

**The intermediary function of NGOs in HIV/AIDS responses:**

A case study of the Lady Frere District of the Eastern Cape

Thesis

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by

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(Tosserams, 2006:1).

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**Make your own notes  
NEVER underline or  
write in a book**

### **Abstract:**

The HIV/AIDS epidemic has serious effects on society. It has been described as the biggest threat to the development of South Africa, with severe economic, social and human impact. In the Lady Frere District in the Eastern Cape Province, like in many other areas that are greatly affected by the epidemic in this country, young people are considered by the local Department of Health to be a particularly vulnerable group due to various predisposing biological, social, cultural, and economical factors. Despite the efforts that have been made to educate and encourage prevention, especially by the local Masibambane Non-governmental Organisation (MNGO) to inform these communities about the dangers of the epidemic, people's behaviour have been slow to change and the disease continues to spread.

This research is conducted against the escalating HIV/AIDS pandemic in the Lady Frere District. The fundamental aim of this project is to examine the intermediary function of the MNGO in HIV/AIDS responses. The study seeks to evaluate the way in which this local NGO operates on the ground in contributing to a community's response to the HIV/AIDS pandemic. In other words, the thesis tries to indicate how this local NGO, in dealing with the HIV/AIDS issue, interfaces with the community and related stakeholders. It examines how young people in the Lady Frere District perceive HIV/AIDS. A literature review demonstrates that the specific aims and objectives of this project represent a fairly new area of research in South Africa.

I propose in the thesis that a simple act of joining and being regularly involved in a community organisation such as the MNGO will have significant impact on individuals' health and well-being. The thesis is crying for a need to restore the notion of "*ubuntu*" (meaning humanity) which is fundamentally based on social capital to assist these communities to rebuild trust which is essential in people living with HIV/AIDS. Based on my assessment it seems that intermediary NGOs, like the traditional NGOs and the private sector, will have little impact in terms of changing the conditions of the poor and the marginalised people. This is because in practice, like the conventional NGOs, intermediary NGOs serve the interests of donors and national governments or those who give them financial support to continue existing.

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## List of acronyms

ANC:	African National Congress
AOA:	Affected Organisations Act
ART:	Antiretroviral Therapy
CADRE:	Centre for AIDS Development, Research and Evaluation
CARE:	Co-operative for American Relief Everywhere
CBO:	Community-Based Organisation
CSO:	Civil Society Organisation
DFFA:	Disclosure of Foreign Funding Act
DNH:	Department of National Health
DoSD:	Department of Social Development
DSSPA:	Department of Social Service and Poverty Alleviation
FGD:	Focus-group Discussion
FRA:	Fund-raising Act
GEAR:	Growth, Employment, and Redistribution
HIV/AIDS:	Human Immune Deficiency Virus and Acquired Immune Deficiency Syndrome
IEC:	Information, Education and Communication
KAP:	Knowledge, Attitude and Practice
MNGO:	Masibambane Non-governmental Organisation
MTCT:	Mother-to-child-transmission
NACOSA:	National AIDS Co-ordinating Committee of South Africa
NAP:	National AIDS Plan
NGO:	Non-governmental Organisation
NRF:	National Research Foundation
OECD:	Organisation for Economic Co-operation and Development.
OXFAM:	Oxford Committee for Famine Relief
PLWH:	People Living with HIV/AIDS
RDP:	Reconstruction and Development Programme
SANGO:	South African Non-governmental Organisations
TAC:	Treatment Action Campaign
UN:	United Nations
USAID:	United States Agency for International Development
WB:	World Bank
WHO:	World Health Organisation

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Pictures of the Lady Frere town<sup>1</sup>

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<sup>1</sup> All pictures are taken by the researcher.

## CHAPTER ONE

### Thesis introduction

#### 1.1. Orientation to the chapter

This chapter provides an overview of the study. In this chapter I present the context and background to this research and introduce the goals of this project and the methodology used to conduct the study. Towards the end of the chapter I provide an overview of how the rest of the chapters of this thesis are structured.

#### 1.2. Context of the study

To begin with, this study was conducted in consultation with the Centre for AIDS Development, Research and Evaluation (CADRE) at Rhodes University, and within the research project on "Social suffering" funded by the National Research Foundation (NRF) under the leadership of Professor Jan K. Coetzee of the Department of Sociology, Rhodes University. This study also formed part of a collaboration with the University of Maastricht, in The Netherlands. The initial part of the study was funded by MUNDO, which made provision for the researcher to visit the University of Maastricht (The Netherlands) for a period of five weeks. The study commenced in 2006 and fieldwork was conducted over a period of two years (2006 – 2007).

The Human Immune Deficiency Virus and Acquired Immune Deficiency Syndrome (HIV/AIDS) epidemic in South Africa continues to grow at a rapid rate, and at a point (2006) it was estimated that a total number of 4.2 million people were infected with the virus in South Africa (Department of Health, 2006:5). The epidemic has been described as the biggest threat to the development of the country, with severe economic, social and human impact. In the Lady Frere District, like in many other areas that are greatly affected by the epidemic in this country, young people are considered by the local Department of Health to be a particularly vulnerable group due to various predisposing biological, social, cultural, and economic factors. Despite the efforts that have been made to educate, to encourage prevention, and to inform

these communities about the dangers of the epidemic, especially by the local Masibambane Non-governmental Organisation (MNGO) people's behaviour has been slow to change and the disease continues to spread.

This research is conducted against the background of the escalating HIV/AIDS pandemic in South Africa. It seeks to evaluate the HIV/AIDS intervention responses by the MNGO operating in the Lady Frere District in the Eastern Cape Province. The thesis is an attempt to examine the way in which this local NGO operates on the ground in contributing to a community's response to the HIV/AIDS pandemic. In other words, the thesis tries to indicate how this local NGO, in dealing with the HIV/AIDS issue, interfaces with the communities and related stakeholders. A literature review demonstrates that the specific aims and objectives of this study represent a fairly new area of research in South Africa.

This research was undertaken as a case study, focusing on the eMkhaphusi village in the eMalahleni Municipality in the Eastern Cape Province. The initial research activity was an overview exercise to take stock of the range of responses to HIV/AIDS in the village and in the Lady Frere town. In particular an inventory was compiled to take stock of all forms of HIV/AIDS responses in prevention, care and treatment, impact mitigation, and the co-ordination of HIV/AIDS activities.

The research was motivated by the realisation that:

Civil society movements on HIV/AIDS have not only been critical in raising awareness of HIV/AIDS issues in terms of health and sexual behaviour, but they have also been the main instigators in challenging government policies (Panos, 2006:286).<sup>2</sup>

Rau (2006:285) argued, however, that

most governments and international agencies have only belatedly acknowledged, or have ignored, the effectiveness and efficiency of the approaches these groups have advocated.

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<sup>2</sup> The Treatment Action Campaign (TAC) first confronted the government for not ensuring that mother-to-child-transmission (MTCT) prevention was available to pregnant mothers. Again in the same year (2001), the TAC laid culpable homicide charges against the Health Minister, Manto Tshabalala Msimang, and the Minister of Trade and Industry, Alec Irwin. The TAC claimed the pair were responsible for the deaths of 600 HIV-positive people a day in South Africa who had no access to antiretroviral drugs ([www.tac.org.za](http://www.tac.org.za)).

This is partly because leadership have been dismissive of the importance and impact of HIV/AIDS, and reluctant to take effective action against it (Rau, 2006:286). Furthermore, Rau (ibid.:289-90) believes that NGOs have been ignored because:

- 1) International agencies have little trust in the expertise of community-led groups and therefore use their funding power to define approaches and regulations.
- 2) Governments and international agencies treated community level civil society organisations (of which NGOs are a prominent part) merely as implementers of programmes and approaches developed outside their communities.
- 3) Many politicians fear providing support and credibility to the initiatives of NGOs, because such groups may then build upon their successes to question and eventually challenge development failures. The significance of this has been a low level of trust and collaboration between NGOs and national governments. This has been quite evident in the South African context, going back to the apartheid regime and also the post-apartheid period. Because of this I argue in the thesis that this lack of trust between the stakeholders in the Lady Frere District compromises the formation of social capital (an issue that I will come back to in Chapter 3).

During the data gathering process for this research, I attached myself to the MNGO. This was done primarily to capture “social meanings and ordinary activities” (Brewer, 2004:103), whereby I participated directly in the setting up of these activities in order to collect data in a “systematic manner but without meaning being imposed” (ibid.). This was part of my strategy to supplement and verify what my participants told me during the interviews and focus group discussions (FGDs). The use of participant observation as part of my data gathering method emanates from the realisation that often what people say during interviews is most likely to be the opposite of what is actually taking place on the ground. This means that as a researcher I needed to be sceptical of what my participants told me, hence I adopted participant observation in order to familiarise myself with what happened on the ground.

The MNGO was chosen on the basis that it deals with people living with HIV/AIDS (PLWH) directly. People from the MNGO visit PLWH on a regular basis in their villages and at the clinics where they go for counselling and treatment for HIV/AIDS and other infectious diseases. The MNGO was selected mainly because it is involved in sensitising and educating the youth in their communities – something which is lacking in many NGOs that deal with HIV/AIDS at national level. I also discovered that this community NGO is operating at grass roots level, bringing PLWH together to provide coping strategies for them on a regular basis.

The research undertaken is mainly qualitative in nature. Qualitative research methods such as participant observation, in-depth interviews (face-to-face), and focus-group discussions were used as the main data-gathering techniques. Qualitative methodology was employed because of the nature of the research questions I am seeking answers to, which do not merely require “Yes” or “No” answers. This approach was useful because my aim in this thesis was not to quantify answers. Instead I wanted to go beyond numbers and generalisations and engage people on the ground. For this I employed an inductive way of reasoning – starting from the specific issues and moving to the general. Based on this I came to the conclusion that the MNGO is playing an important role in informing people when compared with other stakeholders in the area.

The major role players in the village of eMkhaphusi and other stakeholders were interviewed as key informants. These included: a community leader, PLWH, an AIDS community caregiver attached to a local clinic, a local government representative involved in HIV/AIDS responses, a Church leader, and NGO representatives within the MNGO. These interviews were supplemented by semi-structured group discussions (conducted in Xhosa) where the researcher played a facilitator role to elicit information from the respondents. The researcher facilitated focus-group interviews with adults and youth representatives to gain an understanding of how community members perceive the role of the MNGO within their community.

However, it was clear to me that when researching HIV/AIDS one is touching on sensitive and emotional issues that are intricately connected with individuals' private social lives. In particular, "the in-depth, unstructured nature of qualitative research and the fact that it raises issues that are not always anticipated mean that ethical considerations have a particular resonance in qualitative research studies" (Lewis, 2003:66). This means: "Asking questions about individuals' sexual behaviour, beliefs or preferences, use of intravenous drugs and all the other commonest ways of transmitting or contracting HIV/AIDS" (van Landingham et al., 1994:85), requires treading on very personal grounds and involves a high risk of offending and alienating the participants. I argue in the thesis that the implication for this is that the researcher might be tempted to avoid such questions and that may affect the quality of information one would obtain during the data gathering process. Because of the sensitivity of the issues involved in this topic, I ensured that both confidentiality and the anonymity of all my participants were maintained at all times. This is based on the fact that whilst researchers have the right to collect data through, for instance, interviewing people, I realised fully that this should not be done at the expense of the interviewee's right to privacy, confidentiality and anonymity (Babbie & Mouton, 2001). I informed all my participants about the purpose, methods, intended and possible uses of the data.

Data was taped, translated and transcribed. The study adopted an interpretive approach. Data was analysed using two methods: identifying themes and coding the data. According to Kelly (1999:143) "coding means breaking up the data in analytical relevant ways. This entailed making different sections of the data as being instances of, or relevant to, one or more of one's themes". I coded phrases, lines, sentences and paragraphs.

### **1.3. Goals of the research**

Research on community NGOs dealing with HIV/AIDS responses is still in its infancy stage. This served as a motivation therefore for an exploration on how this local NGO interfaces within a given community and with related stakeholders. The

fundamental aim of this project was to examine the intermediary function of the Masibambane NGO in HIV/AIDS responses. This main aim was addressed by the following interrelated research questions:

- What factors have driven the emergence of the MNGOs' responses to HIV/AIDS in the Lady Frere District?
- To what extent is this NGO an intermediary agent which connects communities with the local government and non-governmental support services?
- To what extent has the eMalahleni Municipality and the Department of Health used civil society organisations as a way of reaching communities?
- What role did the MNGO play in shaping the relationship between these communities and the local government?
- What kind of training/support is available to the staff members and volunteers of this NGO at a local level?

#### **1.4. Thesis breakdown**

In the following section I present an overview of the chapters in this study, and give insights into the main themes covered in the chapters.

**Chapter Two** of this thesis focuses on how the study was undertaken. It deals with the design and methodology for this project. I also cover aspects of how the data were collected and how it was analysed. It provides the reasons for the preference of qualitative research methods. The chapter highlights the constraints I encountered in the field. It also addresses the philosophical and methodological commitments associated with the methods I have used in this project. Towards the end of the chapter I also deal with the ethics guiding this research. An attempt is made in the chapter to acknowledge that the research tools I employed for information gathering are not perfect. I suggest in the chapter that all social science data collection methods have their own limitations. For this reason, the fundamental challenge for social science researchers, including sociologists, is to develop strategies that are aimed at reducing the impact of these constraints so that we stay as objective as possible in reporting and analysing what we encounter in the field.

**Chapter Three** is an attempt to develop a conceptual framework for this project. This conceptual framework is based on the importance of social networks in the fight

against HIV/AIDS in the Lady Frere District. For a better understanding of the current debates within the social capital approach, I outline the historical conceptualisation of this term. This is done to illustrate how the term has shifted from its original meaning to its current application in the field of health. The second part of this chapter is a review of the contribution made by different scholars in defining social capital. The chapter goes on to look more closely at the theoretical connections between social capital and good health, and discusses different forms of social capital available to PLWH. Lastly, the chapter discusses the negative dimensions of social capital which could be detrimental if the concept is applied unsuspectingly by health professionals.

**Chapter Four** is an evaluation of the evolution of Non-governmental Organisations universally but with emphasis on South African NGOs. The literature review shows that NGOs came into existence because of governments' and private institutions' failure to meet the needs of people on the ground, especially the poor. I argue that this failure by government and private institutions prompted the development of a new type of NGO that seeks to fill this gap between local issues and national institutions. Because of their distinct features, intermediary NGOs are said to have a sustainable contribution in addressing the needs of the poor. However, I maintain in the chapter that intermediary NGOs, like conventional NGOs and private institutions, are unlikely to change the situation/conditions of the poor and the marginalised. This is because, I would argue, in practice, like the traditional NGOs, intermediary NGOs serve the interests of donors and national governments or those who give them financial support to continue existing. This situation compromises the independence of these NGOs and in the process they will eventually lose their power to challenge local governments. An attempt is also made to evaluate the factors that led in recent years to the mushrooming of HIV/AIDS NGOs.

**Chapter Five** is a reflection on the failures of education-oriented strategies to reduce the spread of HIV/AIDS in the Lady Frere District. In interrogating the effectiveness of these strategies, I examine how people experience and perceive HIV/AIDS in these communities. I therefore discuss the underlying reasons for some of the MNGO

members not disclosing their HIV status to their partners. This is done to demonstrate some of the challenges that confront the programmes proposed by the MNGO in trying to reduce the spread of HIV/AIDS among young people in these communities. This chapter was motivated by the realisation that most people I interviewed for this case study have knowledge about the ways of transmitting the HI virus and they know how they can protect themselves and their partners. Yet, some still continue to engage in high risk sexual practices even though they know that there is no cure for the disease. This led me to question the suitability of the mainstream prevention and awareness education-oriented strategies aimed to change the behavioural practices and to reduce the spread of the epidemic. To address these problems I draw from the data I collected during the meetings and workshops of the MNGO I attended to document people's experiences and perceptions of AIDS in the Lady Frere District.

**Chapter Six** presents the findings of my data. The chapter, drawing from the findings, argues that social capital in the Lady Frere District is under threat. This is of particular concern when considering that these are communities that were characterised by the notion of "*ubuntu*" (meaning humanity). I argue that the lack of cooperation between the government officials and civil society organisation representatives in my study area has created feelings of mistrust. Another important finding in this chapter was a realisation that AIDS has damaging effects on social capital formation in the Lady Frere communities. In fact, AIDS in these communities has led to a situation where some parents even believe that when their children get sick, it is because they are being bewitched by their relatives and neighbours. This also exacerbates denial of the epidemic in these communities.

**Chapter Seven** is the conclusion of the study. In this chapter I recapture the main themes and findings of this project. The chapter evaluates the MNGO activities. These activities appear to be quite small in size and seem to be unappreciated by the local government. In the last part of the chapter I present a reflection on the study as a whole, noting the limitations of the study. In the final section I present a personal

reflection on the voyage of embarking on this project where I believe that conducting this research gave me a chance to make a small contribution in knowledge creation.

## CHAPTER TWO

### Research methodology

#### 2.1. Introduction

In this chapter I describe how this study was undertaken. The chapter deals with the design and methodology for the research. It also covers aspects of how the data was collected and how it was analysed. Towards the end of the chapter I deal with the ethics guiding this research. The chapter further highlights the limitations of the research tools I used in gathering data for this project. In this chapter I review the defining features of qualitative research methodology. The chapter also discusses the reasons for adopting qualitative instruments for its data gathering and analysis (Hartly & Muhit, 2003:103). Furthermore, in this chapter I also address “the philosophical and methodological commitments” (ibid.:103) that are associated with the methods I have used in this project. Because of the nature of the research questions in this study (which do not require ‘Yes or No’ answers), I adopted qualitative research methods. This is because qualitative methods have the ability to take me “into the minds and lives” of the people infected and affected by AIDS, and those dealing with PLWH (McCracken, 1988:10). The tools I employed for the data gathering include: in-depth interviews (face-to-face), participant observation, and the FGDs. I also made use of ethnographic research.

#### 2.2. Methodology

To begin with, it is worth noting that the term methodology has come under a lot of criticism and because of this some scholars believe that the term has lost its original meaning. Archie Mafeje (1996:26) among others holding this view, in his “Monograph Series 4/96” maintains that the term methodology “is one of the most abused terms in social science discourse”. Essentially, this is because the term

“is often used as a collective noun for methods/procedures and techniques. However, in reality, methodology has a higher theoretical status than these. As is known, at the level of methods and techniques, there are no essential differences, all is a matter of convenience” (ibid.).

But for Mafeje the term refers to the fundamental “choices we make as social scientists in knowledge” creation (1996:26).

Methodology is usually employed to indicate the conceptual and philosophical assumptions that justify the use of particular research methods. “It deals with the characteristics of methods, the principles on which methods operate and the standards which govern their selection and application” (Payne & Payne, 2004:150). In other words, methodology helps us to understand not only the products of scientific inquiry but also the process itself (Winston, 1995:38). Methodology entails the whole process of carrying out a study, and is aimed at understanding a social phenomenon (Creswell, 1994:2). According to Saunders (1997:3) research methodology “involves a multistage process which one follows in order to undertake and complete the research project”. The stages that I followed in this project included: topic formulation, literature review, design, data collection, data analysis and reporting of the findings.

This study was conducted in consultation with the Centre for AIDS Development, Research and Evaluation (CADRE) at Rhodes University, and within the research project on “Social suffering” funded by the National Research Foundation (NRF) under the leadership of Professor Jan K. Coetzee of the Department of Sociology, Rhodes University. This study also formed part of a collaboration with the University of Maastricht, in The Netherlands. The initial part of the study was funded by MUNDO, which made provision for the researcher to visit the University of Maastricht (The Netherlands) for a period of five weeks. The study commenced in 2006 and fieldwork was conducted over a period of two years (2006 – 2007).

This research is a case study: studying the eMkhaphusi community focusing on the description and analysis of patterns and relationships within the context of the community’s life. The eMkhaphusi village is situated under the eMalahleni Municipality of the Lady Frere District in the Eastern Cape Province. The Eastern Cape Province is located in the south-east of South Africa, bordering Free State and

Lesotho in the north, KwaZulu-Natal in the north-east, the Indian Ocean along its south and south-eastern borders, and Western and Northern Cape in the west (Statistics South Africa, 2003). The province encloses 169 580 km, constituting 13.9% of the total land area of the country, making it in surface area the second largest province of the country (ibid.). Inhabitants of the former Transkei (where Lady Frere and eMkhaphusi village are located) are dependent on cattle, maize and sorghum farming.



Figure 1: Map showing the Eastern Cape Province where Lady Frere, Dordrecht and Indwe towns are located

I have chosen the eMkhaphusi village as my case study because it is one of the few villages that are playing an important role in promoting awareness, prevention, care and treatment of HIV/AIDS among its people. A case study is defined in this thesis to be an

empirical enquiry that investigates a contemporary phenomenon within its real-life context, when the boundaries between phenomenon and context are not clearly evident and in which multiple sources of evidence are used (Yin, 1984:23).

I have chosen a case study method because it describes “a real event or situation, whereas a statistical study involves abstraction from real situations” (Boyd, 1985:53) which is not my aim in this study. Furthermore, the use of a case study method provided me the opportunity to obtain more accurate data because “of a longer, more intimate association with my respondents” (ibid.:53). This method assisted me in gaining a detailed understanding of the intermediary function of the MNGO in HIV/AIDS responses. A case study was particularly relevant to my study because it “involves the description of an ongoing event such as organizational change” within the MNGO in relation to a particular outcome of interest (e.g. coping strategies and change in leadership positions) “over a fixed time in the here-and-now” (Brewerton, 2001:53).

My interest here was to examine the processes that the MNGO use to mitigate the challenges inflicted on the communities of Lady Frere District by HIV/AIDS. This was of particular interest and importance in my study because the mainstream HIV/AIDS prevention and awareness strategies<sup>3</sup>, which are the core functions of the MNGO, propose that

health related behaviour is determined by an individual’s knowledge and attitude. Thus (it is argued), if people know that AIDS is a deadly disease, and that using condoms will diminish their chances of getting it, they should be more likely to use condoms (Campbell, 1997:145).

In this study I question the suitability of these strategies, because research has proven quite convincingly that “even people with relatively high levels of knowledge about HIV/AIDS often indulge in high risk sexual practices” (Campbell, 2003:145). This means therefore “sexuality cannot be understood as a different and disjointed aspect of the life of the individual” (Crush et al., 2002:9). In the South African context, we cannot ignore the role played by poverty in facilitating the rapid spread of the epidemic within our communities. It is against this background, then, that this study challenges these perceptions and argues that such HIV preventive and awareness

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<sup>3</sup> Mainstream strategies such as abstinence, be faithful and/or use a condom (the South African AIDS Plan is fundamentally based on this so-called ABC approach), and education impacted on passive target audiences, knowledge about how HIV/AIDS is transmitted and attempts to change sexual behaviour and attitude, are all seen as a panacea to reduce the rapid spread of HIV/AIDS in the country.

programme fail to recognize that sexual behaviour is deeply rooted in social, cultural and economic structures of the society (Clark et al, 2005:1).

In this study I investigate the intermediary function of the MNGO because the organisation deals with PLWH directly. As the intermediary organisation, the MNGO is working closely with most stakeholders in the area. People from the organisation visit PLWH on a regular basis in their villages and clinics where they went for counselling and treatment for HIV/AIDS and other infectious diseases. Those who qualify for Anti Retroviral Therapy (ART) are also visited by the NGO. The MNGO was selected mainly because it is involved in sensitising and educating the youth in their communities – something which is lacking in many NGOs that deal with HIV/AIDS at national level. I also discovered that the MNGO is operating at grass roots level, bringing PLWH together to provide coping strategies for them on a regular basis.

The slogan of the MNGO is: “Together we strive to ease the pain and suffering of our people” (MNGO<sup>4</sup>, 2003:1). The vision of the organisation is to provide preventative, supportive and community-based care programmes that mitigate against the social impact of HIV/AIDS and other opportunistic diseases. Their mission is: “To provide quality support for those in need. This will be achieved by being there for each other when in need not when convenient. We shall focus on Lady Frere District and its surrounding areas” (MNGO, 2003:3). The aims and objectives of the MNGO are as follows:

- A. Provide counselling and support to the newly diagnosed HIV/AIDS individuals.
- B. Support HIV/AIDS affected families.
- C. Ensure that members access the treatment.
- D. Facilitate that members are not discriminated against in terms of employment. (Indeed, in my interviews some respondents reported incidents where some community members would insult PLWH until MNGO and other stakeholders had to intervene.)
- E. Involvement in awareness campaigns at schools, clinics, communities and hospitals.
- F. Support orphans and vulnerable children of the people living with HIV/AIDS.
- G. Networking with all stakeholders.
- H. Schedule training activities. (MNGO, 2003:3)

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<sup>4</sup> Masibambane Non-governmental Organisation

All members of the organisation are expected to respect the confidentiality and privacy of any person living with HIV/AIDS who is not open about his/her HIV status. It is said in their Constitution, disciplinary action will be taken against any member who breaches the confidentiality/privacy of any MNGO member living with HIV/AIDS who is not open about his/her HIV status (2003:4). However, I realise that when dealing with organisations (who might have hidden agendas) quite often what is said on paper is likely to be the opposite of what is happening on the ground. For this reason all stakeholders, in particular those who claim to be serving HIV/AIDS vulnerable communities, were interviewed to get a better understanding of what this organisation is doing.

Apart from the case study method, this was also an ethnographic investigation. During the process of data gathering I attached myself to the MNGO. This was done mainly to capture “social meanings and ordinary activities” whereby I participated “directly in the setting of the activities, in order to collect data in a systematic manner but without meaning being imposed” (Brewer, 2004:103). The use of ethnographic research helped me to tease out the linkages between culture and behaviour of PLWH. It allowed a space for me to engage in participant observation to get to understand the ways in which my participants do things. For example, all the members gathered in the organisation’s office every day and I learnt to prepare *amanqina* (chicken legs). The distinction between ethnographic research and participant observation is very difficult to draw, primarily because both these terms draw attention

to the fact that the participant observer [or] ethnographer immerses him or herself in a group for an extended period of time, observing behaviour, listening to what is said in conversations both between others and with the fieldworker, and asking questions (Bryman, 2001:291).

However, the term ‘participant observer’ also has negative connotations because it gives the impression that the investigator just goes to the field to ‘observe’ what the actors are saying or doing (ibid.:291). Participant observation is a useful tool because it provided me with the opportunity to obtain more insights in understanding how those infected and affected by the epidemic cope, among other things, for instance,

with the stigma attached to HIV/AIDS in our communities (Waldorf & Waldorf, 1983:589). However, one should highlight that even though the use of in-depth observational studies may help the researcher to go beyond some of the problems associated with qualitative research, there are also some weaknesses associated with this technique. One particular problem of in-depth observational studies is their reliance on small unrepresentative samples which inevitably means that making statements about the population become impossible (Waldorf & Waldorf, 1983:590).

### **2.3. The qualitative research approach**

Quite often a distinction is made between qualitative and quantitative research methods. An important difference between these two schools of thought is the manner in which each tradition “treats its analytic categories” (McCracken, 1988:16) and this distinction will be expanded shortly in this section. Because of the nature of the research questions I am seeking answers to in this study I employed a qualitative research methodology. This was mainly because I felt that quantitative methods such as surveys and questionnaires would not have been the appropriate tools to collect information as my aim in this project was not to quantify answers. Instead I wanted to go beyond numbers and generalisations and engage people on the ground. In this study I proceeded therefore from the specifics to the general (inductive reasoning).

The term qualitative research can refer to many different ways of conducting research. But for the purpose of my study I adopted a working definition provided by Norman Denzin and Yvonna S. Lincoln (2003). According to these authors, qualitative research refers to:

a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that make the world visible. These practices turn the world into a series of representations including field notes, interviews, conversations, photographs, recordings and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret phenomena in terms of meanings people bring to them (Denzin & Lincoln, 2003:3).

I adopted this definition because of its usefulness in terms of highlighting the methodological foundations that characterise qualitative studies. These include the

fact that my study was situated in a particular location which is the Lady Frere District where I conducted the study. This definition is relevant because it places emphasis on the interpretive nature of my study, the insider's perspective, and it stresses that qualitative research takes place in natural settings. David Silverman (1993:170) contends that qualitative research is "especially interested in how ordinary people observe and describe their lives". According to Babbie and Mouton (2001:271) qualitative researchers should continuously strive to

put themselves in the shoes of people they are observing and studying and try and understand their actions, decisions, behaviours, practices, and rituals and so on, from their perspectives.

Furthermore, qualitative researchers "attempt to view the world through the eyes [perspectives] of the actors themselves" (Babbie & Mouton, 2001:271). Bogdan and Taylor (cited in Babbie & Mouton, 2001:271) relate this to the concept of phenomenology. According to Bryman (2001:506) phenomenology is a "philosophy that is concerned with the question of how individuals make sense of the world around them and how in particular the philosopher should bracket out preconceptions concerning his or her grasp of that world". Some scholars believe that qualitative methods, which are deeply rooted in the phenomenological paradigm, can offer useful insights into our understanding of issues such as the present day HIV/AIDS epidemic (Waldorf & Waldorf, 1983:589).

As a qualitative researcher I went to the field of study (which is in my project the homes and offices of the participants) to conduct the research. This enabled me to develop a level of detail about the individual and place and to be involved in the actual experiences of the participants (Creswell, 2003:181). According to Babbie and Mouton (2001:271) qualitative research is best suited for studying attitudes and behaviours understood within their natural setting, as opposed to the somewhat artificial settings of experiments and surveys. Instead of relying on sources to inform us about what happened, as qualitative researchers, our aim is to study events as they happen in the field. It is for this reason that this method is also known as "naturalistic inquiry" and "field research". The study of participants' behaviour and actions in a natural setting allows the qualitative researcher to capture the "normal

course of events" and certainly to "observe events and actions as they happen" (Babbie & Mouton, 2001:271). The idea is to minimise "intervention" and "interference" as much as possible which is the opposite of what happens in experimental designs and survey research where the researcher intervenes in the research process resulting in a less spontaneous set up (Babbie & Mouton, 2001:271). A further characteristic of qualitative research that is applicable in this discussion is that it is normally conducted in a relatively unstructured and flexible manner (Struwig & Stead, 2001:13). In collecting data for this project, I followed an unstructured approach with a list of themes, also called an interview guide, that covered the different themes. "The phrasing and sequencing of questions varied from interview to interview" (Bryman, 2001:509). In conducting this research, I distrusted the orthodox theories, which are normally the starting point for quantitative researchers (Struwig & Stead, 2001:14). Instead I explored data gathered in the field and attempt to build (a) theory(ies) from them (Payne & Payne, 2003:175). It is because of this that Creswell (2003:181) perceives qualitative research as "highly emergent rather than being tightly prefigured". It is through the use of inductive logic (moving from specific observations towards more general statements) that qualitative researchers "identify [these] emergent categories and theories from the data rather than imposing their prior categories and theories" (Ritchie & Lewis, 2003:4).

What this meant for my study was that when I was planning and conducting my research, I did not follow a rigid research design. Instead, my research plans often changed to allow for unexpected circumstances which often happen in the field (Bryman, 1984:78). I experienced this on several occasions where interviews were set and confirmed by both parties (researcher and participant) but the respondent cancelled appointments minutes before the session. On one occasion the participant postponed the interview as I was walking toward his office in the building but I managed to interview someone else from the Department of Health. It is under such conditions that the researcher needs to be flexible. In other words, instead of following "a linear research path" as is the case in quantitative research, I made use

of a “non linear and cyclical” research design (Neuman, 1997:331). It is on these basis that Neuman believes that:

[r]ather than moving in a straight line, a cyclical research path makes successive passes through steps, sometimes moving backward and sideways before moving on. It is more of a spiral, moving slowly upward but not directly. With each cycle or repetition, a researcher collects new data and gains new insights (1997:331).

This study is “inherently exploratory” because I embarked on a “voyage of exploration” (Bryman, 1984:84). In contrast, “the quantitative researcher embarks on a voyage of verification constantly testing concepts and hypotheses against data” (Bryman, 1984:84). This is the opposite of the traditional chronological model to which quantitative researchers subscribe. For them a research design is a series of stages or tasks in planning or conducting a study. It is for this reason that research design is often seen as a one-directional sequence of steps, from problem formulation to conclusions. According to Hammersley and Atkinson (1983:28):

whatever advantages this traditional chronological approach may have for quantitative research; it does not satisfactorily represent the logic and process of qualitative research, in which each component of the design may need to be reconsidered in response to new developments or changes in some other component.

Qualitative research is fundamentally interpretive. This means that the researcher relies heavily on an interpretation of the data. This includes “developing a description of an individual or setting, analysing data for themes or categories” (Creswell, 2003:182). I was very aware of the fact that, as a qualitative researcher, I need to be sensitive to my personal cultural background and how it might impact on the study. This reflection on my background shows that I was aware of, and indeed acknowledged, the fact that it is not possible to be completely objective. Our historical upbringing will always have an influence on how we perceive and interpret the world. The challenge for me was to reduce the impact of my own cultural influences as much as possible so that it did not impact on my data/findings. This recognition by the researcher represents honesty and openness to research, acknowledging that all inquiry is laden with values (Mertens, in Tashakkori and Teddlie, 2003:162).

A qualitative approach was adopted because it “directs attention to the differences and particularities in human affairs and prompts the social scientist to discover what people think, what happens and why” (Arksey & Knight, 1999:10). In conducting this study, I did not assume the role of an objective scientist, but rather I acted as an “instrument” in the research process (Babbie & Mouton, 2001:273). This means that, as a researcher, I could not have fulfilled the research objectives of this study without using a broad range of my “own experience, imagination, and intellect” (McCracken, 1988:18). In conducting this research, the fundamental task for me was to use my imagination to reconstruct “a version of the respondent’s view of the world by taking up the underlying assumptions and categories” (McCracken, 1988:20).

Finally, rather than seeking to “verify” or “falsify” theory and explain the causal relationship between social phenomena, as is the objective of quantitative research, in this project I used a qualitative approach because the aim was to understand and describe the meanings and interpretations of the PLWH and those involved in the MNGO and in the meanings they attach to aspects of everyday life. In using a qualitative approach I started from the specifics, and it is from the data that I gathered throughout my field work that I developed concepts and explanations to inform my understanding of the social world (Henwood & Pidgeon, 1993:15).

## **2.4. Methods of data collection**

### **2.4.1. Participant observation as a method of data collection**

My first contacts with the MNGO took place when I joined the community members and the MNGO in their social event (the December 2006 end-of-the-year party) and a number of their daily meetings to “record actions” and to interact with members on a social basis/relaxed environment (Ritchie, 2003:35). The use of participant observation in my study “not only [allowed the] phenomena to be studied as they arise [in the field], but also [offered me] the opportunity to gain additional insights through experiencing the phenomena for [myself]” (ibid.). Participant observation as a data collection tool is important to sociologists “and ethnographic research because it provides direct experiential and observational access to the insiders’ world of meaning” (Jorgenson, 1989:15). It is quite useful “when a study is concerned with

investigating a process involving several players" like those infected and affected by HIV/AIDS, those who are concerned with sensitising communities about the epidemic (such as the MNGO) and the Department of Health for whom it is one of their core functions to make sure that health facilities indeed reach communities (Ritchie, 2003:38).

#### **2.4.2. The use of in-depth interviews as a method of data collection**

In-depth interviews were used as the main data gathering tool. The defining feature of in-depth interviews "is their ability to provide an undiluted focus on the individual" (Ritchie, 2003:24). This method provided me with an opportunity to collect detailed data of people's personal perspectives for HIV/AIDS. It gave me an "in-depth understanding of the personal context within which the research phenomena are located" (Ritchie, 2003:24). This method is usually defined as a "face-to-face encounter between the researcher and informants directed toward understanding informants' perspectives on their lives, experience or situations as expressed in their own words" (Taylor & Bogdan, 1984:77). In-depth interviewing is the most widely used data gathering technique in qualitative studies. It is identified by Reid and Smith (1989:213) as being particularly useful in obtaining information on topics that are complex, highly sensitive and emotionally laden such as HIV/AIDS. This study falls into all of the above categories and hence I have chosen in-depth interviewing as the primary method of data collection for this study.

In-depth interviewing is mostly unstructured. The interview guide that I had prepared beforehand covered a list of general areas and contained themes such as the relationship between HIV/AIDS and poverty, and the relationship between the MNGO and the government departments in Lady Frere. A sample of this is attached as Appendix A. The advantage of in-depth interviewing is that the researcher decides how to phrase the questions and when to ask them in the interview situation (Taylor & Bogdan, 1984:92). Unstructured interviews allowed me to move with the flow of the dialogue, starting with the general themes of discussion directed at the interviewee's experience, feelings and beliefs, and the posing of further questions as these emerge (Huysamen, 1994:174).

The data I generated in the field provided useful insights in my understanding of how the participants of this study experience, attach meanings and respond to the daily challenges of HIV/AIDS. During this process the main challenge for me was to stay as objective as possible while making sure that I guided my participants to talk about relevant themes in my study. In-depth interviews aided me to “provide access to the meanings people attribute to their experiences and social worlds” (Miller & Glassner, 1997:100).

Most of the interviews were conducted in the Xhosa language – the indigenous language of both the respondents and the researcher. A tape recorder was used to capture the entire interview. All tapes were transcribed and translated and these texts formed the basis for data analysis.

#### **2.4.3. The use of focus-group discussions**

One of the problems which in-depth interviews in qualitative research often fail to address is the tendency by participants to give what they think are expected or required answers instead of an honest account of their own experiences of HIV/AIDS. To overcome this constraint, I made use of FGDs. FGDs were conducted to provide a platform for participants to share their experiences, beliefs, and reflect on other people’s opinions about issues surrounding HIV/AIDS (Newby et al., 2003:238).

After the interviews with individual members, it became clear that there were some contradictions to the stories that were told to me about how the MNGO cooperated with government representatives. Such issues were selected to be discussed in a focus-group discussion and it constituted a part of my data analysis. FGDs were useful to explore these issues further because “group interaction (has the potential to) produce data and insights that would be less accessible without interaction found in a group” (Morgan, 1997:2). During the session, as the facilitator, I followed a predetermined interview guide to direct a discussion amongst seven selected participants from all the stakeholders involved in HIV/AIDS in Lady Frere District.

The aim was to collect in-depth qualitative information about the group's perceptions, attitudes, and experiences on a defined topic or theme (Seale, 2004).

The defining feature of an FGD is that it "presents a more natural environment than that of the individual interview because participants are influencing and influenced by others – just as they are in real life" (Krueger & Casey, 2000:11). One of the benefits for using this method was that it provided a platform for my participants to exchange as well as challenge each other in a more naturalistic environment (Finch & Lewis, 2003:172). This approach "reflects the social constructions – normative influences, collective as well as individual self identity, shared meanings – that are an important part of the way in which we perceive, experience and understand the world around us" (Bloor et al., 2001 in Finch & Lewis, 2003:172). FGDs "are naturalistic [in nature] rather than natural events [which draw from surveys, questionnaires and experiments to understand and generalize about a phenomenon] and cannot and should not be left to chance and circumstances; their naturalism has to be carefully contrived by the researcher" (Bloor et al., 2001:57). "The practical strength of focus groups lies in the fact that they are comparatively easy to conduct" (Morgan, 1988:20). This method was very useful especially in terms of providing an opportunity for me to observe and assess how people think and feel about a topic, how their ideas are shaped, generated or moderated through conversation with others (Ritchie, 2003:37).

Nonetheless, in using FGDs as a data gathering tool, Jane and Lewis (2003) caution us that we should not confuse FGDs with group interviews which are essentially a "much larger category" (Wilson, 1997:210). It is against this background that Jane and Lewis (2003:171) assert that a focus group is not merely "a collection of individual interviews with comments directed solely through the researcher", but are instead better described as "group interviews" which "lack both depth of individual interviews and richness that comes with using the group process".

However, one should not be carried away to think or give the impression that FGDs are perfect or at least do not have their own limitations. Like any other data collection technique in the social sciences, FGDs have their limitations but what is important is how the researcher deals with or minimises those limitations. When conducting my FGDs, I was aware of the fact that in group discussions participants, especially when being observed, have a tendency to conform to what is said by others. In other words, because respondents know that they are being observed or recorded they can easily agree to what other speakers say in the discussion. Morgan (1997:16) argues that in FGDs the researcher has less control than in individual interviews. This freedom, as it were, is problematic because respondents are well known for being carried away from the real issue in situations where there is little control (Putcha & Potter, 2004:47). It was very difficult for me to organise a focus group discussion and it was difficult to get a representative sample. This is because all participants were not able to congregate in the same place before the start of the session, because most of my respondents were from different areas and working in different departments. In this study most of the participants were staying in different villages and it was difficult for some to be in town before 10:00am, which was a convenient time for some government employees. Consequently, I had to postpone the meeting for more than three weeks. Another limitation of FGDs is that more outspoken or powerful individuals can easily dominate the discussions, making it hard for those who are less assertive. Lastly, in taking up this task I was aware of the problem that FGDs can generate a lot of data which may be very difficult to analyse.

## **2.5. Other aspects involved in data gathering**

### **2.5.1. Primary sources**

The major role players in the eMkhaphusi village were interviewed as key informants. These included community leaders, traditional leaders, youth representatives, adults, community care givers, local government representatives, a local primary health care professional, and NGO representatives within the small town. Several interviews were held with PLWH. These interviews were supplemented by FGDs where the researcher played an active role to elicit information from the respondents. During this process the researcher observed and

participated in the activities of the MNGO. The main aim was to record actions of the participants and to capture “social meanings and ordinary activities ... in order to collect data in a systematic manner” (Brewer, 2004:103). Local level beneficiaries of the programmes offered by the MNGO and the Department of Health were contacted to find out the impact of such programmes on their lives.

### **2.5.2. Secondary sources**

Apart from the primary information, secondary information was collected from different sources. For this, office records of the MNGO, unpublished information, planning documents, and meeting records were collected. A critical part of this orientation and planning phase for the study was a review of the literature, focusing in particular on areas of HIV/AIDS and trying to understand the role of civil society organisations in this field. The literature entailed the scrutiny of a wide range of documents such as journal articles, books, consultants’ reports, research papers, NGO reports, government publications, and government policies which include the National AIDS Plan for South Africa 1994, the National Strategic Plan initiated by the Minister of Health, Dr Manto Tshabalala-Msimang, in July 1999, the Department of Health’s “White Paper for the Transformation of the Health System”, the 1997 Annual HIV/AIDS report, and academic dissertations. This process informed the basis of the study.

### **2.5.3. Constraints and problems encountered**

Among the constraints encountered during the preliminary visits was a lack of policy documents that deal specifically with HIV/AIDS issues in government departments (in particular the Department of Health and the Local Municipality). Some government officials were reluctant to participate in the study and there was clearly a fear to avoid being exposed by “outsiders”. This is often the reaction of officials where there is a lack of effectiveness and coordination. On the other hand, MNGO personnel were keen to participate in the study. This could be as a result of the fact that researchers are often seen as potential funders or at least as people who can link the organisation to sponsors. The major problem encountered was to organise a FGD.

It took more than three weeks to assemble everyone. The industrial action by Civil Servants over wage issues that took place in 2007 also played a role in delaying the FGD meeting because government officials could not be found in their offices.

#### **2.5.4. Familiarising myself with the focus of my research**

I conducted a scouting visit in April and in July 2006 to examine the range of responses to HIV/AIDS in the Lady Frere area. It became clear from the formal and informal discussions with the various stakeholders that the eMkhaphusi village (see the map for the location of the Lady Frere District on page 13 – the village is in this District) is playing an important role in promoting awareness, prevention, care and treatment of HIV/AIDS with the assistance of the MNGO and other support groups. It was during these visits that I got an opportunity to interact with the various stakeholders that are involved in the area of HIV/AIDS in the Lady Frere District. It became clear to me from these discussions that HIV/AIDS is a major challenge in these communities and PLWH are still stigmatised and insulted<sup>5</sup>, and at times they experience social exclusion.

I was invited to attend a meeting with all the stakeholders on 29<sup>th</sup> July 2006 that was held in the Lady Frere town. My role at this meeting was more of an observer but before the closure I was given a chance to introduce myself to these stakeholders. The meeting was attended by the representatives from the Department of Health, Lady Frere Municipality (HIV/AIDS unit), Glen Grey Hospital (HIV/AIDS unit), church members, PLWH, and support group members, and it was organised by the MNGO.

An attempt to get up-to-date primary documents from the key stakeholders (the Department of Health and the eMalahleni Municipality) was a difficult task. This was largely the case because in government departments in the Lady Frere District there were no HIV/AIDS policies in place during the time of my visit. However, this is not to suggest that there was nothing happening on the ground in as far as

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<sup>5</sup> Some respondents reported incidents where they were insulted by some community members as being *izifebe* (the plural use of the term referring to someone who sleeps around with every man asking for sexual intercourse), and being bad examples to the young children in the community. Some said this treatment by community members created a situation where people were afraid to disclose their status in order to get help.

awareness and other education programmes were concerned in the Lady Frere District. But most of what is done is coordinated by the Provincial Government. This is particularly the case with regard to condom distribution to the surrounding villages, education, prevention and awareness programmes. The only document available from the local municipality was a 2003 draft document which focused on employment rather than on a policy that clearly outlined how the local municipality planned to reach out to these communities. After three years this was still a draft and had not been implemented, and that showed a lack of will at local level. The reasons given for not having policies by the officials interviewed included the excuse that HIV/AIDS was a new area and the eMalahleni Municipality did not have at that stage expertise to write and monitor the implementation of this document.

On the part of the MNGO there seemed to be a lack of resources. From the time the organisation was founded in 2003 they never had an office. It was only on 25<sup>th</sup> July 2006 that they were given a two-room office by a local doctor in his surgery building to use for their activities. Before this they used a local Church to hold meetings. According to the group leader, in all these years the organisation had been operating with a very limited budget, relying mainly on the local businesses and membership contribution for food and transport.

During my scouting visit I observed different responses from different stakeholders. The attitude of some government officials was more negative towards me compared with those of the NGO personnel, support group members, community-based organisations and the community. I got the feeling that government officials were aware of their failure in terms of addressing HIV/AIDS and wanted to protect their reputations. It is important to note that although the eMalahleni Municipality and the Department of Health might be involved in one way or another in addressing HIV/AIDS in these communities the fact that there was no written, approved document in place raised questions about their effectiveness. Questions such as "What are you going to do with this information?", "Are you working for the

government?", "Why us in Lady Frere and not Queenstown?" were common from the government officials.

From these meetings it was clear that feelings of mistrust and hostility towards me and other outsiders were prevalent among government officials. One could argue that feelings of trust or willingness to cooperate among NGO personnel and community members stemmed from the perceptions of seeing researchers as people who can link them to an organisation that can provide financial support. It is against this background that one could argue that everyone coming to the government sector for research purposes will be screened before permission/acceptance is granted. Despite all the negative feelings about the aims of this research, and signs of rejection, I was accepted by the officials to conduct interviews.

#### **2.5.5. Community actors in Lady Frere**

Apart from the work done by the MNGO, very little was happening in the area. Few support groups were involved in some way with HIV/AIDS responses. For instance, there were women group organisations that were doing beadwork or gardening as their core function but also visiting HIV/AIDS wards in the Glen Grey Hospital, clinics, and in their communities to give prayers and talk to parents about the importance of being open to their children about sexual matters. These women organised themselves because of a growing number of children who had been thrown away by their parents when they told them that they were HIV-positive (mostly coming from Johannesburg and Cape Town). According to these women, they felt a need to challenge and change a cultural practice in these communities where most parents find it a taboo to talk about sexual matters with their own children. According to the spokesperson of the women's group:

*We believe that HIV/AIDS education has to start within the family environment before children get wrong information about relationships and sexual intercourse from their peers outside (Interview, 29 July 2006).*

Churches in these villages are an important centre in terms of bringing people together and leaders claim that they take this opportunity to talk about AIDS.

*What we have realised is that, people do not come in numbers to community meetings... so church services and funerals are the only platforms where you get them in large numbers. As much as we preach the word of God we also talk about AIDS because it is killing our youth (Church leader, 29 July 2006).*

### 2.5.6. Ethical considerations

When researching HIV/AIDS one is touching on sensitive and emotional issues that are intricately connected with individuals' private social lives. In particular, "the in-depth, unstructured nature of qualitative research and the fact that it raises issues that are not always anticipated mean that ethical considerations have a particular resonance in qualitative research studies" (Lewis, 2003:66). It is for these reasons I concur with Evans (1997:85) that

Asking questions about individuals' sexual behaviour, beliefs or preferences; use of intravenous drugs and all the other commonest ways of transmitting or contracting HIV/AIDS, requires treading on very personal grounds and involves a high risk of offending and alienating respondents.

But at the same time I was aware of the fact that avoiding the risk of digging deeper may affect the quality of the information I obtained during the data gathering process.

It is clear in the literature that scholars and practitioners alike differ quite widely on what is ethically accepted and what is not. For the purpose of this project:

What was crucial [for me] was to be aware of the ethical principles involved [when dealing with PLWH] and of the nature of the concerns about ethics in social research. [This is because] it is only if the researcher is aware of the issues involved that [he] can make informed decisions about the implications of certain choices (Bryman, 2001:476).

As social scientists that are concerned with knowledge creation in a democratic society<sup>6</sup>, ethics should form the basis of our discussions in an attempt to provide explanations and possible solutions to the social problems facing this nation.

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<sup>6</sup> We should not abuse our privilege to write about other people's experiences, especially with regard to sensitive topics such as HIV/AIDS, because the implications for the victims are severe but even worse for us when we breach the agreement. For instance, names should not be mentioned when writing up the findings.

Because of the sensitivity of the issues involved in the subject of HIV/AIDS, I ensured that the anonymity and confidentiality of all participants for this study were maintained at all times. This was based on the fact that whilst researchers have the right to collect data through, for instance, interviewing people, I realised fully that this should not be done at the expense of the interviewee's right to privacy, confidentiality and anonymity (Babbie & Mouton, 2001:527). This was achieved by informing the participants about the purpose of, and methods for data collection, and the intended and possible uses of the data. In conducting this research I realised that by nature, human beings – when they participate in a research project – tend to react differently. For example, some may be more relaxed or anxious to be interviewed, supply inaccurate information, deliberately misinforming the researcher (Mouton & Marais, 1990:76). To reduce the impact of these reactive phenomena I managed to build relationships of trust with the participants and this made them comfortable during the actual interviews.

Quite often it is taken for granted in social research that “Researchers who conduct fieldwork also place themselves at risk” (Lewis, 2003:70). This was particularly the case in this research because I was invading private space and in many ways touching on very personal and sensitive stories. To avoid complications and misunderstanding I met personally with all the participants of this study and it was only after I explained to them the aims of the project that they agreed to take part. This was done primarily to protect the identity of my participants and to make sure that they all knew the value their input would make towards achieving the aims and objectives of this study (Lewis, 2003:70).

Lee (1993:98) states that “privacy, confidentiality and a non-condemnatory attitude are important in providing a framework of trust” especially with government officials to overcome their fears about the intentions of the researcher. I attempted throughout the research to maintain such a framework. From their involvement it was clear that the respondents were able to confront, in a fundamental way, deep and personal issues (such as the disclosure of their HIV status to the group and to the

researcher), threatening and potentially painful experiences. I explained the topic before the interview took place. This was based on the belief that even though HIV/AIDS is a sensitive topic, once trust is established between two/more parties (interviewer and interviewee), consent becomes implicit (Lee, 1993:103). Focus group discussions were also conducted in Lady Frere.

## **2.6. Data analysis**

After collecting primary and secondary information, data were translated, transcribed and analysed. I realised that “The key to doing a good interpretive analysis is to stay close to the data (to visit the field of study as often as possible), to interpret it from a position of empathic understanding” (Terre Blanche et al., 2006:321). Interpretive analysis was used because it provided “a thorough description of the characteristics, processes, transactions, and contexts that constitute the phenomenon, as well as the account of the researcher’s role in constructing this description” (Terre Blanche et al., 2006:321). The adoption of a discourse analysis approach in this project helped me to “extract” myself from a lived culture and reflect on it (ibid.:330).

Data were analysed using two methods: identifying themes and coding the data. According to Kelly (1999:143) “coding means breaking up the data in analytical relevant ways. This entails making different sections of the data as being instances of, or relevant to, one or more of one’s themes”. I coded phrases, lines, sentences and paragraphs.

## **2.7. Conclusion**

This chapter described the methods used in gathering data for this project. The emphasis was placed on describing the advantages of adopting qualitative research methods. However, I acknowledged that it will be too simplistic for me to give the impression that qualitative methods are perfect. I made it clear in this chapter that, like all data-gathering tools in social science research, the methods I adopted have their own limitations. The challenge for me in this research therefore was to minimise

the impact of those limitations as much as possible. Both primary and secondary sources were used in collecting data for this project. Problems and constraints encountered in the field were also highlighted. The reasons as to why the MNGO and specific stakeholders were chosen were also discussed. This chapter also highlighted the reasons why the eMkhuphusi village was chosen and the preference for a case study method. Last but not least, the philosophical assumptions underlying qualitative research were discussed as a way of showing how individuals understand and interpret their social actions. This study sought to examine as to what extent the MNGO was really doing what they set out to do in their constitution. This was done by engaging members of the organisation and those they claim to be serving on the ground.

The following chapter seeks to develop a conceptual framework for this study which is based on the importance of social networks (social capital). I argue in the following chapter that a simple act of joining and being regularly involved in a community organisation such as the MNGO will have significant impact on individuals' health and well-being.

## CHAPTER THREE

### Conceptual framework: Social capital

#### 3.1. Orientation to the chapter

In the proceeding chapter, an overview of the research methodology for this thesis was given, as well as some justification as to why I adopted qualitative methods for this project. The previous chapter also highlighted the problems and constraints I encountered in the field. In this chapter I develop a conceptual framework for this research. The framework is based on the importance of social networks in the fight against HIV/AIDS in the Lady Frere District. The term "social capital" emphasises people's "participation in local community life – referring to their interactions with neighbours, as well as involvement in voluntary associations linked to leisure, hobbies or personal development" (Campbell & McLean, 2002:16). My literature assessment reveals that in recent years, the term "social capital has become one of the most popular exports from sociological theory into our everyday language" (Portes, 1998:2). It has evolved into something of a universal remedy, being treated as a cure for economic problems, political instability between and within communities/nations and now applied in the field of health. "Like most sociological concepts that have travelled a similar path, the original meaning of the term and its value are being put to severe tests by these increasingly diverse applications" (ibid.:2). It was this diverse use of the term that triggered my attention. The worrying part for me is when the term is adopted without any scepticism by new users, in particular by the public health community. In adopting this concept I became aware of the fact that it has its own negative dimensions.

I therefore use social capital as a conceptual tool in this study with a degree of uncertainty to make sense of the MNGO responses to HIV/AIDS in these communities. After a long interaction with the community members in the Lady Frere District it was evident to me that there is social disruption of family life due to HIV/AIDS, poor service delivery, poverty and economic underdevelopment. I propose in this chapter that the MNGO as an intermediary organisation that seeks to

connect communities with local government support services can play a significant role in promoting the formation of social capital. The chapter goes on to argue that there is a need to restore the notion of "*ubuntu*" (meaning humanity) which is fundamentally based on social capital to assist these communities to rebuild trust which is essential in people living with HIV/AIDS (PLWH). I suggest in the chapter that social capital as a conceptual tool can help to develop a sense of trust between the stakeholders which is the basis for any partnership. This approach can facilitate mutual understanding of the pain and suffering of being discriminated against, and of shared values and behaviours that bind these members together (Cohen & Prusak, 2001:4). Empirical evidence suggests that HIV/AIDS awareness and prevention strategies (which are the core functions of an active MNGO) aimed to reduce the spread of infections among young people "have had limited success in the face of profound structural factors that facilitate high rates of transmission within communities" (Campbell, 1997:28).

For a better understanding of the current debates within the social capital approach, it is important to briefly outline the historical conceptualisation of this term. This is important in any attempt seeking to demonstrate how the term has shifted from its original usage and meaning to its application in the field of health in recent years. The second part of this chapter is a contribution made by different scholars in defining social capital. It is based on these contributions that I develop a working definition for this research. The chapter goes on to look more closely at the theoretical connections between social capital and good health. This section is followed by a discussion that looks at the social capital assets available to PLWH. Finally, possible negative aspects or what other scholars refer to as the "dark side" of social capital and studies questioning its influence are presented (Putzel, 1997:941).

### **3.2. Historical foundations of social capital**

Initially, I could not agree more with Portes (1998:2) who argues that "Tracing the intellectual background of the concept into classical times would be tantamount to revisiting sociology's major nineteenth century sources". Besides, such an activity

will not reveal why social capital has become fashionable in recent years. Likewise, it is beyond the scope of this project to engage in such sociological material that will not give us the answers for its current application in the field of health. On the one hand there is some confusion about the history and meaning of the concept of social capital, and on the other hand the point of departure for many historians, researchers, scholars and interested professionals is that the term refers to specific issues, such as networks, norms, and trust. An historical assessment of this term shows that social capital is not a new concept.

In tracing the historical roots of the term, Qyren (2002:12) contends that it is “part of human nature to interact and participate in the lives of other people. For a long time (the term) has been part of social sciences, if not to say that the study of human interaction is the core of social sciences”. In addition, Portes maintains (1998:2):

That involvement and participation in groups can have positive consequences for the individual and the community is a staple notion, dating back to Durkheim’s emphasis on group life as an antidote for anomie and self destruction and to Marx’s distinction between an atomized class-in-itself and a mobilized and effective class-for-itself. In this sense, the term social capital simply recaptures an insight present since the very beginnings of the discipline.

What this means is that what is relatively new is the application of the term in other fields, especially in addressing problems created by HIV/AIDS in our communities.

Some contemporary users of social capital as a conceptual tool, such as Birdsall and Kelly (2005), honour the French Sociologist Pierre Bourdieu for being the founding father of the concept. Birdsall and Kelly (2005:13) also quote in their report, entitled “*Community responses to HIV/AIDS in South Africa: Findings from a multi-community survey*”, Coleman (1988 & 1990), Granovetter (1974) and Loury (1977) as among the first scholars to use the term. However, I concur with Fin (2007:2) that “James Farr is to be congratulated for teasing out John Dewey’s, previously overlooked, use of the term”. As much as Bourdieu’s contribution to the debate is acknowledged, one should accentuate that his first usage of the term was when he defined it as a

capital of social relationships which will provide, if necessary, useful supports: a capital of honourability and respectability which is often indispensable if one desires

to attract clients in socially important positions, and which may serve as currency, for instance in a political career (Bourdieu, 1977:503).

Fifteen years later he refined this position and stated that:

Social capital is the sum of resources, actual or virtual, that accrue to an individual or group by virtue of possessing a durable network of more or less institutionalised relationships of mutual acquaintance and recognition (Bourdieu & Wacquant, 1992:119).

This demonstrates therefore that Bourdieu cannot be regarded as the founding father of the concept social capital as is usually suggested by some scholars, and the following paragraphs serve as evidence to dishonour this claim. Because of this uncertainty, an attempt is made in the subsequent paragraphs to provide a systematic assessment of the roots of the term social capital.

My literature review shows that the notion of social capital first appeared in Lyda Judson Hanifan's discussions of rural school community centres (Hanifan, 1916; 1920). In this material he used the term to describe "those tangible substances (that) count for most in the daily lives of people" (1916:130). Hanifan was particularly concerned "with the cultivation of good will, fellowship, sympathy and social intercourse among those that make up a social unit" (ibid.).

I subscribe to the view that James Farr, in his article "*Social Capital: A Conceptual History*" (2004), offered a good and comprehensive attempt to trace the conceptual history of social capital. Unlike many contemporary users of the concept of social capital who trace the concept either from Woolcock or Putnam and Bourdieu (such as Birdsall & Kelly, 2005; Portes, 1998; Fin, 2001), Farr (2004:11) contends that the first person to use the term was Hanifan in 1916 when he wrote that:

In the use of the phrase *social capital* I make no reference to the usual acceptance of the term *capital*, except in a figurative sense. I do not refer to real estate, or to personal property or to cold cash, but rather to that in life which tends to make these tangible substances count for most in the daily lives of a people, namely, goodwill, fellowship, mutual sympathy and social intercourse among a group of individuals and families who make up a social unit, the rural community, whose logical centre is the school.

Before Putnam's observation that there was a growing lack of social capital in American civic participation, "it was Hanifan in 1916 who noticed that there was a

lack of such social capital in rural districts throughout the country" (cited in Farr, 2004:11). Among the first users of the term was John Dewey in 1909 in his address to the National Negro Conference when he argued that,

All points of skill are represented in every race, from the inferior individual to the superior individual, and a society that does not furnish the environment and education and the opportunity for all kinds which will bring out and make effective the superior ability whatever it is born, is not merely doing an injustice to that particular race and to those particular individuals, but it is doing an injustice to itself for it is depriving itself of just that much of social capital (cited in Farr, 2004:31).

It is not clear, however, "whether Hanifan borrowed the term from John Dewey in his early writings" but it is axiomatic that "neither Bourdieu nor Putnam featured in these early writings about social capital" (Farr, 2004:31). Again it was John Dewey who used the term in 1920 when he defined society as the "association; coming together (of people) in joint intercourse and action for the better realization of any form of experience which is augmented and confirmed by being shared" (Farr, 2004:14). Other notable contributions have come from Jane Jacobs' work (1961) in relation to urban life and neighbourliness, Pierre Bourdieu (1977; 1983) with regard to social theory, and James S. Coleman (1988) in his discussions of the social context of education. According to Farr (2004:7):

The previous uses of the term social capital turn out to be few and far between, and their users unknown to one another. Putnam credits Loury, Bourdieu, and Coleman, as well as the sociologist of urban decline life, John R. Seeley et al. (in 1956). He also identifies Lyda J. Hanifan, an obscure rural educator from West Virginia, as having invoked (in 1916) the first known use of the concept.

Ann Davies (2001:14) considers there to be two theoretical models underpinning social capital which embrace a neo-Marxist and a neo-Liberalist perspective. The former, she suggests, is typified by Bourdieu, and the latter by Putnam (ibid.). A neo-Marxist approach places emphasis on access to resources and issues of power in society. Baum (2000:409) suggests that:

Bourdieu emphasised the role played by different forms of capital in the reproduction of unequal power relations. The important theme that underlies these two theoretical perspectives involves questions about the distribution and maintenance of power in capitalist societies.

Bourdieu sees “social capital as one means by which people compete in class competition” (Baum, 2000:3). This means that as some classes have more economic capital so they also have more social capital. According to Baum (2000:3):

Bourdieu’s neo-Marxist interpretation of social capital is markedly different to that of Putnam, the North American sociologist whose pluralist account of social capital puts far more emphasis on trust, norms and networks and their capacity to contribute to economic and democratic development.

These different approaches clearly demonstrate the importance of theoretical position in the interpretation of the part social capital might play in the production, and most importantly the delivery, of health facilities to the communities. Bourdieu’s account plays a key part in shaping and perpetuating patterns of economic inequity and in reinforcing the material disadvantage suffered by many within advanced capitalist societies (Baum, 2000:4). According to the report on National Statistics (2001:6) of social capital conducted in the United Kingdom different understandings of the term social capital are exacerbated by the different words used by different scholars to refer to social capital. These words range from

social energy, community spirit, social bonds, civic virtue, community networks, social ozone, extended friendships, community life, social resources, informal and formal networks, good neighbourliness and social glue (2001:6).

The report argues that within each of these concepts there are different conceptualisations depending on the theoretical (such as being groomed from a neo-Marxist or neo-Liberal school of thought) background which contribute to this confusion (ibid.). Woolcock (2001:404) believes that the term social capital “risks trying to explain too much with too little (and) is being adopted indiscriminately, adapted uncritically, and applied imprecisely”. Putnam (2000:23) on the other hand has argued that the term has “forceful, even unquantifiable effects on many different aspects of our lives”.

### **3.3. Defining social capital**

In the literature many scholars and researchers have defined social capital and because of this mushrooming of definitions some believe that “the term has led to some justifiable confusion as to what exactly it means” (Onyx & Bullen, 2000:24).

Onyx and Bullen (2000:24) describe social capital as a “slippery concept with roots in several theoretical traditions”. Much of this definitional debate has focused on concerns about the use, context and impact of social networks.

### 3.3.1 Other commonly used definitions of social capital

Author(s)	Definition
Fukuyama (1997:378-9)	The existence of a certain set of informal rules or norms shared among members of a group that permits cooperation among them. The sharing of values and norms does not in itself produce social capital, because the norms may be the wrong ones ... The norms that produce social capital ... must substantively include virtues like truth telling, the meeting of obligations and reciprocity.
Narayan and Pritchett (1999:872)	The quantity and quality of associational life and the related social norms.
Ostrom (2000:176)	The shared knowledge, understandings, norms, rules and expectations about patterns of interactions that groups of individuals bring to a recurrent activity.
Woolcock (2001:13)	The norms and networks that facilitate collective action ... it is important that any definition of social capital focuses on its sources rather than consequences ... This approach eliminates an entity such as “trust” from the definition of social capital.
Lin (2001:24-5)	Resources embedded in social networks and accessed and used by actors for actions. Thus the concept has two important components: (1) it represents resources embedded in social relations rather than individuals, and (2) access and use of such resources reside with the actors.
Knack (2002:42)	I use the term government social capital to refer to institutions that influence people’s ability to cooperate for mutual benefit. The most commonly analysed of these institutions ... include the enforceability of contracts, the rule

	of law, and the extent of civil liberties permitted by the state ... Civil social capital encompasses common values, norms, informal networks, and associational memberships that affect the ability of individuals to work together to achieve common goals.
Sobel (2002:139)	Social capital describes circumstances in which individuals can use membership in groups and networks to secure benefits.
Bowles & Gintis (2002:2)	Trust, concern for one's associates, a willingness to live by the norms of one's community and to punish those who do not.
Durlauf & Fafchamps (2004:5)	(1) Social capital generates positive externalities for members of a group; (2) these externalities are achieved through shared trust, norms and values and their consequent effects on expectations and behaviour; (3) shared trust, norms and values arise from informal forms of organizations based on social networks and associations.

A closer look at these definitions indicates that an important element that runs through them is that of cooperative norms. In this thesis social capital is understood to be the norms that may include forming orderly queues at the local clinics or hospitals, and showing respect and value for poor people and those living with HIV/AIDS rather than discriminating against them. Networks and associational memberships also appear in several of these definitions. Associational memberships in this study include membership to a local organisation such as the MNGO, community choral societies, and church or religious groups for emotional support. The promotion of these networks is more beneficial and effective in community organisations because members know each other.

In this thesis social capital refers to the well known South African value of "*ubuntu*". "*Ubuntu*" involves the notion that a person is a person only through other people (which means in the Xhosa language *umntu ngumntu ngabantu*). *Ubuntu* reflects a concern about the well-being of others, and the realisation that one's own well-being will be harmed when the well-being of others is threatened. Social capital formation is directly associated with the kind of strategic action that seeks to revive the

traditional values of *ubuntu*, that is, values that in turn could be seen as foundational to meeting the social capital goals of social cohesion and inclusion (DSSPA<sup>7</sup>, 2005:5). The promotion of social capital as an important tool to address the prevailing problems facing the eMalahleni Municipality and the Department of Health would ensure that “the hitherto excluded communities obtain new-found access to opportunities, resources and information” (ibid.:12).

Another important aspect of social capital from these definitions is a useful distinction between the three components of the term: social networks – who knows who; social norms – the informal and formal rules that guide how network members behave in relation to each other; and sanctions – the processes that help to ensure that network members keep to the rules of the organisation. Furthermore, the local government’s understanding of social capital formation should be one that sees participation as encompassing government working together with different stakeholders within civil society to deliver services and ensure that the population’s well-being is met. Poor communities in the Lady Frere District suffer from poor health, sometimes due to high levels of unemployment in the area and unsafe drinking water. I am aware of the fact that strengthening social capital will not, in itself, directly lead to job creation. But I strongly believe that it will help to ensure that these communities, where there is a high level of substance abuse in young people (especially marijuana and alcohol) do not suffer all the different aspects of poverty to the same extent as is the case in its absence. The promotion of the notion of *ubuntu* will help re-strengthen an old practice among black people that “Your child is my child”.

In taking the risk of generalising, for the purpose of this study I will adopt a working definition of social capital as: trust, norms, and networks that enable social coordination and cooperation between different stakeholders and the achievement of shared interests, namely to fight the challenges posed by HIV/AIDS (Narayan, 1999:6; Putnam, 1993:167).

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<sup>7</sup> Department of Social Service and Poverty Alleviation.

High social capital presence can facilitate active connections among people infected and affected by HIV/AIDS because of information flow. The trust between individuals thus becomes trust even between strangers and trust of the whole community. Eventually, it becomes a shared set of values and expectations within the community as a whole. Without this interaction, on the other hand, trust decays. At a certain point, this decay (lack of trust) begins to manifest itself in serious social problems (Beem, 1999:20). However, the promotion of trust on its own does not guarantee that a community of many good but isolated individuals would be rich in social cohesion (Putnam, 2000:19). Such good individuals need to work together for the benefit of their community.

A comparison between Bourdieu and Putnam reveals contrasting ways of using the concept social capital. According to Mowbray (2004:7):

Rather than seeing social capital as an integrative or cohesive resource, Bourdieu employed the term to help explain the perpetuation of class and the differential distribution of power, privilege and economic domination.

Putnam's approach, on the other hand, with its emphasis on togetherness, "is more useful for those who prefer to downplay fundamental conflicts of interest in social institutions, localities or nations" (Siisiainen, 2000:23).

Social capital formation further entails the notion of trust as fundamental to PLWH before they can disclose their HIV status to their sexual partners/boyfriends, friends, or health professionals. As such the notion of trust captures the relationship that exists between communities but also between the government institutions and communities (DSSPA, 2005:3). To show how trust can mend broken hearts or bring back hope, a member of the MNGO said:

*After I was told by the doctor that I'm HIV-positive I told myself that I will not tell anyone, not even my mother or sister because I knew it will be a shock to them. But after hearing Masibambane members talking about themselves in our clinic and stressing the importance of sharing your feelings and pain, I asked myself how can I not trust my own mother... I had always shared my problems with her... they helped me to rebuild my trust in her (Interview, 23 April 2007).*

Another respondent commented that

*The reason why I joined Masibambane is because everyone here is either infected or affected directly by AIDS ... The reason why I was able to disclose my status is because I had trust to other members that they will not go around town talking about my HIV status because at that time it was difficult for me but now I don't care whatever people say about us (Interview, 21 April 2007).*

Civic participation and collaborative behaviour are built on trust (Gambetta, 1988; Fukuyama, 1995). For Giddens (1990:27) trust is involved in a fundamental way with modern institutions and in the lives of present-day individuals. It presupposes awareness of circumstances of risk and operates within and between all people in every social situation (Giddens, 1990:31).

This project deals largely with people's perceptions and experience of trust. I wanted to determine what forms of trust are most prevalent in the Lady Frere District and how these different forms of trust contribute to the formation of social capital in the area. Trust is based on the belief that:

by making connections with one another, and keeping (those relationships) going over time, people are able to work together to achieve things that they either could not achieve by themselves, or could only achieve with great difficulty (Field, 2003:1).

### **3.4. Other forms of capital**

In order to understand social capital in its totality it is necessary to discuss all its forms. The following section deals with social capital assets available to the poor, and shows how access to these assets can help PLWH cope with the stigma and social exclusion associated with their status.

#### **3.4.1. Physical capital**

Physical capital as an asset for the poor "includes land and material belongings" (Narayan et al., 1999:39). Access to land is a serious concern for people in need. My respondents in this study reported that since the formation of the MNGO they have been struggling to get a small piece of land so that they can cultivate and grow vegetables that are emphasised in government policies.

*Last year we were given a small garden but when we were kicked out of that office we lost that land ... We really need land so that we can grow vegetables and be able to feed ourselves because not everyone has the money to buy vegetables every day from the market (Interviews, 21 April 2007).*

The access to medication, condoms and information would enable the poor to meet everyday needs. Because the poor cannot afford to pay formal insurances to protect themselves in times of crises such as when a family member is sick or die, "reciprocal social relationships provide wells of financial, social, or political support that can be drawn from during times of need" (Narayan et al., 1999:44).

### **3.4.2. Human capital**

Human capital is considered "an attribute of individuals and comprises a stock of skills, qualifications and knowledge" (Social Capital Report, 2001:7). This is a form of capital created by changes in persons that bring about skills and competences that make them able to act in some productive ways (Coleman, 1988). However, this is an asset that can easily be exploited by members of the family in the following way: "If one decides to have few children in order to limit the drain on the family's resources, one (can) end up caring for children of relatives" (Narayan et al., 1999:45). This puts enormous pressure on the government grant as grandparents have to care for their grandchildren. Human capital is defined, fairly tightly, by the OECD<sup>8</sup> (1998:9) as "the knowledge, skills, competences and other attributes embodied in individuals that are relevant to economic activity". Some authors maintain that "loss of a productive adult whether due to disease, death, divorce, or neglect drastically (r)educes a household's capacity to overcome external shocks and is one of the main causes of destitution" (Narayan et al., 1999:42).

### **3.4.3. Cultural capital**

Gould (2001:78) considers cultural capital as a form of social capital. When a community comes together to share its culture (through celebrations, rites and intercultural dialogue) it is enhancing its relationships, partnerships and networks. Cultural capital could be viewed as something that an individual can accumulate

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<sup>8</sup> Organization for Economic Co-operation and Development.

over time through talent, skills, training and exposure to cultural activity (Social Capital Report, 2001:7). Often the concepts human and cultural capital are used interchangeably.

### 3.5. Why is social capital important in the age of HIV/AIDS?

For the purpose of my study, an important question to ask is: why should the communities of the Lady Frere District, who are greatly affected by HIV/AIDS, care about social capital? I believe that the enhancement of social capital has the potential to facilitate various kinds of beneficial outcomes for the community. At the community level, for instance, when community members come together to build a community playground for children or a day care centre to help orphans and vulnerable children, they are not only making a physical improvement in their village, but also developing the intangible bonds of social capital. Such facilities could be used to generate funds by holding music shows and it might be easier for business people to provide furniture. Furthermore, while such facilities might be exclusively intended to bring children together, they also provide a platform for parents to interact with one another while their children are playing on the equipment.

Because of the stigma attached to AIDS, respondents of this study reported that:

*Once people see you in the ARV clinic they stop being your friends...They will immediately spread rumours about you, saying things like we are not surprised that she is positive, she slept with every man available (Interview, 23 December 2006).*

A South African respondent quoted in Narayan et al. (1999:203) said the following under similar conditions:

A key problem for those with HIV/AIDS is shame, denial and social isolation, and losing access to the social networks they need in order to cope with the psychological and material consequences of illness. A major fear associated with HIV/AIDS is the fear of social isolation that would result for a household and individual if the knowledge of infection became public. This causes many to hide the fact of infection (while in the process infecting their partners), thereby hampering efforts to bring the issue into the open to further public education.

The question that seems to derive logically from here is: how can social capital contribute in a positive way to these communities? During my visits to Lady Frere, it became clear that there is a lack of cooperation between the key stakeholders dealing with the challenges caused by HIV/AIDS in the area. It is every department or community organisation for itself. None of these stakeholders is accountable and none of them report what they do to anyone else. Putnam (1993:164) believes that under these circumstances: "in the absence of credible commitments and mechanisms for their enforcement, each individual has an incentive to defect and to become a free-rider".

The existence of social capital in an area such as Lady Frere can be very important because it promotes mutual coordination and cooperation through trust and norms, and it facilitates networks among its members. "Social capital is productive, making possible the achievement of certain ends that would not be attainable in its absence" (Coleman, 1990:302). At the individual level, dense networks of social interactions have the potential to "instil in their members habits of cooperation and public-spiritedness, as well as the practical skills necessary to partake in public life" (Putnam, 2000:358). Social interactions help community members to learn to speak in public or write letters emphasising their demands to those in power. It also assists them to develop their skills to run meetings, organise and run projects and debate issues of public concern such as HIV/AIDS and poverty or their general concerns about the lack of service delivery.

### **3.6. Social capital: Applying the conceptual framework**

The interest in using social capital as a conceptual framework stems from the idea that "social ties and associated norms of reciprocity are potentially productive" (Healy, 2003:3). Robert Putnam (2000) in his famous book *"Bowling Alone: The collapse and revival of American community"* identified three main reasons to illustrate the importance of social capital. First, he believes that social capital allows people to resolve problems that affect them more easily. According to Putnam (2000:288): "People often might be better off if they cooperate with each individual doing their

part. But each individual benefits more by shirking their responsibility, hoping that others will do the work for them". Secondly, for him:

Social capital greases the wheels that allow communities to advance smoothly. Where people are trusting and trustworthy, and where they are subject to repeated interactions with fellow citizens, everyday business and social transactions are less costly (2000:289).

Furthermore, the way in which social capital

improves our lot is by widening our awareness of the many ways in which our fates are linked. People who have active and trusting connections to others – whether family members, friends, or fellow bowlers – develop or maintain character traits that are good for the rest of society (2000:289-90).

When people lack connection to others, they are unable to test the "veracity" of their own views, "whether in the give or take of casual conversation or in more formal deliberation" (Putnam, 2000:289). Without such an opportunity, people are more likely to be influenced by their worse desires. In view of this John Dewey (1927:151) maintained that "associated or joint activity is a condition of the creation of a community. But association itself is physical and organic, while community life is moral" that is sustained emotionally, intellectually, and consciously. James Campbell (1998:39) asserts that: "Education plays a major role in this regard by helping individuals to learn to live more cooperatively and to appreciate their role in the social process that allows them to work together to accomplish tasks that cannot be accomplished individually".

My study argues that people who are living with HIV/AIDS (PLWH) and who belong to a group such as an NGO are likely to have a longer life expectancy because of the support available to them, than those who live in isolation or without any psychological and emotional support during this difficult time in their lives. My study proposes that PLWH should join support groups so that they can get emotional and moral support to overcome the stigma attached to being infected. In this regard members interviewed for my study indicated that joining the organisation had positive results for them. For example, one informant explains:

*After I was told in hospital, after a long illness that I'm HIV-positive, I felt like my life has come to an end. I didn't tell anyone at home for a long time because I was scared to get a second punishment by being shouted at ... but after joining the support group and realising*

*that I was not the only one living with the AIDS, I gained confidence and I realised that I can live longer by taking advices from other members* (Interview, 22 December 2006. The informant knew her HIV status from 1996).

This shows the positive aspect of having people around you when you are infected or when a family member or partner is affected by AIDS.

Furthermore, the World Bank (1999:2) also brought together statistics to make the case for social capital. They argue for instance that there is evidence that schools become more effective when parents and local citizens are actively involved. This is lacking in many South African communities (World Bank, 1999:3). According to the World Bank (1999:3), teachers tend to be more committed, learners achieve higher test scores, and better use is made of school facilities in those communities where parents and citizens take an active interest in children's educational well-being.

Social capital is necessary because a "society that relies on generalised reciprocity is more efficient than a distrustful society" Putnam (2000:135). Other benefits include greater happiness, better health, higher income and levels of educational achievement and lower rates of child abuse and other crimes against individuals (ibid.). With regard to organisations, especially those concerned with health-related issues in our communities, the benefits include the fact that there tends to be better knowledge sharing, due to established trust relationships and free flow of information. In addition it can be expected that a higher level of trust and a cooperative spirit will prevail. This will be the case both within the organisation and between them and the people they serve (Cohen & Prusak, 2001:10).

### **3.7. Different forms of social capital**

A distinction is often made between different kinds of social capital since some forms could exert a beneficial influence on the community while others could have a rather negative/harmful one.

### **3.7.1. Inward-looking versus outward-looking social capital**

The first distinction differentiates between “inward-looking versus outward-looking social capital” (Putnam & Goss, 2002:11). While the inward-looking forms are usually organised along class, gender or ethnic lines and aim to promote the material, social, or political interests of their members, outward-looking groups are more inclusive and concerned with public goods provision (ibid.).

What this means for my study is that a community should not assume that associational activity which contributes to the creation of social capital would necessarily be inclusive or outward-looking. Close family ties where extended families play a critical role, mutual aid and voluntarism are often strong features of poor areas (Putnam & Goss, 2002:11). It is these qualities which may enable people to cope with poverty, with pain inflicted by stereotypes associated with HIV/AIDS in their communities, with unemployment and with wider processes of social exclusion. As Portes and Landolt (1996:20) point out: “There is considerable social capital in ghetto areas (and in villages), but the assets obtainable through it seldom allow participants to rise above their poverty”.

### **3.7.2. Social capital as bonding, bridging and linking agent**

Closely related to the inward-outward dichotomy, another dividing line runs between bridging versus bonding social capital. According to Healy (2003:7):

Bridging social capital connects different types of people and groups (e.g. ethnic, social, gender, political or regional) and can be particularly effective for people seeking social and economic gain beyond their immediate society for getting on in life. This type of social capital arises when associations and connections are made across social, geographical or strong identity lines.

A range of other benefits for communities that have a high bridging social capital include:

Besides helping communities (and individuals) to transcend narrow and exclusionary identities, cross-cutting ties can open up new opportunities for access to information, material resources (such as condom distribution) and opportunities to participate more fully in economic and political activities. Cross-cutting ties also have the potential to empower communities through the recognition of common interests with other communities and groups and common political mobilisation (Emmett & Butchart, 2000:316).

Narayan (1999:39) proposed a number of strategies in which bridging social capital can be promoted in communities. These include the free flow of information which could be used to educate community members more about how one contracts HIV/AIDS and how one can prolong his/her life after being diagnosed as HIV-positive. It can also be used to keep the government accountable to its citizens.

Finally, another dimension is linking social capital. According to Cote and Healy (2001:42) linking social capital refers to "relations between individuals and groups in different social strata in a hierarchy where power, social status and wealth are accessed by different groups". Woolcock (2001:13-14) further argues that linking social capital "reaches out to unlike people in dissimilar situations, such as those who are entirely outside the community, thus enabling members to leverage a far wider range of resources than are available within the community". Linking social capital is perceived as the ability to benefit from ties with those outside one's immediate group of contacts. The extension of the bonding/bridging typology to include linking social capital, providing the framework for consideration of the role of outside agencies in health, including local government, is useful in this study.

### **3.7.3. Horizontal versus vertical social capital**

Another important distinction is made in the literature on social capital between "horizontal" and "vertical" approaches to community mobilisation. According to Emmett and Butchart (2000:307) horizontal social capital

emphasises community members solving their own problems, (whereas) the vertical approach focuses on the linkages between community life and decisions made at higher levels of power (outside the community).

Based on these two approaches, John Dewey firmly believed in the strength of the horizontal approach to understanding social problems, including the value of seeing individuals as part of an "organic whole" (1927:150). In his analysis, he recognised the importance of collaboration in promoting public and civic interdependency in socially and economically healthy communities. He argued that the success of a community depends on the process of working together. Dewey observed that

We may be drawn together to solve our problems, but it is the togetherness, not the solution, that is the primary result. In our attempts to build and further democratic community, the process of shared activity and values held in common is what matters (Campbell, 1998:40-41).

This means that if a community fails to promote cooperative inquiries then apathy will follow with consequences detrimental to community development (Campbell, 1995:230). Dewey strongly believed that the poor and marginalised people should be included in community networks and decision-making processes. He saw this as an absolute necessity. John Stuhr (1998:95) paraphrases Dewey by observing that “An economy, a government, or a society, then, is not fully free unless it makes available to all its members the prerequisites of their growth – both their growth as individuals and the growth of the social groups through which they live”.

According to the study conducted by Emmett and Butchart in South Africa “both research and practice have focused on horizontal approaches to community-based development, with little attention devoted to vertical strategies” (2000:308). These authors put the blame for this bias on the fact that during apartheid the government was almost unreachable to the vast majority of the population.

Associations can be split into horizontal and vertical associations. Horizontal associations are those in which members relate to each other on an equal basis, for example a local soccer club, a music group, or a community support group. Vertical associations are those “characterized by hierarchical relationships and unequal power among members” (Grootaert, 1999:5). Associations can also be split into those which promote the interests of their members only, like a revolving credit scheme (stokvel) which has become popular among people in rural areas of South Africa. In this case members share resources, be it food, money or clothes, at the end of the year or give money to one individual at one occasion and to another the following month. The success of this form of helping each other depends entirely on trust as there are no legal and official contracts in most of these transactions. On the other hand associations exist which aim to promote the interests of members and non-members alike, such as the MNGO in Lady Frere.

### 3.8. Negative dimensions of social capital

Despite the seemingly beneficial aspects of social capital, some researchers outline its "dark side". It has been argued that social capital is not necessarily beneficial for the health of society by bringing communities and government together. It can have the opposite effect. Dense social networks of engagement and trust can be used by extreme minorities to cultivate and promote bad behaviours (Florida, 2002:269). Critics believe that the term has become the latest buzz word, meaning everything to everyone. It lacks empirical specificity, and it neglects considerations of power.

The term has aroused suspicion because of the huge range of social issues on which it has been used. The concept has tended to be exported wholesale from one context to another which ignores the cultural context of its conceptualisation for the vast majority of research studies (Social Capital Report, 2001:12).

Moreover, Davies (2001:8) suggests that the concept can be heavily criticised for being "gender blind and ethnocentric".

Morris Fiorina (1999:396) also emphasises the "dark side" of social capital. He argues that civic engagement may not necessarily be a good thing, especially since some groups might deploy their "unsocial social capital to the detriment of other groups or society as a whole" (1999:396). He proposes that those who take advantage of participatory opportunities are most often minorities holding extreme opinions. As a result, "a few 'true believers' (are) able to hijack the democratic process and impose unreasonable costs ... on the larger community" (Fiorina, 1999:402). This means, therefore, that high levels of social capital and civic engagement should only be expected to have beneficial outcomes "if those engaged are representative of the interests and values of the larger community" (Fiorina, 1999:403).

Putzel (1997:941) also criticises the theoretical foundation of Putnam's claim that higher levels of social capital are inherently beneficial. Since we cannot be sure which ideas and values are distributed through dense social networks, he argues that "there is a need to distinguish carefully between what might be seen as mechanics of trust (the operation of networks, norms) and the political content and ideas transmitted through such networks and embodied in such norms" (Putzel, 1997:941).

Another problem with the concept of social capital is that, given that institutions of civil society organisations and the government are closely intertwined, it is not easy to determine which way the influence runs. This is because on the one hand, an active civil society organisation such as the Treatment Action Campaign (TAC) has the means to develop effective checks and balances on the power of the government, thus making the government more accountable to its citizens by making sure that PLWH can access ARTs. On the other hand, governments create or destroy the political and social space where people can raise their concerns, which is necessary for the emergence of an active citizenry (Narayan, 1999:12). According to Portes and Landolt (1996:3) another downside of social capital is that in organisations

with strong social ties, newcomers often find themselves unable to compete, no matter how good their skills and qualifications. A particular poignant example is that of African American contractors attempting to carve a niche in the white and immigrant-dominated construction industry [in the USA]. As one such entrepreneur in New York City put it: I think that the reason I haven't taken the next step to having steady big contracts ... is because I'm not in the social circles where those kinds of deals are made ... I can't play golf or go on boats with people.

### **3.9. Conclusion**

It can be concluded therefore that the relatively simple act of joining and being regularly involved in community organisations has a very significant impact on individuals' health and well-being. Encouraging the development and growth of community organisations, such as the MNGO and other small support groups, can make a considerable contribution to the lives and experiences of PLWH. As Putzel (1997:61) has shown in his critique of Putnam's social capital approach, we cannot be sure that the ideas and values disseminated through dense social networks are socially beneficial and conducive to promote better health and cooperation between the community and government. This means therefore when encouraging social capital it has to be ensured that one does not exclusively focus on "bonding" but also on "bridging" social capital (Putnam & Goss, 2002). Especially since, as Levi (1996:51) emphasises: "Neighbourhoods are a source of trust and neighbourhoods are a source of distrust. They promote trust of those you know and distrust of those you do not".

## CHAPTER FOUR

### NGOs as active agents in the field of HIV/AIDS

#### 4.1. Opening remarks

In the preceding chapter I developed a conceptual framework for the thesis, and a theme that runs through that chapter is: “[if] people cannot trust each other or work together in the fight against HIV/AIDS, then improving the material conditions of life can be an uphill battle” (Evan, 1997:2). I proposed, therefore, that the simple act of joining hands and being regularly involved in a community organisation can have a significant impact on the health and well-being of individuals. Encouraging the development and growth of community organisations such as the Masibambane Non-governmental Organisation (MNGO) and other support groups in town can make a contribution to the lives and experiences of the people living with HIV/AIDS (PLWH) in the Lady Frere District.

Throughout contemporary history, the poor and marginalised people have relied on government social institutions to provide health facilities and to protect their rights. Although this is still the case today (with ‘democratic’ governments struggling to meet the needs of the poor), “in recent decades new social institutions emerged that provide the same function of control and ideological mystification – the self-help described NGOs” (Petras, 1997:10). In this chapter I evaluate the evolution of these organisations in general, but a specific emphasis is placed on South African NGOs as the latter are the focus of this thesis. To embark on this task I started from the premise that NGOs are a significant part of the civil society organisations and hence I begin my discussion by understanding different usages and applications of the phenomenon of civil society. I then proceed to argue that the rise of NGOs as a parallel sector of government is both “a reflection and a stimulus of a broader set of social, cultural, political, and economic changes” (Levi & Karim, 2001:55). Drawing from empirical evidence, this section illustrates the fact that over the years it has

become clear that conventional NGOs have failed<sup>9</sup> to meet the needs of the poor, and this failure has led in recent years to the formation of intermediary NGOs. The aim of these intermediary NGOs is to fill this void left by the public, private and now the traditional NGOs in serving the needs of the poor. These organisations act as intermediary agents that connect communities with the local government and non-governmental support services. It is against this main aim therefore that I examine the intermediary function of the MNGO in HIV/AIDS responses.

Furthermore, the chapter also examines the factors that have facilitated the mushrooming of HIV/AIDS NGOs. An attempt is made to understand the relationships between these NGOs and local as well as national governments in the South African context, both during apartheid and in the post-1994 period. I also evaluate the South African government responses to HIV/AIDS since the evolution of this epidemic. The last part of the chapter provides a critical analysis of the literature on NGOs. Based on my assessment it seems that intermediary NGOs, like the traditional NGOs and the private sector, will have little impact in terms of changing the situation/conditions of the poor and the marginalised people. This is because in practice, like the conventional NGOs, intermediary NGOs serve the interests of donors and national governments or those who give them financial support to continue existing. For me their dependence on government and donors that have close ties with national governments compromises their independence and ability to challenge local government.

#### **4.2. Understanding civil society organisations**

In the mainstream literature, civil society organisations (CSOs) are classified as those “groups, networks, and relationships that are not organized or managed by the state” (Narayan et al., 1999:129). According to Ndegwa (1996:17) a civil society organisation is “characterised by active, diverse, inclusive citizenship participation. Political organizations and for-profit businesses are usually not considered as part of civil society organizations”. One thing that emerges from the literature is that there is

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<sup>9</sup> Of course I am aware of the fact that not all NGOs have fallen behind their targets but in general, both internationally and locally, these organisations have been disappointing to say the least.

no single "conception about the class character of civil society because different scholars bring different analysis to serve a particular purpose. It is a concept that varies in its application according to the conditions that exist in particular contexts" (Mayekiso, 1992:35). From the Western perspective, for instance, Alexis de Tocqueville is understood to be one of the first political philosophers who discussed at great length the phenomenon of civil society. He referred to this phenomenon as "free associations that exist as intermediate institutions between citizens and the state, and in which citizens can realize their social freedom and equality" (Woldring, 1998:363). This also means that the intermediary organisations that I am evaluating in this project are not new as is usually implied in the literature. There is very little that differentiates these organisations from the traditional grass roots local NGOs.

In fact, as early as the "first decades of the 19<sup>th</sup> century de Tocqueville took the position that a differentiated civil society had come into existence in the United States and in Western Europe" (Nisbet, 1966:130). For him, "this process of differentiation was the result of private initiatives that would promote democratization and a revitalization of society" (Woldring, 1998:363). In his view

These processes would be threatened not so much by governmental centralization (which is necessary for each state) but rather by administrative centralization, which would restrict the self-regulation of free associations, thus frustrating the competences and responsibilities of citizens who participate in these associations (Woldring, 1998:363).

It is on these grounds that he argued that,

administrative centralization should be feared for the sake of protecting free associations. However, because free associations can cause social struggle, the government should also have the competence to limit self-regulation of free associations. Moreover, each government needs a social basis that gives support to its policy of intervention (Woldring, 1998:363-364).

In this country three positions have emerged with regard to the phenomenon of civil society: firstly, Blade Ndzimande and Mpume Sikhosana, in *African Communist* (no. 128, 1<sup>st</sup> Quarter 1992), "attack the idea of civil society as bourgeois, highlighting its capacity for driving progressive forces from liberation movements, thus threatening the drive towards socialism". The view these two authors are critiquing was first proposed by Mayekiso (1992:33) when he argued that:

It is clear in South Africa that the most developed organs of civil society serve the bourgeoisie: their chambers of business, their wealthy Johannesburg northern suburbs ratepayers associations, their parent-teacher associations, their sports clubs, and heritage foundations. For working-class people, on the other hand, the organs of civil society include civic associations, trade unions, the women's groups, youth groups, churches, burial societies, and other organisations, formal and informal, that represent the interests of the poor and working people.

The second view is the one held by Steven Friedman, in *Politikon* (December 1991), where he attacks the idea of civil society as neo-conservative, highlighting its threat to the ability of the liberal state to provide "representativeness, accountability and public contest to the vital areas of social life". Lastly, Mark Swilling, in *Work in Progress* (Vol 76, July/August 1991), defends a classless notion of civil society, and argues that it is the basis for an associational socialism. This also shows that the way we understand civil society in Africa is different from the conceptualisation of the term by the West. The significance of this debate was to highlight to the sector that as much as civil society organisations, especially NGOs, were playing a critical role in putting pressure on the apartheid government to review their oppressive laws. It was fundamental for the sector not expect friendly treatment when the ANC come to power. It was necessary for the sector to maintain its independence so that it can challenge public institutions when they fail to meet their mandate to the communities. The three schools of thought outlined above point to the fact that it is vital the civil society sector to maintain its independence at all time.

However, as much as there are differences on which organisations form civil society organisations, there is an acknowledgement that civil society organisations lack the coercive or regulatory power that the state possesses. They also lack the economic power of the market but provide the social power or influence of ordinary people (WHO, 2001:3). "Within this domain, individuals and groups organize themselves into civil society organizations (like the intermediary NGOs) to pursue their collective interests and engage in activities of public importance" (WHO, 2001:3). These organisations "draw from community, neighbourhood, social and other connections and provide institutional vehicles, beyond the ties of immediate family, to collectively relate to the state or market" (ibid.). However, in reality

there may be state or market links to CSOs that blur the borders between the non-state and the not-for-profit aspects of these organisations. State or the private for-profit sector may play a key role in the establishment of some CSOs or provide significant funding, calling into question their independence from the state and private sector (WHO, 2001:3).

Broadly, the major factors that influenced the growth and development of civil society organisations, in particular NGOs, are state incompetence, corruption and repression, which led to the perception that social development cannot be achieved through public sector policies only (Davids et al., 2005:67). Matanga (2000:2) concurs with this statement: "NGOs as part of CSOs emerged because of the generally decreased ability and capacity of the state to provide basic services to the citizens". Similarly, Edwards and Hulme (1996:4) argue: "NGOs have been increasingly seen as an alternative and sometimes preferred channel for service provision in deliberate substitution for the state when states prove to be ineffective".

But for the purpose of this thesis, the role and benefit of having civil society organisations (CSOs) is that they provide a platform for community members to interact and build trust with each other, which is an important element of social capital necessary for effective cooperation. Drawing from Putnam's analysis, the importance of having active CSOs is that they provide the networks of civic engagement within which reciprocity is learned and patterns of collective action are facilitated (Knack, 2002:42). These also facilitate the promotion of horizontal networks proposed in the previous chapter.

#### **4.3. The characteristics of development NGOs**

The general characteristics of NGOs include the following: "NGOs are institutionally independent of government (at least on paper). They are privately set up and are normally under the control of an independent board of directors or trustees" (Davids et al., 2005:69). Their legal status is based on freedom of association (Fowler, 1988:5). Theoretically, these organisations are not profit driven. It is assumed that any income generated during the course of their activities is ploughed back into the organisation. In other words, "they might engage in revenue generating activities, but that must be used solely to fulfil the mission of the organisation" (Gariyo, 1998:138).

Furthermore, Salamon and Anheier (1996:3-4) describe these organisations as having “institutional reality and internal organisational structure”. According to these authors, NGOs are not primarily guided by commercial goals and considerations. These organisations are in a position to control their own activities through internal governance procedures, and enjoy a meaningful degree of autonomy; and these organisations embody the principle of voluntary participation (*ibid.*).

Southern NGOs differ from their northern counterparts in their approach and orientation. They differ in “size and location of operation, physical, financial, and technical resources they have, in the scale of their interventions, in the degree of support they receive from national governments and in the socio-political context in which they operate” (Edwards & Hulme, 1996:33). “They range from small localized NGOs working in a handful of villages in a single locality, to large NGOs working at a regional or national level, for the most part with funds from external sources” (*ibid.*). Furthermore, some NGOs work with groups which range from informal CBOs to formal membership bodies. According to Fowler (1988:3-5): “They are bound together by voluntary contributions of time and resources and function for mutual benefit. These traits distinguish them from NGOs which act as service providers or facilitators.”

#### **4.4. Intermediary organisations**

In recent years, non-governmental organisations have become increasingly visible and active in various areas of social life, including poverty alleviation, education, and quite recently in bringing light to the most remote communities about HIV/AIDS. As Edwards and Hulme (1996:962) reported, there was a “[r]apid growth in NGO numbers ... accompanied in some countries ... by a trend toward expansion in the size of individual NGOs and NGO programs”. Generally, NGOs established their presence as civil society actors. However, these organisations failed to address the needs of the poor. An important reason for this failure has been “their inability to bring sustainable impact ... to make the right linkages between their work at the

grassroots level and the larger socio-political systems and institutional structures in which they are embedded" (Sanyal, 2006:2).

This has prompted a new type of NGO that seeks to fill this gap between local issues and national institutions, and the ones that are well established to link the grass roots work to international institutions (Sanyal, 2006:3). These organisations have been named differently by different scholars. For example, some refer to them as "intermediary organizations" (Carroll, 1992), others label them as "bridging organizations" (Brown, 1991), and some perceive them as "support organizations" (Brown & Kalegaonkar, 2002). The defining features of the intermediary NGOs that I am evaluating in this project that differentiate them from the conventional NGOs are:

First, they are located at the center of several constituencies – local groups and national bodies. Second, their activities include innovative programs like organizational capacity building, training and staff development, advocacy, collection and dissemination of information, networking, all of which are not considered to be traditional NGO activities (Sanyal, 2006:3).

These features enable these organisations to establish the "bridging ties" between the community groups and organisations and the institutional structures at the national level. Hence when compared with the conventional service-providing NGOs, intermediary organisations "have a greater potential for making sustainable and large scale impacts" (ibid.). In as far as their political orientation is concerned; these organisations "may be largely apolitical adopting political stands on an issue basis while lobbying governments and international organizations" (ibid.). These organisations often become suppliers of information and active participants in various social movements (Keck & Sikkink, 1998:14). It is on these bases therefore that these organisations are perceived as "local actors depending on the nature of their issue involvement at a particular time. The unconventional nature of their functions and their structural location makes the issue of governance a problematic one for such organizations" (Sanyal, 2006:3).

Intermediary organisations perform the following functions: a) give support to grassroots organisations – capacity-building inputs to strengthen local organisations;

b) provide educational support – working with local governments and foreign donor agencies in creating an enabling environment where the voices of the poor are supposedly taken into account; and c) give sectoral support – enabling partnerships across different sectors of civil society (Carroll, 1992:2-3).

However, several limitations have also been identified which could impact on the performance of intermediary organisations. For instance, some have “limited financial and management expertise and institutional capacity. Others work in isolation, communicating or coordinating little with other organizations. Many may be confined to small-scale interventions” (World Bank, nd:2). These organisations may also not fully understand the broader social and economic context in which they are working. This means not all kinds of activities, therefore, are suited to the operational systems of intermediary NGOs, nor do they always reach the poorest of the poor (ibid.). Most of these limitations apply to the MNGO. The organisation is working in isolation from other civil society organisations that are active in Queenstown, with the exception of the TAC. There is lack of an ongoing interaction with other community support groups. The organisation is run by volunteers with very few management skills, if any.

“Intermediary NGOs have been provocatively labelled as ‘problematic organizations’ in that they must live and work in situations of necessary ambiguity” (Edwards & Hulme, 1996:260). “As a specific kind of social form with particular organizational histories and trajectories, they occupy an ambiguous – and constantly negotiated and reconfigured – social space and are structurally located in a complicated ‘web’ of social relations as part victim and part maker” (Helliker, 2006:8). Often these organisations find themselves caught between the needs of their clients (often the poor) and those of their funders.

In this thesis local intermediary organisations such as the MNGO are understood to be effective and capable in connecting and delivering a range of supportive services to the communities they serve. In this project their role is understood as to link or

connect communities with the local government initiatives. Such an organisation engages in one or more of the following tasks: "Bring together diverse constituencies to increase public involvement (in local projects), design new initiatives, strengthen local groups, and achieve tangible results" (Blank et al., nd:1). As agents working for the communities, these organisations "broker and leverage diverse public and private resources" (ibid.). This involves increasing the efficiency and impact of service providers and attracting resources that individual organisations often cannot secure on their own. Local intermediary organisations educate and bring light to the communities about issues that directly affect those communities. They modify national projects to fit local conditions. Furthermore, to a certain extent they challenge specific policies, such as the provision of ARVs, and promote more effective services for orphans and families affected by the epidemic (Black et al., nd:2). Intermediary NGOs

encourage participation of 'the people' in their own development, are more accountable to 'the people' and act as 'agents of democratization', while on the local level they stimulate the emergence of civic groups and democratic forms of decision making (Nauta, 2004:47).

In the social services arena, intermediary organisations are like the "brokers, conveners, and standard-setters that facilitate decentralized economic activity in the corporate world" (Carroll, 1992:1). Their presence is becoming critical for nurturing the learning, partnership development, and collaboration that community groups need to succeed (Carroll, 1992:1-2). According to (Helliker, 2006:8):

Intermediary NGOs are deeply embedded in contradictory processes of globalization and are implicated in them. But whether in practice they act as 'intermediaries' (rather than say as 'agents', 'representatives' or even 'instruments' of others) is a contingent question requiring thorough historical investigation.

#### **4.5. The evolution of developmental NGOs**

The literature on NGOs is very diverse, and is traditionally drawn from the fields of political science, sociology, public administration, anthropology, social work and adult education (Walters, 1993:1). In recent years the debate within this literature has focused on developmental issues within these diverse fields. My main aim in this section is to provide an evaluation of the historical foundations of non-governmental

organisations. I will do this by tracing the historical roots of this sector and outline the factors that gave rise to this evolution. Gerald Clarke, in his book *The politics of NGOs in South-East Asia: Participation and Protest in the Philippines* (1998), has outlined five main reasons for the proliferation of the NGOs concerned with development in the 1980s. These include:

- 1) The expansion of NGOs from the West into developing countries, either directly or as funders for local NGOs;
- 2) the increasing use by governments in developed countries of NGOs in a neo-liberal climate where the role of the state in providing services came under attack;
- 3) the fact that governments in developing countries increasingly recognised the beneficial role of NGOs in providing cheap services;
- 4) the fragmentation of left wing, class-based movements;
- and 5) the failure in developing countries of political parties and trade unions to articulate a wide range of problems facing the society (Clarke, 1998:7).

In some instances, NGOs have increased because of the strong state "repression against the left, such as in Thailand and Indonesia, or where bureaucratisation of left wing parties such as in India has prevented socialists from becoming representatives of the oppressed in society" (Ungpakorn, 2004:1). However, not everyone agrees with these historical roots of this sector.

Some maintain that the origins of the term non-governmental organisations could be traced back to the "formation of the United Nations in 1949. At that time NGOs were imagined as agencies that would remain at a distance from governments, acting as their conscience and offering a moral critique to states" (Levi & Karim, 2001:53). The World Bank's first formal interaction with NGOs was in the 1970s, focusing mainly on environmental issues. In the early 1980s, a global mechanism for policy dialogue between NGOs and the WB was established (World Bank, 2001:1).

The NGO-World Bank Committee enabled annual discussions on poverty reduction, participation, and other issues of mutual importance to the civil society and the WB. This dialogue was decentralized in 1995 and regional and even national-level NGO-WB committees were established to consolidate and expand dialogue on WB policies, programs, and loans. Since then, interactions have steadily increased and expanded through ongoing mechanisms for dialogue, new participation policies, and greater involvement of Civil Society Organizations (CSOs) in Bank-financed projects (World Bank, 2001:1).

On the other hand, some believe that NGOs evolved "from efforts to reconstruct war-ravaged Europe, NGOs such as the Co-operative for American Relief

Everywhere (CARE) and Oxford Committee for Famine Relief (OXFAM) came into existence serving as relief and emergency agencies" (Matanga, 2000:31-32). According to the Yearbook of International Organizations, by 2001 there were over 28,000 international NGOs, most of which had been created in the past two or three decades. "In the global South, the trend is even more recent: for instance, in Kenya alone some 240 new NGOs are registered every year" (The Economist, 2000:29). "In Bangladesh, the number of NGOs directly receiving foreign funds went from 382 in 1990 to 1245 in 1998" (Levi & Karim, 2001:54).

The term non-governmental organisation is used within the literature to refer to what is called non-profit organisations. In other words, the term refers to non-profit-making non-governmental organisations that are involved in development work in the so called Third World Countries (Sanyal, 2006:17). The term is generally used to refer to the following three kinds of organisations:

- a) international NGOs like Oxfam and Save the Children, b) intermediary NGOs in the South that support grassroots organizations with technical and financial help and engage in advocacy, and c) local community-based organizations that are engaged in service provision at the grassroots level (Sanyal, 2006:17).

This shows that different people use the term for different purposes. The point of agreement though amongst all the users of the term is that these organisations are independent from government (at least theoretically). According to Stromquist (1996:223-225) NGOs include:

- 1) grassroots operations intricately linked to social movements aimed at challenging and transforming unequal social structures; 2) non-profit businesses run by professionals that provide work and income opportunities for the disadvantaged in an effort to incorporate them in political economic arrangements and 3) some NGOs are locally-based institutions that operate on a shoe-string budget derived from the resources of those involved, while others are international entities with sizable budgets built from grants and contracts from international organisations (e.g. development banks, UN agencies, and foundations) as well as national governments (foreign as well as domestic to the locale of any particular project being undertaken).

In Africa, the first NGOs emerged in the latter years of colonial rule as ethnic welfare associations (Bratton, 1988:570). Some of these NGOs were started by missionaries who came to Africa mainly to spread the word of God. "In the rest of Africa NGOs were more often operating within a protocol negotiated with the government,

focusing on basic needs in communities, and functioned with little overt political activity" (Allwood, 1992:54). During this period "these organisations played an explicitly political role in challenging the authority of the colonial regime" (Bratton, 1988:570). The NGO-government relationship in Africa has always been characterised by conflict (Ndegwa, 1996:21; Edwards & Hulme, 1997:16; Cleobury, 2000:97). This is because:

Most African governments [in general] remained suspicious of any independent initiative which attempts to mobilize and provide services to disadvantaged communities without the direct involvement of the state. Because increasing NGO involvement in development has been conceived as a challenge to state hegemony and a response to state failures, this has intensified the suspicion which exists between the state and NGOs (Gariyo, 1998:35-36).

Likewise, in South Africa, NGOs not only played an active role in collaboration with the liberation movements in the eventual demise of the apartheid government, but also contributed in various ways to filling the void left by the apartheid government to meet the development needs of the marginalised and dispossessed sector of the African population. In this country

there has been a major focus on changing the political and economic structure through aid. A major emphasis has been on the politicisation and conscientisation of people groups and an *a priori* assumption was made that, unless the aid and consequent activities were made the NGO would be suspected of enhancing the cause of oppression (Allwood, 1992:54).

Allwood (ibid.) further states that during this period, NGOs were primarily concerned with

motivating and organising the communities towards appropriate mass action, which could pressurise local authorities to supply welfare requirements; that it was a fundamental human right that the state should provide for its poor and that the role of the NGO was to assist the poor in their struggle for their rights.

However, as much as these NGOs were active (operating mostly underground), the government of the time made several attempts to suppress the NGO sector in the country by passing a number of repressive laws. These include (Reid in Kihato, 2001:6):

- a. The Affected Organisations Act (No. 31 of 1974). The main aim of this act was to prevent any organisation involved in anti-apartheid activities from receiving funds from outside South Africa.

- b. The Disclosure of Foreign Funding Act (No. 26 of 1989). The idea behind this act was to force all civil society organisations, especially those who fought against apartheid, to report all funds received to government.
- c. The Fund-raising Act (No. 107 of 1978) (Davids et al., 2005:72). This prevented organisations from receiving funds from the public, both within and outside South Africa, unless they had a fund-raising number obtained from the government.

Basically, these laws gave the government the power to control the NGO sector in the country and to decide which organisations it would allow to exist within the legal framework. The idea was to restrict the operations of anti-apartheid organisations. It has never been easy for NGOs to operate in South Africa, and this also explains the tensions that existed between the government and the NGO sector in general. It might sound peculiar that there are still tensions between some NGOs and the current government, whereas they worked together during the struggle. In working together with the liberation movements the assumption by the NGO sector was that the democratic government would be more sympathetic to them. The NGOs had to operate undercover or have a secret agenda in order to be allowed to function. Swanepoel (1992:15) believes that the emergence of NGOs in general has taken place around two levels: firstly, on an international and national level; and secondly, at the so-called grassroots level. From his (1992:15) analysis, it would seem that most of the growth of the NGOs in South Africa has occurred around the second level of development.

In 1990, some of the oppressive regulations were no longer strictly applied. During this period the apartheid regime initiated a number of dramatic reforms – marked by the unbanning of the major liberation movements and the release of their political leaders (Pieterse, 1997:158). Pieterse states that “in this period, NGOs were starkly confronted by the unusual nature of their identity and roles: being over-politicised, and concentrating primarily on conscientisation and mobilisation strategies as a function of the anti-apartheid struggle” (ibid.). But most importantly for the analysis during this period, the “ANC managed to build a powerful hegemony within the NGO sector which worked on the assumption that it would come to power, and that

it was in the interest of the NGOs to align themselves to its position" (Pieterse, 1997:159). During this period

greater funding was being made available by international organizations, foreign governments, and philanthropic foundations, (as a result) the South African NGO sector experienced phenomenal expansion. Moreover, this expansion continued into the 1990s in the context of the replacement of apartheid with democracy" (Habib & Taylor, 1999:73).

However, as soon as the ANC came to power their relationship with some civil society organisations became characterised by feelings of mistrust and hostility. This is particularly true of the NGOs concerned with HIV/AIDS, such as the Treatment Action Campaign (TAC). Mayekiso (1992:38) seems to have anticipated what NGOs experienced after 1994 when he gave a warning that the examples of Africa and elsewhere tell us that simply because "nationalist organisations like the ANC are apparently progressive today, does not mean they will remain so. The fact that there are, within the ANC, numerous class forces is a reason in itself for strengthening independent organs of civil society". But the problem is that the NGO sector was too loyal to the ANC to foresee this behaviour. Recently, President Mbeki was reported to have questioned whether South African NGOs are being manipulated by foreign donors, and also the extent to which the country's civil society is independent (Smith et al., 2005:1). Smith et al. (ibid.) believe that Mbeki's views serve to reiterate the government's ambivalent line on NGOs, particularly on matters related to contested development strategy and the oversight role of NGOs (ibid.). One should emphasise, though, that the roots of government distrust of NGOs predate the Mbeki era. In a speech to the ANC's 50<sup>th</sup> National Conference in December 1997,

Nelson Mandela, usually renowned for supporting a strong independent civil society, made a scathing attack in which he accused elements within the NGO sector of working with foreign donors to undermine the government and its development programme, and of lacking a popular constituency or membership base among the population (Smith et al., 2005:1).

If one can draw from the experience of civil society organisations in Zimbabwe, it becomes clear that "After Mugabe came to power, (through) a supposedly Marxist-Leninist ticket", within no time NGOs and "trade unions were systematically smashed" (Mayekiso, 1992:38).

Some perceive NGO involvement in “social, political and economic development to be a dim ray of hope for community-based involvement of the people in the development processes” (Korten, 1990:18). It is, however, universally assumed in the literature on NGOs that all NGO activity is beneficial to the community. According to Erasmus (1992:84-85), though, many questions remain unanswered:

What are the different discernible types of NGOs and which problems are best addressed by which NGO?; (ii) To whom are NGOs accountable? (very important question indeed, especially when considering the fact that NGOs are funded by both national and foreign donors and claiming to be representing the voices of the poor and marginalised locally); and (iii) Whose interests are addressed first and foremost in the daily NGO activity?

Indeed, these are key questions relevant to any project in the quest for understanding the operations of NGOs, and hence it is fundamental for any ethnographic study to tease out what is actually happening on the ground. This can only be done in a very systematic manner by getting involved and participating in the daily activities of the NGO under study. An important point in this discussion is the observation made by Cernea (1988:10): “NGOs did not start out as development agencies, but had rather certain other goals and functions ranging from welfare work to political aspirations”. Most of these NGOs, I would argue, changed their focus to developmental issues after money was made available in these areas and for them it was a means to survive (so that directors can pay themselves and give stipends to their regular volunteers).

As much as most scholars perceive the rapid proliferation of NGOs as a result of the social, economic and political changes, I concur with the sceptical thinkers who linked the mushrooming of NGOs, both internationally and locally, to the increase in grant aid made available to private organisations (Levi & Karim, 2001:54). Edwards and Hulme (1995:4) seem to share the same view when arguing that:

the very infusion of capital into the NGO sector today must be understood as a deliberate attempt to undermine class struggles (or solidarities) by privileging alternative forms of identity such as gender and indigeneity and that it effectively produces a new form of imperialism by circumventing, and thus undermining the authority of the state.

Furthermore, the sceptics maintain that these shifts cannot be

disassociated from the post-Cold War 'New Policy Agenda' [one can also add the controversial Structural Adjustment Programmes and GEAR<sup>10</sup> policy in South Africa to the list] of market reforms and liberal democracy initiatives pursued by the IMF, World Bank, UN, and Western governments through their aid agencies in developing countries (Edwards & Hulme, 1995:4).

Development economists and political scientists praise NGOs for their "efficacy in poverty alleviation programmes and their role in facilitating democratic governance, modernization, and civil society" (Levi & Karim, 2001:54). This description of NGOs in a positive way has prompted Edwards and Hulme (1996:3) to compare them with a universal remedy for development, a "magic bullet" that "can be fired in any direction and will still find its target". Yet the experiences of these organisations do not seem to support what these authors perceive to be the reality, rather they show that:

in many post-colonial nations, foreign-funded NGOs provide an array of services in agriculture, education, rural road construction, forest management, credit voter literacy, healthcare, and monitoring of human rights that the state is either unwilling or unable to provide for the majority of its citizens, all in the margins<sup>11</sup> (Levi & Karim, 2001:53).

With regard to the South African context, with the demise of apartheid and drying up of funds that are channelled directly to NGOs, South African NGOs had to redefine their existence. In addition to their original and immediate concerns (motivating and organising the masses to challenge the apartheid regime) they have over the past few years extended their activities into numerous areas of social advocacy, mobilisation and service delivery, and most recently and quite dramatically in the area of HIV/AIDS (Ndegwa, 1996:17). This raises questions about the competencies of the volunteers working for these organisations and, most importantly, the level of training available to them in dealing with a fairly sensitive area in South Africa at the moment. It is against this dramatic increase therefore that I now evaluate the proliferation of HIV/AIDS NGOs with a specific focus on South Africa.

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<sup>10</sup> Although it was claimed to be a home grown macro-economic policy, GEAR was fundamentally based on the principles of Structural Adjustment Programmes imposed on African states by the World Bank and the IMF.

<sup>11</sup> Serving small portions of the poor and making a huge noise about that in their reports and very little mention of the failures of some of the NGO-led projects.

#### 4.6. Mushrooming of HIV/AIDS NGOs

From the beginning of the HIV/AIDS epidemic, local NGOs and CBOs have been active in promoting prevention, care and treatment (Rau, 2006:285). The main reason for this had been that

During the first decade of the epidemic, and in many countries well into the second decade, national leadership was mute, sometimes dismissive of the importance of HIV/AIDS, and reluctant to take effective action against it. Policies representing national, business and social institutional responses to the epidemic were largely lacking (Rau, 2006:286).

South Africa is no exception to this failure to be proactive at a critical stage of the evolution of the HIV/AIDS epidemic. The country has had an unstable past and some of its history may go a long way towards explaining why South Africa has responded the way it has. The first incidents of AIDS in this country were identified in 1982. By that time the HI virus was perceived mainly as a disease of white homosexual men (Weinel, 2005:1). However, at the end of the 1980s it became clear that the epidemic was not restricted to a small, white, gay, minority group of men, but that everyone was at risk. In the late 1980s the majority of people living with HIV/AIDS were no longer white, but black (Weinel, 2005:2).

The fact that the previous apartheid government did not take AIDS seriously when the disease was first diagnosed among white gay men is an indication that their passiveness towards this epidemic had nothing to do with race (black or white) but “this shows ignorance of conservative politicians who refuse to discuss such issues as sexuality and sexually transmitted infections” (Butler, 2005:592).

While the national government(s) as well as the international agencies were very slow in responding to the epidemic,

NGOs were aware of the importance of comprehensive responses ... At least three years before USAID began to provide condoms, NGOs on the ground had been calling for the inclusion of condoms to supplement information, education and communication (IEC) messages on prevention (Rau, 2006:288).

When justifying their ignoring the work done by NGOs, national governments often criticised NGO approaches by claiming that their responses are not sustainable. The

problem is that these "...comments tend to assess local approaches in isolation from wider factors, such as the absence of supportive government policies<sup>12</sup> to prevent HIV/AIDS and protect affected individuals and households" (Rau, 2006:288). This is not to suggest that local NGOs have all the answers to HIV/AIDS, but there is no denying that in some areas such as in the Lady Frere District they are playing a significant role in educating and bringing light to the communities about AIDS. Even though this does not seem to be appreciated by the local Department of Health<sup>13</sup> representatives, as there is virtually no training given to these individuals. According to the MNGO representatives their visibility is needed during AIDS days and at similar functions. As one member of the MNGO put it:

*The department does not care about us; all they need are just toys that they can take to show off when they decide to visit a particular village. We are fed up of that thing now ... it is not a cool thing to be positive. If they don't cooperate now we will work with those who appreciate what we are doing like the TAC and the Department of Social Development (Interview, 23 April 2007).*

In fact, government officials appeared to be reluctant to acknowledge the initiatives and work done by this NGO and other support groups in the area. This could be the result of a fear that these local group organisations might question the priorities of these government departments in terms of addressing the problem of HIV/AIDS.

#### **4.7. South African response to HIV/AIDS**

The first response by the Apartheid government towards the HIV/AIDS epidemic was to make the screening of blood donors compulsory, as it identified this to be the prominent form of transmission (Vachani, 2004:1). It was during the same period that the government also identified that certain regions in the country, like the mining areas, were "breeding grounds for HIV/AIDS" (ibid.:1). In these areas large male communities existed and these men, either single or married, had easy access to alcohol and sex workers. Occasionally they were given leave to go home which only served to see the spread of the epidemic further (Vachani, 2004:1-2).

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<sup>12</sup> As is the case in Lady Frere where there were no HIV/AIDS policies at the times of my visits.

<sup>13</sup> "We see them but we don't know what they are doing or where do these people get the information about AIDS. It is worrying us as the Department because we do not want people to send the wrong messages about HIV" (Interview, 28 December 2006).

In 1990, the first studies designed to keep track of the spread of HIV/AIDS were conducted and according to Weinel (2005:2) showed "a prevalent rate of 0.7 per cent, rising towards 7.6 per cent by the year 1994". Confronted with these increasing HIV prevalence rates it finally became clear to the Apartheid government that a proper response towards the epidemic was necessary. This led in 1991 to the Department of National Health, in cooperation with the ANC, formulating a strategy to fighting HIV/AIDS (Department of Health, 2000b). In October 1992 a conference "South Africa United Against AIDS" was held, hosted by the Department of Health and the ANC and attended by people from different sectors of society. This led to the establishment of the National AIDS Co-ordinating Committee of South Africa (NACOSA) (Schneider, 1998:45). The main objective of NACOSA was to involve all people living with HIV/AIDS in all prevention, intervention and care strategies, "emphasizing a multi-sectoral approach with the apartheid government playing a central role" (Weinel, 2005:8).

The National AIDS Plan was a combination of technical and political issues and was regarded as comprehensive and practical (Schneider, 1998:46). The main goals of this Plan were to prevent HIV transmissions; reduce the social impact of HIV infection and to mobilize a multi-sectoral response (Department of Health, 2000a). After 1994, the Nelson Mandela-led government adopted NACOSA as part of their National AIDS Plan. HIV/AIDS was declared as a "presidential lead project", giving it special status, although it has never been put in practice in a convincing manner throughout the country (Garbus, 2003:3).

Since 1994, HIV/AIDS NGOs have not only been critical in raising awareness of HIV/AIDS issues in terms of health and sexual behaviours, but they have also been the main instigators in politicising it (Panos Institute, 2001:10). In South Africa, for instance, the Treatment Action Campaign (TAC) represents one response by civil society movements to the problems it faces in bringing treatment to the people. The TAC has not hesitated to challenge the ANC led government especially with regard to the provision of antiretroviral treatment (popularly known as ARVs) for pregnant

women. The relationship between the two has been hostile because the TAC does not shy away from challenging the government and taking them to court when they feel that the government is not fulfilling their constitutional obligation. "The TAC first confronted the government for not ensuring that mother-to-child-transmission (MTCT) prevention was available to pregnant mothers" (Treatment Action Campaign, 2005). Zackie Achmat, the TAC chairperson said,

Our government has ignored science, economics, morality, good planning, good governance and the law for more than five years on this issue. We've organised, marched, presented petitions and government has ignored every decent plea for them to do something. That's why we've taken this step (Health Systems Trust, 2001).

This has put pressure on the government especially when considering that the government has a Constitutional obligation to give effect to the right of access to health care services, as entrenched in Section 27(2) of the Constitution. In terms of this Section of the Constitution "government has a Constitutional obligation to take reasonable legislative and other measures progressively to realise the right of everyone to have the right to access health care services, including reproductive health care" (Human Rights Commission, 2002).

#### **4.8. The role of donors**

After the country gained democracy in 1994, it became difficult for some NGOs to obtain funding because their main objective had now been achieved. So for them to survive financially they had to meet the requirements of the donors and change their focus to issues such as HIV/AIDS and poverty alleviation. Hence we are now seeing a rapid growth of community NGOs in South Africa. As the above example (TAC versus government) shows, at times the democratic government has displayed an openly hostile attitude towards the NGO sector. Soon after coming to power, the ANC made "it clear that it felt that the NGO sector was unnecessarily large and that only those NGOs which could deliver services efficiently and were able to compete with the government and private sector could expect to survive in the new South Africa" (Mail & Guardian, 26 January 1994).

Literature on the status of the South African NGO sector after 1994 shows that the NGO sector was in crisis (Smith, 2001:5). The general perception was that many NGOs did not survive the transition, and this was partly due to the changing donor funding patterns, as well as the different ways in which NGOs related to the new government. This resulted in many NGOs redefining their roles in order to meet the challenges presented by the new democratic dispensation. Although we do not know the numbers of NGOs that had to close down through lack of financial support, there is consensus that many have collapsed in the process. Prior to 1994,

NGOs in South Africa enjoyed a remarkable degree of freedom and independence from donors. Donors imposed minimal controls on what recipients spent funds on. After 1994, however, donors have arguably had much more of an influence on what South African NGOs do, and how they do it (Smith, 2001:14).

#### **4.9. A critical reflection on the mainstream NGO literature**

In the mainstream literature, NGOs (both the ones that are concerned with developmental issues and HIV/AIDS NGOs) are depicted in a very positive manner. This has the potential to mislead a new reader of this body of knowledge. These organisations are portrayed as the most useful and reliable organisations that can bring change to the life of an ordinary person. But this is fiction, because first of all in reality these organisations are not private. In Africa, as we know, “NGOs have adopted different relations with African governments. Some being bent on criticism while others have been co-opted by the African governments for political reasons” (Obiro, 2006:2). When working closely with these organisations one realises that sometimes government officials are part of the management team of a local NGO and that has implications on how that particular NGO will relate and reflect on issues about the government.

NGOs receive funding from overseas governments, in the name of foreign donors, or local governments (Petras, 1997:3). In return, they act as service delivery “experts” serving the interests of their funders. The MNGO, operating in Lady Frere District, seems to be following the same trend. This local organisation is getting the bulk of their funding from the Social Development Department of the eMalahleni

Municipality. One can presume that this NGO is fully accountable to this local government department, which again questions the independence of non-governmental organisations. I will explore how the money they receive is spent in my data analysis chapter (Chapter 6).

African NGOs, like their northern NGO counterparts, often claim that their activities reach the poor and most marginalised groups in society. "With this sort of grass roots connections, NGOs in Africa claim that they are able to articulate grassroots reality, much more than African governments can do with their macro-development approaches" (Orute, 2006:1). Furthermore, unlike the central government, which uses the top down approach in its development activities, "NGOs use the bottom up approach in their development activities that take into account the perceived needs of the poor and improve their living conditions. This approach gives the poor in Africa the necessary experience and ability to gain control of their lives" (ibid.).

In theory these organisations are better informed to serve the interests of the poor because they are deeply rooted at grass root level. But in practice, NGOs are mostly located in towns. This is of special interest for an NGO claiming to be assisting, amongst others, rural PLWH. In times of crisis who do these rural people turn to for help if the counsellors are based in town?

As much as Petras tends to overstate his point at times I agree with him that

the subcontracting (of NGOs) undermines professionals with fixed contracts, replacing them with contingent professionals. The NGOs cannot provide the long-term comprehensive programs that the welfare state can furnish. Instead they provide limited services to narrow groups of communities. More importantly, their programs are not accountable to the local people but to overseas donors. In that sense NGOs undermine democracy by taking social programs out of the hands of the local people and their elected officials to create dependence on non-elected, overseas officials and their locally appointed officials (Petras, 1997:3-4).

Essentially, what this means is that local NGOs

shift people's attention and struggles away from the national budget and towards self-exploitation to secure local social services. This allows the neoliberals to cut social budgets and transfer state funds to subsidize bad debts of private banks, and provide loans to exporters. Self exploitation (self-help) means that, in addition to paying taxes

to the state and not getting anything in return, (poor) people have to work extra hours with marginal resources, and expend scarce energies to obtain services that the bourgeoisie continue to receive from the state. More fundamentally, the NGO ideology of 'private voluntaristic activity' undermines the sense of the 'public': the idea that the government has an obligation to look after its citizens and provide them with life, liberty, and the pursuit of happiness (Petras, 1997:4).

Fundamentally, what NGOs are doing is perpetuating dependence of the poor on foreign aid. Poor people continue to use their last cents by paying for services. The NGO literature gives the impression that these organisations best represent the real voices of the poor, which is questionable when you consider the fact that it is rare that the NGO directors meet with people on the ground to hear the experiences of their daily struggling. NGO directors are often overseas, attending conferences with the aim of securing lucrative funds in foreign currencies (Petras, 1997:4). In doing this they claim to be representing the marginalised people of the villages. But how often do they meet and listen to the needs of the poor? It is on this basis therefore that I share the view of Nyamugasira (1998:302) that

NGOs need to stop being preoccupied with their own narrowly interpreted bureaucratic mandates and get down to the business of seeking out and listening to the poor in order to secure a mandate to speak clearly and with conviction on their behalf. The poor live in the so-called culture of silence from which they must be liberated. The first step is, then, to meet them at their own level before they will speak.

In practice NGOs are adopting the same strategy as international agencies: assuming what the poor need. It is rare that people are part of the NGO programmes from the planning stages up until the execution of the project. Instead they come up with projects that suit the need and requirements of donors with little relevance to what the community actually needs. NGOs should be seeking to create an environment for people to represent themselves. When analysing these organisations the critical questions are: Who owns the NGO? Who makes the final decision as to the leadership of the NGOs? Who pays for the NGO? Often staff who hold radical views or 'revolutionary' ideas never reach the top.

They are perceived to be difficult to work with, a threat. They are an embarrassment to donors. Obviously the voice of such an NGO is muffled. It is a poor imitation of the people's voice. Gagging the voice of upcoming leaders, often the brightest and the best, failure to tolerate dissent, can certainly have far reaching adverse effects (Pappetta, personal communication cited in Nyamugasira, 1998:306).

NGOs should strive to empower the poor to advocate for themselves

so that in advocating for them we avoid giving the impression that someone somewhere owes them a living, and that this someone is most probably the government, primarily their own, but also governments of rich industrialized countries. The poor need to demand accountability from their (NGO) leaders who take loans on their behalf (Nyamugasira, 1998:307).

The NGO experiences in Africa tells us that, those NGOs that are in African governments' records or bad books are often

unnecessarily branded as being antagonistic, anti government [as it was the case in South Africa during apartheid], and are referred to as friends and financiers of opposition parties out to destabilize African governments in power (Orute, 2006:2).

This observation is also applicable to the South African situation. As I have argued earlier, NGOs that put pressure on government in areas of service delivery do not have a good relationship with the current government. Such NGOs are perceived to be the enemies of democracy and for that their activities will need to be closely monitored.

The tendency by those NGOs that are in African governments' good books is that they

tend to become more political than apolitical and often become political wings of ruling parties. Their directors pay regular visits to senior government ministers' offices and are often accorded warm reception while there. This is because of the huge donations they always make towards the very issues they are supposed to tackle head-on at community level (Orute, 2006:2).

The survival of such NGOs depends on their loyalty to an African government that is in power on one hand, and on donations from abroad on the other hand. So one can say that most NGOs operating in Africa are more accountable to the government than the people they claim to represent. For me this contradicts their defining characteristic that they are non-governmental.

The so called 'directors' often spend more time writing up new proposals to bring foreign currency. Hence where they work together with local government they talk

the same language because government is also benefiting from the US dollars. It is on these bases that I agree with Petras (1999:2) that:

The NGO leaders are a new class not based on property ownership or government resources but derived from imperial funding and their capacity to control significant popular groups. The NGO leaders can be considered as a kind of neo-comprador group that does not produce any useful commodity but does function to produce services for the donor countries – mainly trading in domestic poverty for individual perks.

#### **4.10. Conclusion**

It can be concluded therefore that as long as NGOs rely on donors and national governments for their survival they will never change the situation of the poor. As much as NGOs are perceived to be independent bodies, supposedly challenging the government, the critical issue is that for them to exist in the first place the government has to provide that platform. This means whatever they do has to fall within the legal framework of the government in power. This chapter has argued that, in the South African context, the relationship between the government and the NGO sector has not changed. It is characterised by tensions and conflict on fundamental issues when it comes to HIV/AIDS.

Nevertheless, in a country where the leadership is so reluctant to take a firm stand, the NGO sector has a critical role to play. The social problems, in particular the livelihood conditions of the people in Lady Frere, call for new and effective roles of different organisations such as public, non-profit and for-profit organisations.

## CHAPTER FIVE

### **Understanding the spread of HIV/AIDS in the Lady Frere District: Voices of the people**

#### **5.1. Opening remarks**

In the face of shocking statistics on HIV/AIDS infections, the most common solution offered to reduce the spread of the disease revolves around changing individual behaviour through education-oriented initiatives. Indeed, education has been treated as a panacea. It is viewed as the key to reducing individual infections by promoting health-maintaining and life-sustaining behaviours (Editorial, 2002:3). Governments, NGOs and international agencies work diligently to educate people about the dangers of the HIV/AIDS epidemic (UNESCO, 1999:2). However, there is very little attention given to the structural conditions that shape/influence individual behaviour on a daily basis. South Africa, like the rest of Africa – with the exception of Uganda and Kenya – is known for the inefficiency of these public prevention education-oriented campaigns to reduce the spread of the HIV epidemic (Winter, 2000:23). In recent years it has become clear that despite these massive actions to inform the public about the risks of HIV/AIDS, behavioural changes are not occurring as expected: instead, infections continue to increase rapidly.

This chapter reflects on the failure of these education-oriented strategies to reduce the spread of HIV/AIDS. In interrogating the effectiveness of the education-oriented strategies, it is appropriate to examine how people experience and perceive HIV/AIDS. Accordingly, this chapter reflects on how people in the Lady Frere District perceive and experience the epidemic. This chapter was motivated by the realisation that most people I interviewed for this case study have knowledge about the ways of transmitting the HI virus and they know how they can protect themselves and their partners, yet some still continue to engage in high risk sexual practices even though they know that there is no cure for the disease. This led me to question the suitability of the mainstream prevention and awareness education-oriented strategies aimed at changing behavioural practices and reducing the spread

of the epidemic. An attempt is made in the chapter to understand why these education-oriented campaigns often fail to change behaviour. To address these issues I draw mainly from the data I collected during the meetings and workshops I attended with the Masibambane NGO (MNGO) to document people's experiences and perceptions of AIDS in the Lady Frere District. But before I engage in this discussion it is appropriate at this juncture to firstly highlight the general characteristics of the population for this study.

## 5.2. Characteristics of my study area and participants

The participants in this research are all black and predominantly young females. Most of the MNGO members have a low standard of education. Some of the leaders of the organisation have matric as their highest achievement in school. Most of the MNGO members live in the villages of eMkhaphusi, Gqhebenya, Nkwanca, Bengu, Maqhashu, Mtsheko, Ntlalontle, Ngcuka, and Cacadu, and some live in the semi-urban township of the Lady Frere town. In most cases they moved to this semi-urban township after the completion of the RDP houses (popularly known by residents as *oovezi-nyawo* – meaning you sleep with your legs outside because of the small size of the houses).



Picture of *oovezi-nyawo* in Lady Frere.

Most of the group members are in their late twenties with few married women in their late thirties. I also had interviews with the manager from the local Department of Health as well as with nurses working in the local clinic of eMkhaphusi.

The small town of Lady Frere is characterised by high levels of unemployment, illiteracy and poverty, and young people are severely affected by unemployment and poverty. Most people have a low quality of living standard and experience low quality of public services. In most of these villages the majority of the people do not have toilets, electricity or running water. Because of the absence of public toilets in town, the trees that surround the Lady Frere town are used by people to hide themselves when they urinate.<sup>14</sup>

The RDP houses are generally of poor quality and they lack the features of a modern urban household. These houses are generally occupied by younger people who leave their families in search of employment in the Lady Frere town. The general trend is that *oovezi-nyawo* are used for cohabitation by young men and women. Most of these inhabitants live below the poverty line, with no sustainable income. Based on my observation most of these young people rely on their children's government grants which means the more children you have the higher the amount one is likely to get. As one informant explains

*My boyfriend does not have a permanent job but things are much better now because we have two children and the amount has gone up. For instance, we managed to buy a second hand television set now (Interview, 10 September 2007).*

It was evident from my interaction and observation with young people from the MNGO that there seems to be a close correlation between teenage pregnancy and receiving a government grant for a child. Under the lack of job opportunities, these young people see children's government grants as a means to have a sustainable income every month.

Most of these young people are particularly vulnerable to HIV/AIDS. These young people have limited access to a secure livelihood, and to health care. Other groups vulnerable to HIV/AIDS include newly married women, teachers, and taxi drivers. The reasons given for this include the fact that young women get into marriage too

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<sup>14</sup> Occasionally this has led to people getting sick because of contaminated water, because most people fetch water from their nearby fountains which are also used by animals such as pigs and dogs to quench their thirst and wash themselves. In some villages running water was installed but the schemes soon collapsed after the contractors left those villages.

soon and sometimes realise that they were not ready for this kind of commitment. It was said that sometimes they realise later that they are not yet ready for the marriage commitments. A married young woman says that

*Sometimes I feel like the girls of my age in the village are much happier than I am in this marriage. Before we got married we were happy but ever since we got married that enjoyment seems to be fading away – I guess we got used to each other now (Interview, 11 September 2007).*

The MNGO peer educators reported that teachers and taxi drivers generally refuse to wear condoms. This was particularly the case where they have secret lovers who might feel that they disrespect them. Due to high unemployment, the majority of the people can barely afford medical aid and thus they rely on poor<sup>15</sup> government health care services.

Most families in the eMalahleni Municipality in surrounding villages depend on social grants and pensions for their survival. The local economy is traditionally based on subsistence farming, but increasingly households are primarily supported by remittances from family members living elsewhere. The eMkhaphusi headman said that

*In the past our parents used to cultivate these veldts that you see over there but now most families rely on money sent by other family members working in big cities (Interview, 10 September 2007).*

From the data I collected it seems that many of these young girls do not live with their parents.

*I left my village because I wanted to start a small business in town. Now I am selling clothes and fruit on the streets and my business is doing well. But I visit my family whenever I want to. I cannot stay there permanently now, I am so used to my freedom here (Interview, 23 April 2007).*

The implication of this is the breakdown in the family structure and values that Walker and Gilbert (2001:4) identified as one of the main factors influencing the spread of HIV/AIDS. According to the literature, this feature of disrupted family and communal life is also due in part to apartheid, the migrant labour system, poverty,

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<sup>15</sup> My respondents often complained that whether people have headache or stomach pains, you are most likely to get Panado or Disprins from the local clinics due to a lack of adequate supply by the district department. However, the manager from the local Department of Health disputed these claims, saying that it is the failure of the clinic Supervisors to ensure that medication is ordered in advance.

change in family structures, and a new array of pressures of traditional versus modern lifestyles (Webb, 1997:64). In these villages the spread of the HI virus is further aggravated by the breakdown in communication between parents and children around HIV/AIDS and sex. The MNGO peer educators said that

*It is still very difficult for most parents, especially old parents, to talk about sex issues with their children. When we do these education campaigns in clinics and hospitals we see the uneasiness from parents because they are not used to hear children talking about sex. So one can imagine how difficult it is for them to talk about it at home (Interview, 10 September 2007).*

Some of the respondents from the eMkhaphusi village reported that they live with their grandparents. The age gap between these young children and their grandparents constitutes some of the difficulties faced by the youth in bridging the gap between their traditional values (such as silence around sex, belief in myths around HIV/AIDS, and lack of open communication) and their changing needs and the present challenges that they face (such as HIV/AIDS, sexuality, teenage pregnancy, age mixing with regard to sexual partners, and lack of open communication with parents).

*It is very difficult to talk about sex to your grandmother because she treats you like a child who does not know anything about boys. As much as sometimes you know that she can give you good advice, you do not want to break her trust and love that she always gives you and that is why we end up taking advice from our peers who do not have experience (Interview, 11 September 2007).*

In support of this, Mbetse (2001) reports that children mostly take the cue from their peers about when it is appropriate to begin with sexual experimentation. This has raised important issues with regard to peer education in AIDS prevention, in that value and risk judgments are made in relation to the attitudes and behaviours of peers, especially in the formative years of teenage and adolescence (ibid.). Against the background of these living conditions of a large part of the Lady Frere District's population, it is now appropriate to examine the suitability of the mainstream HIV/AIDS prevention and awareness strategies in changing the sexual behaviour of these young people.

### 5.3. Mainstream HIV/AIDS education strategies

The mainstream HIV/AIDS prevention and awareness strategies, which are the core functions of the MNGO, propose that

health related behaviour is determined by an individual's knowledge and attitude. Thus (it is argued), if people know that AIDS is a deadly disease, and that using condoms will diminish their chances of getting it, they should be more likely to use condoms (Campbell, 1997:145).

Mainstream strategies such as abstinence, be faithful and/or condom use (the South African AIDS Plan is fundamentally based on this – the so-called ABC approach), and education impacted on passive target audiences, knowledge about how HIV/AIDS is transmitted and attempts to change sexual behaviour and attitude, are all seen as a panacea by Fishbein (cited in Mlungwana, 2001:8) to reduce the rapid spread of HIV/AIDS in the country. However, in spite of this assumption, Campbell's work has revealed that "even people with relatively high levels of knowledge about HIV/AIDS often indulge in high-risk sexual behaviours" (1997:145). Most of the literature in this area tends to overlook the living conditions faced by the poor people on a day-to-day base. Campbell's work conducted in the gold mines of South Africa discusses the experiences and perceptions of the miners and how they react towards dangerous situations.

The question that seems to emerge from Campbell's study is: under such dangerous underground conditions, can one expect mine workers who face death every day to care about protecting themselves from an infectious disease that might kill them in ten to fifteen years? The informant explains that the dangers and risks of the job they are doing are such that "no one can afford to be motivated with life – so the only thing that motivates these workers is pleasure" (Campbell, 1997:150). This kind of attitude has led Campbell to conclude that even if mineworkers are aware of the dangers of unprotected sex with multiple partners "such behaviour may be beneficial at a range of other levels in the stressful and socially impoverished living and working environments of the gold mines" (ibid.:152).

It was for this reason therefore that I argue that to assume linkages between knowledge and practice is problematic. In the South African context, we cannot ignore the role played by poverty and other social factors in facilitating the rapid spread of the epidemic within our communities. It is on these bases therefore that this study challenges the mainstream education-oriented strategies and argues that such HIV programmes failed to recognise that sexual behaviour is deeply rooted in social, cultural and economic structures of the society (Clark et al., 2005:1). The mainstream education-oriented strategies led by the health community and NGOs often assume that if vulnerable people can be reached and warned/told about the dangers of HIV and how they can protect themselves, "they would quickly take care to safeguard their behaviour" (Lomas, 1998:1182). Slogans such as the popular "Abstain, Be faithful and use a Condom (ABC)" became the buzz phrase of the late 1990s among the health promoters and religious community (ibid.).

This study suggests that greater knowledge (derived from people's experiences and perceptions of AIDS) of the factors driving the epidemic will allow for a better understanding of the factors helping or hindering existing programmes (Campbell & MacPhail, 2002:1614). Such an approach has the potential to help with improving existing intervention programmes. The problem with the current strategies is that information generated from the popular "Knowledge, Attitude and Practice" (KAP) model does not enable developers of intervention programmes to consider the contexts in which knowledge is gained and sexuality is negotiated, thus giving only a partial picture of the complex factors shaping sexuality (Clark et al, 2005:1). Besides, the success of HIV intervention programmes is frequently evaluated using these KAP approaches despite the realisation that increased knowledge does not necessarily impact on future behaviour (Zuma et al., 2004:18).

The mainstream strategies do not recognise that where daily survival may be "precarious and social bonds loosened, there tends to be diminished concern about health (or at least diminished access to health care), increased risk taking and reduced social concern about casual relationships" (Zwi & Cabral cited in Marks,

2002:17). Brandt (1988:148) asserts: "The way a society responds to problems of disease reveals its deepest cultural, social and moral values". He went further to argue: "The epidemic has been shaped not only by powerful biological forces, but by behavioural, social and cultural factors as well" (ibid.).

Furthermore, the KAP model fails to recognise that in South Africa (with modern infrastructure) women and men move from rural to urban and from urban to rural areas. Some people are no longer stationed in the so-called rural areas. This means therefore that "in an ideal world one vital strategy for reducing HIV-transmissions would be to reduce rural-urban social inequalities that undermine the life chances of so many" (Campbell, 2003:184).

#### **5.4. Poverty – a bridge for spreading the HI virus**

Irrespective of how poverty is defined by different scholars and politicians, the fact of the matter is that poverty and HIV/AIDS are closely related. The link between the two reinforces the rapid spread of the epidemic in poor communities. For poor people, poverty means that they are unable to meet basic necessities in their lives. But most importantly, "when they contract the disease they have no resources with which to strengthen their immune (system)" (Mbere, 2002:6). "Poverty decreases people's autonomy and control over their lives, and thus increase their vulnerability to health and social problems, including HIV/AIDS" (van Maanen et al., 2002:12). It is on these bases therefore that I see poverty as a bridge for the spread of the HIV virus.

In fact, HIV/AIDS is becoming more and more to be seen as a disease of the poor, "with existing inequities becoming more pronounced as new treatments become available which are inaccessible to the poor" (van Maanen et al., 2002:12). This means the majority of the people in isolated villages of the Lady Frere District have little chances of accessing medication, because ARTs are only accessible in the Glen Grey Hospital which requires people spending a lot of money to get there. The MNGO member said that

*So far people can only get ARVs in the Glen Grey Hospital. The government is refusing to make ARVs available closer to where people live in the clinics (Interview, 23 April 2007).*

Poverty has devastating effects for individual families who rely mostly on government grants to survive. Family members of persons with AIDS are sometimes forced to sell off their assets and belongings and expend all of what little money they have in desperate but futile efforts to find a cure for their dying child or children (Help Age International, 2001:7). One of the informants of this case study shared similar experiences with regard to this issue with me:

*My parents were worried to see me lying in bed with pains throughout but there was nothing they could do as none of them is working. So my father had to sell a cow so that they could hire a car to take me to hospital. I really feel that I disappointed my parents ... I created more problems for them ... because every parent has dreams about their children but ... yha, I guess it is part of life (Respondent, 23 April 2007)*

This shows the expenses families go through sometimes in attempts to save the lives of their children. This becomes worse when children hide from their parents that they are HIV-positive as parents might reduce some expenses.

In addition to this, black communities are known for extravagance when it comes to funerals. African "families go into debt to finance the best funeral yet in the village, going to such excesses as hiring a generator for the week, offering abundant food and drinks to everybody" (Narayan et al., 1999:149). It has become a custom for grieving families to buy new clothes for family members to look beautiful on the funeral day and this only serves to deepen poverty among black communities.

Young children with AIDS in the Lady Frere District report that, because of the lack of job opportunities they are heavily dependent on their elderly parents' meagre income to support them and their children. One participant said that

*I lost my parents due to AIDS so now I live with my grandparents. They are helping me to raise my child. I want to go back to school next year but I will need their permission because I have a child now (Interview, 10 September 2007).*

It is on these grounds therefore that I believe that the HIV/AIDS epidemic and its effects on families cannot be adequately addressed without reducing the high levels of poverty which characterise black communities. As long as young people have little to do (dropping out of school early and there are no job opportunities for them) they

are likely to resort to drugs and sex for pleasure (mostly without protection). As this young boy explains

*I dropped out of school in standard seven last year hoping that I will get a job so that I can also contribute at home but so far there is nothing. Because of the frustration you end up joining groups that are involved in robbery so that you can have money to buy nice clothes and chicks will be crazy about you in town (Interview, 13 September 2007).*

HIV/AIDS needs to be “tackled in the context of the multiplicity of societal problems faced by poor communities and families” (Help Age International, 2001:7). Kark (cited in Marks, 2002:17-18) share the same view when arguing that:

Without an understanding of the socio-economic factors involved and the historical development of the vast social pathological changes brought about during the last seven years, no treatment will save the spread of HIV/AIDS in South Africa. Treatment of individual[s] cannot succeed in any but a few cases. The first line of treatment must be to remedy the unhealthy social relationships which have emerged as the inevitable result of masses of men leaving their homes every year.

The above means that in areas such as in the Lady Frere District, where there are very few job opportunities, poverty forces people to look for employment elsewhere, creating a disruption of family and community structures. In turn, this situation creates an increasingly mobile population of young men and women, outside their traditional support network and cultural tradition. This exposes young people “to new conditions that may render them more vulnerable to HIV and other sexually transmitted infections” (van Maanen et al., 2002:12-13). In most cases these young people only “return home to die” (Clark et al., nd).

Women’s economic dependence on men further intensifies their social status as second class citizens in our society. Consequently this situation makes it difficult for women to insist on measures that will protect them against infections. This is especially true for women who have children and put the well-being of their children first (Hunter, 2006:149). One of the participants in this study also comments that:

*It is better to have a man who is working because he can help you to raise your child or pay for your bills (Interview, 23 April 2007).*

The respondent also highlights that most men have no problem in raising children who are not their own as long as they are kept happy in a relationship. She explained to me her own situation with regard to this.

*The secret to hold a man is not to keep asking questions about his whereabouts. Even if you suspect that he got another affair just pretend as if you don't know anything. In that way he will always come back to you. My man knows that my child's father is alive but he does not mind because I give him love (Interview, 12 September 2007).*

AIDS increases the number of female and orphan-headed households. The result is a continuing loss of family values and good morals. Recently the plight of orphans and child-headed households due to AIDS has come to be recognised in these villages. During my visits in April (2007) to Lady Frere, the MNGO officials were collecting names and birth certificates of all the children who lost their parents due to AIDS.

*Once we have their names we will facilitate government grants for them because some of them are really suffering and in some cases we have already involved the Social Workers to monitor their situation. They are sometimes shouted at ... insulted by those who look after them. We hope that the grant will also help them go to school (Masibambane official, 22 April 2007).*

It was evident that some of these children lack access to necessities such as school uniforms and school fees, resulting in expulsion from school. To overcome this problem, a community member who started a support group in 2004 for PLWH but lost courage as there was no financial support, reported that:

*We are also talking with the Department of Health to see if these children (those who lost parents due to HIV/AIDS) can be excused to attend school even if they are not wearing school uniform (Field notes, 29 July 2006).*

She reported the lack of identity documents as parents may have died before applying for these. This situation makes it difficult to help these children to access social security grants. Mwape (2003:13) concurs with this when saying:

AIDS orphans and vulnerable children experience great difficulty accessing education services. A lack of free primary education means that school fees – as well as school uniforms, books, transport, etc. – are often unaffordable for vulnerable children.

There is no denying the fact that poor access to services makes the poor more likely to adopt behaviours that expose them to increased risks of HIV infection (Treatment Action Campaign, 2005). This means that simply telling the poor what to do or how to change behaviours should not be treated as a remedy to all HIV-AIDS-related

problems. The fact is that even if the poor understand what they are being urged to do, “they rarely have the incentive or the resources to adopt the recommended behaviours. For the poor it is the here and now that matters” (Mbere, 2002:13).

Strategies to reduce the spread of the epidemic should not be imposed on communities. Such strategies require community involvement in drafting and implementation. However, the above discussion is not to claim that if we can do away with poverty, there will be no more transmissions. I am aware of the fact that to make such a claim is to adopt a narrow-minded view. The reality out there is much more complex than this. This above discussion was merely an attempt to show how poverty in particular can have detrimental effects on education-oriented prevention and awareness efforts.

#### 5.5. A sociological view

The major premise of a sociological study in disease is that “even though all diseases are medical phenomena” (Rushing, 1995:4), they cannot be understood and explained in medical or biological terms only. As the above discussion showed, illnesses also have a social dimension that can be understood only by the appreciation that such diseases are also perpetuated by social factors and pressures. AIDS is no exception (ibid.:5). In this assessment it is important to remind ourselves that individuals do not live in a vacuum: they are part of a social group. This means their behaviour within a particular social group is influenced and regulated by the group norms. These norms dictate what is acceptable while also labelling other behaviours as “deviant”. For instance, a tearful young girl during a support group meeting commented that:

*My friends laugh at me when I tell them that I tell my boyfriend to use a condom. They say I'm stupid I don't know what I'm missing (Respondent, 23 April 2007).*

It is this kind of pressure therefore that forces people sometimes to want to be seen complying with the group norms. Later she commented that she is now finding it difficult to insist on using condoms with her boyfriend. She said that:

*Because they laugh at me I find it difficult to insist now. What scares me is that I know he is got another girlfriend in another village (ibid.).*

Against this background, it becomes problematic therefore to locate “the cause of sexual behaviour at the individual level only” (Campbell, 2003:7).

A sociological analysis of behavioural differences between populations is guided by the principle that these differences are related to variations in social conditions (Rushing, 1995:5). Thus social factors that influence person-to-person transmission may go a long way in explaining why the prevalence of a disease continues to grow when NGOs widen their wings in providing education to communities. These social factors include, among other things, high levels of alcohol consumption by young people. With regard to this, the MNGO member said that

*The problem is that young people go to the shebeens and once they are drunk they sleep with anyone, even older people to them. For me this is the reason we are now seeing more and older people getting AIDS (Interview, 23 April 2007).*

The social life of young people today is signified by being ‘cool’ (which often means going to the bars and getting drunk and any young person not doing this is seen as backward/boring) – consequently getting a sexual partner. Under the influence of alcohol very few people are in the right frame of mind to use condoms when having sex. It is because of these realities therefore that I concur with the view that, as much as “HIV is the (apparent) biological cause of AIDS, social factors determine the behaviour that is crucial in most transmissions of HIV and explains why some (age) groups and populations have higher rates than other groups” (Rushing, 1995:5).

An increasing new phenomenon that emerged in my interviews was a constant reflection by the group members that people who are in denial that they have *ikiss-kiss* (this is how the MNGO members talk about HIV/AIDS) in these villages often claim that they are bewitched when they get sick. The MNGO official reports incidents whereby people are sick in the village of eMkhaphusi and most of them say they are being bewitched by their neighbours or relatives who are jealous of them. One participant said to me:

*When I go to eMkhaphusi their parents come to me at night asking for help ... people don't want to come forward. They are in denial and the majority of those who are already dying claim to be bewitched by their relatives. People do not want to accept that they have ikiss-kiss and because of that we cannot assist them to get treatment early ... sometimes when they disclose it is too late to reverse the situation (Respondent, 23 April 2007).*

Nzenza-Shad Sekai (1997:11-12) also report a similar tendency in his study conducted in Zimbabwe where parents seem to support the bad behaviour by their children:

Patrick's parents could not believe that their mission-educated boy could have been sleeping with prostitutes. They felt that if this *hedzi* (HIV/AIDS) existed, it should affect other people – surely not their handsome boy. They started to believe that their son had an evil spell cast on him by someone in the village or someone jealous of his success.

Parents, who are mostly illiterate, often believe what their sick children tell them. In some instances, young people tell their parents that they have been called by the elders to act as *iqghirha* (a traditional healer practicing as a fortune teller) (Field notes, 2007). The cost of becoming an *iqghirha* is just too much for a poor family as it involves slaughtering a goat for *invvuma-kufa* (accepting the call by the ancestors). The cost of a goat may range between R600 and R900 – making it too expensive to send the person to a well-known *iqghirha* to assist him/her in this initiation process.

Some MNGO members said that most people hide the fact that they have *ikiss-kiss* because of shame. This includes professional people with social standing in the community, such as teachers. They said that because the AIDS disease is acquired primarily through sexual intercourse, the sick person is thought by other community members to have worked as a sex worker in urban areas or someone who does not engage in proper moral conduct (Field notes, April 2007). Married and young women in this group also pointed to the tendency by other community members to refer to someone with *ikiss-kiss* to have been *isifebe* (the singular use of the word – literally meaning a person who has sexual intercourse with every man). A group member said that:

*For us women, if you have this kiss-kiss people say ubulihule (equivalent to isifebe – referring to a female who has many sexual partners). They would count all the men you have ever been involved with (Interview, 13 September 2007).*

For men it is believed that one had been *udlalani* (the singular use of the word – literally meaning a playboy). A community member said that:

*For any family to be known to have someone suffering from AIDS is embarrassing ... that is why sometimes people hide the sick person or simply say she has another disease such as uyahambisa (running stomach) or intloko engapheliyo (a continuing headache) (Respondent, 23 April 2007).*

Some alluded to the fact that AIDS has raised many suspicions among neighbours and relatives with the result that it divides the community of eMkhaphusi. A young female from the eMkhaphusi village shared her own experience with me:

*AIDS is breaking families in my village. Sometimes people do not go to each others' houses and it is so embarrassing and sad to watch when there is a traditional beer or when there is a traditional work, where all community members get together, to see relatives not assisting each other. This is even worse when one of the families is mourning. As you watch you wonder about the future relations that will develop between their children (Interview, 13 September 2007).*

It becomes clear therefore that HIV/AIDS has contributed in a negative way to the formation of social capital in this community. In other words, it is destroying bonds that bring people together which are necessary for members to realise that if I have AIDS today it is most likely that it will affect you directly or indirectly tomorrow. This means if you get involved today you will develop ways of protecting yourself and those around you in future. But as I see it now the disease is destroying the trust that these community members used to have in each other.

The data I collected from these group meetings had many references to evil-minded individuals who know that they are HIV-positive but continue to infect their boyfriends or husbands. For example, one participant said to me:

*I don't know who infected me, so why should I care about insisting on using condoms if he does not want to use it. I have lost my child due to AIDS which I got from a man (Interview, 23 April 2007).*

This behaviour has a lot to do on the one hand with the labelling by the community members of those who are HIV-positive as *izifebe* (the plural use of the word). On the other hand it has something to do with women nursing or protecting their relationships. A married woman said that:

*I cannot afford to lose the father of my children ... he is undofawam (my man for real that I will die with/for). If I tell him that I'm HIV-positive I don't know how he would respond (Respondent, 23 April 2007).*

It was evident that men are seen in most relationships by women as economic providers. But this also means that where there is a strong reliance on the man for economic gains/survival it becomes really hard for the woman to let it go.

These perceptions alluded to the fact that while AIDS, as a medical problem, entails searching for medication to treat the disease, the social challenges of HIV/AIDS require a social approach (Jonsson & Soderholm, 1995:461-462). Such an approach should call for the integration of education, behavioural change, and consideration of social factors to go along with medical as well as biological approaches (ibid.). The challenges of HIV/AIDS are many and cannot be addressed only by technical/medical and formal institutional mechanisms. The above perceptions and tendencies show that people are prepared to risk the lives of others in order to protect their relationships. The starting point for a sociological investigation therefore should be a clearer understanding of how disclosure of one's HIV status will impact on the livelihood of that particular individual. In other words, what risks are involved in disclosing to one's boyfriend? According to these participants it includes losing a potential husband or money provider.

I am of the view that the majority of South Africans are aware of how HIV/AIDS is transmitted and how they should be protecting themselves. With this assumption in mind, to understand that very few have "seen the necessity to turn this awareness into personal behaviour change" (Winter, 2000:23) requires that we interact with people themselves. People's perceptions and experiences of life can go a long way in giving us explanations of what the mainstream strategies perceive to be 'ignorance' concerning a deadly disease.

It appears that from the beginning of the HIV epidemic the burden of the epidemic has fallen on the shoulders of individual households and local communities. Young people who leave their families looking for employment opportunities in big cities go

back home helpless and some are already experiencing serious illness. The manager from the Department of Health reports that:

*Young people are sometimes dropped off by taxis from Cape Town or Johannesburg in the hospital because they are already dying. Because we do not have space to accommodate everyone, we send people to their families (Interview, 28 December 2006).*

This pressure on the individual household is the result of government's failure to provide the necessary assistance (Mbere, 2002:5). In other words, government's failure to pro-actively prevent HIV/AIDS and government's failure to provide financial assistance to infected people. This is particularly the case in South Africa as Chapter Four has shown that both during apartheid and in post-1994 the governments have failed to prevent the spread of HIV/AIDS. This is also exacerbated by government's "inability to interface effectively at the local level where the pandemic impacts most" (ibid.:5). However, the fact is that as much one can blame the government for being inactive, individuals and communities need to take responsibility in addressing the challenges posed by HIV/AIDS. This is true when considering that parents often fail to act responsibly at the early stages of their children's life. How do parents explain, for instance, a situation where a 13-year-old girl would sleep outside the family premises? Lack of proper guidance on their part should be blamed for early exposure to sexual involvement as well as early exposure to possible HIV infection.

It is important to note that in the olden days in black communities, family members used to come together at night to listen to *oomakhulu* (grandmothers) telling *iintsomi* (folktales). *Iintsomi* played a big role in moulding the behaviour of young people. The eMkhaphusi headman explains:

*When we grow up we used to play with our sisters during the day games like khetha (meaning you chose the one you like to be your wife) or undize (meaning hide and seek). It was on these games that we as men learnt to make love but we never penetrated girls. Instead you just do it between her thighs and in those days we had fewer pregnancies among young girls as compared to what you see today (Interview, 10 September 2007).*

This period was characterised by few incidents of teenage pregnancies. But today with the government grants, the MNGO members asserted that teenage pregnancy

has become a fashion among young girls, leaving school before they finish because of a grant of R180 per month. In the past female children respected and valued their bodies because for a female child to be pregnant was a disgrace to the whole family. Children did not have separate rooms in black families. Everyone (boys and girls) would sleep together, and sometimes females would share blankets with their brothers. The availability of television to almost every household has also changed the lifestyle of these communities. In some instances children have television sets in their own bedrooms which make it easy for them to view erotic movies at night. Today children have constitutional rights<sup>16</sup> which make things even worse for some parents to instil a sense of responsibility in their children. Unfortunately, in the modern era we cannot do away with these things. But as much as I blame the government for a slow response to the epidemic, individual families (in particular parents) must take the blame for early infections, while grown-up individuals are accountable for their actions, especially those who knowingly engage in unsafe sexual intercourse.

Lastly, breaking the culture for silence in our communities and creating a culture of openness and acceptance of those living with the HI virus are important ways to deal with the stigma associated with AIDS (Mbere, 2002:21). But the major challenge in South Africa is to encourage political leaders to realise the kind of power that they have over the people. For the President of the country to be stuck in such debates as whether HIV causes AIDS is really not sending the much-needed message to the masses on the ground. In my case study the culture of silence seemed to have a gender dimension. The positive that can be taken from the HIV/AIDS epidemic is that the issues surrounding the epidemic have empowered women to take up leadership positions. Within the MNGO, men are clearly outnumbered by women both in management positions and by those who come to the organisation for support.

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<sup>16</sup> I am aware of the fact that in some cases there is a need in our days for these constitutional rights to protect vulnerable children. However, the very same rights have detrimental effects on how parents can raise their children these days.

## 5.6. Sexuality

One key social issue involved in safe sexual behaviour is how men and women define their sexuality in the context of poverty, unemployment, and violence (Campbell & Mzaidume, 2002:230). The following issues require a close investigation: an uncontrollable sexual desire driving men to have multiple sexual partners; "a biological need for the pleasure of flesh to flesh sex; and the desire to father many children" (ibid.). Campbell and Mzaidume (ibid.) found that in their study "young women who carry condoms are considered to have loose morals". Similarly, the participants of this case study shared similar experiences:

*It is so embarrassing to tell a man that I have condoms when it happens that you see each other in the bar or party. As much as I want to protect myself I also don't want to be seen as someone who was looking for sex (Interview, 13 September 2007).*

As a result, women avoid carrying condoms because of such labels.

More recently there has been a growing understanding that

while sexuality cannot be divorced from the physical body, and from our instincts and emotions, it is also socially constructed. This has led to a series of studies that have sought to show that HIV/AIDS is in some or other way the result of African culture (Campbell, 2003:7).

The tendency has been to blame such African practices as polygamous marriages and circumcision for the continuing spread of the epidemic. Such narrow-minded assessments unfortunately cannot help us to understand why HIV/AIDS is spreading very fast in most parts of the country.

Understanding sexuality and sexual behaviour is important for the development of behaviour-change approaches. More insight is needed into what people say and think about sex, into issues of family violence, and into taboos. Why do people continue to take risks even after education programmes? How do they motivate themselves when conducting these perilous behaviours? How much value do people put into their relationships? These are issues that require ethnographic investigation.

The participants of this case study shared their feelings on some of these issues. During the group meeting with my participants I asked them why somebody would have sexual intercourse without using condoms when she/he knows that he/she has been diagnosed as HIV-positive? A group member said:

*I cannot tell my boyfriend that I'm HIV-positive because he will dump me and what would I do after that? It worries me to think about what would happen if he find out about my status. I cannot imagine being thrown out of the house at this stage. I can't stop thinking about what people in the village would say if they find out and who else would want to be in a relationship with me? (Interview, 23 April 2007).*

This means that as much as there are those who intentionally infect innocent victims (who act out of retribution because they have been victims themselves), for some disclosing means taking a risk of losing a partner/relationship.

*My boyfriend does not know that I am HIV-positive. It is my secret in our relationship. I can't take a risk of losing him by telling him that I'm HIV-positive (ibid.).*

This means therefore there is a need for a better understanding of the consequences of disclosure at individual level (besides the stigma), the family, and the community at large. Another member expressed concern that:

*Yho bhuti, with man you can never tell what he is thinking ... maybe by telling him after you have already slept with him without condomising that you are HIV-positive he might even kill you. So the best thing to stay in your relationship girls (pointing to other group members) is to keep quiet ... pretend as if you don't know anything (Interview, 12 April 2007).*

In poor communities, providing information about health risks is most likely to “change the behaviour of, at most, one in four people” (Campbell & Mzaidume, 2002:229). This is because health-related behaviour such as condom use is determined “not only by individual choice but also by the extent to which social conditions enable such behaviours” (ibid.). According to Campbell (1997:145) “investigations of a number of heterosexual settings have suggested that the dynamics of condom use or non-use cannot be understood without taking cognizance of a context in which men see their virility as compromised by using condoms”. It came out from the discussions that when women insist on condom use the other partner feels that he is not trusted in a relationship. One of the informants says that:

*Before I got infected I used to condoms but the problem I was not consistent. Sometimes when I have a new boyfriend and tell him to use a condom he would say I do not trust him or say things like have you been sleeping around? So that is how I think I got infected (Interview, 13 September 2007).*

It was pointed out that in a happy relationship people do not want to spoil that happiness by *small things* (Field notes, 29 December 2006).

The emphasis by parents that children should be sexually active when they are in a stable or serious relationship is problematic because it encourages premature trust of partners and therefore non-use of condoms (Campbell & MacPhail, 1997:1615). In other words instead of promoting abstinence this view encourages young people to engage in sexual practice. Informants of this study indicated that within regular relationships trust mitigates against using condoms. Young women argued that for them to insist on condom use when with steady boyfriends is seen as indicating a lack of respect and trust.

*The problem with condoms is that, once you develop trust with your boyfriend you stop using condoms ... men have a serious problem when it comes to condoms. Even when you tell him that you are HIV-positive he just forces himself. They say it's different from flesh-to-flesh. My boyfriend refused to use it the other day. I then put a female condom, within no time he just threw it away (Interview, 23 April 2007).*

These women reported that men refuse to use condoms by arguing that they are married ("I am your husband") how can they use a condom? Don't you trust me? One of the respondents said that:

*My husband said to me we are married there is no need for us to condomise. He said if I insist he will then know that I have another man that I sleep with when he is away (Interview, 13 September 2007).*

## 5.7. Turning points

In conducting my interviews, it was always important for me to look for turning points in the life stories that were told to me. This required that I become sensitive when selecting what would count as a significant turning point in someone else's life. This is because every life is filled with little turning points, but as sociologists we should be looking to identify the major turning points (Giele & Elder, 1998:203). According to Plummer (2001:194), at particular moments lives face critical turning points or major life events around which a lot of activity happens. In dealing with

people living with HIV/AIDS, these turning points include being diagnosed as HIV-positive. This is a significant event to everyone living with HIV/AIDS. Indeed, many individuals refrain from testing for HIV/AIDS because of the fear of having to face this critical stage. As one informant explained, this event can bring the end of what could be described as a happy/free life and be the beginning of a new life characterised by stress, stigma and isolation.

*Hey when I was first told that I have ikiss-kiss my life changed. I didn't know how to handle the news ... I was devastated, my life was destroyed ... thinking about my parents, my child who is this ... that infected me. Even today I don't know who infected me. I think if I can know him I will be relieved because now I'm just cursing every man I slept with and that is not fair (Respondent, 29 July 2006).*

Another respondent put it like this:

*For me the first thing that came to mind was my child. I was praying that my child would be HIV-negative ... unfortunately he was positive and it was too late to save him. I also thought about my parents, brothers and the humiliation for my family in that village (Respondent, 23 December 2006).*

In tears she further said that

*Even though I accepted my status but it's hard to accept that I can no longer have a normal child like other people (ibid.).*

Even if people are part of a support group, they will always be aware that they are different from other people. They might pretend to be like everyone else in a support meeting but when they are by themselves, they come to terms with reality that they are sick and therefore different. After a long silence she said that

*People say that we are strong because we have accepted our HIV status but I must say it is not easy. At times you feel you can just have the group members all the time, especially at night. I don't know about other people but sometimes I feel like what people are saying about us is true that we are different. Yes knowing my status has advantages but when I am lonely I feel it's better to be those who are still in the dark about their status (ibid.).*

A further significant event mentioned by one of the respondents was to lose a baby.

*I lost my first baby although I'm not sure whether it was due to AIDS or what. I then told myself that I must have another one. I then stopped condomising with my fiancé but he also died of AIDS at a very early age. I really needed my own baby but now I have given up (Respondent, 28 December 2006)*

Even though parents who are not HIV-positive also experience the loss of children some respondents living with HIV/AIDS believe that if it was not for their AIDS

related illnesses, their children would still be alive. They think that if they had known about ways of prolonging life after infection maybe something could have been done to save their children. As one of the respondents who lost her child put it:

*I believe that if I had the knowledge that I have now my child would still be alive. When I was told that he is also HIV-positive it was just too late because he died after two weeks. This is one of the reasons I joined the Masibambane so that I can help other mothers save their children (Interview, 13 September 2007).*

It makes it hard for them to forgive themselves.

Furthermore, being isolated because of the stigma associated with AIDS is a significant turning point that made my participants realise that they are different. At the individual level, stigma takes the form of behaviours, thoughts, and feelings that express prejudices against persons infected with HIV/AIDS. A report by UNAIDS (2001:7) argued that HIV-AIDS-related stigma affects self-esteem, mental health, and access to care. "Stigma removes power from the stigmatised person, promoting differences and reducing the stigmatised group or person's social status and self worth" (Link & Phelan, 2002:4). When people realise their HIV status, they immediately think about their relatives and what the community will say about them.

*When I thought about my relatives I took a decision that I will never go back to that village. I was not ready to hear people calling me by names such as unengculazi (she is HIV-positive) because of my situation (Interview, 12 July 2007).*

Some authors observed that stigma attached to HIV/AIDS may be different between men and women (Bunting, 1996:64; Vlassoff et al., 2000:1356). In many communities men are likely to be excused for their behaviour that resulted in their infection, whereas women are not (Shefer, 1999:18). In a marriage, it can lead to violence against the woman or to her exclusion from the household (Strebel, 1993:32). The impact of HIV/AIDS on women is particularly acute in the Lady Frere District. In this community women are perceived to be the main sources of sexually transmitted diseases.

*Men here do not see themselves as also contributing in infecting us. They believe that it is women who bring the virus in a relationship and you see that from the fact that they do not want to talk about or join a support group (Respondent, 22 June 2007).*

Some respondents expressed frustration of being stigmatised to attend public gatherings because of their openness about their HIV status.

*It's so hard, you have to prove yourself that you are just like them* (Respondent, 28 December 2006)

Another participant said when expressing her feelings about the treatment she receives from her community.

*The moment people learn that you are HIV-positive, they treat you differently. Neighbours shun you. Children are told not to touch or associate themselves with you* (ibid.).

In some cases having to disclose to one's family or sexual partner can be a difficult thing to do.

*I didn't know how he will handle the news so I decided to keep it to myself* (Interview, 23 December 2006).

Turning points are not always negative events in one's life. They can also change one's life in a positive way. For instance, joining a support group has changed the attitude of many individuals in my case study. It also changed the way they think about themselves.

*Before I joined this support group I never talked about my status but now I joke about the fact that I'm positive ... I know now that it is better to know your status and do something about it instead of being in the dark and just continue infecting others* (Interview, 28 December 2006).

This shows that turning points can also represent circumstances or decisions that would lead to new opportunities or events that would influence individuals in a positive way (Plummer, 2001:194).

### **5.8. Barriers for testing and disclosure**

The most common barriers to testing and disclosure mentioned by my respondents were stigma and fear of desertion from a relationship. In some cases men become defensive when asked by their partners to go for an HIV test.

*My husband refused to test, saying that there is no AIDS in his house. He said if I go and they tell me that I'm positive I should not mention it to anyone* (Interview, 23 April 2007).

The reality of stigmatising those living with the virus results in people keeping away from prevention and care, creating fertile ground for people not to get tested and

thus they remain unaware of their HIV status. This contributes to furthering the spread of HIV (UNAIDS, 2003:7).

Some also expressed fear of abandonment. This is closely tied to the fear of being thrown out of the marriage and losing economic support from their partners. A married woman in her early 40s said:

*I have five children and if I lose their father now how would I cope in raising them because he will run away. I cannot go back home with these children (Interview, 23 April 2007).*

Some argued that they would rather keep that information to themselves than upsetting their family members by telling them that they are HIV-positive.

### **5.9. Africans – why spend so much money on dead bodies?**

African communities are well known for preparing abundant food for funerals. It has become a competition for families to have the best funeral accompanied by an expensive casket. Families join many burial societies to ensure that “at least in death (family members) are respected and accorded dignity according to local rites” (Narayan et al., 1999:149). Indeed: “Funerals remain the one event which still unites most communities. Family members feel great pressure to show their worth by properly honouring the memory of the deceased with a large funeral meal” (ibid.:150).

However, this becomes problematic in times of an epidemic such as AIDS. The disease is known for infecting more than one family member at a time and very often victims are likely to die in short succession of each other, a was the case with this respondent:

*I lost two sisters because of AIDS. It has been really difficult for my parents ... whenever I get sick, even if it is just a flu I could see that they think I am going to follow my sisters (Interview, 12 September 2007).*

Besides, to care for one individual takes a lot of family resources. This is because a sick person will be taken to both the traditional healers as well as the cost buying western medication in the hope that things will improve. For poor people, the consequences of these expenses are way beyond imagination. In the age of HIV/AIDS communities might find it necessary to review the value and meaning of this

practice. This is particularly important when considering that the practice has nothing to do with culture where there could be strong beliefs about the meaning of the practice: it is purely to comply with socially created standards. The MNGO member said that:

*The reason as to why families go out of their way to have the best funeral is because of the pressure from community members ... people compare funerals in terms of food, hiring of a tent, cars that came and now the coffin. If it is not a casket, you do not get the kind of recognition and respect usually awarded to someone buried by a casket. So it is up to individual families now to weigh the long term benefits of this (Interview, 12 September 2007).*

The fact is that all dead bodies go underground, whether accompanied by an expensive casket or cheap coffin; they all go to the soil. Whether one is a Christian, Hindu, Protestant or non-believer, the fact remains we will never see these people alive again.

It was interesting therefore for me to find out from my respondents why people spend thousands of rands for one day's display. In the past, deaths were rare and it was not as expensive as it is today to bury someone. Is this really a testimony to the fact that as group members people don't want to challenge what they believe to be the right way of doing things even when this is no longer suitable to the current conditions? (Sometimes others would even call it 'our culture'.) To wait for three weeks before the funeral could take place because families are waiting for the so called 'relatives'<sup>17</sup> to come back will need to be reviewed. A community member from the eMkhaphusi village says that:

*I think sometimes we extend the waiting period for too long ... I think sometimes we grieve for too long. Because throughout this period you have community members and relatives who come to comfort you but the reality is that you have to give them food and make coffee for them otherwise they will not come to your house ... nowadays families buy groceries twice before the funeral and that is not on (Interview, 10 September 2007).*

Some of my respondents indicated that people would do anything during the funeral to impress friends/neighbours and relatives who come to pay their last respect to the

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<sup>17</sup> People who did not make any effort to take the deceased person to the doctor. For me this is really unfair to say the least. This becomes problematic when thinking about the cost that the deceased families have to undertake such as buying food for those who come to mourn every day and the cost of the mortuary.

deceased (Field notes, 23 December 2006). To me this is a complete waste of money especially where young people are dying in big numbers.

The data also revealed a lot of evil minds where people, as soon as they realise that someone has AIDS, start joining more burial societies.

*People know that you cannot help someone with AIDS, so the best you can do is to make sure that you provide the best funeral for her (Interview, 28 December 2006).*

But for others it was simply a way of saying goodbye to their loved ones/children.

### **5.10. Conclusion**

In this chapter I argued that the current dimensions proposed by the mainstream HIV/AIDS prevention strategies, in particular the Knowledge, Attitude and Practice (KAP) model, have limited impact in reducing the spread of the epidemic. The chapter emphasised that structural factors such as the persistent poverty and deprivation dilute the effectiveness of educational-oriented prevention and awareness strategies. This is particularly the case considering that educational-oriented strategies do not confront these structural factors. Rather the mainstream strategies are confined to individual behavioural aspects. These approaches downplay the fact that the material conditions of the people may have a greater influence on their behaviour. I argued that for a better understanding as to why people continue to take risks even after they have been educated about the dangers of AIDS is more complex, and it requires, among other things, an engagement with people on the ground to hear those deep personal stories. It requires that we understand the long-term consequences of disclosure to one's sexual partner. It needs an appreciation of the fact that, as much as AIDS is the apparent result of HIV, it also has a social dimension to it. In communities characterised by high levels of poverty, women will do whatever it takes to remain in their relationships. An attempt was made in this chapter to tease out the underlying reasons for people engaging in high risk behaviour. The aim of this chapter was to illustrate that there is a tendency by those in power to address problems at a superficial level and not at a deep structural level.

## CHAPTER SIX

### The Masibambane Non-governmental Organisation

#### 6.1. Introduction

This chapter is a discussion of the main findings of my study. It is structured according to the main research goals introduced in Chapter One. The focus is on how the Masibambane Non-governmental Organisation (MNGO) acts as an intermediary agent that connects the eMalahleni government with surrounding communities in dealing with HIV/AIDS.

After a long association and continuous interaction with this community organisation, I discovered that social capital, which I use as a conceptual framework in this research to make sense of what is happening in the Lady Frere District, is under threat. This is due to a lack of cooperation between the government officials and the civil society representatives. As I have argued in previous chapters, the history of this lack of trust between the stakeholders has its roots in the apartheid era where they saw each other as "them" and "us". Because of this, I argue in this chapter that this lack of trust between the stakeholders compromises the formation of social capital.

I also discovered in the field that AIDS has damaging effects on social capital formation for the Lady Frere communities. HIV/AIDS in these communities has created a situation whereby parents believe that when their children get seriously ill it is because they are bewitched by their relatives and neighbours. I argue that this form of denialism is detrimental to the positive impact of the education campaigns proposed by the MNGO in these communities. It is for this reason that I believe that the preventive and curative efforts of the AIDS campaign require more than technical and medical help as is usually proposed in the literature. It calls for a social approach to build social solidarity, mutual help, trust, and to remove social stigmas by means of social inclusion. In this regard, social capital formation may become a useful tool in the fight against HIV/AIDS (Jamil & Muriisa, 2004:8).

The main purpose of the chapter is to examine the factors that led to the formation of the MNGO in the Lady Frere District. The chapter examines the extent to which the eMalahleni local government has used this community NGO to reach communities, what role the MNGO has played in shaping the relationship between the local government and surrounding communities, and finally, what kind of training/support is available to the staff members and the volunteers working for the MNGO. An attempt is made to investigate how these stakeholders interact with each other in dealing with HIV/AIDS. In other words, how does this NGO interface with communities and related stakeholders? The chapter also examines the way in which the MNGO operates on the ground in establishing a community's response to the HIV/AIDS pandemic. Is there a clear understanding as to who does what in which village(s)?

## 6.2. Leadership dynamics within the Masibambane NGO

The MNGO is largely dominated by young women.



A picture of some of the Masibambane NGO members.

According to the members this is mainly because men do not want to be seen as part of an organisation focusing on AIDS. For most men, being part of an AIDS-related organisation does not provide positive benefits in the long term. Among other things that were frequently cited by members is that, for men belonging to an AIDS-related

organisation reduces the chances of getting beautiful women in future in town or in the village. It also relates to the stigma associated with AIDS. It is on these grounds therefore that I see that the challenges posed by HIV/AIDS have uplifted women into leadership positions: the AIDS issue has empowered women by providing a platform for them to show their leadership skills.

However, within the MNGO cracks are beginning to show between the group leaders. After the death of one of the organisation's founders, certain individuals contested the chairperson position. This resulted in a conflict when the organisation received funding from the Department of Social Development. Some individuals who were part of the organisation when it was still in its infancy had gone astray but when the organisation obtained money they made themselves available for leadership positions. Some were already working in town but came back to demand their stipends. The problem started when those managing the organisation's finances gave themselves stipends without telling other group members. Other group members felt that those in power were beginning to abuse their power.

### **6.3. Village-level organisations**

It is often argued that the increase in the number of people living with HIV/AIDS (PLWH) results in a mushrooming of community-based NGOs that provide care for affected people. However, as much as this may hold true for some areas, in the Lady Frere District the opposite is true. There is very little happening on the ground. Very few people feel the need and have the courage to do something about HIV/AIDS. Instead, in most villages the more people talk about HIV/AIDS the more some community members withdraw their support for initiatives addressing this issue. The MNGO peer educator says that:

*In some villages people insulted us...saying we are a bad influence to their children. At Bengu village we were told during our campaign that people know about AIDS and therefore we can leave (Interview, 12 July 2007).*

During the initial stages of this case study, most of the support groups and community-based organisations (CBOs) that were originally regarded as active in

dealing with the issues related to HIV/AIDS were no longer functioning. Most former group leaders pointed to the lack of financial support in the area for such organisations. One of these people said that:

*Even organisations such as Masibambane have been struggling to get funding. The only reason they are still visible and working is because they have connections with the TAC and are supported by some local businesses (Field notes, 29 July 2006).*

Similarly, even MNGO members highlighted the lack of financial support:

*Because we do not have donors we had to pay from our own pockets. Sometimes you work the whole day and you did not have money to buy bread and take a taxi to go home but we continued because we want to save lives (Interview, 23 April 2007).*

Most people interviewed for this project said that the main reason for their joining the MNGO was to get emotional support and learn more about HIV/AIDS. One of the participants said that:

*By joining Masibambane we are getting support and valuable information that help us realise that AIDS is not a death sentence as we used to believe. There is life after infection ... being infected means that you have to change your way of life. Now we know that AIDS is a chronic disease just like TB or cancer (Interview, 23 December 2006).*

In the Lady Frere District, young people are considered a particularly vulnerable group due to various predisposing biological, psychosocial and economical factors. It was reported by the community members that the use of drugs in these villages is very high. This is especially the case in as far as dagga and alcohol are concerned. A local church leader explains:

*Young people are so committed to drugs in our communities here. We try to get them involved in church activities with the aim that they will change but they go back to the streets where they smoke dagga and drink alcohol ... they lack motivation to go to school (Interview, 13 September 2007).*

Despite the numerous efforts that have been made at a national level to educate for and to encourage prevention, the behaviour of young people in these communities has been slow to change, and HIV/AIDS continues to spread. The local government and the Department of Health have been very ineffective in putting in place programmes to prevent the spread of HIV/AIDS, mainly due to a lack of human capacity that greatly affects service delivery in the District. Similarly, communities that are directly affected by the effects of HIV/AIDS on young people did nothing to

combat the disease until the late 1990s. AIDS in these villages was considered to be an urban/township disease. This situation impelled two female individuals living with HIV/AIDS in 2003 to establish a community support group with the aim of sensitising the youth against the dangers of the pandemic.

#### **6.4. Contributing factors leading to the formation of the Masibambane NGO**

During my scouting visits to the Lady Frere town early in 2006, it was clear to me that there was very little happening in this small town in as far as dealing with HIV/AIDS was concerned. This was confirmed by different community members and government departments I visited when I was still looking for community organisations active in the area of HIV/AIDS. The people I interviewed confirmed that civil society is very ineffective in these villages regarding HIV/AIDS. Most of my participants reported that before the formation of the MNGO, which started as a community support group, there was virtually nothing happening in as far as HIV/AIDS activities in the Lady Frere District was concerned. CBOs that existed were mainly politically-oriented and were not concerned with other social problems such as HIV/AIDS challenges.

Accordingly, the little knowledge that people had was through the media (radio in particular). Some local clinics made attempts to provide education about the AIDS epidemic. However, their impact was very limited because the majority of people do not attend clinics except when they are sick. Because of this, the information through these education campaigns reached mostly females as they attend clinics regularly for pregnancy prevention. As one informant put it:

*Men do not come to clinics unless they are sick. So it is very difficult to get the message across to everyone, especially the use of condoms which is an important focus of our campaigns. And the problem in educating females only is that men are the ones who are expected to use male condoms. This means if they do not have the necessary knowledge for condom usage our efforts are meaningless ... sadly we know that most men hate condoms (Interview, 28 December 2006).*

Among the challenges that faced the health professionals interviewed in educating communities about HIV/AIDS is the culture of silence about sexual matters. The majority of the health professionals/nurses working in these local clinics are female,

Xhosa speaking people. Respondents reported that these nurses found it difficult at the beginning of these campaigns because they were not used to talking about sexual matters with older people. With regard to this a local nurse says that:

*Our culture as black people does not allow us to talk about sexual matters with old people. Its ok when you talk to people of your own age but when we had to teach people about AIDS and sex it was really difficult because we see them as our parents. But we overcame that fear now (Interview, 11 September 2007).*

It was a new territory that they were expected to break.

The non-existence of civil society organisations in dealing with the HIV/AIDS challenges to complement the government efforts, led to two community members taking the initiative in 2003. Both these members were formerly members of support group organisations (one in Johannesburg and the other in Cape Town). When they came back to their villages in Lady Frere, they approached the Department of Health in an attempt to establish a support group for people affected by the HIV/AIDS issue. The idea was welcomed by the health professionals from the eMalahleni Municipality. To sell their idea they went further and approached various schools in the area. It was reported that some school teachers appreciated the idea and became fully involved in the project. The interaction between different individuals led to the formation of a community support group early in 2003 which later became known as Masibambane (meaning "let us hold hands and work together") NGO. Masibambane is also part of Masihlanganeni (meaning "let us come together") South Africa Partners, from the United States of America in Boston. Masihlanganeni South Africa Partners joined the Department of Health in the Eastern Cape Province in 2003 to facilitate HIV/AIDS programmes, and strive to reduce the spread of HIV and to improve the health and well-being of PLWH by assuring their active and effective participation in strategies to end the epidemic. Specifically, the project seeks to achieve its goals "by improving HIV/AIDS service delivery, care and support, and by promoting PLWH involvement in mobilization and system development" (South Africa Partners, 2003:1).

Another main reason for the formation of the MNGO was a concern for the growing number of young people dying of AIDS-related illnesses in these villages. The most important stimulus in the formation of MNGO was that in some families, parents were reported to have told their children to leave the household when told by medical professionals that they were HIV-positive (Field notes, 12 April 2007). The group leaders said that this was a result of a lack of knowledge of the disease by these parents. It was on these bases that they felt that there was a need to educate people about the AIDS epidemic and to encourage individuals to join support groups.

*On our arrival here we realised that people do not talk about AIDS. Most people had strong beliefs that AIDS is an urban disease and not for people living in rural areas. When there is a funeral, people will be given false information instead of the real cause of death. Because of that we felt that someone has to take responsibility because that was not good for those who are left behind (Interview, 27 December 2006).*

Another founder of the MNGO said that:

*Most people were in denial here. Although the AIDS symptoms would be there such as loss of hair, change in skin colour and thrash in their lips, those who attend the funeral would be told other things such as being sick because of jealousy from neighbours (Interview, 29 July 2007).*

These are some of the factors that led to the formation of the MNGO.

## **6.5. The MNGO activities**

The MNGO is involved in educating people in different villages of the Lady Frere District about HIV/AIDS. Most local inhabitants of this District believe that the formation of this community organisation has made a contribution to bringing hope to the communities and changing the sexual attitudes of young people. Group leaders of this organisation take part in local funerals to talk openly about themselves and how one can deal with living with HIV/AIDS.

*During funerals, especially of our members, we tell people about the importance of knowing their HIV status and knowing where to get help. Most people approach us after these workshops asking for help and I think what we are doing as an organisation has really helped a lot of people to get ARVs on time ... We believe that through our campaigns, we have saved a lot of children who might have been infected during the delivery period (Interview, 12 April 2007).*

Part of what the MNGO does is to provide counselling and support to the newly diagnosed HIV-positive individuals (MNGO, 2003:3). The organisation has two members who specialise in providing counselling: one of them is a professionally trained counsellor, the other relies mostly on her own experiences in working with HIV-positive individuals over the past few years, and believes that counselling is critical both before someone is tested and after the test.

*Most of the people that I am dealing with at the moment are people who have tested. Some have seen us doing awareness campaigns in Glen Grey Hospital. They approach us in town asking for help and that is how we get members because we encourage people to join our support group (Interview, 23 April 2007).*



During a support group meeting, the counsellor is providing counselling to the group members.

When it is necessary, former members of the organisation also provide counselling to comfort people. The group members believe that counselling plays an important role in helping people to accept their HIV-positive status once tested:

*It is important that people go for counselling before and after testing because you can commit suicide if you are not strong. And also when you have someone who is in the same situation like you it becomes much easier to understand that you can still live longer and do things like everyone else (Interview, 10 September 2007).*

The main function of the MNGO is to conduct awareness campaigns in the surrounding schools, clinics, communities and hospitals (MNGO, 2003:3). The hospitals that they cover include the Lady Frere (Glen Grey), Indwe, and Dordrecht Hospitals. Because of their location, the organisation focuses more on Lady Frere

Hospital (Glen Grey). Their education-oriented campaigns are, however, very limited in scope and size because they cover mostly the villages from which they have members within the organisation (those close to Lady Frere). According to the members of MNGO:

*It becomes difficult for us to visit villages that are not represented because we do not know who to approach in those villages and from our experience in some villages people do not like being told about AIDS ... they would rather live in darkness (Field notes, 23 April 2007).*

Furthermore, it is reported that because the organisation does not have its own vehicle it becomes impossible to cover all the villages.

*We rely on the Department of Health for transport. Sometimes they do not tell us when they visit a particular village because they have their own programmes (Interview, 23 April 2007).*

Because of the lack of resources in this District, it will be helpful in building social capital to make use of all available resources. This specifically applies to the Department of Health: one would expect that the Department would make use of this organisation. Such cooperation will be beneficial in facilitating the building of other community groups as people will be motivated to cooperate in dealing with the HIV/AIDS problem when they see individuals who have accepted their HIV status and who are willing to arrange their lives around this acceptance.

According to their constitution, the MNGO also gives support to orphans and vulnerable children who lost their parents due to HIV/AIDS. This is done by assisting in registering all such children at the Department of Social Development and Welfare in order for them to get the government grant. It was reported that in some cases they asked for police intervention, especially where children are sexually abused.

*At eMkhaphusi village we found that a fourteen-year-old girl had been sleeping with her uncle and neighbours kept quiet about it. After we discovered that we took the case to the police and social workers and now that child is undergoing counselling (Interview, 23 December 2006).*

As part of their intermediary function, the MNGO network with different stakeholders in the district, including government departments (Department of Health, Department of Social Development, eMalahleni Municipality, and

Department of Education). Community leaders such as the headmen, chiefs, and the local businesses are also involved in the activities of the organisation. The organisation gets most of their financial support from local businesses, supplemented by small donations from individuals. It was only early 2007 that they started to receive funding from the Department of Social Development of the eMalahleni Municipality.

By all accounts, the MNGO is the only active civil society organisation in the Lady Frere District. Its members have made attempts to establish other CBOs in their own villages but these attempts have not been successful:

*I tried to form a support group in my village but people were not interested. Instead they gave me names so now I just help those who need help on how they can access ARVs (Interview, 12 June 2007).*

The reason cited was the belief by community members that if you belong to an HIV-AIDS-related organisation you are regarded as someone that has to be avoided. Children are told not to associate or play with you.

*When people learn that you are HIV-positive the only thing that they see from you is the virus (Interview, 23 December 2007).*

Some community members believe that an HIV-positive individual cannot work or do anything that an HIV-negative individual normally does. Furthermore, in some villages the Masibambane peer educators reported that they have been told not to come back again to conduct awareness campaigns because there is believed to be no AIDS or they are disturbing peace in these villages:

*We were told that there is no AIDS in those villages and people were not interested on what we had to say about AIDS. So we had to leave (Interview, 23 April 2007).*

Regardless of this opposition, since its formation the MNGO has attracted a number of community members, especially female members.



The Masibambane NGO members praying before the closure of a support group meeting.

By May 2007 the organisation had 54 members who were registered and had paid the R20 joining fee. This number rose from 18 after the organisation received funding from the Department of Social Development. According to the group leaders this is because members are given R600 per month as part of the HIV grant that PLWH access from government whereas active members (those in leadership positions) get R1 000 per month for their contribution to the activities of the organisation. Money in this case could be seen as a motivator for people to join the organisation. I say this because when the organisation was operating on a shoe-string budget due to a lack of resources members were not forthcoming.

In the past the organisation relied heavily on volunteers to serve the organisation to fulfil its mandate and obligations, namely to sensitise people and to bring light to the communities of the Lady Frere District. This meant that members had to take from their own pockets to pay for transport and buy food. Besides the funding by the Department of Social Development, the organisation struggles to secure sustainable funding from donors. According to the group members the organisation does not have a permanent physical address and they are forced to use the postal address of the Department of Health. Consequently, and due to the somewhat unfriendly relationship between them and the Department, the Department does not pass the

mail on to them on a regular basis. This leads to them not applying in time for other funding.

*They keep our letters there until we miss the due dates and we do not know why they are doing this (Interview, 23 December 2006).*

At times the relationship between the MNGO and the Department of Health is characterised by tensions and lack of cooperation, which seems to have a negative impact on their function as an intermediary organisation that seeks to connect communities with government facilities in the area of health. According to the group members the Department (including the local Municipality) failed on several occasions to inform the group members of funding opportunities.

The organisation assists individuals to access HIV/AIDS treatment and to get antiretroviral treatment (ARTs). One of the MNGO members said that:

*We work with Doctor Nongculaza<sup>18</sup> when he goes to the feeder clinics (Interview, 23 December 2006).*

It is reported that if people are not getting the treatment, members mobilise with assistance from the TAC to put pressure on the government.

*It is said in the government constitution that if people are not getting the treatment we should toyi-toyi against those who are suppose to give it to the people. It is stated clearly in the constitution that there is no person who will be sent back home without his/her treatment. So the government is appealing to us (people who are living with HIV) to assist the government so that people access their treatment (Interview, 21 April 2007).*

According to this participant this is because of the opportunistic diseases like meningitis, thrush, pneumonia, cancer, etc. that can be treated if people go for treatment early.

*The constitution says people should read wide about HIV/AIDS so that they can live longer. It also encourages people to know their rights about HIV/AIDS (ibid.).*

However, despite the claims by the MNGO members and government officials that there are always enough condoms, people on the ground reported a lack of condoms on two levels. Firstly, there is a virtual absence of female condoms in almost all

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<sup>18</sup> Pseudonym

government health facilities. Some members reported that they have never seen a female condom, let alone know how to use it. As this community member explains:

*I would be lying if I say I have seen a female condom let alone how to use it. I don't understand why condoms are not made available in the shebeens and local spaza shops (Interview, 10 September 2007).*

Secondly, some reported that they receive unkind treatment from the nurses when they ask for condoms:

*Some nurses they ask you why do you want condoms and what are you going to do...they make you feel uncomfortable. This is even worse when she knows you or your parents (Interview, 11 September 2007).*

## **6.6. The training available to the group members and volunteers**

Throughout the research process participants of this study expressed concerns about the lack of training that they experience. The group leaders who usually conduct awareness campaigns in the local hospitals and in schools have no formal training; they obtained their knowledge through working as peer educators for the Treatment Action Campaign (TAC) in Queenstown. In some instances the TAC organised workshops and the MNGO members would be taken for training. Other educators acquire knowledge through observing and listening what the group leaders do and say:

*We did not get any formal training from the Department of Health. All our new peer educators learn and use their own knowledge of AIDS to advice people (Interview, 12 June 2007).*

This raises concerns about the accuracy of the information that they give people. But most importantly it contradicts what was said to me by the government officials. The Department of Health officials said that they are working closely with the local groups in the area of HIV/AIDS. Based on my interviews, however, the only time that the Department and the MNGO worked together was on 29<sup>th</sup> November 2006, when they took part in home visits in the Bengu village. The officials said that this was part of the Department's strategy to involve everyone in the fight against HIV/AIDS.

In other cases the Department of Health claim to have approached the local chiefs, headmen, parents and church leaders to get involved in dealing with HIV/AIDS. With regard to the door-to-door campaign the government officials said:

*We worked integratedly because it is not just me ... I should not work alone as the Department of Health. Right enough as the Department, AIDS is our core business but at the same time it is a social problem. So all the departments took part and I was impressed because I had the idea that each Department should commit itself that it will be there with all its resources ... their vehicles (Interview, 28 December 2006).*

It appeared that as much as there is a lack of resources to deal with HIV/AIDS, the Department does not have a clear AIDS policy on what needs to be done and how it should execute it. When considering that the Lady Frere District have more than 19 villages, it is questionable that there is only one doctor working in these feeder clinics, expected to serve everyone from these villages. Everyone I interviewed, both from government and the MNGO, mentioned the door-to-door campaign. But other than that there was no other active involvement by the Department of Health. What came out clearly from the interview with the manager of the Department of Health was a lack of capacity in her Department. According to her this is because of ignorance and lack of cooperation by the provincial government. For instance, the Department did not have a finance officer. The manager reported:

*The person we have at the moment is someone who is dedicated ... a level two person. It is someone who does not even have standard 10 but she loves the job. So you need to sit next to her and tell her that you need to do an awareness campaign in Qoboshane village for instance ... so this is my budget. You need to be there until the end and that is time consuming (Interview, 28 December 2006).*

She said that vacant posts had been reported to the provincial government a long time ago but there was still no response.

*These are the challenges we are faced with at service delivery point. Because you find that we don't have an information officer – it is just someone who is dedicated also. Where you find that the information from the clinics is just meaningless ... because you need to interrogate that data and this person is not on the level to do that. I'm not criticising the person per se but the government because information is just like finance, you can't do without it (ibid.).*

The fact that most of what the MNGO does is based on the skills that are acquired through observation raises concerns about the accuracy of the information given to the people. This was of particular concern among other members of the MNGO:

*Well thus far we have not got any training let us say from the Department of Health. We asked for training a long time ago from the Department of Health but they don't respond. Even with regard to getting access to transport they tell us that they are also struggling because they do not have enough vehicles. They tell us that the money for training was not enough. They will get some funding to train us ... we are still waiting, hoping that they will see the importance of what we are doing. Because AIDS is killing our people. So that is the situation we are in. But we didn't give up. We told ourselves that we will pay from our own pockets if need be to hire a taxi. To show that they don't care about us, we have another group called Masihlanganeni (meaning "let us come together") which is also an organisation for people living with HIV/AIDS. So they send faxes to the Department of Health to inform us what they are doing in Queenstown but the Department just keep quiet (Interview, 11 April 2007).*

These members believe that it is the Department of Health's responsibility to train them as the work that they do is supposed to be done by the Department. There was a strong feeling amongst group members that the Department has failed them as promises to train them were made but they never materialised.

*The reason why we are able to grow as Masibambane is because of the TAC. They give us information and skills. Thus we are able to educate people. At the beginning we did ask the Department of Health together with their facilitator to help us with skills and they agreed. But they never fulfil their promises to us. But when they visit schools they call us and we do what we were supposed to do if we had training. They know that we have enough information with regard to HIV/AIDS but when it comes to employing us they don't give us a chance (Interview, 21 April 2007).*

#### **6.7. To what extent is the Masibambane NGO an intermediary agent between communities and the local government and non-governmental support services?**

On top of the fact that there are very few activities in as far as HIV/AIDS is concerned, the MNGO is the only active civil society organisation operating in these villages. When I asked the members what it is that makes them spend their time and energy doing this, they said that they would love to see more people coming out about their HIV status so that the community members can see the seriousness of the disease and can stop discriminating against people living with HIV/AIDS. The informant said that:

*There is a need to conduct awareness campaigns in these villages so that people can realise that it is not because we were sleeping around or with every men. You can have one boyfriend if he is HIV-positive you will get it. Our people need to know the importance of testing and be faithful to their partners (Field notes, 12 July 2007).*

Based on my interaction with the group members, I am of the opinion that the MNGO is making great strides to help communities realise their rights and know what they are entitled to demand from their representatives. Although they focus on HIV/AIDS, the organisation is also taking the issues of poverty and unemployment seriously as factors that need urgent attention. They are also growing vegetables to assist their members with good nutrition.

*We understand that not everyone can afford to buy healthy food every day and that is why we are growing vegetables so that our members can take home something at the end of the day without having to pay for it (Interview, 21 April 2007).*

It has been argued in the literature that "Civil society movements on HIV/AIDS have not only been critical in raising awareness of HIV/AIDS issues in terms of health and sexual behaviour, but they have also been the main instigators in challenging government policies" (Panos, 2006:286). The Masibambane NGO is no exception. They made use of the regional TAC structures to compel the local government to provide ARTs to people living with HIV/AIDS in these communities.

*It was difficult for most people to access ARVs because they had to go to Frontier Hospital in Queenstown to get their ARVs. We were not happy with that and decided to talk to the TAC in Queenstown because there is no TAC here in Lady Frere to assist us to put pressure on government to provide ARVs. Now our people go to the Glen Grey Hospital to get their ARVs (Interview, 23 April 2007).*

#### **6.8. To what extent is the local government using community organisations to reach people?**

Government officials interviewed argued that they are working very closely with the MNGO, and pointed to the fact that when they visit communities they invite MNGO members to come along with them. But they were quite sceptical about the kind of information the group members have.

*We don't know who trained them so we are not sure whether they are sending the correct information to the people (Respondent, 28 December 2006).*

When I raised this concern with the group members they accused the Department of Health for having failed to give them the training that they had been asking for.

*The Department had been promising us that they will get someone to train us but up until now we have not been trained. The knowledge that we have is through the workshops that we attend from the TAC (Respondent (a), 23 April 2007).*

*Last year they promised us that they will train us. The next thing they told us is that there is no money. So we must wait for this year's budget (Respondent (b), 23 April 2007).*

The pointing of fingers at each other could be seen as a defence mechanism, especially by the government officials. It illustrates that where there is little monitoring of what each department does, there could be a lot of malfunctioning that is not reported. This points to a need for active civil society organisations that can put pressure on those in power positions to ensure that they meet their mandate, which is to serve the needs of those who elected them. The Eastern Cape Province is known for a lack of service delivery in general. I believe that this is likely to continue as long as government officials are not accountable to the public. Constitutionally they are supposed to account for their actions, but from my observations and interaction with people on the ground there is very little interaction between government and people on the ground.

Although there could be some underlying reasons for some of the MNGO members engaging in activities such as HIV/AIDS awareness campaigns, there is no denying that there is still a need in these communities to educate people about the dangers of HIV/AIDS. This is particularly important when considering that the majority of older people still consider talking about sexual matters with their children to be a taboo subject. For this reason, as much as I am sceptical of education-oriented strategies imposed on passive audiences, I believe that there is still a need to conduct awareness campaigns to break the culture of silence about sex. There is a need in these communities to move away from the culture of raising young people solely through observation from their peers. Parents must learn to talk about all challenges that young people will encounter in life.

It is often said by the MNGO members that the interaction between the Department and the organisation is mainly during awareness days such as the World AIDS Day. There is no consistent interaction between the MNGO and some government

departments such as the Department of Health. However, this is not to suggest that the fault is solely on the part of government. At times the MNGO members appeared to contradict themselves when asked the same question about the level of cooperation between the two. For instance, in 2006 an MNGO member commented that there is no cooperation between the two. The same member when asked the same question in 2007 said:

*We are working close with them ... even last year we were working with them*  
(Interview, 23 April 2007).

Again, this raised a need for me to be careful of what my participants told me during our discussions. I was aware of the fact that the group members could make such accusations towards the Department so as to portray the MNGO as the only active and caring organisation in the area. For this reason I also relied on my observation for verification of what the organisation claimed to be doing. Indeed, my observation confirmed their claims except in a few instances where they were struggling to meet their claims. For instance, based on my observation there was a clear lack of financial management amongst the group leaders. This led to a few incidents where some community members felt that they should be getting the stipend but were denied by those handling the money. This was basically through a lack of a clear guideline in the MNGO's constitution as to who should qualify for the grant. Additionally, when I asked the group leaders how often they met with other stakeholders that they allege to be working with, it became clear that it was not in their agenda even to meet with the Department of Social Development to give them feedback as to how the money they received has been spent thus far.

This is very interesting and worrying because civil society organisations are quick to accuse government officials for being unable to account for financial spending. This raises critical issues such as: if the group members are unable to account for a small amount, would they be able to account for bigger donations if they get these in the future?

On the side of the local municipality, on few occasions I observed a situation where the local municipality got involved. During my visit they invited someone from Tunisia in North Africa to come and help the MNGO to grow in order to overcome the problems that they face in their attempts to establish other community groups in other villages and in bringing men to support groups (Field notes, 28 June 2007).

### **6.9. Young women at risk of HIV/AIDS in Lady Frere**

On a global scale, the AIDS epidemic has been identified as an issue that impacts upon gender relations, so much so that it has been referred to as a “gendered epidemic” (Patton, 1994, in Hoosen & Collins, 2001:2). Studies indicate that women are often economically, psychologically and socially dependent on men and this influences the way in which AIDS affects women. It has been argued that central to understanding women’s vulnerability to HIV infection is their economic disempowerment. This is particularly the case when considering that (Hoosen & Collins, 2001:3) poverty places women at greater risk as they need to exchange sex to meet the basic needs of their family members and themselves. Increasing unemployment and the need to provide for households further exacerbate women’s vulnerability, according to Ankrah and Long (in Hoosen & Collins, 2001:5).

Participants of this study highlighted the need to have a male partner that they can rely on for economic survival. As the previous chapter pointed out, women do not have to be sex workers in order to depend on men for money. Even within stable relationships, some women indicated that sometimes they find it necessary to have a second boyfriend (affectionately known as a secret lover – *umakwapheni wam*). As one informant put it:

*We have a good understanding with my secret lover that during the day we pretend as if nothing is happening between us. We communicate by phone only and no messages should be kept ... you delete everything. I don't know if I really love him though but I can't drop him because he is not stingy when it comes to buying things for me (Interview, 23 April 2007).*

Married women in their late thirties complained that because of a lack of sex in marriage, they sometimes see it as necessary to have a secret lover.

*I have tried so many things in my marriage but it does not work. My husband tells me that he is old now and therefore I cannot expect to have sex every day/week. This is really frustrating*

*as a result sometimes I just feel like asking someone to share sex with not as if we will be dating ... just to satisfy that need (Interview, 21 April 2007).*

However, this is not to suggest that all women in who experience lack of sex feel this way. In my view the actions of these women to have a secret lover serve as a good evidence to show that in our society there is a new form of prostitution that is not questioned. The only difference from what these married women are doing is that they do not go to the streets to sell their bodies. Whether this is done for financial purposes or to meet the biological need, their actions fit the category of sex work in my view. The complaint by the respondent that there is a lack of sexual intercourse in her marriage shows that people get into marriages for the wrong reasons. The lack of sex in the marriage should not be a justification for promiscuous behaviour by women. If the marriage was based on indisputable love, she should be patient enough for them to find a long term solution to the problem.

Some scholars have also provided a biological explanation for the vulnerability of women. Mlungwana provides the following reasons in explaining women's vulnerability to HIV infection:

*As a receptive partner, women have a larger mucosal surface exposed during sexual intercourse. Moreover, semen has a far higher concentration of HIV than vaginal fluid. Women are epidemiologically vulnerable: women tend to marry or have sex with older men who may have more sexual partners and hence are more likely to be infected (Mlungwana, 2001:3-4).*

The United Nations (1995:20) believe that women are socially vulnerable to HIV: men are expected to be assertive and women passive in their sexual relationships. Whenever these social norms predominate, the result is sexual subordination and this creates a highly unfavourable atmosphere for AIDS prevention (United Nations, 1995:20). The latter two points are crucial in understanding the vulnerability of women to HIV/AIDS in South Africa.

The above discussion shows that women's social and economic dependence on men support my view that they will always be treated as junior partners in their relationships. It also exemplifies that we can have all the progressive laws in our constitution about gender equality, but in practice those rights end at the door. The

fear of the respondents of this case study to be thrown out of the household if they reveal their HIV status is testimony to this claim. As one of the group members express her reaction towards this issue:

*I would rather be treated like a child ... I would rather be told what to do than having to face the humility of being thrown out of the house because of my HIV status (Interview, 10 September 2007).*

My interaction with the local headman of the eMkhaphusi village made reference to the fact that the control men have over women is the only way that they can exercise their lost manhood. This discussion means that the political situation of the country can change but there are things that are deeply rooted in the structure of the community. From my observation it is natural for most African men not to treat women/wives as equal partners, and this perpetuates the view that women are secondary citizens both in their communities and within their marriages/relationships.

#### **6.10. Implications of HIV/AIDS**

It is important for local governments to realise that HIV/AIDS is not only a health problem that affects families "but a development crisis, with an impact not only on community members' health but on nearly all aspects of community development" (Mbere, 2002:7). HIV/AIDS destroys developmental efforts. It leads to a loss of human capital and this has a negative impact on the economic development as young and energetic people die. It threatens social cohesiveness, and aggravates and creates new forms of poverty. Effectively, HIV/AIDS threatens the sustainability and livelihood of the communities. Thus I believe that it is the local government's responsibility to ensure that at least the social, economic and material well-being of communities are well looked after as these have proven to be among the great contributing factors to the spread of HIV/AIDS. It is therefore important that the Lady Frere Municipality begins to understand the impact of HIV/AIDS on development and the impact that development can have on mitigating HIV/AIDS (Mbere, 2002:7). This could be done by creating more jobs and other cultural and sporting activities to keep young people busy. Additionally, the creation of more jobs in the area would mean that less young people go to big cities in search of

employment where some end up being frustrated and take to the streets to sell their bodies.

The increasing numbers in the MNGO show that with limited government responses, the formation of community organisations to provide support, care, and education to the PLWH is encouraged. The benefit in working closely with local NGOs is that the NGO programmes focus on the collective efforts of members rather than on individual initiatives. This collective action has made many people infected and affected by the epidemic to “manage the stigma and social exclusion and address issues of prevention and control” (Jamil & Muriisa, 2004:4). Low levels of human development and inadequate access to education and health fuel the spread of the disease (van Maanen et al., 2002:12).

#### **6.11. The need for building social capital in Lady Frere**

One of the major ingredients that sustain social capital in a community is trust between and among its people and groups, facilitating cooperation and coordination for mutual benefit (Putnam, 1995:67). This feature of social capital is not only confined to groups and only formal groups, it includes all forms of associations and relationships (formal and informal) intended to benefit.

The formation of social capital requires that the local government use its financial, human and other resources in new ways. The Eastern Cape is known for not spending all the money received from the national government. The Department of Health, in particular, could train all those who have matric qualifications and deploy them in these villages to work as educators. This would be beneficial for the individual and for the Department in the long term. At the individual level it could serve as part of empowerment and the experience gained could help these individuals when applying for jobs in the future. For the government, once the programme has been implemented these individuals could be used to train other community members in other villages, and the Department can call these

participants to assist when there is a high demand for health professionals in local hospitals and clinics.

The major task for the eMalahleni local government is to build trust among all existing stakeholders to ensure their full cooperation in government initiatives to address the HIV/AIDS problem. The concept of social capital deals directly with the need for social cohesion, avoidance of social marginalisation and exclusion of people living with HIV/AIDS. It promotes the treatment of every community member to be seen as part of the society.

The local government has a key role to play if social capital formation is to succeed. This is because it is at the local government level that community members from the different surrounding villages come together to express their needs and interests, and discuss how they can work together with each other to share their experiences in dealing with HIV/AIDS.

Establishing social capital is likely to lead to social inclusion of those previously stigmatised in their communities. In fact, the impact of HIV/AIDS on social capital needs to be considered both in terms of organisations and institutions, and in terms of the customs and practices that influence people's livelihoods (Jamil & Muriisa, 2004:26). Families affected by chronic illness and death used to rely on social networks for support. However, as calls on these networks increase, they are likely to become overburdened. Social capital is notoriously difficult to measure, but qualitative information from a range of studies suggests that it is becoming increasingly overstretched by the growing demands related to HIV/AIDS (Shah et al., 2002; Nalugoda et al., 1997; Rugalema, 1999; De Waal & Whiteside, 2003).

Government leadership should create the assurance of government support to PLWH. This may lead to a sense of trust in the government. Government initiatives to mobilise resources to fund organisations that are engaged in the fight against HIV/AIDS may lead to a formation of more grassroots organisations to fight AIDS.

This presence of more community groups may facilitate easy access to resources such as information and how to cope with the stress associated with AIDS. This is particularly important where the government finds it difficult to reach all the communities in remote villages.

Lack of cooperation in this regard may hinder the formation of social capital. To facilitate social capital formation, communities should mobilise funding to supplement government funding through their social networks (from outside donors). The promotion of internal social capital will imply that PLWH need to stop seeing themselves as victims, but should rather see themselves as 'change agents'. This should extend beyond the meeting of support groups of those infected only. These people should see themselves as members of their own communities working to build the community-government links that are necessary for the formation of social capital.

Local government should support local communities and voluntary efforts. The government needs to create an environment (by creating job opportunities where people live) that makes it easier for young people who are at risk to stay closer to their families. This may help communities sustain social ties and bring positive health benefits (Cote, 2001:34).

HIV/AIDS has the potential to undermine existing social capital, which demands investments of time and resources to cultivate and grow it. In spite of their wish to do so, individuals and households often find themselves unable to give of their time or resources to the community (Baylies, 2002:623). As shown in my interviews, people stigmatised as a result of HIV/AIDS are sometimes excluded from participation in social institutions.

A positive aspect of HIV/AIDS in these communities where I did my research is that it led to the formation of the MNGO in an attempt to mitigate the impact of the epidemic. New community-based organisations can emerge in response to

HIV/AIDS, and community organisations such as burial societies should add their efforts to combating AIDS. The responses of societies to HIV/AIDS, however, are not necessarily positive. For example, Help Age (2003) has noted an increase in older women being accused of witchcraft in relation to HIV/AIDS (Harvey, 2004:12-13). This directly affects social capital formation in a very negative way. Indeed, the issue of witchcraft and not-so-good-looking old women need special investigation because there have been incidents where old women falling under these categories have been killed. Such an African sociological investigation is necessary to provide flesh to these untested mystifications about African people. This therefore is an appeal to young researchers to realise that African cultures are rich and can make a big contribution to the knowledge production. In the 21<sup>st</sup> century there is a need for African scholars to appreciate the richness of our cultures. However, such an exploration is beyond the scope of this particular study.

It is important to note that the more people are connected to each other, the more they are able to access information, resources, and develop appropriate behaviour towards each other. The MNGO has played a critical role in bringing people together through constant interactions and community visits, and in the process they built solid relationships that led to members developing trust relationships. Such trust relationships are important in making members exchange views and other useful information for their survival. This reduces the potential costs on the part of government for mobilisation of the dissemination of information (Jamil & Muriisa, 2004:17).

A better understanding of the AIDS epidemic and a personal commitment to contribute to positive action in response to the many new challenges that the epidemic poses for society, is needed. Such an approach might create a culture of mutual respect, tolerance and cooperation among PLWH. In addition, it is a step towards the creation of cross-cutting ties with those infected and the general community, since by getting informed about HIV/AIDS people gain knowledge and understanding of the disease and how to cope with it (Jamil & Muriisa, 2004:19).

Each Department should commit itself to re-organise its existing budget so that it is aligned to the strategy. The social capital formation will require all government departments to redistribute existing and new resources to areas of greatest need and highest priority. For this reason government will have to increase its funding to the community organisations who, as significant partners, also need to deliver services within government's new mandate and therefore require strengthening of this important network.

#### **6.12. Human capital**

HIV/AIDS affects human capital in a number of ways. First, it adds to the burden of illness for a household. Individuals become chronically ill, suffering from a series of opportunistic infections before dying of AIDS. Illnesses related to AIDS are particularly damaging because they are often chronic and prolonged, and disproportionately affect prime-age adults (Harvey, 2004:10). Illnesses reduce both the labour of the person who is ill and of the people who have to care for the sick. In rural households, such as those in the Lady Frere District that depend on agriculture for their livelihood, studies have shown measurable falls in production as a result of HIV/AIDS (ibid.:10).

Furthermore, when someone dies of AIDS, her/his labour is permanently lost to the household and time and money need to be spent in attending funerals. HIV/AIDS often strikes more than one household member, and the shock of multiple deaths within a household can be particularly devastating. People who adopt orphans will also take on additional levels of care, although it is also possible that orphans will contribute to household labour. Finally, HIV/AIDS damages the transfer of knowledge from one generation to the next, due to the death of adults in their prime and by the fact that children are often withdrawn from school as a response to HIV/AIDS (Harvey, 2004:10).

It is the key function of the local government to ensure that preference is given to the previously under-serviced areas when expanding primary care services.

Improvements in health as a result of increased access to services are likely to facilitate the building of human capital by freeing up people's time and increasing their ability to engage in social interaction. Locally provided services should encourage community ownership of the health facilities. The Department of Health can achieve the latter through establishing clinics and community health centre committees closer to the people as provided for in the National Health Act of 2003. Most people in these villages are expected to walk long distances when in need of medical treatment: this discourages people from constantly checking their health status, except when they get seriously ill – when it is sometimes too late to save someone's life.

### **6.13. The impact of HIV/AIDS for the local government**

The HIV/AIDS epidemic has led to the near collapse of already fragile health facilities of many local municipalities in South Africa. Likewise, the health professionals and community members reported that the Glen Grey and Indwe Hospitals are struggling to accommodate all patients that have been diagnosed HIV-positive. As a result, people are sent back to their families at home, and this is rapidly eroding the ability of these households to cope with the growing threat of an unsustainable livelihood. The rapid spread of the virus in rural areas is diminishing the existing capacity to mitigate the consequences of HIV/AIDS (van Maanen et al., 2002:15). The dramatic dimensions of the epidemic have created formidable setbacks to development such as care for sick members and an increase in the number of poor and vulnerable households. In the context of poverty and HIV/AIDS, family care needs to be supplemented with support from governments. This needs to be done urgently.

The impact of HIV/AIDS has severe consequences for the eMalahleni Municipality. Because of the dissatisfaction in service delivery some members of these communities have started showing less interest in elections. HIV/AIDS has become a test for this local government in its capacity as a service provider and as a participant and key stakeholder in the community and the development of the community. It is

important therefore, that HIV/AIDS be regarded as a challenge not only to the government but also to governance per se (van Maanen et al., 2002:7).

Shula Marks (2002:22) says that "history teaches us that people can and do learn". While we can only move forward if we understand the complexity and depth of behaviour – "there are no easy fixes, no easy cures – we are not simply victims of the past" (ibid.). Human agency is important, as the Treatment Action Campaign has shown. Individuals and communities can be empowered, even if these are complex and tangled processes, and this empowerment can transform behaviour. It is in understanding the complex meanings that lie behind behaviour, and in exploring the conditions of the possibility of effecting such changes, that the challenge to social change lies (ibid.).

#### **6.14. Breakdown in traditional family structures**

A lack of parental care was highlighted as an important factor in HIV/AIDS, and with regard to teenage pregnancy (Interview, 28 December 2006). There are various explanations for this, but it is important to stress that, in the case of young people in this area, African families had been experiencing breakdowns in their normal structures over a long period due to urbanisation and change in family structures. The government representative that I interviewed highlighted that parents in these communities find it difficult to talk about sexual issues with their children. The manager from the Department of Health says that:

*Most parents are not used to this culture of sitting down with their children and tell them about the challenges they are going to face in their lives. I have cases where parents could not tell their female children to go for pregnancy prevention (Interview, 28 December 2006).*

They would rather ask someone outside the household like a nurse to talk with their own daughters. This account raises an important cultural issue, namely that sex is often seen to be a cultural taboo and not discussed openly. Consequently, much knowledge regarding sexual behaviour is acquired from peers and personal experiments.

In support of this, Friedman (1993:4) draws our attention to a commonly held myth in many African contexts. Young people are viewed as being sexually promiscuous by nature and that providing them with information about sex will make them even more sexually active. South Africa now has to deal with the consequences of its silence around sexuality and HIV/AIDS. We are also facing the consequences of shifting values and the failure to provide bridges to assist young people to cope within a modern context (Mlungwana, 2001:18). Social values, especially those of African cultures, have been going through transformation, and according to Mlungwana (ibid.:21) this has had a negative impact on the lives of African youths because the structures that served vital roles of nurturing the social and psychological growth of teenagers were abandoned in favour of Western ways of doing things. Delius and Glaser (2001) further describe the transformation in values that is occurring within the African Culture. These authors state that in the past, African communities were relatively open in their recognition and discussion of sexual issues. The power of adolescent sexual activity was recognised and techniques such as limited intercourse, and controls such as virginity testing, existed to help minimise the socially destructive dimensions of sexual issues. However, in the late 20<sup>th</sup> and early 21<sup>st</sup> centuries, these forms of sexual socialisation have diminished, leading to an increase in teenage pregnancy, sexual coercion, and violence against women (Delius & Glaser, 2001:17).

#### **6.15. Conclusion**

Based on my findings the MNGO is making a significant contribution as an intermediary NGO in the Lady Frere District. As much as there are challenges in achieving this role, they have played a critical role in linking the communities and government. The group's efforts often seem unappreciated by some government officials. This could be due to their lack of formal training in the area of HIV/AIDS. Without downplaying government efforts in dealing with HIV/AIDS in these communities, it was clear that the MNGO is playing a critical role in educating people about HIV/AIDS, although their efforts are somewhat limited in scope and size. For the local government and other stakeholders, it is worth realising that:

Every young person that is reached by an HIV/AIDS prevention message and who successfully adopts safe patterns of behaviour is a saved life. Our children and our youths are the most important resource that our nations have and we owe it to them to create an environment in which they can learn skills that will help them negotiate life successfully in this era of HIV/AIDS (Nduati & Kiai, 1997:222).

This could be achieved by all existing community organisations that are able to meet the new challenges implied by the HIV/AIDS. They should be funded to extend coverage to areas which are presently under-served and underrepresented. Special funding should be made available for emerging organisations, especially in poorer and disadvantaged communities such as in the eMkhaphusi village that have shown commitment to deal with HIV/AIDS challenges. In this regard local government has a critical role to play by making facilities available, especially funding and transport. This can reduce the workload on the local government so that they can focus on other service delivery issues by delegating some work to local organisations. I would suggest that, after reviewing what is happening in Lady Frere between different stakeholders, the government should consider seeing NGOs as partners in the fight against HIV/AIDS. The government could facilitate this by providing facilities such as a place to hold meetings. Communities and their organisations should contribute their energy, time and resources to assist the government in ensuring that the infection rate is reduced to the lowest possible number. Government, from its side, will need to ensure that it not only draws on and uses the energy, time and resources of communities, but that it also compensates groups and individuals for their contribution through providing resources and other support.

## CHAPTER SEVEN

### Thesis conclusion

#### 7.1. Orientation to the chapter

In this chapter I recapture some of the main themes and findings of my study. I also reflect on the philosophical and methodological commitments I employed in conducting this research. Many issues need to be recaptured not only because they deal with the intermediary function of the Masibambane NGO (MNGO), but also because of their significance in closing the gap between knowledge and behaviour.

#### 7.2. Conclusion

This study set out to examine the intermediary function of Non-governmental Organisations, using the MNGO as a case study to assess its HIV/AIDS responses in the Lady Frere District. In order to achieve this objective I made use of qualitative approaches due to the nature of the research questions I wanted to explore. By adopting a qualitative approach, I was able to fulfil the role of an active learner who is a participant and not an expert who is inclined to pass judgement on participants (Creswell, 1998:18). The main features of qualitative research used for this research are to describe, interpret, and understand the phenomena of interest. Qualitative research is adopted because it relies heavily on description and interpretation of the experiences of my participants. The qualitative research techniques are therefore important in understanding the intermediary function of the MNGO and people's perceptions of HIV/AIDS in the Lady Frere District. As I emphasised in the chapter on methodology (Chapter 2), in this study I did not start with a theory. As a basic principle in qualitative research, I applied inductive reasoning and knowledge was gathered through field work. Meaning was formulated by using the knowledge collected from the field over a period of two years (Mouton, 1996:78). This inductive reasoning provided me with the opportunity to develop general principles from specific observations made during my field work in the Lady Frere town and in the eMkhaphusi village (Babbie, 2004:55).

To make sure that my findings were accurate I used a tape recorder and I eliminated any confusion by contacting the respondents again to verify. Indeed, verification was a continuous important process that happened throughout the collection of data during field work, analysis and the report writing (Creswell, 1998:194). Among other data collection tools I used were participant observation techniques and focus group discussions (FGDs). Strydom et al. (2002:289) perceive participant observation as a valuable procedure for data collection in qualitative studies as it has an exploratory character.

In trying to understand the intermediary function of NGOs, it is important for me to firstly trace the evolution of these organisations. For this I argued in the thesis that throughout contemporary history poor and marginalised people have relied on government social institutions to provide them with basic services such as health facilities, clean running water, and so forth. However, empirical evidence revealed that over the years it became clear that the national governments on their own, especially in developing countries, were struggling to meet the needs of the poor. Attempts were then made to assist national governments by giving private institutions some social responsibility to service the poor. This often led to some state assets being privatised. However, private institutions made little impact to change the lives of the poor on the ground, because private institutions are often concerned with the interests of the share holders.

This situation led to the formation of development NGOs aimed at serving the needs of the poor. Conventional NGOs struggled with this challenge, and consequently, a new type of NGO that sought to fill this gap between local issues and national institutions, and the ones that are well established to link the grassroots work to international institutions came into being (Sanyal, 2006:3). These organisations have been named differently by different scholars: some refer to them as “intermediary organizations” (Carroll, 1992), others label them as “bridging organizations” (Brown, 1991) or “support organizations” (Brown & Kalegaonkar, 2002). The defining

features of the intermediary NGOs evaluated in this project that differentiate them from the conventional NGOs are:

First, they are located at the center of several constituencies – local groups and national bodies. Second, their activities include innovative programs like organizational capacity building, training and staff development, advocacy, collection and dissemination of information, networking, all of which are not considered to be traditional NGO activities (Sanyal, 2006:3).

These features enable these organisations to establish the “bridging ties” between the community groups and organisations and the institutional structures at the national level. Hence when compared with the conventional service-providing NGOs, intermediary organisations “have a greater potential for making sustainable and large scale impacts” (ibid.). In as far as their political orientation is concerned, these organisations “may be largely apolitical adopting political stands on an issue basis while lobbying governments and international organizations” (ibid.). These organisations often become suppliers of information and active participants in various social movements (Keck & Sikkink, 1998:14). It is on these bases therefore that these organisations are perceived as

local actors depending on the nature of their issue involvement at a particular time. The unconventional nature of their functions and their structural location make the issue of governance a problematic one for such organizations (Sanyal, 2006:3).

Intermediary organisations perform the following functions: a) give support to grassroots organisations – capacity-building inputs to strengthen local organisations; b) educational support – working with local governments and foreign donor agencies in creating an enabling environment where the voices of the poor are supposedly taken into account; and c) sectoral support – enabling partnerships across different sectors of civil society (Carroll, 1992:2-3).

Likewise, these organisations have their own limitations. For instance, some (like the MNGO) have “limited financial and management expertise and institutional capacity. Others work in isolation, communicating or coordinating little with other organizations” (World Bank, nd:2). The MNGO is no exception: although efforts are made to work with other stakeholders there is very little connection with other civil society organisations in Lady Frere. “Many may be confined to small-scale

interventions" (ibid.). These organisations may also not fully understand the broader social and economic context in which they are working. This means not all kinds of activities, therefore, are suited to the operational systems of intermediary NGOs, nor do they always reach the poorest of the poor (ibid.).

The MNGO acts as an intermediary agent that connects communities with the local government and non-governmental support services. It is against this main aim therefore that I examine the intermediary function of the MNGO in HIV/AIDS responses. I believe that because of their reliance on government funding, it will soon become difficult for the MNGO to put pressure on government as a service provider. In order for them to maintain their independence, they must seek outside funding, although there will be requirements and obligations with that too. They are most likely to maintain their role as a watch dog institution if they remain independent and not subservient to government.

In the thesis I also examine the factors that led to the mushrooming of HIV/AIDS NGOs, including the MNGO. An attempt is made to understand the relationships between these NGOs and local as well as national governments in the South African context, both during apartheid and in the post-1994 period. Based on my assessment it seems that intermediary NGOs, like traditional NGOs and the private sector, will have little impact in terms of changing the conditions of the poor and marginalised people. This is because in practice, like conventional NGOs, they serve the interests of governments in the name of donors or those who give them financial support to continue existing.

In this study I chose to investigate the intermediary role of the MNGO in shaping the relationship between these communities and the local government. The MNGO was chosen because of their active engagement in informing people about the dangers of HIV/AIDS and also their efforts in putting pressure on the government to take AIDS seriously. I chose the MNGO because it deals directly with PLWH. Additionally, as a community organisation, the MNGO is directly involved in sensitising and involving young people with regard to the HIV/AIDS problem, which is something lacking in

most NGOs dealing with AIDS at national level. This organisation is taking the problem of orphans who lost their parents due to AIDS seriously with the realisation that these children are tomorrow's leaders and therefore must be cared for.

To assess the impact of the services provided by the MNGO, I used the eMkhaphusi village as my case study. The eMkhaphusi village is one of the few villages in the Lady Frere District that has taken HIV/AIDS seriously and decided to take action. Although the number of people who died of HIV-AIDS-related illnesses is not known in this community for various reasons (including denial of being infected and people not testing), it is said that young people are the most infected. The eMkhaphusi village is closer to the Lady Frere town, when compared with other villages going to the upper Machubeni villages which are closer to Indwe and Dordrecht towns.

It is often believed that the effectiveness of NGOs depends on the environment in which they are working. In other words, where the political sphere does not allow the formation or free operation of independent bodies that can question and challenge the government, such organisations find it very difficult to function. Certainly, this was particularly the case during apartheid South Africa, where some society organisations had to operate underground or had secret agendas.

After the new political dispensation, one would have imagined that the formation of the MNGO (at a time when apartheid and its oppressive legislations were officially abolished), and their continued relationship with the majority government would have been friendlier. This is particularly the case when considering that the service that they provide is an essential component of service delivery that the eMalahleni Municipality is struggling to meet. However, as this research shows, their relationship with some government departments is often characterised by tensions and feelings of mistrust. The Department of Health in particular is very sceptical about the quality of services/information that this community NGO is providing to the people. This seems consistent with the view that many national governments and

politicians fear providing support and credibility to the initiatives of NGOs, because such groups can build upon their successes to question and eventually challenge development failures (Rau, 2006:286). The significance of this has been a low level of trust and collaboration between the MNGO and the local government with very little support from the latter.

In this thesis the emphasis is placed on the fact that, although knowledge about the ways of contracting HIV/AIDS is important, it should not be the only focus or treated as the solution to the problem. The culture in which people live and the context within which behaviour occurs are important dimensions that cannot be neglected. I concur with the view that there is a need to encourage young people to use condoms. However, we need to realise that if the context in which people live does not allow access to such prevention methods then how can we expect behaviour to change? Similarly, we can focus our efforts on encouraging young people to use condoms, but if one's culture is rooted in male domination and long established patrilineal lines like the communities in Lady Frere District, where men are predominantly in charge and make important decisions for their families and communities, how then do we expect young women, who have spent their entire lives in these villages and have very little knowledge about their rights as individuals, to speak out in such settings and insist that their partners wear condoms? In this study, women participants expressed their concerns over bed and breakfast issues which force them to stay in relationships.

Furthermore, African women know that questioning men's authority or their ways of doing things will most likely lead to them being beaten up and possibly being kicked out of the household. This is not to suggest that these women do not care about their health, but the conditions they live under make it difficult for them to take action. Because of men's economic power, women in these communities find it very difficult to report incidents of rape on them or their children. The Anglican Church leaders in

Queenstown<sup>19</sup> reported that women sometimes report incidents of rape to the police but later withdraw the charges. She said that:

*This is because women realize that if this man is put behind bars then there will be no one to provide for food. Neighbours who encourage people to report such incidents will not provide food for the household (Field notes, 12 July 2007).*

This therefore raises important questions around trying to understand the gap between knowledge and behaviour, as it points to the need to explore the context and the culture in which behaviour change is meant to occur (Strebel, 1992:54). Hence the need to understand the consequences of disclosing one's HIV status to a partner who in most cases is the provider for the family.

This is not to downplay the role of education-oriented strategies. In the absence of a vaccine that can cure the HI virus, prevention strategies remain the only hope for arresting the spread of HIV/AIDS. However, as was shown by empirical data from the field in Chapter Five, the preventive strategies that have been advocated (such as condom use) are strategies that men have in their control. Because most men have power over women by being providers, it is easy for men to refuse to wear condoms. Because of the need for a bed to sleep in at night women are somewhat compelled to engage in behaviours that are sometimes against their wishes. This means then, in pursuing education-oriented prevention and awareness strategies, programme and policy developers need to realise that such strategies cannot be divorced from structural problems such as poverty and male domination. The culture of women's reliance on men for economic survival needs urgent attention if any long term positive results are to take place. As long as African women in particular have little say in the relationships, they cannot be expected to insist on using condoms to protect themselves.

I argued in this thesis that the mainstream HIV/AIDS prevention and awareness strategies operate on the assumption that knowledge about the dangers of the disease will automatically lead to behaviour change. Such an approach ignores

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<sup>19</sup> This was said during a visit with American students to the HIV/AIDS organisations in Queenstown and Lady Frere towns, organised by the international office of Rhodes University and Dr Kevin Kelly of CADRE.

factors that might have a bearing on this behaviour change which are sometimes beyond one's control. Chapter Five revealed that where people depend on others for their daily survival, insisting on condom use becomes problematic. The interviews have shown that disclosing one's HIV status could have severe consequences which most people are not prepared to take because of high levels of poverty and unemployment. In reality, women in particular are faced with a situation where they must choose between securing their lives which might mean starving and a situation where they get involved with men whom they know are promiscuous in the area simply because they have money.

Based on my findings I argued in Chapter Five that the majority of the people in Lady Frere know about the ways one can contract HIV/AIDS and how they can protect themselves. As part of their community engagement, the MNGO members distribute condoms in their own villages to other community members. Yet some still engage in unsafe sexual intercourse. These members noted that they themselves find it very difficult in their relationships to insist on condom use because their partners hate condoms and they would rather not talk about it. This was also illustrated by the fact that none of the partners or boyfriends of the MNGO members are part of this organisation. It was because of these tendencies therefore that I argued in the thesis that "even though diseases are medical phenomena" (Rushing, 1995:4), they cannot be understood and explained in medical terms only. For me AIDS is no exception from other infectious diseases. In interrogating the effectiveness of education-oriented strategies it was appropriate for me therefore to examine the underlying reasons why these members continue to have unprotected sex when they have knowledge about the dangers of HIV/AIDS.

My participants reported that most people are still afraid to go for an HIV test in these villages. The most common barriers to testing and disclosure that were mentioned were stigma and fear of desertion from a relationship. In some cases men become defensive when asked by their partners to go for an HIV test. The reality of stigmatising against those living with the HI virus results in people keeping away

from prevention and care. Most people now use this as a justification for not testing and hence remain unaware of their HIV status. This contributes to further the spread of HIV/AIDS (UNAIDS, 2003:7). Surely people need to be educated about the importance of knowing their status. The initiatives of the MNGO can make a big difference in changing people's perceptions of AIDS, but their efforts are too little as they do not cover all the villages due to a lack of resources. Much greater effort is needed to ensure that all villages are covered.

Some also expressed fear of abandonment. This is closely tied to the fear of being thrown out of the marriage and economic support from their partners. A married woman in her early late 30s said:

*It is difficult when you have children because you want to raise your children within a marriage. So to break up with their father might create problems for you as a mother when you are not coping with their demands (Respondent, 23 April 2007).*

It is because of this fear that people would rather hide their status and in the process they continue to infect others. Often when they get sick it is too late to help them. This defence mechanism has a negative impact on efforts to reduce the spread of the epidemic.

In dealing with PLWH it is always important for me to look for turning points in the life stories that were told to me. This emanates from the realisation that every life story is filled with little turning points, but for us as sociologists we should be looking to identify the major turning points within those life stories (Giele & Elder, 1998:203). In dealing with PLWH, these turning points include being diagnosed as HIV-positive, losing a child due to AIDS, and being rejected by the community because of HIV status. However, I also highlighted that turning points are not always negative things that happen to PLWH: they can also change one's life in a positive way. By joining a support group the participants of this study believe that PLWH are more likely to have a prolonged life than those who live in hiding and isolation. This is because in a support group people share their feelings and experiences and by doing that they can manage their stress level.

Both primary and secondary sources were used in collecting data for this project. Problems and constraints encountered in the field were also highlighted. The reasons why the MNGO and specific stakeholders were chosen were also discussed, and the thesis also discussed the reasons why the eMkhuphusi village was chosen and the preference for a case study method.

The philosophical assumptions of qualitative research were discussed as a way of showing how individuals understand and interpret their social actions. The study sought to examine to what extent the MNGO was really doing what they set out to do in their constitution. This was done by engaging members of the organisation and those they claimed to be serving in the community.

It became clear in my interviews that as much as the idea to form a support group was welcomed by all stakeholders from the eMalahleni Municipality, very few have actually become active in the formation and implementation of the idea. As much as everyone feels that there is a need to reduce the spread of HIV/AIDS at all levels of the society, including focusing in schools, other departments appear to be preoccupied by other things which could be greatly affected by AIDS in the future.

In the study I made use of social capital as a conceptual framework to help make sense of my data. For this, I argued that a simple act of joining and being regularly involved in an organisation such as the MNGO has a positive impact on individuals' health and well-being. By being part of such an organisation members get emotional and psychological support which is important in assisting PLWH. I believe that those involved in such an organisation have greater chances of having a prolonged life than those who live in isolation. This is because those involved in this community organisation learn more about the disease and realise that AIDS is not a death sentence. Instead, in the era of information the disease should be seen as a chronic disease which can be very dangerous if one does not live a healthy life, such as stopping being a regular drinker or smoker and having unprotected sexual intercourse.

Social capital as a conceptual tool attempts to set social relationships, social interactions and social networks within the context of wider structural factors. It seeks to incorporate community and neighbourhood factors. A focus on “social capital” as a community level attribute allows research to prioritise the social context of young people’s everyday lives, rather than their individual health behaviours. Social capital is useful as a tool because it enables research to move away from individual models of health and focus on social context where behaviour is expected to take place. The organisation of the MNGO members shows that as much as AIDS is destroying social ties within communities, it also has the potential to bring people together. As it can be seen when people share a *common* problem that can be addressed by *group* action, they are more likely to mobilise themselves and work with support agencies to change the situation than if the problem applies to only a few members, in this way contributing towards rebuilding social networks.

The efforts of establishing a community NGO such as the MNGO have proved to be useful because some community members are beginning to realise that one does not have to be HIV-positive to be part of a support group. In many ways this will serve as an effective way to deal with the stigma people usually attach to those who become involved in an HIV/AIDS-related organisation. It will also bring those already infected to join support groups. As much as people get a chance to learn more about the HI virus they also get the reality of what it means to be HIV-positive as they interact with HIV-positive individuals daily. This provides a good platform for those who have not been directly affected by the epidemic to know what to do when it comes to their immediate family members.

Encouraging and supporting the development of associational life for PLWH and those affected by the epidemic can make a significant difference in destigmatising AIDS, because when everyone in a community gets involved, orphans who have lost their parents due to AIDS are likely to be cared for. The social capital concept suggests that better health can be fostered through the strengthening of its values such as trust among health professionals.

An emphasis is made in the thesis to show that poverty among black communities has had detrimental effects in reducing the spread of HIV/AIDS. Its causes can be traced to the past apartheid system of the country. The oppressive nature of the system led to black people losing their power of control over their lives, and these problems led to the disintegration of the families and communities. The disintegration of the families has many consequences for the development of black children. Children growing up without solid family structures end up owning houses at a very early age. This is a view that was expressed by the members of the MNGO.

This research revealed that young people in Lady Frere District are increasingly becoming infected, and the number of orphans continues to grow. Illiteracy remains a problem where cultural views see AIDS as a myth or an urban problem. It has been argued that in a mature epidemic such as HIV/AIDS in South Africa, there is a need to move beyond awareness campaigns and to focus on providing information and resources that orient individuals, families, and communities to appropriate forms of action (Kelly & Parker, 2001:1). I have consistently maintained in the thesis that we cannot begin to conceptualise and understand AIDS without taking into consideration the socio-economic and cultural context of the beliefs and practices within which the disease is spreading.

When the HIV/AIDS epidemic first started it was considered to be a health problem but now because of its significant negative impact, many people agree that AIDS is not only a health crisis. It poses the greatest threat to the socio-economic development of the country (Naamara, 2002:1). In already impoverished communities, such as the ones in Lady Frere District where the majority of people rely on government social grants, if something is not done urgently to address the spread of HIV/AIDS, it will take decades to bring a decent life to these communities. It might be more useful to direct awareness programmes at young people than programmes directed at everyone as such programmes are able to target people before their sexual behaviour patterns have been established. Given the low status of

women in these communities and the lack of power women have in general in their relationships, prevention programmes will need to target men first so that they realise the important role that they can play in reducing the spread of the epidemic. Focusing on young women who are already vulnerable both biologically and socially will have minimal consequences in reducing the spread of the HI virus. For me the first attempt should be to encourage more men to join support groups so that they can learn more about the virus. Men need to be assisted to come out and play an active role in education campaigns.

When researching HIV/AIDS, the use of a case study method is handy because PLWH are not always open about their status to strangers. In addition, when we ask our respondents about personal things often they tell us what they can remember at that particular moment. They give us what they think are the correct answers and not their everyday feelings and thoughts about the epidemic of this nature. The case study method provided me with an opportunity to pose the same questions at different times and in different situations. It was only through this that I was able to identify contradictions and get a complete picture of how people experience HIV/AIDS in these communities on a daily basis. By becoming their friend they felt comfortable in sharing their personal stories with me. This would not have been possible had I been with them only once. But because I was able to move from my comfort space and be part of them they began to trust me and hence were able to accommodate me.

I conclude that the MNGO is acting as a bridge, connecting communities with government services. In the minimal presence of government education programmes that are specifically designed to deal with the needs of the people in Lady Frere, one can imagine the situation in this area if this organisation was not active as it is. Clearly the majority of people would be victims because of the lack of knowledge, as was the case with some members of the MNGO who lost their children because they did not know what to do. After having worked closely with community members and other stakeholders, it became clear that AIDS in many ways has led to a

disintegration of communities. These communities are losing *ubuntu* (meaning *humanity*). The idea that "Your child is my child" seems to be fading away. Most people in these communities mind his/her own business. Because of strong traditional beliefs amongst community members in evil spirit, the concept of 'oneness' with neighbours and relatives is lost. I believe that if these communities could restore a sense of oneness, most social problems that they are confronted with including AIDS and poverty, could be dealt with.

However, I strongly believe that NGO dependency on donors and government institutions for financial survival compromises their status as independent organisations. The fact that the MNGO is getting the bulk of their financial assistance from the government department means that this organisation is accountable to this department instead of being accountable to the communities that they serve. It is understandable that for every NGO to survive there must be enough financial assistance, but it is important for NGOs to maintain their independence and not become agents of government and donors. Due to the size and nature of this study I cannot generalise about the interactions between civil society organisations and local government departments in other areas.

Last but not least, it is true that methodology helps us to understand not only the products of scientific inquiry but also the process itself. The use of a case study method made it possible for me to understand the organisational dynamics within the MNGO which would not have been possible in a quantitative approach. It is important for other role players to realise that the MNGO (which is the only active civil society organisation) cannot solve the HIV/AIDS problem in the Lady Frere District on its own. What they are doing is highly appreciated, but is just a drop in the ocean. Everyone has to come on board.

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### Interviews:

- Field notes, 29 July 2006, Lady Frere. Time: 08:40am.
- Interview, 29 July 2006, Lady Frere. Time: 10:30am.
- Women's group. 29 July 2006. Lady Frere. Time: 12:10pm.
- Church leader. 29 July 2006. Lady Frere. Time: 14:00.
- Interview 22 December 2006. Lady Frere. Time: 09:45am.
- Interview, 23 December 2006, Lady Frere. Time: 11:10am.
- Interview, 27 December 2006, Lady Frere. Time: 10:20am.
- Field notes, 28 December 2006, Lady Frere. Time: 12:00pm.
- Interview, 28 December 2006, Lady Frere. Time: 09:00am.
- Interview, 11 April 2007, Lady Frere. Time: 08:45am.
- Field notes, 12 April 2007, Lady Frere. Time: 13:00pm.
- Interview, 12 April 2007, Lady Frere. Time: 08:30am.
- Interview, 21 April 2007, Lady Frere. Time: 10:00am.
- Interview with Masibambane Official, 22 April 2007, Lady Frere. Time: 11:10am.
- Field notes, 23 April 2007, Lady Frere. Time: 14:20pm.
- Interview, 23 April 2007, Lady Frere. Time: 08:50am.
- Respondent (a), 23 April 2007, Lady Frere. Time: 10:00am.
- Respondent (b), 23 April 2007, Lady Frere. Time: 12:40pm.

Field notes, 12 July 2007, The HIV/AIDS tour to Queenstown and Lady Frere to visit HIV/AIDS organisations including the TAC and Masibambane NGO. It was organised by Dr Kevin Kelly at CADRE and the international office of Rhodes University to take American students on a tour where I was assisting him. Time: 09:15am.

Interview, 10 September 2007, Lady Frere. Time: 09:30am.

Interview, 11 September 2007, Lady Frere. Time: 09:00am.

Interview, 12 September 2007, Lady Frere. Time: 10:00am.

## Appendix A Biographical details

Age	15 – 22	23 – 31	32 – 40	41 – 55	56+
Education	Lower Primary	Higher Primary	Tertiary	University	Tech
Religion	Methodist church	Anglican church	Roman Catholic church	ZCC	Any other
Employment	Unemployed	Unskilled	Skilled What?	Profession What do you do for living?	Specify
No of your own children	No of alive/deceased children	2 – 3	4 – 4	7 – 10	More
Family structure	Extended or Nuclear family	Number of siblings (alive and deceased)	How many related to you directly? Why are they living with you?	How are they related to you?	
Remittances	Govt grants	Father or Mother	Brothers or sisters	How regular?	Any other income?
Marital status	Are you married? Divorced/ Widower/ Separated?	How long have you been married?			
Residential	How long have you been staying here?	Why? (did you leave your family?)	Any contact retained with original place? Why?	Frequency of contact with original place/home? Why?	Who are you living with here? What is the relationship with this person?

## Appendix B

### Interview questions for the Masibambane leaders

1. Part of your aims and objectives is to provide counselling and support, does the organisation have a well trained person to do that job?
2. What is their level of training?
3. Part of your aims is to support HIV/AIDS affected families, how do you go about doing this?
4. What kind of support do you give to family members?
5. How often do you visit those families to ensure that they get the support they need?
6. What would you consider to be the main challenges in achieving these goals?
  
7. Part of your aims and objectives is to ensure that members access the treatment – what did you find to be the obstacle when people look for government treatment on their own?
8. This implies that Masibambane is concerned with its members (those who pay the joining fee R20); as a community organisation how far does your organisation go in helping non-members?
9. What kind of treatment are you referring to?
10. How long does it normally take for a person to access this treatment?
11. How long have Masibambane been involved in AIDS activities?
12. What challenges do you encounter in providing this service?
13. How do you deal with those challenges?
14. According to your constitution, Masibambane also strive to ensure that members are not discriminated against in terms of employment, how does the organisation go about doing this/
15. What is it that you do to protect your members?
16. Are there any incidents where this happened?
17. Do you have a policy on how this should be done?
18. What do you consider as discrimination against someone living with the HIV virus?
19. Masibamabane also conduct awareness campaigns in schools, clinics, communities and hospitals, what kind of campaigns are you referring to?
20. How often do you visit those communities?
21. Which schools/ clinics or communities do you go to?
22. Why those ones and not others?
23. Who get to be chosen to speak and why them?
24. What training do those speakers have?
25. Who train them and how often?
  
26. Part of what you say the organisation seeks to do is to support orphans and vulnerable children of HIV/AIDS, how do you support /what kind of support do you give them?
27. Which children do you consider/regard as orphans?
28. And which ones do you regard to be vulnerable?
29. how do you get those children/
30. Can you give me the number of such children that you are dealing with at the moment?
  
31. It is said in your constitution that to achieve your aims and objectives, Masibambane is constantly networking with all the stakeholders, how do you do this?

32. Who are these stakeholders that you are working with?
33. Which ones do cooperate and who does not?
34. Is Masibambane a recognised organisation by the government representatives as making a useful and important contribution in the fight against the spread of HIV/AIDS in Lady Frere?
35. How often do you meet with these stakeholders?
36. Does Masibambane get orders on what to do from these departments?
37. What is the relationship between Masibambane and these other stakeholders?
38. What challenges do you face in working with these stakeholders?
  
39. What factors have driven the emergence of Masibambane in Lady Frere?
40. If you can think back when did you see/felt that there is a need for a support group in Lady Frere?
41. What was happening before the formation of Masibambane in Lady Frere in terms of addressing the challenges posed by HIV in our communities?
42. At what stage did you personally decide to get involved?
43. When thinking about the impact of HIV/AIDS, what does Masibambane mean to you?
44. How do people respond when you do/tell them about HIV/AIDS in these villages?
45. Do you think most people know about HIV/AIDS in our communities?
46. If you were not HIV-positive, do you think you will be involved in a project like this?
  
47. What role have Masibambane played in shaping the relationship between these communities and the local government?
48. What do you do as Masibambane to facilitate communication between these communities and government departments?
49. Who are the people that you are working with in these communities? Why them and not others?
50. Do you think people on the ground know their rights and or what they are entitled to have/ask from government?
51. What does Masibambane do to empower these communities?
52. Do you think people in Lady Frere take AIDS serious? If not what could be the reasons for this careless behaviour?
53. Which age group do you think is mostly affected in these communities? What could be the reason(s) for that?
54. What could be done to change the behaviour of young people?
55. Do you think the money that HIV-positive people receive from government have positive or negative impact towards this behaviour?
56. How vocal is the government especially in educating people about the seriousness of AIDS?
57. From your experiences when visiting these communities, do you think people have easy access to condoms?
  
58. What kind of training/support is available to the staff members and volunteers of Masibambane to ensure that they passing the correct messages to the people / fulfil their mandate to these communities?
59. Is Masibambane an affiliate to the TAC?
60. What kind of support do you get from them?
61. Who are you accountable to / do you report to?

1. Where did you get this idea of forming a support group for people living with HIV/AIDS?
2. What were the challenges in starting an organisation like this?
3. How did you overcome them?
4. What would you like to see happening between the government, Masibambane and these communities in terms of addressing HIV/AIDS here?

Follow up questions were made in all the interviews

**Thank you very much for your time**