live, forced the women of the OPSG to find employment to supplement the family income. According to Barret (1997) sub Saharan African women have triple roles, those of mother, social producer and economic provider. Although they have the additional role of economic provider, and now share this responsibility with males, they are still responsible for the other two roles. Males in Ocean View, on the other hand, do not traditionally compromise by taking on some of the female's responsibilities. Partaking in all three roles left the women of the OPSG with little time or energy for anything else (see Theme 2).

According to Hope and Timmel (1999) women, for centuries, have been the carers of communities. They looked after the elderly, the poor, the sick and the people with impairments. They were responsible for not only the basic needs of the community but also for "the passing on of the cultural and spiritual values that bind together and give life to the family and the community" (Hope and Timmel, 1999: 86). However, as the women are forced to perform multiple roles, including that of economic provider, they tend to neglect many of their traditional tasks around carers of the community (Hope and Timmel, 1999). Within Ocean View, the women wanted to conform to tradition and care for their community by developing the community. However, the multiple roles, that they perform, impacted negatively on their ability to do this.

While the women from the OPSG have to fulfill multiple roles, they also have to work towards getting themselves out of the deprivation cycle. Their attempts to do this are not only to educate themselves about their own situation and how to change this, but to focus on self-development. In focusing on the self, they were attempting to regain the opportunities they had missed in the past. However, this focus on self-development and the multiple other roles they have to fulfilled, impacted negatively on their ability to perform self-help tasks (see Theme 2). They simply had too many priorities and roles and too little time. Consequently this created a disjuncture between fulfillment of individual needs and group/ community needs (see Theme 2, category 2). Social change within their community, one of the initial objectives for the group, was often neglected in lieu of achieving of personal goals. This created tensions within the group as some members focused on self-development while the others urged the group to be more community focused in their achievements (see Theme 2). In focusing on self, the women were also only focusing on the consequences of the problems and not always on the root causes of the problems (see Figure 3).

The questions raised here are: Are the women ready to perform self-help functions of awareness raising, advocacy and networking? Should they not have initially focused on self-development before social-change? Can these two processes take place alongside each other if the women of the OPSG are still caught in a cycle of deprivation?

Often within this research process it was found that the self-help functions were put on hold for a 'support need' by one of the members within the group (see Theme 1). This phenomenon could be due to two reasons. Firstly, they have been socialised to the support role as part of their gender identity. Secondly, it could be because the women of OPSG, were not ready to focus on self-help functions with social change as the outcome.

5.6. Living in the shadow of disability

Just as the needs of disabled people are often ignored by society causing them to be isolated (Stone, 2001), so are the needs of the carers also ignored, putting them not only in the "shadow of disability" (Boylan, 1991: 64) but also in the shadow of the community. They are isolated (Read, 2000) by the attitude of the community toward their disabled children as well as by their time consuming role as a caregiver (Read, 2000). According to Stone (2001) isolation not only means being ignored by society, but also isolation from information, opportunities and access to support and resources. This means that the mothers of disabled children have to work harder to obtain all that they need for themselves as well as for their children (Read, 2000). Looking at the revised version of the deprivation trap by Stone (2001) (see Figure 4) it becomes clear that there is a direct link between isolation, being powerless and impairment and disability (see Chapter 2).

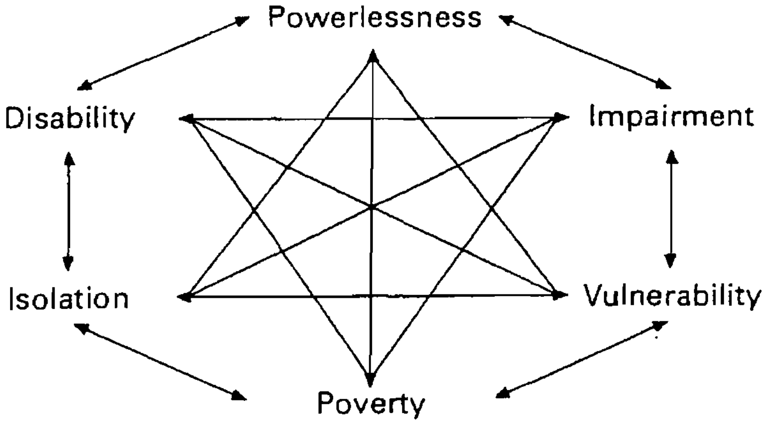

Figure 4: Revised version of the 'deprivation trap' (Stone 2001)

The time consuming role of mothering a disabled child affects the lives and the needs of the mothers significantly (Olson and Esdaile, 2000; Read, 2000). The mothers need additional skills, knowledge and organisation to be successful in their task (Larson, 2000). They need to know about their child's impairment and how to manage the child and their disability. As the primary carer of the child, the mother needs to ensure that she develops these extra skills and abilities to ensure her child's well-being. Often the child is physically dependent on the mother for daily activities like dressing, eating or even moving (see Joan's situation) (Read, 2000). Caring for a disabled child might require more emotional energy from the mother, as she needs to guide the child with verbal cues to perform tasks. She might have to make decisions and solve problems on behalf of the child or become more vigilant about safety measures since the child is more susceptible to injuries and illness.

These extra responsibilities decrease the mothers' quality of life, as it taps into their resources (both physical and emotional energy). It dictated their schedule, occupied their time, and limited their activities and choices, thereby, decreasing their availability in terms of time, energy and motivation to do self-help tasks. It also curtailed opportunities for self-development (Mckeown, Porter-Armstrong and Baxter, 2003). Consequently, this led them to neglect their own physical, emotional and social well being which further disempowered them (Read, 2000).

In addition to the extra responsibilities that the mothers have to cope with, they often also have to deal with feelings of failure, guilt, doubt, resentment, anger and protectiveness (Meyer and Moagi, 2000). These feelings place extra emotional strain on the already overburdened mothers. These feelings also make mothers very protective and vigilant when it comes to the well-being of their children, often to the neglect of their own well-being.

5.7. Habitual behaviour

The OPSG members gained knowledge that was not always reflected in a change in their behaviour (see Theme 2). On further investigation of this phenomenon it became evident that the women's behaviour was habitual. When they felt stressed, threatened or overwhelmed, they tended to fall back on their habitual behaviour. To understand this behaviour we need to look at what shaped and sustained their habits.

Garrison (2002) suggested that habits are an acquired function that require co-operation from the environment in order for it to be established and sustained. The same environmental and social factors that shaped the women's identities and behaviour (as discussed above) also shaped their habitual behaviour (see examples in Theme 2). Growing up in an impoverished environment during the apartheid era, having to make sacrifices for the well-being of their families and the socialisation of their role as women and mothers all shaped the habits that they presently have. Some of the habits that the women needed while growing - up were no longer necessary and therefore impacted negatively on their behaviour within the group setting (see examples in Theme 2). Unfortunately, they found it very difficult to change these habits.

Reasons for these difficulties become clear when looking at literature on habits. Charmaz (2002) proposed that humans have a predisposition to respond in the same way given the same stimuli to ensure economy of thoughts and actions. When they are feeling very pressed for time, overwhelmed or threatened they might not have the emotional energy to think logically about their situation and to incorporate new knowledge in the situation. These non-productive habits were especially evident when conflict situations arose during group discussions and when tasks were planned and executed. This prevented tasks from being executed successfully and made it difficult for them to achieve the goals that they have set for themselves. According to Garrison, "Learning, judging and believing involve doing and feelings, not just knowing" (2002: 11s). A change of habits does not happen just because the person knows about the habit and how to change behaviour. For people to change a habit it is essential that they understand the impact of the habit on their lives and the need to change. They also need opportunities to 'do'. To implement these changes, a structured environment is needed that supports change (Rogers, 2000). The context in which the women of OPSG live does not, however, support this and the opportunities they had to develop the skills needed for change, were limited.

5.8. Moving towards action - the process

Through repeated engagement in the action research cycles of 'look', 'think' and 'act' (Stringer, 1996), the group members had multiple opportunities to reflect on their own behaviour, each other's behaviour and their behaviour as a collective (see Theme 3). The aim of repeating the process was not only to increase the depth of their reflection, but also to familiarise them with the process of reflection, thereby, increasing their skills in reflection. The aim was to create an opportunity to develop the skill of reflecting on their behaviour in order to enhance their performance. According to Rogers (2000), opportunities should be given to people to increase their confidence in their newly acquired skills. Many repetitions of the cycle ensured that the women became comfortable and familiar with this process of reflection. Rogers (2000) also suggests that any change in behaviour and habits need to take place in a supportive environment. The fact that the researcher initially facilitated this process of reflection ensured that it took place in a supportive and structured environment. The women appreciated (see Theme 3) this 'safe space' and they equated it with a space to learn and an opportunity to develop themselves and the group. The process of Action Research created an opportunity for the women from the OPSG to learn about themselves as individuals and as a collective.

Peter Grove, the chairperson of PLOEG, a rural development network, introduced the concept of 'action space'. According to Barberton *et al.* (1998: 9) 'action space' is a " term that encompasses the idea that people are only likely to *act* if their actions have a very high possibility of success or if they have a secure alternative if they should fail". The legacies of poverty and apartheid have robbed people, including the OPSG members, of these 'action spaces'. By creating an opportunity for the women from OPSG to reflect on their behaviour, to identify hindrances and to brainstorm possible solutions to overcome these hindrances, this research project has created an action space for them in which they can address their own as well as the community needs. The women, close to the end of the research process, illustrated this success, as they were able to plan and implement an action plan that was needed in order to achieve one of their goals (see Theme 3 for details).

5.9. Conclusion

The OPSG identified that the group aimed to achieve both support and self-help. Their individual and group identities led to them feeling more at ease with the roles and responsibilities associated with a support group. However, it created tension when they had to perform the self-help group functions. The women from OPSG experienced missed opportunities, multiple roles, negative habitual behaviour and time poverty as consequences of their socio-political and socio-cultural environment. This negatively impacted on the success of achievement of self-help goals.

When addressing the barriers to self-help, the women attempted to challenge their missed opportunities, time poverty, negative habitual behaviour and multiple roles factors in order to alter their situations. This approach meant that they only addressed the consequences of the problem and not its origin. These women and others in similar situations may benefit from reflecting on and understanding the consequences that the socio-political and socio-cultural environment has on their ability to fulfill the self-help group functions. This reflection would allow them to analyse the root causes of the hindrances to the achievement of their self-help goals. It would also create the opportunity to explore possible solutions to the hindrances.

An experienced facilitator may be a valuable resource within the above-mentioned reflection process.

CHAPTER 6 RECOMMENDATIONS

6.1. Way forward for OPSG

The Integrated National Disability Strategy (OPD, 1997) suggests that special attention be given to groups who experienced high levels of exclusion (for example disabled women and children) in order to redress the past and present inequities. To do this role-players from all sectors, for example form governmental and non- governmental sectors, need to gain an understanding of and address conditions that led to this exclusion. Although the women of the OPSG are not disabled, their lives are severely impacted by their roles of caring for their disabled children. The parents, particularly the mothers of disabled children have an important role to play in the development of their children. If they have difficulties performing this role, it can adversely affect the development and integration of the child into the community and thereby negatively affecting their health and quality of life. This study identified and attempted to facilitate an understanding of conditions negatively impacting on carers of disabled children. The next step is for group to explore possible actions.

Organisations, focusing on empowerment of the disabled, need to consider the hindrances identified in this study, when planning programmes.

The women of the OPSG need to identify and implement strategies to overcome hindrances that affect the group's achievement of goals. In order to be able to identify and implement strategies, it is recommended that the group invite an experienced facilitator to facilitate this process.

However, the facilitator and the OPSG should be mindful of the hindrances (that was identified through this study) and how it may impact on the women's abilities to fulfill their required roles and functions. The relationship between facilitator and group should be negotiated. The group members should make it explicit to any outside facilitator that the facilitator's role is to initiate the process and that the ultimate goal is for the group to complete the process by themselves.

6.2. Future research

This study has evoked many unanswered questions for future research.
The following research topics are suggested:

- An exploration of each individual cause and consequence of the hindrances to fulfilling self-help group goals. This would contribute to a deeper understanding of the causes and consequences.
- Research needs to be conducted with people who had successfully facilitated groups in the process of overcoming hindrances caused by

deprivation. This would aid in developing strategies that have proven to be successful.

- To identify successful termination strategies for professionals/ outside facilitators from parent groups.
- This study could not identify whether professional involvement had helped or hindered the development of the OPSG. A research project investigating the presence of an experienced group facilitator within a self-help group would be valuable.
- To investigate the impact that the organisational development stage (Kaplin, 1996) of the OPSG has on their performance.
- This study could be conducted with other self-help groups to identify hindrances that they are facing.

6.3. Limitations

This study identifies causes of the hindrances that the women experienced in attaining their goals. It did not set out to facilitate the resolution of these hindrances. During the research process, possible solutions to some of the difficulties were identified. The onus remained with the OPSG members to engage in discussions that could have facilitated this. The absence of an experienced facilitator during their regular meetings limited their ability to reflect on the information gained during the research process.

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Appendix 1

Identified goals of the OPSG

During the first session the participants identified their goals as:

- Ons wil die kinders bystaan. *(We want to stand by the children.)*
- Ons moet groei. *(We must grow.)*
- Moet die kinders van die straat af kry. (*Must get the children off the street.)*
- Moet die kinders safe hou. *(Must keep the children safe.)*
- Ons moet in die community werk. *(We must work in the community.)*
- Ons moet outreach werk doen. *(We have to do outreach work.)*
- Ons moet huis besoek doen. *(We have to do home visits.)*
- Ons moet ander ouers bewus maak van die group. *(We need to make others aware of the group.)*
- Ons moet 'n first aid course doen. (*We must do a first aid course.)*

Goals focused on awareness raising and community development

- Ons wil 'n aftercare oopmaak. *(We want to open an after care.)*
- We want to apply for funding for the group.
- Ons will ander ouers bewus maak van die groep. *(We want to make other parents aware of the group.)*

- Ons will ander mense bewus maak van die conditions in die gemeenskap wat ons kinders in leef. *(We want to make other people aware of the conditions in which our children live.)*

Goals for group development

- Do fundraising for the group.
- Learn conflict handling.
- Get new members.

When asked to identify goals for the year, members automatically assumed the researcher meant individual goals. She had to redirect them to look at group goals (this is discussed further in Theme two, under results).

Appendix 2

Consent Form

As the Ocean View Parent Support Group you have set goals for the group. Presently you are expressing that you are having difficulties achieving these goals. This study is about looking at how you go about achieving your goals and looking at what is preventing you from achieving these goals (doing what you planned to do).

This study is a Action Research study. This means that we (the researcher and all the members of the group) will work together to gather information about the problems you, as a group are experiencing in reaching your goals. This information we will use to decide what can be done about these problems.

The study will take place over 7 months (May to November). The research will be done in a group. All the members, who agree to be part of the research, will be part of the group. I suggest that we meet every 2 weeks initially. This is just so that we can get use to working together as a group. After our 4th group, we will decide if we are changing this to once a month. Each meeting will last for about 2 hours.

You will take part in all the stages of research and you will also have a say in how the research is done. I cannot tell you exactly what we will be doing at every meeting, because a lot of it will depend on what you as a group decide to do. I suggest that we decide what we want to do in these groups; how we want to do it and how often are we meet, at our first meeting. We will also decide what our group rules will be for these groups (e.g. Not speaking when someone else is speaking.). We will look at the goals you have set for yourself as well as for the group.

Your name will not be used when I write up this information for my studies. I may say what you have said, but I will not say who said it. The groups will be tape-recorded and these tapes will be kept at a safe place. Only myself and the person typing out what was said will listen to the tapes.

You are free to say that you do not want to take part in the study at any time without any negative consequences. If you feel uncomfortable at any time about the study or about what we are speaking about, please do not hesitate to discuss it with the group or with me. The aim of this study is to help the group achieve your goals and not intended to cause any harm. I cannot guarantee that we will achieve this aim. It depends on how we work as a group. Will promise to do my best from my part to assess in achieving the goals that we set for the group.

It you agree to be part of this study please complete the form.

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. I have been informed about the research process and understand it. I am aware that all groups will be tape recorded and transcribed. The researcher will not disclose my identity at any one stage of the research process. I understand that the content of the groups will be discussed during peer briefing and consultation with the researcher's supervisors. I also understand that I don not have to take part in the study and that I am free to withdraw from the study at any point without any negative consequences.

Consent confirmed by:

Participant:

____

Acknowledged by

Researcher: Fasloen Adams

____

Date:______________

Appendix 3

Toestemmings vorm

Hierdie navorsing projek kyk na hoe die groep te werke gaan on julle doelstellings the bereik en wat voorkom julle om die doelstellings te bereik. Ons gaan informasie insamel aan gaande die probleme wat julle as 'n groep ervaar om die doelstellings wat julle geidentifiseer het te beriek. Die informasie gaan ons gebruik on te besluit hoe om die probeme wat julle ervaar, op te los

Die studie is 'n action research studie. Dit beteken dat julle aktief gaan deelneem in besluitname in al die fases van die navorsing. Die navorsings studie gaan plaasvind vanaf May tot November. Ons sal as 'n groep ontmoet tydens elke sessie. Ek kan julle nie presies se wat ons gedurende elke sessie gaan doen nie aangesien dit afhang van die wat julle as 'n groep besluit. Ek stel voor dat ons gedurende ons eerst sessie besluit wat ons wil doen, hoe ons dit wil doen, hoeveel sessies ons gaan he en hoe gereeld ons gaan ontmoet. Ons moet ook gedurende ons eerste sessie besluit wat ons groep reels gaan wees (byvoorbeeld: Moet nie praat terwyl iemand anders praat nie.) Ons gaan kyk na die doelstellings wat julle vir julle-self asook vir die groep gestel het.

Julle name gaan nie genoem word as ek die navorsing opskryf as deel van my studies nie. Ek mag se wat julle gese het, maar ek sal nie se wie dit gese het nie. Al die groepe gaan opband geneem word. Die bande gaan op 'n veilige plek gebere word. Net ek en die persoon wat dit gaan uittik gaan daarna luister.

Julle is vry on ten enige tyd te onttrek van die studie sonder enige negatiewe nagevolge. As u ten enige tyd ongemaklik is met wat ons doen, hoe ons dit doen en wat in die groep gese word, voel vry om dit met my of die groep te bespeek.

Die doel van die studie is om die groep te help om julle doelstellings te beriek en nie om nadelig te wees vir diegene wat daaraan deelneem nie. Ek kan nie waarborg dat ons ons doelstellings gaan bereik nie aangesien dit afhang van die groep. Ek kan wel belowe dat ek my bes sal doen on te verseker dat ons die doelstellings bereik.

Indien u instem om deel te neem aan die studie, vul asseblief die permissie vorm in.

Toestemmings Vorm

Ek, ____ Is bereid om deel te neem aan hierdie navorsings projek. Ek is bewus dat alle informasie konfidensieel sal bly. Ek is ook bewus dat geen name bekend gemaak sal word tydens die transkripsie, analiese of publisering van die inligting. Die navoeser het die navorsings proses aan my verduidelik en ek verstaan die proses. Ek is bewus dat alle groepe op band opgeneem sal word en deur 'n eksterne persoon transkripeer sal word. Die navorser sal nie die identitiet van enige deelnemers op enige stadium van die projek openbaar maak nie. Ek is bewus dat die inhoud van die groepe bespreek sal word gedurende peer briefing en konsultasie met die navorser se toesighuoer. Ek weet dat ek vry is om op enige tydstip van die projek te kan onttrek sonder engige negatiewe gevolge.

Toestemming van
Deelnemer

____

Navorser: Fasloen Adams

____

Datum: _______

APPENDIX 4

Time line of focus group sessions conducted

Focus group sessions	Date	Duration
1	22 May	3 hours
2	29 May	3 hours
3	12 June	2.5 hours
4	10 July	3 hours
5	14 August	1.5 hours
6	11 September	2 hours
7	9 October	2 hours
8	13 Novembers	2.5 hours

UNIVERSITY OF CAPE TOWN

Research Ethics Committee
Faculty of Health Sciences
OMB E53 Room 44.1, GSH
Queries : Xolile Fula
Tel : (021) 406-6492 Fax: 406-6411
E-mail : Xfula@curie.uct.ac.za

24 May 2004

REC REF: 106/2004

Ms F Adams
Health & Rehabilitation Sciences
F56 OMB

Dear Ms Adams

EXPLORING FACTORS THAT INHIBIT THE OUTLOOK PARENT SUPPORT GROUP FROM ACHIEVING THEIR STATED GOALS

Thank you for submitting your study to the Research Ethics Committee for review.

It is a pleasure to inform you that the Ethics Committee has formally approved the above-mentioned study on the 20th May 2004.

Your comments to the queries raised are noted with thanks.

Please quote the above Reference number in all correspondence.

Yours sincerely

PROF T. ZABOW
CHAIRPERSON