Figure 5: A look inside the new soup kitchen

4.3.3 Project Management 4 Africa

The project manager of Project Management for Africa (PM4 Africa) is the person responsible for achieving Heavenly Promise's project objectives. Chevron, the project sponsor and principal stakeholder, assigned PM4 Africa to this project in 2007. The project manager has 20 years' experience in project management and has specialised in information technology. PM4 Africa, as part of its social responsibility initiative, has taken on the project of working for previously disadvantaged persons in informal settlements.

According to the project manager Mr R Brown (personal interview on 23 July 2010), the PM4 Africa mission is to significantly increase the awareness of the importance of project management as a life skill by means of transferring skills to the project participants of community-based projects in previously disadvantaged areas such as Dunoon. This will ensure that the individuals and communities are more likely to take control of their own future rather than depending on government to sustain them. The project manager believes that empowerment of the previously disadvantaged in Dunoon can lead to the alleviation of poverty in Africa. Project management as a life skill is an effective method of enabling empowerment. Mr Brown argued that project-based learning is the best method to teach project management as a life skill and simultaneously PM4 Africa engages with corporate clients through their corporate social investment business units. In addition, PM4 Africa acts

as the implementer of its community engagement programme and offers project management as a life skill to all project participants.

4.3.4 Department of Social Development

In 2009, the Western Cape Department of Social Development (DSD) collaborated with Heavenly Promise to combat the increasing number of HIV/AIDS instances in the Dunoon community. The HIV/AIDS programme is significant to the DSD and, in partnership with Heavenly Promise, helps in developing social amenities for people affected by HIV/AIDS. The department's intention is to join families to a variety of applicable incorporated facilities throughout DSD programmes and other departments within their community, such as housing, healthcare, community safety and education (Department of Social Development, 2009).

The DSD provides the caregivers with two days of training on minimum norms and standards, which includes the code of conduct for HBC and networking the HBC team to other role players within the community. The department also facilitates and co-ordinates family consolidation programmes for relatives infected with and affected by HIV/AIDS and ensures that caregivers obtain recognised capability building programmes are subsidised correctly and provide excellent services (Department of Social Development, 2009). Caregivers are unemployed volunteers who receive a small stipend of R720 per month from the DSD.

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4.4 Conclusion

This chapter provided an overview of the socio-economic profile of the Dunoon community, Heavenly Promise, Caltex Chevron, PM4 Africa and the DSD. The project and context in which the project was established has been described, including the organisational structure. The Heavenly Promise HBC group is part of a CCAP programme. Hence, an overview of the CCAP mission, objectives, and the roles and responsibilities of the programme and project approach were provided. The latter descriptions serve to provide an insight into the empirical fieldwork and research findings presented in the following chapter.

CHAPTER FIVE: DISCUSSIONS OF RESEARCH RESULTS

5. Introduction

Theron (2005) views participation as a structured endeavour wherein a group of persons stand in an affiliation with the government in order to gain access to resources and development programmes and projects. The origin of community development initiatives for programmes must be based on the beneficiaries' own thinking and deliberations. Therefore, beneficiaries take control of the development process, and the needs of a particular group of people, called a *community*, lie at the heart of the programme. De Beer and Swanepoel (2006:8) argued that participation is a process of initiating community-based development though projects with local members and is aimed at empowering communities, ensuring sustainability, building self-reliance and thereby releasing them from the poverty trap.

With this in mind, the research findings of the study regarding the extent and nature of community participation in Dunoon and the role and function of Heavenly Promise, the organisation that provides caregivers to the wider community, will be presented in this chapter. The analysis will firstly focus on the participatory role of community members in the case study area. Attention will then shift to the Heavenly Promise organisation in order to examine the function and responsibilities of the different categories of staff to the community.

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Finally, the participation and contribution of partner organisations in Dunoon will be explored. The research findings will be based on the analysis of data collected through observation and the use of semi-structured interviews. The chapter is divided into three sections in accordance with the different categories of respondents that were targeted by the research, namely the role of the community, the role of the Heavenly Promise home-based care organisation, and the partner organisations discussed in Chapter 4.

5.1 The role of community residents

This section provides empirical information gleaned from the data collected during the research study with regard to the nature and extent of participation of community residents, which, it is hoped, will offer insight into the community's knowledge and understanding of the concept and process of participation.

This first category of respondents includes 30 community members from the Dunoon case study area. The semi-structured interviews focused on the members' participation within the local community and their level of involvement in decision-making processes regarding their health in the community. Other information gathered from respondents focused on the community's active involvement in HIV/AIDS campaigns, as well as their level of knowledge of HIV/AIDS and the methods used to combat its prevalence in the community (see Appendix B).

5.1.1 Community organisations and participatory structures in Dunoon

A number of community organisations operate in Dunoon. In addition to the Heavenly Promise NGO, which is the focus of this research, two other home-based care organisations operate in Dunoon, namely St John's and Zusakhe. Both of these organisations operate in a similar manner to Heavenly Promise in providing voluntary and health education, in the home and in the community.

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In Dunoon, eight community development workers (CDWs) operate from the Masincedisane Advice Office. These CDWs are community-based individuals who work together with other district members to assist local community members to acquire information material, such as background and statistical information from service suppliers with the intention of educating them about how to interpret their needs, understand their ambitions and sustain their welfare. Furthermore, the CDWs' role is to inform and create awareness among the communities regarding available resources and services, and to attend to problems raised by community members (Mr. Tex Dludla. Personal communication with the author, 28 July 2010).

The South African National Civic Organization (SANCO) plays a vital role in Dunoon and was established initially to attempt to address the backlog in the housing sector. SANCO is a decentralised, local grassroots civic structure and works at different levels within communities. SANCO's executive committee is composed of residents who are elected by and accountable to the local community and whose main function is to address local issues and conditions. Furthermore, SANCO functions outside of governmental organisations and political parties and exists as an alternative to statutory structures.

The Dunoon Masincedisane Advice Centre is an information hub, which acts as a participatory structure where community members can express their views and concerns through community meetings. The role of the advice centre is to create an opportunity for local residents to improve their lives through access to information. The advice centre acts as a link between the government, various organisations and the community in order to offer assistance with social problems, acting as a proponent for community participation. Local government therefore utilises the advice centre in dealing with the community. Other non-governmental organisations such as the Black Slash and St John's home-based care also use the centre for training and awareness programmes.

The project co-ordinator of the advice centre, Tex Mboniseni Dludla, who was interviewed during the study, is convinced that access to information helps to educate the community. Therefore, the centre also makes its facilities available for community projects, which encourages community participation. One voluntary female respondent who participated in the research study reported having established a senior citizen's club at the centre, which runs two skills development workshops each week to train elderly women to create handbags and pillow-cases out of recycled material.

5.1.2 Community participation in Dunoon

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The local municipality in Dunoon runs campaigns to ensure that people living with HIV/AIDS have access to anti-retroviral medication and treatment, and to prevent new infections. In addition, it also runs a literacy programme to educate people living with or at risk of contracting HIV/AIDS, their family and friends about the prevention and treatment of the disease. This is in line with the aims of the World Health Organisation (1978:2) as stated by the authors of the report:

> *Physical wellness, which is a specification of comprehensive physical, psychological and social well-being is a primary human right and that the accomplishment of the maximum possible level of health is a most essential social objective whose comprehension necessitates the achievement of several other social and economic sectors in addition to the health sector and that the communities have the right and the responsibility to partake*

> *discretely and co-operatively in the development and execution of their health-care.*

Semi-structured interviews were conducted to collect data from the community members relating to the nature and extent of participation in the case study area. The interviews contained closed- and open-ended questions. A total of 30 interviews were held with community members of the Dunoon community.

When asked if they attended any HIV/AIDS campaigns in the community, 66.3% of the respondents said they never attended any, while 43.7% said they did. One respondent noted that "*the community doesn't bother any more as they say it is just another HIV/AIDS awareness campaign*". Another respondent claimed that the municipal clinic does not collaborate with the people at grassroots level: "*If the clinic comes with their HIV/AIDS campaigns to the community, they approach us with their strategies and plan of action, and never consider our thoughts and proposals*."

These findings fit in well with Cornwall and Pratt's (2003) research which reveals that in many cases decisions are made by actors behind closed doors, without pretence of broadening the boundaries for inclusion. These "closed" spaces are selectively restricted to bureaucratic power-holders, whereas others are excluded, and this does not lead to the empowerment of people in the community or to the sustainability of projects. Oakley (1991) reiterated this view, in his book *Projects with people,* that in many supposed Third World countries, indigenous people have for decades been subjugated by aristocratic groups.

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However, one respondent appreciated the clinic's awareness campaigns, stating: "*I now understand the importance of how the ARV treatment works, as my sister is HIV-positive*." In this regard, De Beer and Swanepoel (2006:8) explained that, when community involvement is promoted, co-operation is fostered and positive change can be observed.

With regard to understanding the concept of participation, a total of 28% of respondents understood that community participation is the active involvement of the community in decision-making processes in collaboration with health authorities. One HIV-positive respondent explained: "*Now that I'm HIV-positive, it is my duty to stay informed and to work alongside the municipality to effectively combat HIV/AIDS*." Another respondent, who had

lost a family member to HIV/AIDS, emphasised that members of the community need to "*stand up and join hands with the local clinic if we want to conquer this disease*".

Whilst 8% of the respondents had no idea what community participation meant, 64% of respondents regarded it as unnecessary. The majority considered community participation as unnecessary as they viewed Dunoon as a place of mere survival. An unemployed single-parent respondent remarked, "*My concern is that my children remain in school, therefore I focus all my attention on raising them, and not community matters*." These findings are disconcerting as they corroborate Brenner's (1993:56) warning that unemployment and the lack of access to sustainable livelihoods are often accompanied by increases in certain types of dysfunctional conduct, such as depression, suicide, delinquency, and participating in hazardous sexual behaviour that leads to HIV infections.

The interview results indicated that all nine employed respondents actively participated in the community and this group clearly had a far greater sense of hope and optimism towards the community than the 21 unemployed respondents. One respondent, who is a computer technician, enthusiastically described his involvement with the arts, dancing and hip hop music in Dunoon. Another female respondent, who is employed at Woolworths, stated that she is involved with a group of physically challenged persons in the area. "*Once a week I visit the disabled group and assist the staff in bathing the disabled*", she added.

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A number of employed respondents belong to football clubs and a few run programmes to recruit and teach young boys in the community football skills. One male respondent, who works as an operator at a nearby factory, mentioned his active involvement in coaching boys' football: "*These boys need role models in the community and often I make financial contributions to see that the football club in Dunoon excels*."

The other 21 unemployed respondents were not so positive in terms of community participation. The unemployment status in Dunoon clearly determines the individual's opportunities for participation in their community. One respondent said, "*I need employment and food in my house, therefore I don't care what goes on in the community*." Chambers (1984:109) elucidated what he identified as the deficiency trap. He expounded how many effects of poverty have lead to a ferocious cycle whereby the poor are ensnared in a situation of poverty from which it is extremely difficult to escape. He argued that the poverty situation

in informal settlements has many consequences, what he called "clusters of disadvantages". These groups interrelate with one another and this interaction is what leads to the deprivation trap. Chambers identified five intertwined clusters of disadvantages that characterise the lives of the poor in informal settlements: poverty, physical weakness, isolation, vulnerability, and powerlessness. These disadvantages cause the poor and unemployed to hardly ever participate in community programmes.

5.1.3 Community sense of belonging and community pride

The data reveals that community members who participate actively in community initiatives have a stronger sense of belonging than those who do not. Figure 6 shows the sense of belonging within Dumont, as perceived by the community.

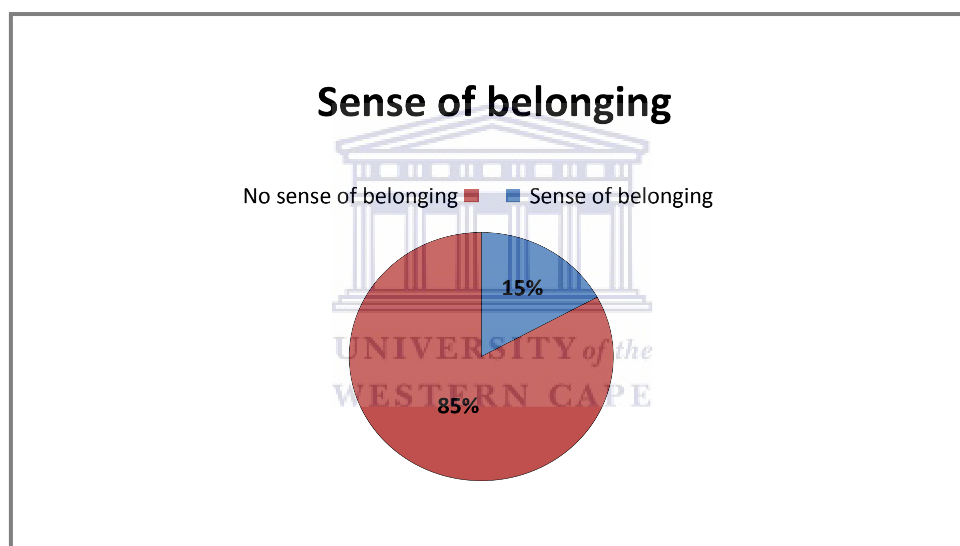

Figure 6: Respondents' sense of belonging

A total of 85% of respondents indicated that they did not have a sense of belonging to their community. One of the reasons given was the dangerously high levels of crime in the area. A few respondents described how they had been robbed, stabbed and threatened. One respondent, who earns his livelihood selling sweets and fruit, explained how he had been robbed and humiliated by a mob of youngsters. Other reasons cited were rampant unemployment and lack of housing. "*I feel dehumanised living in this matchbox (informal house)*", replied one respondent. "*We cannot afford to hang out our washing overnight and dare not leave our houses unattended*", another respondent remarked.

An elderly woman, when asked if she had a sense of belonging in the area, stated "*Dunoon, hayikhona* ["Dunoon, never"], *we as elderly people feel unsafe*." She stated that the young have no respect for the senior citizens, who fear the youth. An unemployed interviewee stated: "*Maybe I should move to Khayelitsha or Gugulethu; I hate this place*". The reason why the majority of interviewees had no sense of belonging, and did not participate in community matters, can be attributed to the fact that the majority of Dunoon residents are unemployed, have little, if any money, and are struggling to survive.

Figure 7 represents the sense of community pride of the Dunoon respondents. A total of 83% of the respondents stated that they were not proud of the community, and only 17% indicated that they were proud of the community despite facing immense challenges in Dunoon. One of the reasons for this lack of pride relates to the visibly polluted community environment. During the observation phase, it was noted that residents dump their rubbish, for example, cans, carrier bags and household refuse, in the streets throughout the community.

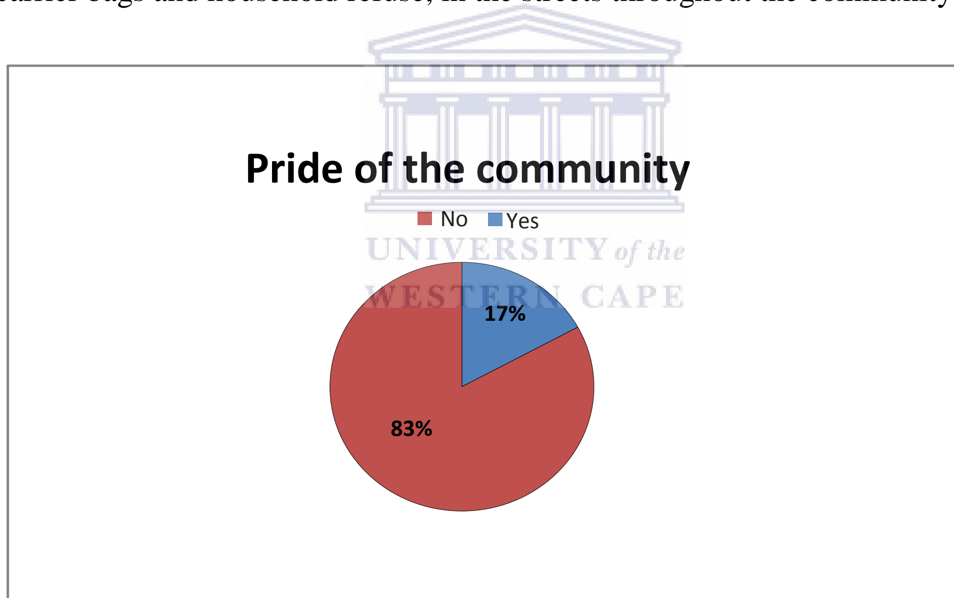

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Figure 7: Dunoon respondents' sense of community pride

Interviews revealed that community pride in Dunoon was strongly linked to the poor conditions experienced by residents in the community. Respondents were clearly very dissatisfied with service delivery processes in the community. One respondent felt that Dunoon is not fit for habitation as it is an industrial area with a high population, and remarked: "*I want to move to Delft. It is better there.*" Another respondent commented, "*This is just a place of survival*", and said she could see herself leaving the area within the next two

years. Oakley (1991: 13) claimed that this mind-set is further reinforced by the fact that mere "existence is for most residents their ultimate challenge and exhausts much of their energies, leaving them barely opportunity to participate in health matters".

However, two respondents mentioned that they have better access to facilities such as health and education in Dunoon than in the Eastern Cape. One respondent, who was born in Dunoon, reasoned that "*looking back from where the area comes from, it is only fair to acknowledge that a good task has been accomplished in the area. All the basic needs of our people have been provided for in a small space of time*".

5.1.4 Community perception with regards to HIV/AIDS

A variety of suggestions were offered on how to reduce the number of people living with HIV/AIDS in the community. One respondent said that if the community adhered to the government's "Abstinence, Be Faithful, Condomise" (ABC) approach, it would reduce the incidence of the pandemic in the area. Another respondent reiterated that "*condoms should be placed at strategic points such as public toilets and shebeens,* (unlicensed drinking establishments) *to ensure our community practices safer sex*". Yet another respondent stated that the message of the Love Life Campaign is not distinct enough and noted that: "*Young people are not urged to abstain from sex until marriage; sex is God-given but should be practiced only in the framework of a spousal relationship (marriage), and remaining faithful to your spouse is therefore the solution for the AIDS pandemic*".

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Other respondents indicated that young people flock to the shebeens and when they become inebriated, all morals seem to desert them. Alcohol encourages sexual risk-taking, together with encouraging sexual craving. One male respondent stated that "*in that respect there are some women in the community who do not sexually conduct themselves appropriately due to alcohol. As soon as they are under the influence, they are unable to think rationally, and turn into victims of exploitation, ending up HIV positive, not knowing who they had sex with*".

Another respondent claimed that unemployment seemed to be a great concern as "*coming to taverns is connected with sexual trade as a merchandise of financial difficulty, several teenage girls visit our taverns for fund-raising because of their social circumstances, in order to acquire alcohol and money in exchange for sex*". Menda (2006:23) considered that

women's vulnerability stems from an inferior power, unlike men whose vulnerability to HIV transmission is caused by their masculine power, predominantly explained by the dominant role of male sexuality, which is often characterised as natural, spontaneous and initiatory, and expected to be more energetic and dominant. Furthermore, Menda (2006) contended that females' financial dependence on males strengthens their susceptibility to HIV/STI infection by increasing the likelihood that they will exchange sex for money or favours and by decreasing the likelihood of them succeeding in negotiating protection against highly risky sexual practices.

5.2 The role of the Heavenly Promise home-based care organisation

The second category of respondents included the different levels of staff of the Heavenly Promise home-based care (HBC) organisation. The role of the home-based care workers, the function and responsibilities of the supervisor of the organisation and, finally, the role of the directors of Heavenly Promise will be examined in this section.

5.2.1 Home-based care workers

Ten home-based care workers, employed by the Heavenly Promise HBC organisation, were targeted in order to examine their role and function in the organisation and the community. Focused in-depth interviews were conducted with each worker in order to provide background information about the home-based care project. The sample population group was exclusively African. Although all the participants' mother tongue was isiXhosa, they were able to converse in English.

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The interview schedule also included open-ended questions in order to gather in-depth data about the types of emotional and psychological support being provided by and for the caregivers at the Heavenly Promise HIV/AIDS Programme, the degree and extent of their training, as well as the type of issues that they have to deal with on a daily basis (see Appendix C).

5.2.1.1 Motivation for the participation of home-based caregivers

Of the 10 caregivers interviewed, 80% stated that the reason for their participation in the community health service was the personal loss of a family member in their household due to HIV/AIDS. Their participation in the community has been on-going throughout both the

project and operations management phases, and this is one of the key factors which sustain the programme. Paul (1987:36) associated sustainability with "continuity" and saw participation as important in fostering a self-sustaining impetus of growth in a specific capacity. Likewise, Rahman (1987:37) noted that "participation intensifies the effectiveness of developments as mechanisms of community development." He further claimed that, if partaking permits people to have an influence in "influencing objectives, supporting project administration and making their local knowledge, skills and resources more available, it will result in more effective projects".

The respondents noted that when their family members were initially diagnosed with HIV, care givers were ignorant of the disease and some of the care givers were even discriminated against. However, this stance has since changed and their involvement in community health services has significantly improved their knowledge about HIV/AIDS and skills in dealing with people living with HIV/AIDS, thereby strengthening their ability to determine their own values and priorities, and to organise themselves to take action regarding health matters. For the remaining 20%, employment was the overriding motivation for participating in community health.

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However, 100% of the caregivers interviewed indicated that they had not participated in any decision-making process concerning the establishment of the partnership during either the implementation or the construction of the soup kitchen. When asked if they participated in any decision making at all, they stated that they never attended any of the planned meetings organised by the directors of Heavenly Promise. Most of the information they received only became available after the directors had held meetings with other relevant stakeholders.

The spaces in which individuals are capable of participating are of essential importance in development and democratisation. These findings are in line with what Cornwall and Pratt (2003) referred to as "closed spaces", where that many decisions are made by actors behind closed doors, without pretence of broadening the boundaries for inclusion. Closed spaces are selectively restricted to bureaucratic power-holders, whereas others are excluded.

Furthermore, the organisational structure of Heavenly Promise is clearly hierarchical and follows a top-down approach in terms of decision making within the organisation. Arnstein (cited in Baum 2008:479) voiced her concern in this regard and stated that "the idea of

hierarchical participation has often been used in health to distinguish genuine from pseudo-participation." Baum (2008) argued that a bottom-up decision-making approach is a decisive form of participation and has great potential for power sharing. The benefits of true participation lead to the empowerment of communities through the building of skills and capacity and enhance the sustainability of projects. These findings are in line with Rifkin and Cassels's (1996:39) belief that participation in development initiatives can lead to the following:

- Compliance: people are motivated to accept interventions, or act according to the advice of professionals.
- Contribution: the community supplements the contributions of professionals.
- Collaboration: the community participates in planning and introducing initiative.
- Control: the community controls the activities and available resources by the communities.

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5.2.1.2 The relationship among the Dunoon Clinic and local community

During the observation phase, it was notable that there was minimal collaboration between the HBC and the local municipal clinic of Dunoon. This is not in accordance with the National Health Act No 61 of 2003 (DOH, 2003), which specifies that local municipalities should engage with the community and community organisations to ensure effective planning, provision and evaluation of health services. All the caregivers reported having an essentially negative relationship with the staff at the Dunoon clinic. One respondent stated that HBC-givers are not treated as professionals and they have to queue for hours even while wearing their visible HBC identification badge: "*They treat us as patients and it is not a pleasure to go into the clinic, and we only go there because of our patients*." These findings are of concern as, besides the fact that the Dunoon Clinic has shown no interest in joining the partnership, it should be playing a prominent role in the community as a government instituted health provider in terms of supporting the Heavenly Promise HBC.

The reports from the Department of Health (DOH, 2001), in contrast, have clearly stated and documented its commitment to participation in healthcare by all stakeholders. DOH policy documents highlight its members' determination to incorporate communal healthcare in its approach and its aim which is to inspire local groups, families, fellow citizens or volunteers

to support on-going household needs, thus inspiring involvement in communities. In addition, the Alma-Ata Declaration (cited in Oakdale & Kahssay, 1999) promotes the maximum community participation in the preparation and procedure of primary healthcare through education, thereby enabling communities to contribute to healthcare. Thus, these research findings reveal that the Dunoon Clinic is not following the guidelines and objectives promoted by the Department of Health.

However, all the caregivers of Heavenly Promise have built trust between themselves and the community and are held in high esteem. One family member of a HIV patient exclaimed, "*The care givers shaped us as a family, as they are very people orientated. They have made a lot of friends here in the community and we are proud of them*." Yet another respondent echoed, "*They are trying to resolve some of our difficulties we are experiencing, and are hands on with the people"*.

This was evident to the researcher while conducting home visits with a group of caregivers in an area notorious for muggings. A group of young men had identified the researcher as a potential victim, but after interacting with the caregivers, they desisted from any wrong-doing and allowed the researcher to complete the home visits unhindered.

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5.2.1.3 Inspirations and challenges within the HBC Programme

The caregivers reported that they were inspired about the work they conducted in the community for various reasons. It was clear that they all found their work very rewarding and desired to see real change and to assist the community through their involvement in Heavenly Promise. One interviewee mentioned that "*to experience the radiance on my patients' faces and seeing them out of bed every day makes me happy*". Another caregiver indicated that attending to her patients' problems helps her to deal with her own stress. Another caregiver enthusiastically stated, "*They speak to us, inform us, the moment we come; when they see us, they get re-vitalised. They get strength. They get power. That's where they get their enthusiasm from. They get it from us*."

She further explained that her patients' problems are far greater than her own. A different caregiver indicated that to observe patients getting healthy after they had all but given up hope inspires her even if she does not receive her monthly stipend.

Interviews further revealed that some of the greatest challenges facing the caregivers are that they are not able to holistically support the patients in their needs by, for example, rendering financial assistance to those living in extreme poverty. The caregivers also have to deal with the growing youth problem, such as drugs and alcohol in the community and the increase in unemployment and prostitution in the area. The caregivers all agreed that there is a great need for a hospice centre to be established in the community as a holistic approach is needed to effectively render services such as home-based care in Dunoon.

The respondents suggested that, upon entering the HBC programme, caregivers should already have been provided with three months of training in basic home and community healthcare. The majority feel that they do not have adequate training and there needs to be on-going training as home-based caregivers should be kept informed about the rapid change in AIDS-related infections.

Not only does a lack of collaboration between the local clinic and caregivers exist, but during observation, it was clear that the City of Cape Town's Health Department in Dunoon lacks the capacity for effective engagement with the home-based caregivers. Another challenge is the low monthly compensation that caregivers receive. One interviewee stressed that the monthly R780 stipend is inadequate as it is her only source of income. During discussions, it was revealed that caregivers often apply to other HBC organisations, which offer higher stipends, in order to sustain their families. However, they all agreed that better health-care facilities should exist for all in the community: "*They* [the community] *need us and we cannot let them down; we are their hope*".

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5.2.2 The role of the supervisor of Heavenly Promise

In-depth focused interviews were conducted with the supervisor of the HBC project, who is the chief spokesperson for the home-based care project in Dunoon. Exploratory and open-ended questions were used to elicit information relating to the length of the programme, the overseeing role and responsibilities of the respondents, the selection criteria in terms of appointing home-based caregivers, the training of caregivers, the caregivers' level of supervision, debriefing, and the strengths and weaknesses of the programme (see Appendix D).

5.2.2.1 Role and functions of the supervisor

The supervisor is responsible for the daily monitoring of the HBC programme, disseminates information to caregivers and other stakeholders, and ensures that the monthly stipends are allocated to the caregivers. In addition, she is responsible for dealing with any queries the community or patients of the caregivers have pertaining to their various needs, and acts as the link between the caregivers and the directors of Heavenly Promise. She stated that caregivers are "*nurses on the go*" and that she is responsible for counselling the caregivers: "*Whenever they have problems, we would have a round table and discuss personal problems and I'm able to debrief and assist them in any matter*".

The supervisor stressed the importance of the soup kitchen, which is one of the projects managed by the programme to provide food to community members. She noted that the community sees the soup kitchen as a resource centre and any problems regarding grants, food parcels and other health matters are reported at the centre. Observation of the supervisor's participation in daily maintenance revealed that it pertains mainly to decision making, planning and monitoring the work of HBC staff employed in the soup kitchen.

5.2.2.2 Validity of the home-based care programme

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In terms of the validity of the HBC programme, the supervisor averred that it has had a very positive effect in the community and has made a huge difference to the lives of residents. It is a resource centre, where advice is given and workshops are conducted. The respondent explained that the home-based care programme is less expensive for families as care is provided at home. She noted further that the cost of hospitalisation and transportation to and from a hospital would be financially crippling, adding that "we *observed that sick people are comforted by being in their own homes with community members and friends around them*".

The supervisor stated that participation in the programme has a life-changing effect on the caregivers. Having lost loved ones in their own families to HIV/AIDS-related illnesses, the caregivers are able to assist the affected members of the Dunoon community in their plight. She emphasised that the caregivers go out of their way to serve the community, as is evident whenever they return from their daily visits: "*Our caregivers return from their home visits with harrowing reports of the appalling conditions of their clients. It has shaped their characters and made them strong leaders in Dunoon*." This reinforces opinions expressed in

the literature that affirm that people who are sick or dying prefer to stay at home so that they can spend their last days in familiar surroundings (Frölich, 1999; Peu, 2008; Uys, 2003: Van Dyk, 2005).

The supervisor also observed that "*the home-based care programme has made the caregivers more sensitive to the culture and value system of the local community*", adding that they gain "*a sensitivity that is often missing in clinical hospital settings*". Commenting on the value of the programme for the caregivers, she maintained that "*home-based care for the caregivers is empowering; we observe how our caregivers are able to identify the needs of children who are affected by the illness of parents, and to assess whether the child is attending school or not*".

The supervisor said that there had been notable successes within this programme, for example, the recovery of patients who were on the verge of death and whose CD4 count had been stabilised. Other successes concerned patients who had completed their tuberculosis (TB) treatment and recovered, and previously bedridden patients who had been reinstated at their respective workplaces and were earning an income for their families. The value of the service that the HBC programme offers was explained as follows: "*We experienced how this programme allows the patient and family to come to grips with the illness and to prepare them for the impending death of the patient. Our patients are comforted by being in their own homes and communities with family and friends around them*".

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The respondent also explained that the ambience of the home prevents the patient from feeling isolated and rejected. "*Our focus is therefore on a patient-centred approach; this programme is supported by the community, which includes the neighbours and extended family who focus on caring for the patient and family*," she added. She stressed further that that the programme is operational and effective.

In accordance with the findings of caregivers, the supervisor stated that there was no relationship or communication between the local NGO and the municipal clinic of Dunoon: "*The staff at the clinic does not recognise us as health workers; our home-based caregivers have to wait in the line even if they wear their HBC uniform*," she explained. Although there have been noteworthy successes in the community, the challenge is that Heavenly Promise cannot supply the patients with food parcels. Another challenge is the high unemployment

figure in Dunoon and that the NGOs are unable to assist the patients with employment after they have recovered. This affects the schooling of the patients' children, as children cannot go to school on an empty stomach.

The South African DOH (cited in Van Dyk, 2005:229) recommends the following guidelines for supervisors for the care of caregivers:

- Guide the process of case management and ensure that counselling is helpful and not harmful to the client.
- Provide the counsellor with continuing education, updates and input relevant to counselling by introducing journal articles, techniques and strategies related to HIV/AIDS/STIs and TB.
- Act as a sounding board for the counsellor in terms of perceptions, interpretations and understanding of the issues and problems presented by the clients and how these should be addressed.
- Recommend sources of referral to the counsellor and advise the counsellor on when to employ these.

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5.2.3 The role of the directors of Heavenly Promise

This section will provide the results of an interview conducted with one of the directors of Heavenly Promise. The section will also conceptualise the role and function of the partnership in terms of common interest and complementary capacity. Questions were focused on the tasks, functions and challenges of the directors. The director interviewed for the study is a co-founder of the organisation and has been actively involved in the project from its inception.

5.2.3.1 The role and responsibilities of the directors

The directors' role in the organisation is to take responsibility for the maintenance of the projects within the community. The interviewee affirmed that the supervisor of the centre reports to the directors and that it is their duty to assist the supervisor in the appropriate execution and functioning of the programme. Reciprocally, the directors, in collaboration with the board, are responsible for developing strategic plans with regard to the HIV/AIDS

projects. The director explained, "*We also select the home-based caregivers who apply as candidates for home-based care work. A minimum of Grade 10 is required for every potential candidate and three months training in home-based care*."

According to Fox et al. (2002), caregivers in South Africa attend a three-month programme on elementary skills of home-based care and palliative care. The training is centred on the DOH curriculum for home-based care. Relevant material on STIs, HIV/AIDS and TB is incorporated into these workshops. Additional skills incorporated during the training are communication and teaching skills, spiritual and traditional issues, community assistance and infection control.

The director viewed the partnership between Heavenly Promise, Chevron and the Department of Social Development, as involving people who have a co-operative relationship with one another and who agree to share responsibility for achieving their particular objectives. She further explained that the members of the partnership have respect for another's differences and work in harmony in order that the community as a whole can benefit from them as a group networking together. The respondent explained that

> *Although Chevron plays an instrumental role in contributing financially to this project, they don't dictate the partnership. There is a perceived need for this partnership in terms of common interest and complementary capacity. In this partnership we are willing to share ideas, resources, influence and power to strengthen our relationship. As this partnership grew we observed that there is a core group of skilled and committed staff that have continued to mature within the partnership*.

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Lastly, the respondent explained that there are regular opportunities for informal and voluntary contact between staff from the different agencies and other members of the partnership.

Verzuh (2008) explained that the directors are the substance and the motivators who support the entire project and put it into action. Couture (2003) also thought that the principal charge of the directors is to lead all the shareholders, the patrons, management and project team and inspire them to work collectively throughout the progression of the project.

5.2.3.2 Challenges of the HIV Programme

The director noted a high incidence of HIV/AIDS in the economically depressed refinery community, with many patients being bedridden and malnourished. She estimates that the prevalence of HIV/AIDS could be as high as 50%: "*The number of people affected with HIV/AIDS has inspired us ordinary women to be actively involved in community health in Dunoon. However, there is still a great deal of ignorance amongst the residents of Dunoon regarding aspects of community participation*," the interviewee explained, adding, "*Our people are still battling with primary issues such as housing, unemployment and lack of water; therefore they don't regard participation as an important function in the community."* This confirms the findings of the caregivers whose responses revealed that as the community focuses mainly on survival, the importance of participation in community matters is minimal.

The interviewee pointed out that often when patients' CD4 count improved, their relatives would take them back to the Eastern Cape without medication: "*These patients sadly return just to die here in Cape Town. That is one of our greatest challenges*." However, the interviewee pointed out that one of the achievements of their group's intervention is that they manage to work together as a unified group. She mentioned that, on completion of their treatment, some of the patients send their CVs to companies and are currently employed.

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Another important challenge was the care of orphans affected by the death of both HIV/AIDS parents. The respondent stated that "*planning for the future of bereaved children before the death of their parents is important and this includes aspects like the making of a will and ensuring the aspirations these parents have for their children's future*". Orphan-care options should be looked into and the best option chosen, whether extended families, family type groupings, child-headed families, or orphanages (Fox et al., 2002; WHO, 2002).

5.3 Partner Organisations: Project Management 4 Africa, Chevron Refinery and Department of Social Development

The third category of respondents included representatives from the partner organisations of Project Management 4 Africa (PM4 Africa), Chevron Refinery and the Department of Social Development. The scheduled interviews with both organisations focused on gathering data relating to their involvement as partners in the Heavenly Promise Home-Based Care Project

and their role and responsibility within the partnership (see Appendices F, G and H). This category also included an interview with a representative the Department of Social Development in order to highlight its contribution to the HBC programme and partnership.

5.3.1 The role of Project Management 4 Africa

An interview was conducted with a representative from Project Management 4 Africa (PM4 Africa) in order to gather information about the organisation's partnership role with Heavenly Promise and its contribution to the Dunoon community. The respondent indicated that his role as a partner in this project is to act as an implementer of the HBC community engagement programme. In addition to managing the HBC project, PM4 Africa offers project management and life skills training to all project participants, especially those from disadvantaged communities. The representative explained that there is a "*perceived need for the partnership in Dunoon so that areas of common interest and complementary objectives can be achieved.*" PM 4 Africa believes that a healthy community in Dunoon will involve joint activity, have joint goals and show a commitment to achieve this through healthy partnerships.

Consequently, the respondent sees community participation as "*community members working together to achieve community benefit*", and believes that "*continual achievements, as a consequence of learning and applying the correct methods of community participation, ensure sustainability*".

Concerning the accomplishments of and challenges faced by the partnership, the respondent believed that there is a "*lack of commitment*" on the part of the local clinic in Dunoon. This has resulted in the caregivers not receiving adequate refresher training, which is vital when dealing with health issues in the community. The PM4 Africa representative noted that from the beginning of this project, the local clinic failed to show any interest in joining the partnership and does not collaborate with the partnership in any way.

The respondent claimed their partnership has been relatively successful, although they have experienced a few setbacks He added that, considering the modest beginning of Heavenly Promise, the organisation has every reason to be proud of its achievements since the inception of the NGO four years ago. He indicated that achievements included the

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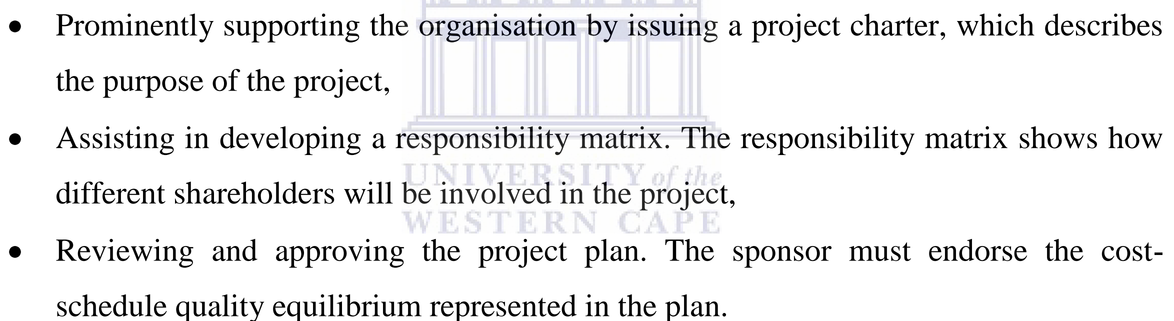
establishment of the soup kitchen; the provision of capacity training and the important training provided by the DSD in minimum norms and standards and, most importantly, the assistance rendered to HIV/AIDS patients to regain a sense of hope and strength. The respondent confirmed that PM4 Africa will continue to be a partner in 2011 and 2012 and that there is no real threat to this programme.

5.3.2 The role of Chevron Refinery

An interview was also conducted with the other partner within the HIV/AIDS Programme, namely Chevron Refinery, whose contribution to the partnership and Dunoon community is crucial in that it contributes significantly to the operation of the programme. Chevron Refinery is the main sponsor and, as such, plays a critical role in the partnership. Scholars such as Verzuh (2008: 43) stated that the main contribution of sponsors is their authority and there are numerous concrete methods through which sponsors can apply their authority to projects, such as



- Prominently supporting the organisation by issuing a project charter, which describes the purpose of the project,
- Assisting in developing a responsibility matrix. The responsibility matrix shows how different shareholders will be involved in the project,
- Reviewing and approving the project plan. The sponsor must endorse the cost-schedule quality equilibrium represented in the plan.

In the section below, information gathered about the organisation’s partnership role with Heavenly Promise and its contribution to the Dunoon community is presented.

5.3.2.1 Chevron's role in the partnership

The respondent is a manager and responsible for community projects supported by Chevron South Africa. He explained how the partnership started:

> *Women in the community approached us through the Community Advisory Panel and discussed the pressing need to render community health services to HIV/AIDS patients and this community. In response, Chevron, in conjunction*

with the DSD and PM4 Africa, collaborated to establish the Dunoon community home-based care centre in 2009.

The interviewee indicated that Chevron's role in the partnership is to train caregivers from the community and to provide between 100 and 150 meals each week to homebound HIV/AIDS patients. He explained that over and above supplying funding to build and stock the Heavenly Promise centre, Chevron and its partners provided project management training to community women to run the centre. Thus, the community has taken ownership of the centre and keeps it sustainable. "*We provided Heavenly Promise with a soup kitchen facility, and also provided the NGO with project management skills*," he added.

The interviewee further elaborated that "*project management is so important because it helps Heavenly Promise in their skills to run the project properly, the way it should be done; I think that's the very simple thing that we can do and we'll have a big impact*". The respondent held the view that the idea of partnership is fundamental to everything Chevron embarks on, and that healthy partnerships are based on collaboration and corporate trust. He explained that Chevron will continue to access resources and invest in infrastructure for the community. He further indicated that partnerships ensure the long-term health of the company, benefit the Dunoon community, and contribute to economic growth and human progress for the future generations.

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5.3.2.2 Contextualisation of community participation and ownership

The interviewee viewed participation as the "*involvement by the community, and in some instances additional stakeholders, in the conception, content and executing of a programme to change lives within the community*". The respondent stated further that the community themselves take ownership of the centre and that the centre belongs to them. He added that Chevron is very proud of the HBC programme, and that one of its highlights is that it is being led by women, which is in line with one of the national mandates in South Africa, namely to empower women.

5.3.2.3 Chevron's evaluation of and expectation for the partnership

The respondent explained that for Chevron, this programme is about life and death every single day for many in the Dunoon community. Chevron's expectation is that in the near

future, communities will no longer talk about HIV/AIDS as a life-and-death situation, but local communities will understand how to prevent it and have effective medication to treat the condition. The respondent stated that Chevron will continue to network with Heavenly Promise and this will be an on-going process in the community. Lastly, he pointed out the following achievements of the partnership:

- the construction of a new multi-purpose mobile facility;
- the supply of soup to between 100 and150 people daily;
- the creation of a monitoring and evaluation plan for the operation of the soup kitchen and the home-based care programme; and
- the development of a scoreboard based on the Department of Social Development's norms and minimum standards for home- and community-based caregivers.

5.3.3 The Department of Social Development

A representative from the Department of Social Development (DSD) was interviewed in order to gather information on the DSD's role in the HBC programme. The interview for the DSD representative focused on descriptive criteria such as the duration of the DSD in the HIV/AIDS programme and the type of training it provides (see Appendix H).

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5.3.3.1 Department of Social Development's role in the partnership

The DSD representative is the district officer and co-ordinator of the HIV/AIDS programme in Dunoon and other allotted areas in the Western Cape. Consequently, the respondent is responsible for the official liaison between the DSD and the partnership, and is responsible for the monitoring and evaluation of the project. It is the task of the supervisor of Heavenly Promise to forward all the monthly reports, such as a progress report and the minimum norms and standard report, to her department.

The DSD's involvement with the Heavenly Promise NGO was instigated because of government's commitment to supporting home- and community-based care to mitigate the socio-economic impact of HIV/AIDS at community level. The DSD was initially part of the established Heavenly Promise organisation that was conceptualised in 2007. The respondent commented that a group of women first gathered in an RDP house in the community and distributed soup to HIV/AIDS patients in 2007. This pivotal role the women played was

invaluable in that it prompted the DSD to commit itself to offering its support and guidance in the fight against HIV/AIDS.

5.3.3.2 Significance and aims of the partnership

The interviewee indicated that it is the desire of the DSD to see the community themselves taking the initiative for active programmes. She further mentioned that the DSD wants to ensure that communities are empowered in order for them to deal with their own challenges and find their own solutions. The respondent pointed out that HBC programmes should be developed, implemented and monitored by the community to ensure full community ownership. She has confidence that these programmes will empower and strengthen families and communities to care for those affected by HIV/AIDS.

The respondent specified that external organisations sometimes do not understand the term *partnership*. She observed that often, when there is a partnership, small organisations want to dictate the terms, not realising that government needs to comply with legislation. "*Usually it is us (the DSD) who often provide the necessary funding; but certain protocols need to be in place, for example rules, guidelines and accountability obligations. Furthermore, certain targets need to be met, and government requires that partners adhere to this*." She mentioned that NGOs often regard this as a threat, believing government wants to dictate to them. She stressed that this programme does not involve shifting the responsibility of government to families and communities, but that it recognises the value of partnerships between governments, communities (the public) and the private sector.

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The DSD representative highlighted the importance of the minimum norms and standards training workshop which each HBC caregiver has to attend, and noted that the two-day training workshop is important as it contributes to the success of the partnership. Table 3 briefly outlines the benefits of having minimum norms and standards in HBC training. The motivation for having minimum norms and standards is that they ensure that quality services and funds are utilised effectively, with a clear correlation between funds invested and the quality of services rendered.

The respondent stated that, during the conception phases of the NGO, the women had no guidelines for interventions to facilitate the implementation of the HBC programme. There

was no record of any patients, bookkeeping, staff ratios, and no clear system for referrals. Feedback on referrals was not in place. She stated that the kind of training workshops assists the DSD in dealing with the ever-increasing number of NGOs offering HBC programmes. The training highlighted in Table 3 informs the development toolkit for starting and running HBC programmes, thus ensuring standardisation of practice.

Table 3

National norms and standards (Department of Social Development, 2007)

Norms	Standard
Compile and submit reports timeously to relevant stakeholders including sponsors.	Host weekly staff meetings and monthly Management Team meetings with caregivers and ensure that weekly, monthly, quarterly and annual reports are available.
A procedure for recruitment, selection, engagement and disengagement of community caregivers is in place.	Written documentation that outlines recruitment, job descriptions, code of conduct and exit strategies for community caregivers should be maintained.
Every caregiver to have one supervisor.	The programme supervisor to ensure the efficient running of the organisation. Supervise community caregivers on a regular basis. Develop job descriptions for all staff.
Each organisation to have at least 10 caregivers.	Caregivers to render comprehensive services to vulnerable groups in the community.
Each caregiver to render services to a minimum of 15 households at least once a week.	Each HBC to maintain a care plan for each household and individual. Community caregivers should keep record of their clients.

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5.3.3.3 The accomplishments and successes of the partnership

The respondent specified that, in retrospect, since the origin of the partnership when the particular group of women met in an RDP house to render assistance to the community, it has

become increasingly successful. In the commencement phases of the NGO, there was no visible structure. Heavenly Promise as a programme emerged from humble beginnings but evolved into one of the integrated parts of the DSD Western Cape's interventions. Their aim is to build the capacities of communities and to ensure that members of these communities are able to access integrated support and care within their communities. The DSD appointed a supervisor to this programme to ensure that a high work ethic within the NGO will be maintained.

The Department of Social Development (2009) claims that government recognises the necessity for the sustained complete provision necessary to reach the appropriate level of service customary as set in the norms and standards. Additionally, it recognises that improved consistent and continual HBC programmes will only be safeguarded through rigorous determination by all partners involved, particularly NGO's, within an efficient supportive setting.

This programme is also designed to ensure that a minimum comprehensive package of care and support service is rendered within the home-based care programme. The training of the caregivers in the norms and minimum standards workshop was notably the success of the partnership. The approach of the DSD, according to the respondent, is to place people at the centre of development, thereby increasing the effectiveness of development:

> *We, as partners in this programme, would desire to see this project extending and filtering through to as many HIV/AIDS patients and their families in the future as possible. The DSD will throughout 2011 render our support and services to Heavenly Promise so as to ensure they are effective in their community.*

5.4 Conclusion

The findings presented in this chapter have demonstrated that, thus far, the awareness of community participation and the role of home- and community-based health services came about as the result of the rapid spread of the HIV/AIDS pandemic in Dunoon. Initially, there were some weaknesses in the levels and types of participation displayed by the organisational

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structures within Heavenly Promise and the community members of Dunoon. Similarly, weaknesses were revealed in the inability of the City of Cape Town's health department to implement and facilitate a strong participation programme. However, it was revealed that through the strength and vision of ordinary women in the community, an effective HIV/AIDS programme has been designed and implemented in the Dunoon.

Furthermore, community members demonstrated weak areas in capability regarding awareness and knowledge of HIV/AIDS. However, members who have been directly affected by family members living with HIV/AIDS display a high level of awareness and knowledge of operational issues in community participation and social sustainability, as well as a strong capability in terms of enthusiasm and interest in maintaining the HBC project. Financial resources are limited, but Heavenly Promise has sustained the project with limited funds and donations from individuals and partner organisations.

Also, a high level of collaboration is displayed and demonstrated by the commitment of the partnership (Chevron, PM 4 Africa and DSD) as they are willing to share ideas, resources, influence and power to strengthen their critical function within the community. Therefore, using these exploratory findings as a base, the following chapter will present the general conclusions of the study and recommendations for the future.

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CHAPTER SIX: RECOMMENDATIONS AND CONCLUSION

6. Introduction

In this chapter, the general findings of the research conducted are set out. A number of theoretical considerations are outlined to provide a critical reflection on community participation, and recommendations for improving the community's involvement in health and meeting the HBC challenges to various stakeholders in the Dunoon area are presented.

6.1 General findings

The purpose of this study was to focus on investigating the nature and extent of HBC as an alternative strategy to institutional care at grassroots level in the Western Cape in order to ascertain its value and contribution to the overall development goals of primary healthcare. It is evident from analysis of the study results that the main barriers to successful active participation among residents in Dunoon are unemployment, poverty, lack of housing, no sense of belonging in the area and a lack of pride apparent in the community.

This section also includes general findings regarding the nature and extent of participation among Heavenly Promise NGO and the collective partnership, to gain an insight into the community's knowledge and understanding of the concept. The findings from the research in the case study areas are summarised in this section.

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6.1.1 The Dunoon community

The research findings indicate that the Dunoon community is faced with enormous challenges, which contribute to passive or, in some cases, no participation. Housing, unemployment and crime are the three main concerns in the community. Poverty in Dunoon has produced a large number of people living in shacks, which is the only alternative in the absence of housing. During the interviews, most people reported that they consider not having a house as their greatest problem. Home ownership therefore, is considered an aspect of healthy living by many and provides secure tenure.

The findings also highlight that many women enter prostitution for economic reasons in order to provide for their families. Regrettably, men in Dunoon are willing to offer a higher price if they have sex without condoms, which increases the risk of sexually transmitted infections.

All these factors have contributed significantly to the residents of Dunoon's lack of participation in their community health matters.

Furthermore, widespread marginalisation of informal settlement people from community development has led to a lack of confidence and to a mood of despair. The dependent mentality that still exists within the community of Dunoon is further strengthened by the fact that mere existence is, for the majority of informal dwellers, their major goal and consumes a large portion of their energy, leaving them little time to participate in health matters (Oakley, 1991). Many of the informal dwellers therefore tend to accept the status quo and their destitute position, in which economic and social arrangements remain in the control of bureaucrats whilst the majority remain poverty stricken.

6.1.2 Heavenly promise home-based care

The research findings reveal that caregivers play a very important role in HIV/AIDS treatment at Dunoon. They also indicate that the HIV/AIDS pandemic has placed a large burden on public health facilities. Therefore, the Heavenly Promise HBC programme needs to respond to the demands identified and to be more involved in decisions pertaining to the community. In addition, the study results reflect an increasing acknowledgment by institutionalised organisations that community participation is essential to the main task of renewing democracy, changing service distribution and constructing effective communities.

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Throughout this research study, Heavenly Promise was found to display a dynamic, vigorous, and energetic degree of participation in the community. Unfortunately, HBC establishments are facing a combination of demands which indirectly affects their ability to deliver adequate services to their clients. Consequently, the HBC programmes are limited in their ability to carry out activities such as proper anti-retroviral treatment (ARV) adherence and support.

6.1.3 The Partnership

The findings show that there is a need for strong partnership support to the HIV/AIDS programme. Without this support, the programme cannot function to its fullest potential. The findings also revealed that the partnership between Heavenly Promise, Caltex, Project Management 4 Africa and the Department of Social Development in Dunoon has the potential to deal with the complications and variations that represent most health-related

matters. An effective networking system appears to exist between the partnerships as they are interested in trading information for their common benefit. Chevron's financial contribution is essential; however, it appears not to dominate the partnership.

Also a healthy co-operation seems to exist between the members of the partnership as they are able to exchange information and share resources, and this appears to entail a considerable amount of time, together with a high level of commitment by the partners. Finally, collaboration within the partnership seems relatively good because elements of teamwork are visible, which, additionally, increases the capacity of the other associates to gain mutual advantage and follow the collective objective.

6.2 Theoretical reflections

This section provides reflections on existing models, legislation and frameworks for participation in terms of the empirical fieldwork results.

6.2.1 Participation

Proponents of participatory development, Slocum, Witchart, Rocheleau and Thomas-Slayter (1995) contended that this method requires the involvement of beneficiaries in all phases of a project. Furthermore, active participation is an important means to secure sustainability; it places emphasis on beneficiaries as initiators, owners and controllers of a development process based on their needs as a self-organised community (Groenewald, cited in Theron, 2005; Rahman, 1993).

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The researcher observed that the caregivers have a strong interaction with all the people with whom they deal, are optimistic about the future and show a positive behaviour change toward the HIV/AIDS pandemic. Although caregivers are actively involved in community participation, they never attend meetings or formally arranged gatherings pertaining to decisions and matters concerning the partnership. It was observed, during operations management of the home-based care project, that decision making lies with home-based care staff and the partnership and not with the caregivers. Cornwall and Pratt (2003) maintained that hidden power may be present not only inside political processes but also in management and other group contexts, such as in the working force, in NGOs or in community based establishments. Furthermore, scholars such as Brock et al. (2001), Gaventa (2002), and VeneKlasen and Millers (2002) identified this form of power as the "mobilization of

partiality", where some issues are structured into management level whilst others are structured out.

However, as Kroon (1995:111) pointed out, upper management is occupied with strategic design such as planning, which requires adequate information on those variables that may have a direct influence on the efficient functioning of the organisation. Moreover, critical decision making at upper management level determines the condition, affairs and expected outlook of the organisation. Kroon (1995:112) further explained that those at the lower level are primarily responsible for the operational implementation of the planning of the organisation.

The results of the study, however, indicated that caregivers who were personally affected by HIV/AIDS displayed strong levels of participation, even from the conceptualisation of the project. Heavenly Promise has been constituted essentially to focus on the HIV/AIDS pandemic in Dunoon, and in addition, the centre is staffed by women openly committed to the radical changes that participation implies.

From observing the caregivers throughout the various home visits, it was clear that home-based care was preferable to institutional care. The caregivers' patients who are sick or dying prefer to stay at home in familiar surroundings, especially when they cannot be cured in hospital. The caregivers were mindful of the culture and ethical code of the patient and family, an important consideration that is often overlooked in institutional settings.

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Caregivers displayed a high degree of compassion as they were in touch with potential orphans and family members who really need help. The findings demonstrated how caregivers were able to recognise the necessities of children who are affected by the illness of parents and to assess issues such as whether the child is attending school or not. Participation for the caregivers involved having strong leadership skills and character traits, which distinguished them among the community.

Active participation, however, amongst the majority of community members in terms of networking and collaborating in health services is unheard of in Dunoon. The local community shows a lack of enthusiasm and some resistance to taking part in participation matters. Overall, the assessment indicated that if a community has no sense of belonging or

taking pride in its community, participation will be considerably weakened and inevitably passive. The research has shown the reasons for this lack of pride relates to some degree to the polluted environment in the community.

Moreover, throughout the observation period, it was noticeable how residents conducted themselves by dumping their garbage, waste material and household refuse in the streets. Respondents were clearly very disgruntled with service delivery processes in the community. Another factor that contributed to the lack of a sense of belonging was the crime rate in the area. Respondents mentioned their desire to move to other areas due to the high incidence of crime. Burglary, theft and assault were reported to be common offences in the community. Poverty in Dunoon was also seen to be a clear reason for passivity in the community, as many households are ignorant of their legal rights, which make them an easy target for exploitation. Their deprivation increases their inability to participate in community affairs.

However, it was observed that all employed respondents actively participated in community matters, compared to those who are unemployed. The findings clearly indicated that employed respondents with a secure financial income had a far greater sense of hope and optimism about the community than the unemployed respondents. Unemployment and lack of income in Dunoon led to despair, feelings of hopelessness and to young people resorting to crime and prostitution.

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6.2.2 Capacity building

Brynard and De Coning (2006) confirmed the concept that *capacity building* refers to support rendered to organizations or communities which lack particular expertise or capabilities or to the improvement of their capability to execute their objectives. With regard to capacity building, areas in which the home-based care project demonstrated either strong or weak capacity were identified in the course of the study.

Strong capacity was demonstrated in the area of resource capacity, which includes a commitment and passion to caring for PLWA, their knowledge, commitment to and determination to provide home-based care programmes in Dunoon. The study also revealed that there is sufficient training of home-based caregivers in the HIV/AIDS project. This is due to sufficient resources available to conduct training and the expertise available, such as support from PM4 Africa and the Department of Social Development, which play a vital role

in the HIV/AIDS programmes. Burke (2001) affirmed that capacity building encompasses human resource development, which is regarded as the method of training people in understanding their roles, in acquiring skills and accessing information, and cultivating knowledge, all of which empower community members to perform effectively.

However, weaknesses were also evident in capacity building with regard to technical expertise in key areas of ongoing primary health training, due to a lack of collaboration between the partnership and the City of Cape Town's Health Department. Furthermore, weaknesses were identified in capacity building with regard to the community members' attempt to gain knowledge and skills in the participatory process concerning health matters. Barely any support is given to the community by the City of Cape Town's Health Department to provide expertise or skills or to improve their ability to accomplish their task in active participation in health matters.

6.2.3 Constitutional framework

South Africa is regarded as having the most advanced constitution in the world. Regrettably, implementation of participatory healthcare and compliance with community participation in the City of Cape Town's Health Department (particularly in the Dunoon local clinic) is fraught with a number of challenges. One of these challenges can be related to Weaver's (2004) estimate of 48,000 migrants moving into Cape Town every year.

The mere existences of a legislative framework, though essential as a basis for action, does not in itself provide a solution to community participation, particularly in health matters. Furthermore, the goal of the HIV/AIDS and the STI Strategic Plan 2007-2011 is to plan co-operation with stakeholders independent from government, such as the community, thereby constructing and expanding efficiency in combating HIV/AIDS (DOH:2007). From observations, it was apparent that the local health clinic was not involved in partnership with the home-based care programmes in the Dunoon community.

This research disclosed the City of Cape Town Health Department's lack of effective engagement with the public through using health committees, in the community. The local municipality facilities accessed at this community clinic are inadequate and only include child care, family planning, TB treatment, HIV inspection, cervical smears and therapy, and analysis of sexually transmitted infections. Other aspects such as the shortage of personnel

and an uncaring, unfriendly approach of the professional personnel at the Dunoon municipal clinic are of great concern.

Subsequently, no long-term mechanisms have been established to keep the community actively involved in health, which plays an important part in the life of any community. This coincides with the opinion of De Kadt (1982: 174), who stated that the notion of community involvement as presented in the South African legislation "has popularity without clarity and is subject to growing faddishness and a lot of lip service."

6.3 Recommendations

The following is a list of recommendations based on the findings of this research, which should be implemented to help substantiate community participation in Dunoon. This community participation should also be considered to help strengthen the existing HBC programmes and pave the way for a higher level of services to PLWA.

6.3.1 Dunoon residents

There should be a concerted effort to build community participation from one of passivity to a community that takes responsibility for its own health. Public participation is fundamentally about empowering people. Decisions pertaining to the health system should be clearly communicated to the public in an open and transparent manner.

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The public needs to be simultaneously provided with the opportunity to give feedback or to alter the decision-making process or its outcome if necessary. This process of capacity building should be coupled with broader civic education initiatives. Communities should have the opportunity to be trained by their local health professionals to read policy documents, interpret health indicators and be able to provide constructive feedback.

The community is only passively involved in health services at local government level. This is evident as they have no sense of belonging and are not proud of their community. Poverty and unemployment also play a role in passivity in community participation. There needs to be practical participation as part of the deeper agenda of building a local democracy. A wide range of skills needs to be developed, including the protocols of public meetings, negotiations and conflict resolution skills, especially for stakeholder groups. Gaventa (2002) postulated that visible power presumes that decision-making arenas are unbiased playing fields, in

which any actors who have concerns to raise may contribute without restraint. It also assumes that actors are conscious and aware of their grievances and have the resources, organisation and agency to make their voices heard.

The Health Department of Western Cape should develop a proper budget for community participation in health. This budget should go a long way in ensuring that community participation in the health plan is effectively carried out. In order to create a climate of active participation, adequate health facilities should be catered for. The Dunoon community lacks other health facilities, such as a day hospital, hospice and a 24-hour emergency centre.

6.3.2 Heavenly Promise home-based caregivers

The HIV/AIDS pandemic has resulted in local community members, in particular the caregivers of Heavenly Promise, becoming involved in health matters in Dunoon. Hence, a renewed effort and commitment in community home-based care support is needed. Due to a lack of collaboration between the local clinic and Heavenly Promise, there is a lack of on-going health training. If home/community-based care is to be sustained, the providers of home-based care should receive a comprehensive education. The WHO (2002) affirms that *providers* include families, health and social welfare authorities, community health employees and volunteers.

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Nemathaga (cited in Peu, 2008: 140) was of the view that the future of HBC should be planned carefully and adjusted according to the development needs of the different communities. Van Dyk (2005: 266) agreed and highlighted that it is important to train home-based caregivers accurately and thoroughly to provide a high standard of holistic care.

6.3.3 Partner organisations

The partnership in this home-based care programme should consider preventative measure strategies. Although not a primary finding of this research, numerous HBC programmes have integrated prevention and voluntary counselling and testing education as a central activity of their work. Prevention education and the functioning of support groups for people living with HIV/AIDS should be increasingly documented to encourage their implementation within HBC activities/services. For example, the correlation between HIV/Aids and alcohol use should be investigated and special awareness campaigns should be targeted at shebeens, youth groups, and local soccer and netball clubs in the community.

Shebeens or taverns are the most commonly cited places where men and women meet with friends for recreation in informal settlements. In the course of this research, respondents reported that most of the youth in Dunoon increased their drinking of alcohol at weekends. Clients at shebeens also meet new sexual partners there.

Awareness and strategy campaigns such as the ABC approach of the South African government need to be revised. Questions about the effectiveness of the Love Life Campaign in reducing HIV/AIDS statistics in South Africa need to be asked. The partnership should co-operate with these strategy campaigns and consider a call for strong family values and abstinence from sexual intercourse before marriage as viable options in the fight against the spread of HIV/AIDS.

It is important to ascertain if the Heavenly Promise HBC project has accomplished any objectives and if these are replicable. Various HBC programmes have authenticated best practices in the quest to attain and sustain a high level of service. A thorough investigation of these programmes is needed for substantiating a step-by-step approach to achieve the goals and deal with the challenges.

6.4 Conclusion

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There is a characteristically fallible referral structure between the home-based care organisations in Dunoon and the local public sector of the Western Cape. Therefore, purposeful interaction between patients, caregivers and health professionals is required. This will destroy barriers between health professionals and the Dunoon community and improve the understanding of each role-player's function. Consequently, it will improve the exchange of information to generate more networks for the client in the community and develop efficient service delivery, which is essential in Dunoon.

Nonetheless, a good level of co-operation exists between HBC programmes and larger, experienced NGOs and authorities that have a vast knowledge of socio-economic and nutritional services for people living with HIV/AIDS. The disregard for ongoing health training is a fundamental problem encountered by HBC programmes and requires immediate attention and technical expertise.

Lastly, the approach to development at the local and national levels should be holistic in order to confront the challenge of community participation. Similarly, there should be a persistent enhancement of the recognition and progression of the community of Dunoon. Participation is, above all, a governmental procedure, which should incorporate the general population, the elite, bureaucrats and the political rulers of government. Without substantial commitment at the highest level of national government, it is unlikely that development programmes and projects will be designed to achieve community participation and mobilisation, particularly in informal settlements.

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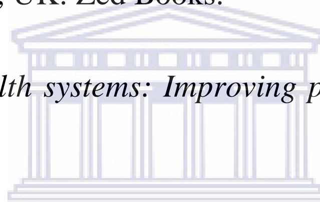

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Appendix A: Consent to participate in study

Dear Participant

I, Abraham Warren am currently studying for a master's degree at the above university in the Department of Social Development. I am interested in doing a study on the importance of community participation in health-care programmes, focusing on home-based care projects as an alternative strategy to institutional care, within the Dunoon community (Western Cape Metropole). Your participation will be highly appreciated.

Terms and condition of the agreement

Should you agree to participate in this study please note the following:

a) Your participation is voluntary.

b) The interview will be conducted with respect for your privacy.

c) Your information will be treated with confidentiality.

d) With your permission, this interview will be recorded on tape.

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e) You will remain anonymous (i.e. your name will not be mentioned to anyone).

f) You are free to withdraw from the study anytime should you feel uncomfortable.

g) The information obtained will be used for research purposes only.

h) All information will be kept secure by the researcher at all times.

Thank you for your participation.

Abraham Warren Signature (Participant)

I agree/do not agree to participate in the study Witness

Appendix B: Semi-structured interview with community members of Dunoon

1) Are you proud of Dunoon community?

If *yes* please state

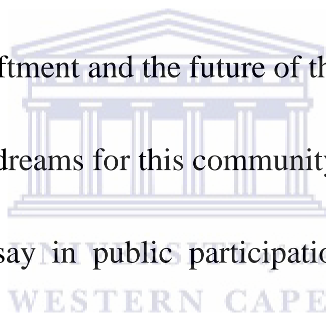
If *no*, please state

2) Do you have a sense of belonging in the community?

Please state in which way

3) Do you participate in any community activities in Dunoon?

Please list a few of activities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4) Who is responsible for the upliftment and the future of this community?

5) What are your aspirations and dreams for this community?

6) Who should have the final say in public participation processes pertaining to health services?

7) Have you ever attended an HIV/ AIDS awareness campaign in Dunoon?

If *yes*, how many?

8) Do you think HIV/AIDS is a threat to your community?

If *yes* why is it?

9) Have you ever spoken to a HBC worker in Dunoon?

10) What can be done to reduce the incidence of HIV/AIDS in Dunoon?

Appendix C: Semi-structured interview with home-based carers of the HBC Program

1) Please state the reason you became involved in the HBC programme?

2) How long have you been involved in the program?

3) As a home-based carer:

- What motivates you to volunteer?
- What are your needs/expectations as a home-based carer?
- How have your needs/expectations changed over time?
- How must the partnership manage the project to sustain this programme?

4) Participatory participation:

- Has your decision to be active in the development of appropriate health services increased your knowledge of health?

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- Are you part of the decision-making process within the partnership?
- Do you have a good relationship with the local health services in the community?
- Do you have a good relationship with the local people in the community?
- Is there a sense of community involvement in health matters?
    - If *yes* please state.
    - If *no*, please state.

- If answer is *no*, what needs to be done to improve the community involvement in health?

5) What have been the obstacles carers have experienced within the HBC programme?

6) What are the challenges that you are facing as an HBC?

7) What are your aspirations and future plans for this program?

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Appendix D: Semi-structured interview with supervisor of the HBC programme

1) How long has the HBC programme been running?

2) What is your length of service in this programme?

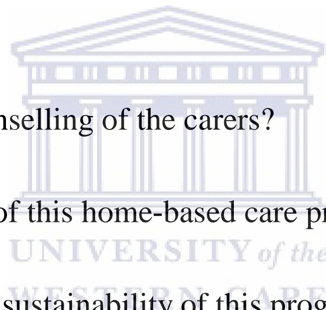
3) Please describe your role as overseer in this programme?

4) Please describe the criteria in recruiting HBC to this programme?

5) How does the community see the role of HBC?

6) How has this programme had a positive effect on the community?

7) Please describe if the programme has had a life-changing effect on the personal lives of carers.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8) Who is responsible for the counselling of the carers?

9) What have been the successes of this home-based care programme?

10) Please list some threats to the sustainability of this programme?

Appendix E: Semi-structured interview with director of the HBC Program

1) What is your length of service in this programme?

2) Describe the HIV/AIDS pandemic your organisation faced within the Dunoon community.

3) Describe the challenges the community has addressed in assessing the needs of home-based care for HIV/AIDS patients in Dunoon.

4) Describe the importance of the role of home-based caregivers.

5) How would you define *community participation*?

6) What does your organisation understand by the term *partnership*?

7) What role does the director play within the Dunoon partnership?

8) What has been the success of this partnership?

Appendix F: Semi-structured interview with PM4 Africa Partner

1) How did PM4 Africa become involved in this partnership?

2) Please state how long (duration) PM4 Africa has been involved in the programme.

3) What does your organisation understand by the term *partnership*?

4) What is PM4 Africa's role in this partnership?

5) How would you define *community participation*?

6) How important is participation to your organisation and where does it fit into the department structure?

7) What has been the success of this partnership?

8) What are your aspirations and future plans for this partnership?

9) Are there any possible threats to this home-based care program?

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Appendix G: Semi-structured interview with Caltex/Chevron partner

1) How did Chevron/Caltex become involved in this partnership?

2) Please state how long (duration) Chevron has been involved?

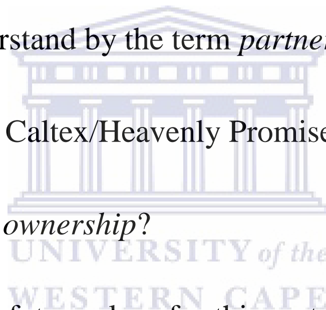
3) Describe the role of partnership and level of collaboration?

4) Describe Chevron's global commitment to HIV/AIDS and illustrate how Dunoon HBC supports the Global Fund initiative?

5) How would you define *community participation*?

6) How important is participation to your department? Where does it fit into the department structure?

7) What does your company understand by the term *partnership*?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8) What have the successes of the Caltex/Heavenly Promise partnership been?

9) How do you define *community ownership*?

10) What are your aspirations and future plans for this partnership?

11) Are there any possible threats to this home-based care program?

Appendix H: Semi-structured interview with the Department of Social Development (DSD)

1) How did DSD become involved in this partnership?

2) Please state how long (duration) DSD has been involved?

3) How would you define *community participation*?

4) How important is participation to your department? Where does it fit into the department structure?

5) Does your department see participation as a means to an end, or as an end in itself?

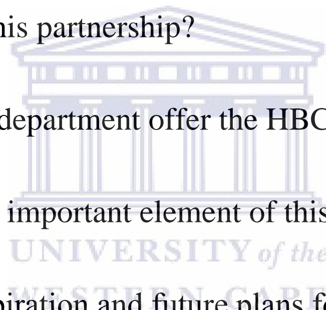
6) What does your department understand by the term *partnership*?

7) What has been the success of this partnership?

8) What type of training does the department offer the HBC?

9) Describe why the training is an important element of this partnership.

10) What are the department's aspiration and future plans for this partnership?



Appendix I: Request to undertake research in the Department of Social Development Western Cape

Verwysing:
Reference:
Isalathiso: **Research into Home based care as an alternative strategy to Institutional Care: A case study on Dunoon home based caregivers**

Navrae:
Enquiries:
Imibuzo: **Ms P. Brink**

Telefoon:
Telephone:
Ifowuni: **+27 (21) 483 4512**

Mr A. Warren
Warrenac1@gmailcom

Dear Mr Warren

Request to undertake research in the Department of Social Development, Western Cape

It is a pleasure to inform you that your request to undertake research in the Department of Social Development has been approved by the Research Ethics Committee of the Department. Please liase with Ms Petro Brink on 021 4834512 or pebrink@pgwc.gov.za regarding arrangements for the interviewing of Departmental officials.

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Yours sincerely

Head of Department...

Directorate Research and Population Development
Private Bag X9112, Cape Town, 8000
Union House, 14 Queen Victoria Street, Cape Town, 8001
Tel: (021) 483 4595, Fax: (021) 483 5602
www.capegateway.gov.za/social_services

Appendix J: Letter of Introduction

Private Bag X17, Bellville 7535, Cape Town, South Africa
Telephone :(021) 959 3858/9 Fax: (021) 959 3865 /49
E-mail: pkippie@uwc.ac.za

To whom it may concern

Mr Abraham Warren is a registered master's student at the Institute for Social Development at the University of the Western Cape. Part of the requirements of the master's degree is that candidates complete a mini-thesis which documents research in a particular case study area.

Mr Warren has recently presented a research proposal to the Post Graduate Board of Studies entitled *Home/community-based care as an alternative strategy to institutional care: A case study in Dunoon home-based caregivers*. The Post Graduate Board of Studies has approved his proposal and ethical commitment. Mr Warren has now been given consent by the University of the Western Cape to commence with his research.

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WESTERN CAPE

It is Mr Warren's responsibility to consult with the relative organisations and committee representatives in his selected case study area and gain permission to conduct the research and to explain the purpose of the intended investigation. Should you require any additional information, please do not hesitate to contact me.

Sharon Penderis

Senior Lecturer

Institute for Social Development, University of the Western Cape: 084 510 2772

Appendix K: Aerial Photo of Dunoon

Source: Strategic Development Information and GIS Department- City of Cape Town (2010).