EXPLORING THE FACTORS INFLUENCING NON-PARTICIPATION OF WOMEN LIVING WITH HIV/AIDS IN EMPOWERMENT PROJECTS ATTACHED TO PRIMARY HEALTH CARE CLINICS, TEMBISA, SOUTH AFRICA

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Thesis presented in partial fulfilment of the requirements for the degree of Masters of Philosophy in Sustainable Development Planning and Management at Stellenbosch University

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DECLARATION

By submitting this thesis electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the owner of the copyright thereof (unless to the extent explicitly otherwise stated) and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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ABSTRACT

The research was conducted to explore the experiences of people living with Acquired Immunodeficiency Syndrome (AIDS) (PLWAs), especially women, as well as the factors influencing their non-participation in development projects aimed at improving their socio-economic status. The study was conducted amongst PLWAs who are members of the Tembisa Main Clinic and Winnie Mandela Clinic support groups in Tembisa, South Africa.

The researcher was motivated to conduct the research because in her work as a social worker she is confronted daily with PWLAs who are from disadvantaged backgrounds and are struggling to make ends meet. Initiatives have been undertaken to try and encourage self–reliance and improve the health status of these women by developing food gardens to provide them with fresh vegetables and possible income sources from these gardens. The reluctance of members of two support groups of PLWAs to stay involved in these projects encouraged the researcher to explore these issues.

The researcher consulted various sources to obtain literature on the factors influencing non-participation in development projects. In addition she undertook a qualitative study, wherein twenty participants participated. The data from this study was then interpreted and compared to the literature.

The findings of this study highlighted several factors such as discrimination, local beliefs, stigma and lack of support, which influence the non- participation of PWLAs in sustainable development projects. The findings of this research also indicate that developments projects often fail to thrive because of top-down decisions about the projects, the fact that there is no start-up funding available for the projects and participants who become demotivated to participate. The research therefore concludes with recommendations in order to address these problems.

OPSOMMING

Die navorsing is onderneem om die ondervinding van mense, veral vroue, wat met Verworwe Immuniteitsgebrek Sindroom (VIGS) lewe, te ondersoek, asook die faktore wat hulle daarvan weerhou om deel te neem aan ontwikkelingsprojekte wat daarop gemik is om hul sosio-ekonomiese status te verbeter. Die studie is onderneem onder pasiënte wat lede was van ondersteuningsgroepe by Tembisa Hoofkliniek en Winnie Mandela Kliniek in Tembisa, Suid-Afrika.

Die navorser is gemotiveerd om die studie te onderneem omdat sy daagliks in haar werk as 'n sosiale werker gekonfronteer is deur mense wat met VIGS lewe, wat uit minder bevoorregte agtergronde kom en wat sukkel om te oorleef. Inisiatiewe is onderneem om hierdie vroue se selfstandigheid te bevorder en om hul gesondheidstatus te verbeter deur groente tuine te ontwikkel om hulle van vars groente te verskaf, asook moontlike inkomstebronne uit hierdie tuine. Die onwilligheid van die lede van twee ondersteuningsgroepe om in hierdie projekte betrokke te bly, het die navorser aangemoedig om hierdie aangeleentheid verder te ondersoek.

Die navorser het verskeie bronne geraadpleeg om literatuur te verkry oor die faktore wat die nie-deelname in ontwikkelingsprojekte beïnvloed. Sy het ook 'n kwalitatiewe studie onderneem waaraan twintig respondente deelgeneem het. Die data van hierdie navorsing is daarna geïnterpreteer en met die literatuur vergelyk.

Die bevindinge van hierdie navorsing het verskeie faktore uitgelig wat die nie-deelname beïnvloed van mense wat met VIGS lewe, soos diskriminasie, plaaslike gelowe, stigma en gebrek aan ondersteuning. Die navorsing het ook bevind dat ontwikkelingsprojekte dikwels nie floreer nie as gevolg van die 'top-down' besluitneming oor die projekte en omdat daar nie genoegsame vooraf befondsing beskikbaar is vir die projekte nie en die deelnemers dus demotiveer om verder deel te neem. Die navorsing sluit dus af met voorstelle om hierdie probleme aan te spreek.

DEDICATION

This research is dedicated to my Grandmother – Mrs Selina Nkidi Motong who passed away on 23rd September 2007. She has instilled in me a spirit of hard work and determination through her strict guidance. She will always be remembered.

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LIST OF ACRONYMS AND ABBREVIATIONS

AIDS:	Acquired immunodeficiency syndrome
ART:	Anti- retroviral
CD4 count:	Number of CD4 T- cells (a type of white blood cell) per cubic millilitre of blood in the human body (a measure of the strength of the immune system)
DOH:	Department of Health
DEAT:	Department of Environmental Affairs and Tourism
EU:	European Union
GDI:	Gender Development Index
HAART:	Highly Active Antiretroviral Therapy
HDI:	Human Development Index
HIV:	Human immunodeficiency virus
MDGs:	Millennium Development Goals
NAPWA:	National Association for People Living with AIDS
NGOs:	Non-governmental organisations
PLWAs:	People living with AIDS
SACSSP:	South African Council of Social Service Professions
SANAC:	South African National Aids Council
SARPN:	South African Regional Poverty Network
STIs:	Sexually Transmitted Infections
TAC:	Treatment Action Campaign
TASO:	The AIDS Support Organisation
TB:	Tuberculosis
UN:	United Nations
UNAIDS:	United Nations Programme on HIV/AIDS
UNDP:	United Nations Development Program
UNESCO:	United Nations Educational, Scientific and Cultural Organization
USAID:	United States Agency for International Development
VCT:	Voluntary counselling and testing
VIGS:	Verworwe Immuniteitsgebrek Sindroom (Afrikaans for AIDS)
WHO:	World Health Organisation

CHAPTER 1: INTRODUCTION TO THE RESEARCH

1.1 Contextualising the research

Over the past 25 years, the HIV/AIDS global epidemic has intensified poverty worldwide, especially in underdeveloped countries and in the poor neighbourhoods of the cities of industrialised nations. HIV/AIDS is no longer only a health issue, but affects all aspects of the socio-economic development of countries. It is probably the greatest constraint to human and economic development in Africa – a continent where governments are faced with multiple challenges in their endeavours to provide citizens with a better quality of life, including access to basic services (such as health services) and equal opportunities to live a fulfilling life irrespective of their health status. HIV/AIDS is therefore not just a compelling moral issue or a humanitarian issue, and it is far more than just a health issue – it is also an economic and developmental challenge. To illustrate the impact of the epidemic on the work force, Chikwendu (2004:245) notes that teachers in many African countries are dying at such high rates that young people are in danger of losing the adults from whom to acquire the skills that will make them contributing members of society.

UNAIDS (2005) puts forward three scenarios for 2025 regarding HIV/AIDS in Africa. The first is the *Tough Choices* scenario that rests on the understanding that there is much that Africa can do on its own taking into consideration that the attitudes and practices of the rest of the world with respect to Africa are unlikely to change. Under this scenario, Africa focuses on long-term investment in social, economic and human capital. The outcome is therefore reduced HIV incidence although the number of People Living with AIDS (PLWAs) remains steady (due to population growth). The second scenario, *Traps and Legacies*, has as its essential message that it will be difficult to make progress if HIV/AIDS is viewed in isolation from its social, economic and political context. This causes good intentions and plans to be derailed by fundamental development challenges that are not addressed, and the result is a doubling of the number of PLWAs to 2025. The third and

preferred scenario, *Times of Transition*, is where the HIV/AIDS epidemic magnifies the wider crisis and acts as a catalyst for action, by states, international organisations and civil society. Actions are based on a new understanding of solidarity and citizenship, sustained social investment, and fundamental changes in aid policies. Under this scenario, the number of PLWAs is dramatically reduced and the future of Africa and the world for the 21st century is fundamentally altered.

As indicated above, there are strong links between HIV/AIDS and poverty. According to the Panos Institute (1992:8), throughout the developing world, and in Latin America and Africa in particular, the number of people living in absolute poverty increased during the 1980s. Low levels of education, crowded and unsanitary living conditions, limited access to health care, poor nutrition, and high rates of unemployment may all lead to behaviour that could place people at risk of acquiring and spreading HIV and AIDS. Furthermore, poverty can have a profound impact on social phenomena such as rural-urban migration and transactional sex that are increasingly associated with HIV infections (Dunkle *et al*., 2004). Moreover, poor people who contract HIV tend to develop AIDS much faster than individuals of a higher socio-economic status (Panos Institute, 1992:8).

Loewenson and Whiteside (2001) discuss five priority areas for action in addressing the impact of HIV/AIDS on national poverty alleviation programmes: prevention of the collapse of essential services, adaption of poverty reduction programmes to be responsive to the local expressions of the epidemic in each region, protection of educational achievements, mitigation on the impact on the supply of labour, and the promotion of opportunities for women.

With regard to the South African situation, South Africa is still suffering from one of the most severe AIDS epidemics in the world, and there are no indications that HIV prevalence is decreasing. Fast, effective action will be needed if progress is to be made. It has been suggested that by 2012 around 1.5 million people would have died from AIDS-related illnesses if the treatment scale-up continues at the current rate. Around 200 000 of these

lives would have been saved if universal access to treatment were to be achieved by 2011 (Pembery, 2008).

According to Everatt and Maphai (2003:96-97) the urgency of dramatically enhancing poverty eradication efforts is starkly underlined by HIV/AIDS, as its high impact on South Africa is devastating. The HIV/AIDS epidemic is deepening poverty, reversing human development achievements, worsening gender inequalities, eroding the ability of government to maintain essential services, reducing labour productivity and supply, and putting a brake on economic growth. As the United Nation Development Programme (UNDP) noted, HIV/AIDS is a developmental crisis for which the most effective response is sustained equitable development aimed at alleviating poverty (Everatt and Maphai, 2003:97).

There are however recent local developments that give reason for a degree of optimism. The South African government revealed a draft National Strategic HIV/AIDS plan to guide the South African National AIDS Council (SANAC) from 2007 to 2011. The primary aims of the plan are to reduce the number of new HIV infections occurring in South Africa by 50% by 2011 (Pembery, 2008).

While these plans take effect, HIV/AIDS remains a shock that the poor cannot deal with as it results in additional medical costs, funeral costs, loss of jobs, social stigma and loss of social networks. Sherr *et al*. (1996:210) indicate that while HIV/AIDS is a global epidemic, African countries are especially facing the devastating impact of the epidemic on families and children. A strong theme in addressing the global and domestic epidemic is that assistance to orphans and their families should not be seen as only a short-term project, but rather as a long-term commitment that supports local sustainable initiatives. Sherr *et al.* (1996:210) further state that a long-term commitment relates to sustainable development, through which future generations could benefit and which is based on the promotion of human development. Human development could lead to sustainable development through local initiatives meant to empower people to be more self reliant and have more confidence.

Sherr *et al*. (1996:47) also state that there is ample evidence to show that a lack of social support has a great impact on psychological resources which help individuals cope with illnesses. There is also evidence that diagnosis of a chronic illness may erode existing support and that those people with a poor prognosis may receive the least support. According to Thampu (1995:43, cited by Ntsieni, 2005:28) people living with HIV/AIDS are discriminated against and their rights are often violated. AIDS sufferers are perceived as a threat to the health of others. Public opinion shows signs of intolerance. Many people still believe that those with HIV and AIDS and infections should not be treated with compassion.

HIV/AIDS is characterised by shame and blame. Communities tend to believe that a person affected by the disease has been promiscuous and has invited it. As Thampu (1995:43) indicates, there are numerous reports of discrimination and negative societal reactions against people with HIV/AIDS, e.g. loss of employment and denial of insurance. There is also evidence that such attitudes may be internalised among people with HIV/AIDS, resulting in them feeling stigmatised even if they have not experienced discrimination (Green, 1995, as cited by Ntsieni, 2005:28-29). Fear of discrimination, rejection, disruption of social relationships, and fear of an inappropriate response has been identified as some of the reasons why people tend not to disclose their HIV status. Keeping a secret may be very stressful and heightens a sense of shame. Those who feel stigmatised are also likely to feel anxious and isolated from others and experience disruptions in normal social relationships (Deacon, 2005:34).

The success of improving one's quality of life through engaging in sustainable projects has been illustrated by what has been reported by Cunningham (2005:2) from Swaziland, where middle-aged, HIV-positive women launched an initiative called 'Swazi for positive living', with the aim of breaking new ground and develop self-sustaining agricultural projects, in an effort to be less dependent on donor organisations. This initiative was successful because they were selling whatever they grew; they ploughed half the profit back into the project, a quarter was distributed amongst the members and the

remaining quarter used to directly assist people with HIV and AIDS. This case study shows how people improved their own circumstances by doing something for themselves, which is also empowering and boosts their self-worth. In this project, both greater self-reliance and self-esteem have been achieved.

The premise of this study is that people living with HIV/AIDS can be empowered through participatory development projects such as food gardens. Participatory development emphasises people's creativity and their ability to investigate and analyse their own reality.

1.2 Motivation for this study

The researcher is employed as a social worker in clinics in Gauteng, South Africa (the Tembisa Main Clinic and the Winnie Mandela Clinic). These clinics render services related to primary health care, tuberculosis (TB), voluntary counselling and testing (VCT), antenatal needs, mental health and general social work. There is also a baby clinic that provides scheduled assessment of child nutritional needs, parental concerns and medical needs and also assesses child development and provides scheduled immunizations. The majority of patients who receive health services from these clinics are from poverty-stricken backgrounds. As a social worker, the researcher has to facilitate support groups for People Living with AIDS (PLWAs) who are unemployed and struggling to make ends meet.

According to Aronstein and Thompson (1998:394) the social worker's role is to assist people in every stage of their life, from childhood to advanced age, to deal with daily challenges such as poverty, discrimination, unemployment, stress and death. The social worker's role is to advocate for people and to find programmes in the community that will help them live a more fulfilling life. Mancoske and Smith (2004:4) state that in dealing with PLWAs, social workers must emphasise the empowerment of the infected and affected, so that they can learn to confront the stigma and be more self-reliant.

Self-reliance can be encouraged through development projects and therefore the researcher became involved in community development. There have been efforts to alleviate the state of poverty amongst the patients, specifically PLWAs, through development projects launched at the clinics. As part of the requirements of her position, the researcher initiated food garden projects and a soup kitchen for members of the Winnie Mandela and Tembisa Main Clinic support groups and other needy patients referred by the primary health care nurses. From the soup kitchen, the beneficiaries receive one nutritious meal a day for five days a week. The idea behind the food gardens was that the vegetables from these gardens could potentially help to improve the health status of patients and also generate income for them. Patients were therefore encouraged to participate in the vegetable gardens at the clinics.

It was also thought that these projects could have the potential to reduce the dependency syndrome, because the majority of PLWAs currently rely on food parcels and disability grants that they receive from the Department of Social Development. One of the criteria for PLWAs to qualify for this social grant is that their CD4 counts must be below 200 (the CD4 count of a healthy person is usually above 600). Natrass (2004:21) and Stepaniak (2007:1) indicate that it seems as if some of the PLWAs are compromising their own health by not taking their medication, in order that their CD4 count will not improve, so that they can continue to receive the disability grant. This reflects the extent of poverty experienced by the majority of PLWAs – they choose to compromise their health for the sake of getting a grant to survive. The researcher therefore felt that the services rendered to these patients should be optimally geared towards addressing their needs.

The participants of this study are unemployed women from different ethnic groups infected by the HIV virus. These women are from poverty stricken backgrounds and are struggling to survive with limited resources. Based on the reported success of the “Swazi for positive living” project (Cunningham, 2005:2), the researcher had hoped that the food garden projects would have assisted them to generate their own vegetables for consumption and possibly also to generate additional income from selling products to the community.

However, participation in the projects was low. Members of the support groups participated for a few weeks in the food garden projects and gradually withdrew. At the beginning there were 14 participants, and at the time of writing, only three people were actively participating. Members of the support group from the Winnie Mandela Clinic only prepared the ground for growing vegetables and then stopped participating.

To meet the needs of the PLWAs, the reasons behind this behaviour needed to be investigated. Therefore, the researcher wanted to establish the factors that contribute to the lack of participation by PLWAs in the food garden projects, possibly resulting in recommendations to increase motivation to participate.

Because the majority of people living with HIV and AIDS are experiencing the multiple effects of poverty, the degree to which their living conditions affect their ability to participate in empowerment projects is also important. For instance, as the majority of them are unemployed, many PLWAs cannot afford the most basic necessities such as nutritious food and they may be too weak to participate in projects.

The statistical records at the clinics that formed part of this study showed that the number of HIV-infected people is increasing and that these patients are also poverty stricken. This is also confirmed by the media, where it is continuously reported that the numbers of HIV infections are increasing daily. Pembery (2008) states that at the end of 2007, women accounted for 50% of all adults living with HIV/AIDS worldwide, and for 59% of those living in Sub-Saharan Africa. Therefore, the specific experiences of poor women living with HIV/AIDS also needed to be explored to understand how their circumstances contributed to their lack of participation in the food garden projects.

1.3 Research question and objectives of the study

It was the aim (with *aim* being defined by Fouché (2002:110) as “the end to which effort or ambition is directed”) of the researcher to answer the following question:

What factors contribute to the non-participation of poor women living with HIV/ AIDS in food garden projects aimed at empowering them socially and economically?

The objectives of the study were therefore to:

- Provide a broad overview of the link between HIV/AIDS, poverty and development;
- explore requirements for successful participation in general;
- explore the experiences of poor women living with HIV/AIDS in general and especially the factors that hinder them from participating in empowerment projects such as the food gardens, and
- formulate recommendations to address the factors that de-motivate HIV patients from participating in empowerment projects such as the food gardens, so as to facilitate and promote participation.

1.4 Overview of research paradigms applicable to the study

A number of research paradigms guided the researcher in this study. These are briefly discussed below (and discussed in more detail in Chapter 5 of this thesis).

Firstly, this study is applied research, which is defined by Monette *et al*. (1994:6) as research focusing on solving problems in practice. A research study is designed based on the assumption that some group or society as a whole will gain specific benefit from the research. In this study, HIV-infected patients will benefit from the findings.

Secondly, the research has a phenomenological basis. According to Fouché (2002:273), a phenomenological study is aimed at understanding and interpreting the meaning that subjects give to their everyday lives. In this study, rich information was obtained from the participants that facilitate understanding of their circumstances and their lack of participation in the food garden projects under consideration.

The third paradigm used in this research links to the phenomenological nature of the study. The study namely also gives expression to feminist action research (Weiner, 2003:3) in that it is grounded in women's experiences and gives value to women's lived realities.

In the fourth and final instance, a qualitative approach was used in this study. According to Schurink (1998:241), a qualitative research approach is aimed at understanding social life and the meaning that people attach to everyday life. Qualitative research is descriptive in nature, as opposed to quantitative research which is aimed at testing predictive and cause-effect hypotheses about social reality (De Vos *et al*., 2005:75).

1.5 Overview of the research process followed

The research involved collecting data from a sample of poor women living with HIV/AIDS registered at two clinics in the Tembisa area. The objective was to investigate the reasons for their lack of participation in food garden projects set up to empower them socially and economically. The information was collected by two means. In the first instance twenty women were interviewed and secondly the researcher obtained information by employing participant observation as a research strategy. The interview schedule used was piloted beforehand on two women (who were not part of the sample) to make sure that the questions were understandable and presented in a sensitive manner. The languages used in this study were Setswana and Zulu and the replies of the women were translated into English by the researcher.

The research project was concluded in the following phases:

- Literature review
- Research design and pilot testing of interview schedule
- Field research
- Data analysis and interpretation
- Report writing

1.6 Ethical considerations

Research involving PLWAs brings to the fore many ethical aspects which the researcher took into consideration to ensure that there was no physical or emotional harm to the participants. Consent forms were given to participants to confirm that they were participating voluntarily. The researcher was honest in explaining the purpose of the study and did not make any false promises to encourage participation. The participants were assured of confidentiality. Fields notes were taken during the interviews, and no concealed equipment was used to record the data. After the conclusion of the research, the researcher held debriefing sessions with the participants to rectify any misperception which might have arisen during the data collection phases.

1.7 Feasibility of and constraints to the study

The researcher is a social worker rendering services to patients infected with HIV and AIDS in the clinics of Tembisa Township. The study was therefore considered to be feasible as the researcher has ready access to the participants when they meet regularly at the clinics for their support group meetings. The researcher therefore did not have to travel far to reach the participants. The costs incurred were manageable, as the study was conducted within the researcher's area of operation at work. Permission to conduct the study was granted by the Gauteng Provincial Department of Health.

Constrains were that participants who could not afford to pay taxi fees, walked long distances to the clinic. Some would complain of hunger, but fortunately they would get one nutritious meal from the soup kitchen in the clinic. Some participants would complain about swollen and painful feet due their condition.

1.8 Layout of the research report

In Chapter 1 the context of and motivation for the study are given, along with an overview of the research process followed and ethical aspects that were considered. In Chapter 2, a number of key concepts are defined and the institutional context (both local and international) for the research is discussed. Chapter 3 deals with an exploration of the linkages among

HIV/AIDS, poverty, development and participation. In Chapter 4 the experiences of PLWAs relevant to empowerment projects are investigated to shed light on aspects that may impact on the degree to which they participate in projects designed to empower them, such as the food garden projects in this study.

The research design, sampling and description of the projects being investigated are given in Chapter 5. The results of the research are discussed in Chapter 6, and the thesis concludes with Chapter 7 which contains the conclusions and recommendations for increasing the participation of poor women living with HIV/AIDS in empowerment projects.

CHAPTER 2: DEFINITIONS AND INSTITUTIONAL CONTEXT OF THE RESEARCH

2.1 Introduction to the chapter

This chapter has three aims. In the first place, relevant key concepts are defined. Secondly, information is provided on the institutional context in which empowerment of people living with HIV/AIDS, and therefore this research, takes place.

With regard to the institutional context of the research, the information provided sheds light on the main institutions that impact on HIV/AIDS work in South Africa. Information is provided on the following:

- International guidelines and institutions
- South African legislation and guidelines, as well as South African organisations dealing with HIV/AIDS.

Thirdly, as the study centres on projects initiated within the context of the job description of social workers, the chapter also provides information on how the training of social workers prepares them for working with people living with HIV/AIDS.

This chapter therefore highlights the prominent guidelines, policies and institutions and organizations that all contribute towards a holistic approach to the prevention of HIV/AIDS, as well as the treatment and empowerment of people living with HIV/AIDS.

2.2 Definition of key concepts

2.2.1 HIV and AIDS

The Human Immunodeficiency Virus (HIV) is the virus that causes Acquired Immunodeficiency Syndrome (AIDS) (Lynch, 2000:3). HIV may be passed from one person to another when infected blood, semen or vaginal secretion comes into contact with the uninfected person, broken skin or mucous

membrane, through the placenta and infected mother's milk (Lynch, 2000:2-3). AIDS is defined as an incurable and chronic variable disease caused by the above retrovirus which infects lymph glands and destroys lymphocytes through gene alteration, spreading the disease between individuals mostly through semen, blood and uterine secretions. The retrovirus destroys the immune system of the human body, allowing the body to be infected by a great many other opportunistic diseases. There is a stage were an infected person becomes seriously ill and the body has very little defence against any sort of infection. Without drug treatment, HIV infection usually progresses to AIDS in an average of ten years. This average is however based on a person having a reasonable diet. Someone who is malnourished may well progress to AIDS and death more rapidly. Food insecurity leads to malnutrition which can aggravate and accelerate the development of AIDS (Gillespie and Kadlyala, 2005:13).

2.2.2 Poverty

According to Walker (1994:11) poverty can be defined in terms of a shortfall in resources in relation to a set of legitimate needs. This is an example of the income approach to poverty. This researcher's study began by looking at poverty as a lack of adequate resources for daily living, for instance a family of six living in a four-roomed house or shack, on an income of less than R800 a month, and those of working age being unemployed. All of the study subjects fell into this category.

However, it also became clear that poverty is about much more than income. Other conceptions of poverty include approaches relating to social exclusion, capability, human development, and human rights (Walker, 1994). In addition, the concepts of ill-being or well-being and Quality of Life are also important (Walker, 1994). The concept of well-being is much broader than poverty, as is discussed in more detail in Chapter 3.

As noted by Neubert (2000:9), the UNDP regards poverty as a multi-dimensional concept characterising a situation where people are denied the opportunities and choices most basic to human development to lead a long,

healthy, creative life and to enjoy a decent standard of living, freedom, dignity, self respect and the respect of others.

2.2.3 Development

Development refers to planned change in a specific direction and is sometimes divided into economic, political and social development (Swanepoel, 1997:9). According to Burkey (1993:37, as cited by Swanepoel, 1997:9), the specialised areas of development, namely economic, political, social, and human development overlap with each other. This study touches on these dimensions of development.

2.2.4 Sustainable development

Sustainable development is defined by the Brundtland Commission as development that meets the needs of the present without compromising the ability of future generations to meet their own needs (Hattingh, 2001:5). In the South African National Strategy for Sustainable Development (DEAT, 2006:6), the term sustainable development is defined as follows: "Sustainable development means the integration of social, economic and environmental factors into planning, implementation and decision-making so as to ensure that development serves present and future generations".

From these definitions, it is apparent that sustainable development is based on long-term approaches to social, economic and environmental needs. In this study sustainable development is therefore viewed as development aimed at empowering the participants to be socially and economically independent, while still taking care of the environment.

It should however be noted that sustainable development is a contested concept, which can have various meanings, depending on the perspective of the person defining the concept. In the context of this study, the focus is on development projects that will promote positive human development and will keep on providing benefits over the long term.

Development projects are considered to be sustainable when they enhance the participants' capabilities and self-sufficiency, and when the local resources are not being exploited but preserved for the use of future generations. Development projects are sustainable if they are able to create a future economic base for the community, and are also able to support the social, cultural, spiritual and environmental welfare of the beneficiaries (Theron & Wetmore, 2005:151-157).

2.2.5 Participation

Participation is defined as the taking of initiative by the collective in gaining access to programmes and projects (Rahman, 1993, as cited by Theron, 2005:114). For the purposes of this study, the researcher viewed participation as the process were people have control of actions initiated and are actively involved in the activities and decision-making.

Theron *et al.* (2007:5) states that in relation to development, participation requires the recognition of local capabilities and the belief that local communities have the responsibility to shape their own future. In this vein, participation can then be seen as a tool towards empowerment and good governance (Laderchi, 2001:4).

2.2.6 Empowerment

Trevellion and Beresford (1996:17) define empowerment as a way of working with people to identify options and the corresponding blocks to their development. Essentially this is about learning to cope with personal challenges and pressures and about learning to "go on". This encourages independence and self-reliance. According to Menike (1993:181) participation is a tool for empowerment.

2.2.7 Self-reliance and dependency

Self-reliance is "the act of the people mobilising themselves, inquiring, deciding and taking initiatives of their own to meet their felt needs" (Rahman, 1993:19, as cited by Theron, 2005:114) and relying on local resources,

knowledge, technology and strengths (Burkey, 1993:31). Self-reliance is one of the principles and outcomes of participatory community development (Swanepoel, 1997:123-124). It is the opposite of dependency. “Self-reliance is the way out of dependency” (Bruwer, 1995:81). Self-reliance is hampered by dependency on people for handouts and on technology that cannot be sustained without outside assistance.

2.2.8 Gender

The European Union (EU) defines gender as “a concept that refers to the social differences, as opposed to the biological ones, between men and women, which have been learned, are changeable over time and have wide variations both within and between cultures” (EU, 2005:10,18).

As will be discussed in this study, gender is an important factor that needs to be taken note of in preventing HIV/AIDS and empowering those living with the disease. In South Africa, there are still serious flaws in the implementation of socio-economic rights for women (Gouws, 2005:3). This author states that despite good representation of women in government and enabling conditions to implement and monitor gender equality, the realities of South African women’s lives include gender-based violence, high HIV-infection rates (among the highest in the world), as well as a high incidence of poverty.

2.3 Institutional context of the research

2.3.1 International guidelines and organizations

International guidelines on HIV/AIDS are contained in the document entitled *International Guidelines on HIV/AIDS and Human Rights* (UNAIDS, 2006). The purpose of these guidelines is to assist states in translating international human rights norms into practical observance in the context of HIV and AIDS. These guidelines are based on the Second International Consultation on HIV/AIDS and Human Rights (Geneva, 23-25 September 1996), and the Third International Consultation on HIV/AIDS and Human Rights (Geneva, 25-26 July 2002) which were organized jointly by the Office of the United Nations

High Commissioner for Human Rights and the Joint United Nations Programme on HIV/AIDS.

These twelve guidelines relate to the following aspects to be addressed by states (UNAIDS, 2005):

- An effective national framework for their response to HIV;
- community consultation in all phases of HIV policy design, programme implementation and evaluation;
- the reform of public health laws to ensure that they adequately address public health issues raised by HIV;
- the review and reform of criminal laws and correctional systems to ensure that they are consistent with international human rights obligations and are not misused in the context of HIV;
- putting into operation or strengthening of anti-discrimination and other protective laws that protect vulnerable groups;
- legislation to provide for the regulation of HIV-related goods, services and information, to ensure widespread availability of quality prevention measures and services, adequate HIV prevention and care information, and safe and effective medication at an affordable price;
- implementation of legal support services to educate people affected by HIV about their rights and provide free legal services to enforce those rights;
- supportive and enabling environment for women, children and other vulnerable groups by addressing underlying prejudices and inequalities through community dialogue, specially designed social and health services and support to community groups;
- wide and ongoing distribution of creative education, training and media programmes explicitly designed to change attitudes of

discrimination and stigmatization associated with HIV to understanding and acceptance;

- codes of conduct by government and the private sector regarding HIV issues that translate human rights principles into codes of professional responsibility and practice, with accompanying mechanisms to implement and enforce these codes;
- monitoring and enforcement mechanisms to guarantee the protection of HIV-related human rights, and
- cooperation through all relevant programmes and agencies of the United Nations system, including UNAIDS, to share knowledge and experience concerning HIV-related human rights.

In addition to these above guidelines, various international development organisations have developed guideline documents related to HIV and AIDS. For instance, The United Nations Educational, Scientific and Cultural Organization's (UNESCO) International Guidelines on Sexuality Education (UNESCO, 2009) are aimed at providing a framework for offering guided access to information and knowledge to children and young people about sex, relationships and HIV and Sexually Transmitted Infections within a structured teaching/learning process.

The World Health Organization (WHO, 2009) has a database on HIV/AIDS containing reports and guidelines on aspects such as immunization, infant feeding, nutrition, oral health, reproductive health and Tuberculosis (TB). Among these are also guidelines on indicators for monitoring national HIV/AIDS programmes.

The WHO is a co-sponsor of UNAIDS, a supra-national organisation devoted to "stop and reverse the spread of HIV and scale up towards universal access to HIV prevention, treatment, care and support services" (UNAIDS, 2009). Other co-sponsors of UNAIDS are: Office of the UN High Commission for Refugees (UNHCR), UN Children's Fund (UNICEF), World Food Programme (WFP), UN Development Programme (UNDP), UN Population Fund (UNFPA),

UN Office on Drugs and Crime (UNODC), the International Labour Organization (ILO), UNESCO, and the World Bank (UNAIDS, 2009).

The United States Agency for International Development (USAID) is an agency that provides economic development and humanitarian assistance around the world in support of the foreign policy goals of the United States. This agency has continuously been giving support to developing countries such as South Africa. USAID (South Africa) has two strategic objectives, namely (1) sustainable development and transformation, and (2) an HIV/AIDS epidemic response. In terms of the second objective, the focus of USAID is to channel resources to reduce the prevalence rates, to reduce HIV transmission from mother to infants and to increase support services for people infected and affected by AIDS (USAID, 2009). USAID (South Africa) has consistently supported the South African Department of Health (DOH) in primary health care clinics with the roll out of the anti-retroviral programme. The organisation has also assisted with free access to condoms, HIV counselling and HIV testing. However, during the time of the Bush administration, USAID has also been criticised for the setting of specific conditions on the spending of USA funding, which had a negative effect on HIV prevention. These conditions have now been lifted.

As HIV/AIDS presents with a myriad of physical symptoms such as diarrhoea, cough, shortness of breath, nausea, weakness, fever and fatigue, and emotional distress such as fear of death, as well as social distress such as stigmatization and alienation, USAID strongly supports palliative care as an overall philosophy of care. Palliative care is a holistic, culturally sensitive approach centred on empowerment of patients, family and community.

2.3.2 South African guidelines, legislation and organizations

In the face of the HIV/AIDS challenge confronting South Africa, the South African government has entered into a partnership with civil society by way of SANAC (South African National Aids Council). The purpose of this council is to advise the government on HIV/AIDS in South Africa (SANAC, 2009). The objectives of SANAC are the following:

- to advise government on HIV/AIDS and sexually transmitted infections policy and strategy;

- create and strengthen the partnership for an expanded national response to HIV/AIDS in South Africa;

- receive and disseminate reports on all sectoral interventions to HIV/AIDS and consider challenges, and

- oversee continuous monitoring and evaluation of all aspects of the Strategic Plan on HIV/AIDS and STIs, 2007-2011 (SANAC, 2009).

In line with the UNAIDS and WHO guidelines discussed above, the South African Department of Health (DOH) lists four priority areas in their five-year strategic plan (2007-2011), and for each of these priority areas the guidelines as shown below, apply. These are also contained in the *Fact Sheet on HIV/AIDS for Health Care Workers*, dated 25 October 2000.

Priority area: Prevention

- Guideline on rapid HIV/ AIDS testing

- Guideline on management of occupational exposure to HIV

- Guideline on prevention of mother-to-child HIV transmission

- Guideline on feeding of treatment, care and support

Priority area: Treatment care and support

- Guideline on prevention and treatment of opportunistic and HIV-related diseases in adults

- Guideline on managing HIV in children

- Guideline on Tuberculosis and HIV/AIDS

Priority area: Research, monitoring and surveillance and human rights

- Guideline on ethical consideration for HIV/AIDS clinical and epidemiological research.

- Guideline on a Draft "Testing for HIV" Policy

Priority area: *Human and Legal Rights*

- Ensure knowledge of and adherence to the existing legal and policy frame work.

- Mobilise society, and build leadership of HIV-positive people to protect and promote human rights.

The *Code of Ethics for Social Workers* (SACSSP, 2007), stipulated by the South African Council of Social Service Professions, also guides social workers in relation to HIV/AIDS. The code of ethics is relevant to HIV/AIDS as it governs working with clients in the following ways, among others:

- Recognize the uniqueness of each client.

- Acknowledge the right to self-determination of the client.

- Take into account the client's rights, preferences and objectives when structuring service-rendering, even in the absence of the client; strive towards the client's optimal use of his/her abilities.

- Respect the client's right to decide whether or not to co-operate with the social service practitioner and maintain the client's right to confidentiality.

- Not refuse service-rendering to a client irrespective of whether or not the client is in a position to pay the fees for such services.

In addition to this code of ethics, registered social workers must consider the Social Service Profession Act, Act 110 of 1978 that defines the parameters of the social service profession in South Africa. Chapter 6 of this Act is relevant to HIV /AIDS as it advocates that professionals are obliged to treat clients with

respect and dignity and that clients should be given quality services (SACSSP, 2007).

Other pieces of legislation that are relevant to the context within which HIV/AIDS is addressed in South Africa are the following:

- *Domestic Violence Act, 116 of 1998:* This act advocates for the protection of every individual from any form of abuse (emotional, physical and economical). Women and children are especially vulnerable to sexual abuse that poses a high risk of contracting HIV.

- *Children's Act, Act 38 of 2005:* Chapter 7 (Part 3) of this Act emphasises protective measures relating to children and the confidentiality of information on HIV/AIDS status of children. Children are entitled to be offered counselling before testing for HIV. Those children who are below the age of 12 must have guardian consent for testing for HIV. In children, HIV testing is also done for the purpose of foster care and adoption.

- *Older Persons Act, Act 13 of 2006:* This Act promotes and maintains the status, well being, safety and security of older persons. The act advocates for the protection of the elderly and their right to be treated with dignity and respect. The aged are likely to be vulnerable to domestic violence such as rape with high risk of contracting HIV, assault (physical abuse), as well as economical and emotional abuse.

Davids *et al*. (2005:234) state that the Batho Pele Principles – meaning "People First" in the White Paper on Transforming Public Service Delivery, 1997 are regarded as relevant to HIV/AIDS. These authors indicate that all eight principles are relevant, namely Consultation, Service standard, Access, Courtesy, Information, Openness and Transparency, Redress, and Value for Money. These principles are also supported by the Constitution of the Republic of South Africa, 1996 (Chapter 2, Bill of Rights) that every person should be treated equally irrespective of their status, race, or religion.

There are a number of South African institutions that operate within the field of HIV/AIDS. The National Association for People Living with HIV and AIDS in South Africa (NAPWA-South Africa) is a non-political non-profit organisation based in South Africa, with global links to similar organisations under the same name in the United States and Australia. It is a community-based organisation operating within a human-rights and social-justice framework. It focuses on advocacy to promote the highest quality of care for people living with HIV/AIDS, education (empowerment), health promotion and outreach at a national level. The activities of NAPWA also include policy development and analysis, representation on issues affecting people living with HIV/AIDS, and health- and research-based programme development.

According to their website (NAPWA-South Africa, 2009) the objectives of NAPWA include:

- Maximizing and demonstrating opportunities to promote meaningful social participation of people living with HIV

- Support for and enabling of representations from across the spectrum of HIV- positive people's lives and experience

- Promotion of the development of evidence-based policy responses that address the social impact of HIV diagnosis.

The Treatment Action Campaign (TAC) is a non-governmental organisation operating in South Africa. The organisation has more than 16 000 members, 267 branches and 72 full-time staff members. The organisation advocates for increased access to treatment, care and support services for people living with HIV/AIDS. The TAC aims to strengthen awareness and advocates for greater access to specifically comprehensive HIV and TB prevention. An important focus of the organisation is to campaign to reduce new HIV infections, and they also support social referral services at grassroots community level. The TAC has intensified its advocacy on behalf of women by leading a campaign to end violence against women and mobilising communities around the rights of women (TAC, 2009).

2.4 Training of social workers

Sullivan *et al.* (2003:98) state that a principal outcome of education in the social work foundation is the development of a set of generalist skills, applicable to practice with a variety of systems and client populations. Field seminars can bring together classroom and field practicum experiences to support this development. This "conscious disciplined use of one's self and one's abilities" is fundamental to the role of the social worker. The approach to social work training involves three dimensions, namely the demonstration of on-the-job skills, the intellectual and research base of social work, and the facilitation of social care (Trevellion and Beresford, 1996:17).

According to Walton (1982:51) social workers are trained in four generic methods, namely casework, group work, community work and research. These methods will be discussed in brief below.

2.4.1 Case work

Social workers are trained to be information givers; hence they need to be continuously updated with the current developments. Social workers are trained to provide counselling where a relationship between the clients and the social workers has been established. Counselling involves sessions where a client relates his/her problem, and the social worker together with the client, identify and discuss various solutions to the problem.

The current global social crises, be it HIV/AIDS, teenage suicide, child-headed households, family disputes, unemployment or poverty, all require social workers who are dedicated to helping needy communities (Walton, 1982:51). Sullivan *et al*. (2003:98) state that a good case worker must be "born and made", cautioning the profession that its elements of error is the failure to recognise how much is being done in social work "to develop a native gift though training and specialised experience".

This component of training relates to the work that social workers do with PLWAs, for example counselling them before and after being diagnosed with the disease. Social workers give comfort and brainstorm with the client and

his or her support system (family or relatives) to find alternative coping mechanism after the diagnosis. According to Willinger *et al*. (2003), case work is a method where a social worker can analyse family dynamics and help a family member to disclose an HIV/AIDS diagnosis. Case work is also where the social worker advocates and considers community-based resources available to families in need and offers support to families, especially those who lack knowledge about HIV/AIDS.

2.4.2 Group work

According to Walton (1982:53) group work encompasses a cluster of approaches ranging from discussion, education and activity groups through to therapy groups. Activation of the community and self-help groups could also be included in this list. Group work, as one of the methods of social work, assists the members of the group, for example when the members of an HIV/AIDS support group, or a bereaved parents group share their common problems and support each other.

The use of groups has great potential but it requires resources such as space and time. With the high case load social workers have to carry, they may not be able to find the necessary time to use group work systematically. Because of the limited resources available, the use of groups currently largely depends upon the initiative of individual social workers, rather than being a structured part of the services rendered (Walton, 1982:53). Group work relates to HIV/ AIDS as the continuing goal is to educate, empower and build community - a community of hope, understanding, mutual concern and shared effort (Willinger *et al*., 2003:159). These authors highlight that HIV/AIDS patients are dependent on chemicals (medication) with few internal resources to cope with the devastation of the disease. Therefore group work provided a venue in which patients are able to discuss their fear of dying, rejection and stigma. These issues are addressed within the powerful healing currents of group process. Patients described these meeting as “information sharing”, “getting in touch”, “reinforcement for life and relaxation” (Willinger *et al*., 2003:159).

2.4.3 Community work

Walton (1982:53-54) states that community work is another method of social work that is used to develop and empower communities. There may be limitations to the degree to which social workers can use community work methods if there are extreme conflicts between community organisations and local authorities. Even despite this potential limitation, there is strong encouragement for increased community orientation and responsiveness to participation. Community work does mobilize untapped resources and also gives vital stimulation to the ways in which services are structured and used.

Trevellion and Beresford (1996:17) state that the emphasis on participation and empowerment in community work gives priority to different skills. This includes information giving, facilitating people's own efforts to describe what their needs are and what they will do to get have these needs met. These authors further state that with regard to the role of social work in promoting social inclusiveness, the skills required will involve those traditionally associated with community development.

Willinger *et al*. (2003:53) state that through this method (community work) social workers continue to advocate on behalf of people living with HIV/AIDS through community organization and policy development. Social workers provide education on HIV/AIDS through health promotion campaigns together with multi-disciplinary team (nurses, nutritionists, medical practitioners and civil society). All these efforts are aimed at empowering the infected and those affected by HIV/AIDS.

2.5 Conclusion

This chapter contained information on the international and national context for HIV/AIDS work, and therefore, this research. This context involves both governmental associations and strong national NGOs, such as the TAC. In particular, attention was given to the way in which social workers are prepared for their crucial role as change agents in development projects involving

PLWAs (as discussed further in Chapter 3). The particular areas of training of social workers that are utilised in their dealing with the needs of PLWAs are case work, group work and community work.

CHAPTER 3: EXPLORING THE LINKAGES AMONG HIV/AIDS, DEVELOPMENT AND PARTICIPATION

3.1 Introduction to the chapter

According to Lawson (1997:9), although HIV/AIDS is a health matter, above all else it is a general development concern. The approach of the UNDP locates the factors determining the virus, the manifestation of the epidemic and the nature of its consequences in the cultural, social and economic determinants of people's daily lives.

It therefore follows that factors related to HIV/AIDS, as discussed in this study, have to be addressed against the background of development issues, such as poverty and the need for sustainable development. This statement can be substantiated by a discussion of the linkages between HIV/AIDS and the Millennium Development Goals (MDGs).

In particular, communities and PLWAs need to be empowered through participatory development. A developmental approach to HIV/AIDS will strengthen the capability of communities and PLWAs to respond in effective and sustainable ways to the demands of the epidemic.

The aim with this chapter is therefore to explore the linkages between HIV/AIDS and these development-related issues. In the first place the linkages between HIV/AIDS and poverty are discussed, including how the epidemic relates to the MDGs. This leads to a discussion of development, and in particular sustainable development and participatory development. Then an exploration of participation in general follows, where after the role of the change agent is discussed to conclude the chapter.

3.2 HIV/AIDS as a problem of poverty and development

Research has shown that there are a number of factors that contribute to people being exposed to HIV, and some of these factors are beyond the

control of the individual. These factors include poverty where people are engaged in the struggle for basic needs such as food, housing, water and employment (Lawson, 1997:10). This author states that other factors over which the individual has limited control, are the low status of women, the high level of untreated sexually transmitted diseases, migrancy, and social dislocation and war.

In viewing HIV/AIDS as a problem of poverty, the various manifestations of poverty are relevant. Poverty relates to more than just a lack of adequate income. Sachs and Agrawal (2002:46) said that "poverty is a lack of power, rather than a lack of money and so reinforcing the rights of the poor is the condition of poverty eradication". The manifestations of poverty also include lack of access to education, health and infrastructure. As the World Bank (2009) states:

> "Poverty is hunger. Poverty is lack of shelter. Poverty is being sick and not being able to see a doctor. Poverty is not having access to school and not knowing how to read. Poverty is not having a job, is fear for the future, living one day at a time. Poverty is losing a child to illness ... Poverty is powerlessness, lack of representation and freedom. Poverty is a call to action - for the poor and the wealthy alike - a call to change the world so that many more may have enough to eat, adequate shelter, access to education and health, protection from violence, and a voice in what happens in their communities."

Ackron (2002:4-5, as cited by Rust 2007:3), categorises well-being into four dimensions - as viewed by the poor themselves. These dimensions are as follows:

The material dimension of well-being: Food security and possession of assets (e.g. secure land tenure and the means to work the land, secure employment or capital and other means to start a self-employment business)

The physical dimension of well-being: Physical health and the strength to perform physical work, and human dignity and appearance

The security dimension of well-being: Protection against corruption, crime and violence, recourse to justice, absence of war and ethnic strife, resilience against natural disasters, and

The freedom-of-choice dimension of well-being: Power to control one's own life, opportunity to acquire education, skills and means to self-improvement, opportunity to live in decent conditions instead of being forced to live in decaying areas.

The Ministerial Committee for Poverty and Inequality (1998:6) states that it is the interaction between all these dimensions of poverty that makes it so difficult for the poor to escape poverty.

In South Africa, almost half of the population live below the poverty line (UNDP, 2005). In addition to these very high levels of general poverty, relative poverty between racial groups and genders is also an important factor in South African society (Lawson, 1997). The gendered nature of poverty is particularly relevant to this study, and will therefore be briefly discussed below.

The degree to which poverty is determined by gender in South Africa is captured in the Gender Development Index (GDI). The GDI is calculated by determining the Human Development Index (HDI) for only the women in the population. The HDI is a composite index reflecting real per capita income, life expectancy and education (UNDP, 2005). Afrol (2009) reports that over the past few years SA's HDI has decreased by 35 places to 120th on the UN HDI list, due to the lower life expectancy caused by HIV/AIDS. South Africa's GDI value of 0.680 should be compared to its HDI value of 0.683. Its GDI value is 99.6% of its HDI value. Out of the 155 countries with both HDI and GDI values, 40 countries have a better ratio than South Africa does (UNDP, 2009).

With regard to Africa, Budlender (2003:8) reports that 47% of African females live in households where there is no earned income. Furthermore, 80% of PLWAs in the age bracket 15-19 years are female. The EU (2005: 9) states that gendered differences in rights, access to natural resources and

infrastructure, labour markets and participation in political processes lead to situations where, for example, women in Sub-Saharan Africa produce up to 80% of the food, but own only 1% of the land.

As discussed by Nierenberg (2002:34) highly unequal gender relations expose women to violence, which is one of the determinants of poverty (as discussed above). For instance, women and girls are exposed to sex-selective abortions, infanticide, female genital manipulation, domestic violence, rape, and murder. The South African Regional Poverty Network (SARPN, 2007) reported that the South African rate of reported rapes per capita is one of the highest in the world.

A consideration of the linkages between the MDGs and HIV/AIDS substantiates the argument that HIV/AIDS is a developmental, rather than merely a health issue. The discussion below also further sheds light on the gender implications of the HIV/AIDS epidemic.

The MDGs are the result of the commitments and targets that originated during the UN development- and poverty-related world summits of the 1990s. South Africa and 188 other countries endorsed the MDGs at the 2000 Millennium Summit (UNDP, 2006). The MDGs are eight specific goals relating to development issues such as extreme poverty and hunger, universal primary education, gender equality, child mortality, maternal health, HIV/AIDS and malaria, environmental sustainability, aid, debt relief and trade. The relevant MDGs are discussed below to illustrate their implications in relation to HIV/AIDS.

Goal 1: Eradicate extreme poverty and hunger

Extreme poverty is frequently defined as the inability to meet basic food requirements (Bissio, 2003:1). The UNDP (2006:4-24) reports that between 1990 and 2006, the number of people living in extreme poverty in Sub-Saharan Africa increased by 140 million.

HIV/AIDS is a significant factor contributing to the Southern Africa food crisis (Pembery, 2008). The increasing number of young people dying of AIDS

leads to fewer agricultural workers. This results in decreased food production as well as a smaller variety of crops being grown. Empowering women to take part in small-scale farming is a crucial strategy in ensuring food security, as women are the main food producers, and are also looked upon as the key food providers in the family (Pembery, 2008). However, as this author states, PLWAs are often too weak to undertake farming activities**.**

HIV/AIDS is contributing to the impoverishment and malnutrition of households and communities that are affected by the epidemic. Pembery (2008) states that poor nutrition is worsening the condition of PLWAs. Those living with the disease have a more acute need for good nutrition (Gillespie and Kadiyala, 2005:5). Good nutrition increases resistance to infections, delays the progression of the disease, and improves energy. HIV/AIDS causes stress to the household of a bread winner when she or he becomes ill, as the savings are used for medication and transport to and from the clinic/hospital, rather than for food and other ways of combating poverty (Pembery, 2008).

Goal 2: Universal primary education

Although the net enrolment rates in Sub-Saharan Africa have increased between 1990 and 2006, the UNDP (2006:4-24) reports a gender gap, with more girls of primary school age out of school than boys (42% girls and 38% boys). Educating girls and mothers leads to sustained increases in education attainment from one generation to the next. Multiple studies indicate that a mother's level of education has a strong positive effect on their daughter's enrolment (Birdsall *et al*., 2005:62-99). There is a phrase, "Educate a woman and you educate a nation" that might be taken to indicate that women play an important role in their children's education, and so, in the eventual well being of society.

The AIDS epidemic has made the goal of universal primary education much more difficult to achieve, especially in the hardest-hit countries. This is due to the high number of children, especially girls who need to care for ill parents and relatives or to replace them on the farms and in the work place (United

Nations, 2004:69). Many parents die as a result of HIV/AIDS leaving behind dependent children. These children leave school at an early age to look after siblings or the terminally ill parents. Poverty becomes a vicious cycle because these children will grow up to be poor adults, as they never get a chance to complete their education. They might work on farms or as domestic workers where their parents used to work and where the salary is insufficient to meet their own basic needs. These examples illustrate how HIV/AIDS can lead to absolute poverty as well as aggravate already existing poverty levels.

Birdsall *et al.* (2005:64) state that universal primary education could save at least seven million young people worldwide from contracting HIV over a decade (700 000 cases a year), and can greatly decrease their poverty levels. Education can serve as a "social vaccine" against HIV, particularly for young adults and school-age children. These authors further state that empowering children about low-risk behaviours and prevention strategies is important (as this would help them reject the myths associated with sex).

Goal 3: Promote gender equality and empower women

HIV/AIDS affects both men and women, but at different ages and stages of their lives. Nearly one in four women aged 20 to 24 is HIV positive compared to one in 14 men of the same age. The reason for this is also anatomical, as women more easily gets infected with the virus. Women are particularly vulnerable to HIV/AIDS due to high poverty and low education levels which contribute to unsafe sex practices (Strebel, 2004:3). Furthermore, the burden of caring for AIDS victims in household falls heavily on girls and women (UN, 2004:68). Caring for terminally ill patients, might force women to become house bound, thereby constraining their opportunities for employment and education. It is furthermore acknowledged that women play an important role in fighting HIV/AIDS by improving efforts to prevent infection and treating those already infected (Ogunbayo, 2004:11).

According to Lawson (1997:10) most women lack the power to insist on either monogamy or safe sex practices. In many communities the low status of

women also means less access to the education and health-care services which may protect them from HIV infections (Lawson, 1997).

As shown above, women are also vulnerable to domestic violence and rape, thus further exposing them to HIV infection. Rape plays a significant role in the high prevalence of HIV among women in South Africa (Pembery, 2008:2). According to this author, police reports show that in 2004-2005 there were at least 55 000 reported cases of rape in South Africa, although the actual figure is undoubtedly higher than this, since the majority of cases go unreported.

Women often face more severe discrimination than men if they are known to be HIV positive (Pembery, 2008). This can lead to physical abuse and the loss of economic stability if their partners leave them.

Goal 4: Reduce child mortality

According to the UN (2004), children under the age of five die owing to mother-to-child transmission and to the weakened ability of infected mothers to care for their infants and young children. Mothers with HIV and AIDS at ante-natal clinics are given medication (Neverapin) to reduce mother–to-child transmission of HIV and AIDS. The Strategic Plan for 2007 – 2011 (Department of Health, 2007-2011:14) aims to reduce child mortality rates in South Africa.

As discussed above, women are very vulnerable to HIV/AIDS. They have a huge responsibility to take care of children and the entire family and where there are small children without a mother figure, neglect is very obvious. This neglect has serious psychological and social impacts on the health and welfare of the child. (UN, 2004)

Goal 5: Improve maternal health

According to the UN (2004:69), HIV/AIDS impairs the maternal health of infected women. In countries of Sub-Saharan Africa where women are more affected by HIV/AIDS than men, the impact on maternal mortality is more severe than in other regions. The UNDP (2006:4-24) reports that in this

region, the maternal mortality rates showed little change between 1990 and 2006.

In South Africa, clinicians are for instance obliged by the National Guideline for Cervical Cancer Screening Programme (Department of Health, undated) to take pap-smears from women as they are vulnerable to cervical cancer and other sexually transmitted diseases. The low degree of power that women tend to have in their relationships with men, often make them unable to control decisions regarding fertility and contraceptives use. Women are also exposed to violence and sexual abuse at the hands of their male partners (Van Rensburg, 2004:265) which increases their risk of contracting HIV/AIDS.

Goal 6: Combat HIV/AIDS, malaria and other diseases

The UNDP (2006:4-24) reports that in Sub-Saharan Africa the number of new Tuberculosis (TB) cases (excluding HIV-positive people) has increased by 5% between 1990 and 2006. Despite this increase, there are also some improvements. The number of people infected with HIV declined from 3 million in 2001 to 2.7 million in 2007. Furthermore, with the introduction of antiretroviral treatment services, the number of deaths has declined from 2.2 million in 2005 to 2.0 million in 2007. Antiretroviral drugs are adding years to people's lives, but the need for treatment still outpaces the available supply. Therefore, the achievement of universal access to treatment for HIV 2010 will still be a challenge for most developing countries.

According to the UN (2008:34), Malaria and TB also present challenges that affect the poorest countries. Despite the progress made with regard to the introduction of insecticide-treated mosquito nets and vaccinations of children, these diseases still affect a high number of people. HIV/AIDS and TB have recently being linked through the incidences of mortality from TB and the emergence of extremely resistant TB (XDR-TB) which are linked to immune suppression caused by HIV/AIDS. Poverty and undeveloped district health services are also important in this regard. The double stigma which a patient encounters when infected with both TB and HIV has become a stumbling

block to patients seeking health services (Department of Health, 2007, 2011:11).

Goal 7: Ensure environmental sustainability

The UN (2004:69) highlights that HIV/AIDS is reducing the ability of nations and communities to integrate principles of sustainable development into their policies and programmes, in particular the provision of safe drinking water and adequate housing. These conditions also facilitate the spread of the HIV/AIDS epidemic as there is a great deal of pollution, malnutrition, domestic violence, child abuse, as well as other diseases such as TB that can further compromise the health of HIV/AIDS sufferers.

3.3 A discussion of development

3.3.1 From colonialism to people-centered development

To understand the dimensions and challenges of participation as a building block of development, an overview of the progression in development theory is first presented. According to Davids (2005:4) development theories emerged after the Second World War, progressing from merchant capitalism, through modernization and dependency, to humanistic approaches. These are discussed briefly below, mostly after Davids (2005:4). The implications of the human development paradigm for HIV/AIDS are also discussed.

Merchant capitalism (colonialism)

An example of the practices during the 1950s was for capitalists to exploit Africans by selling them low-quality weapons and clothing in exchange for agricultural products such as sugar and cotton, thereby making a high profit. The results of this paradigm were the devaluation of local currencies; putting the control of raw materials in the hands of Western organizations, and the emergence of European and American elites that still exist today in African countries. According to Davids (2005:9) these are some of the reasons why

African countries are still in the mode of developing and struggling to make ends meet.

Modernisation theory

According to Davids (2005:9), modernization theory was established after the Second World War based on the view that underdeveloped countries should follow the development style of the Western developed countries. Modernisation theory regarded indigenous knowledge as inferior, and valued Western culture as superior. This phase was characterised by high productivity and profit with the use of new technologies, as opposed to manual labour, high levels of illiteracy, low investment, and low agricultural productivity (Davids, 2005:9).

Dependency theory

Davids (2005:12) state that after the failure of modernization theory to develop under-developed countries, dependency theory emerged during 1960s as an alternative explanation for the lack of development. Viewed from an international perspective, developed countries such as Britain, Australia, and America still exploited the underdeveloped countries by drawing highly skilled people such as medical practitioners and engineers from these countries. These practices perpetuated poverty in the underdeveloped countries, which then continued to depend on the developed countries. From a national perspective, urban areas also draw resources from rural areas, leaving them in the state of poverty which still exists today. According to Finance Minister of South Africa, Trevor Manuel (2009), the success of rural development in South Africa will reduce migration of people to urban areas, thereby decreasing overcrowding in the cities.

People-centered development

South Africa experienced both colonialism and apartheid whereby the majority of the country's citizens were exploited. The first democratically elected South African government introduced a development policy framework in 1994 to enhance people-centered development though the Reconstruction and Development Programme (Davids, 2005:18**).** People–centered development is

development aimed at empowering communities (human development). Ready-made assistance or development within communities has not being successful as it neglected the greatest assets in any community e.g. human resources of people, talents and energies (Rogers, 1987:59). This policy framework subscribed to the principle of self-reliance to be achieved via public participation, social learning, empowerment and sustainability. These aspects are briefly discussed in following sections.

Human development and HIV/AIDS

According to Pharaoh (2005:37), HIV/AIDS is one of the most important current global socio-economic and development problems. The range and projected magnitude of the socio-economic impact of HIV/AIDS indicate that the epidemic should now be regarded as a national crisis and receive from each government ministry and sector of society, the attention that such a crisis deserves. For the most part, however, the problem of HIV/AIDS is still seen through a 'service delivery' lens, making it largely a community focused issue, requiring a predominantly external response. The bulk of activities are currently focused on community-oriented activities, such as equipping people living with HIV/AIDS and their families with skills (human development) to establish home food gardens, educating people about how to eat healthier and, in some districts, providing technical and material support to children orphaned by HIV/AIDS.

Swanepoel (1997:2) indicates that human development recognises and increases people's capabilities. It is a holistic approach that embraces the whole person. The human development paradigm goes beyond the quality of economic growth to look at the quality and distribution of such growth, recognising that only public policy can ensure that economic activity produces the desired societal results. Growth must not be rejected as it is essential to alleviate poverty in poor societies, but development must go beyond growth.

Swanepoel (1997:2) further states that the human development approach can encourage self-reliance and boost self-esteem. It places considerable emphasis on the mobilization of local resources as a way of allowing people to develop their capabilities and on participation as an agent of constructive

change. The development of human capabilities is increasingly regarded as a right to which all people are entitled. This right includes the ability to access basic health care and freedom from starvation. People living with HIV/AIDS are to be encouraged to participate actively in development projects that are meant to uplift their standard of living and improve their health status and socio-economic condition.

According to Barnett and Whiteside (2002:121), Botswana has done well in terms of human development. The adult literacy rate is 75%, and 96% of primary school age children are in school. It is one of the fastest growing economies in the world and the UN classifies it as an upper-middle-income country. Even though Botswana has a high HIV/AIDS prevalence, it has achieved high levels of growth thereby illustrating that human development can capacitate societies and encourage economic growth, which in turn lead to poverty eradication.

3.3.2 Sustainable development and sustainability

In the previous section it was shown how HIV/AIDS is a development problem, rather than just a health problem. If HIV/AIDS is to be addressed as a development problem, the requirements for sustainable development are relevant. Therefore sustainable development is briefly discussed below.

As stated in Chapter 2, Hattingh (2001:38) argues that sustainable development is a contestable and complex concept that can be understood in many different ways, based on one's value position on issues such as equity and participation. Nevertheless, the Brundtland Commission (Dresner, 2002:64) provided what has become an often quoted definition for sustainable development: "development which meets the needs of the present without sacrificing the ability of future generations to meet their needs".

The South African National Strategy for Sustainable Development (DEAT, 2006:6) defines the term *sustainable development* as follows: "Sustainable development means the integration of social, economic and environmental

factors into planning, implementation and decision-making so as to ensure that development serves present and future generations".

Rust (2008a:26-27) states that the value of a sustainable development paradigm lies in the fact that it captures the interactions between the social, economic and environmental dimensions, rather than narrowly focuses on for instance economic growth, employment creation or poverty alleviation. This author also says that a sustainable development paradigm enforces a long-term perspective. Cloete *et al*. (2003:3) reiterate the value of such a perspective by saying that "this implies not only short-term progress towards progress towards increasing quality of life, but also longer term durability of those higher standards of living".

According to Chambers (1983:11) as cited by Laderchi (2001) sustainability is closely related to self-reliance. Development projects should therefore consider socio-economic, institutional and environmental factors to promote sustainability. Furthermore, development projects should sustain the natural resources for use by future generations. If the project can continue even after development workers have left the scene, this would show that empowerment and human development have been achieved.

To achieve sustainability, there is a need for good planning, prioritizing needs to achieve the set goal, developing a sense of ownership by defining behavioural standards, simplifying the action strategy, self monitoring and the setting of reasonable targets (Swanepoel, 1997:9 as cited by Egan, 1994). This author further indicates that the sustainability of development projects relies on the following factors: the project should address the felt need, it should be consistent with the values of the community, there should be continuous skills development to maintain change, and active participation of the action group is to be emphasised. The development project should also be affordable and manageable.

As participation is fundamental to this study, a more detailed discussion of participatory development follows in the next section.

3.3.3 Aspects of participatory development and participation

According to Theron *et al.* (2007:5), participatory development uses local decision-making and capabilities to define and steer the nature of facilitation. Participation requires recognition of the local capabilities and avoidance of imposition of priorities from outside. Participatory development is also premised on the principle of self-determination and it promotes equity in that local decisions are considered to be as legitimate as those taken at the national level. Such an approach is driven by the belief that local communities have the responsibility to shape their own future. Theron *et al.* (2007:5) state that grassroots-level participation in development depends on the change agent who should make sure that the beneficiaries are the driving force behind the initiative they promote. But participation is also being advocated on a larger scale, and is being moved beyond the boundaries of projects or grassroots interventions to the larger spheres of social, economic and political life. In this way, participation can then be seen as a tool towards important policy objectives such as empowerment and good governance (Theron *et al.,* 2007).

Laderchi (2001:4) highlights that participatory development is important in analysing poverty and suggesting poverty reduction strategies through the engagement of the local community. This author defines three tributaries of participation, namely mutual learning, efficiency and self-actualization of the intended beneficiaries of the development project.

Participation contributes to ownership and the sustainability of development efforts. The facilitator or change agent empowers people by providing information and facilitating their self-determination. Participation ensures that the valuable indigenous knowledge of the local people is used and the prescriptive approach or top–down approach is avoided, thereby facilitating sustainable development (Theron*,* 2005:129). People are not passive spectators of their development but have a voice in any effort directed towards change. The participants determine, implement and evaluate the

social development projects aimed at improving their lives (Swanepoel, 1997:9).

Muller (2006:12) discusses the intrinsic, as opposed to the instrumental value of participation, stating that it should be viewed as "part of a process to build social and human capital within communities as part of human development". Therefore, participation is more than just a necessary action to have a plan or a project approved.

Public participation is important because it gives people an effective say in their lives and the services they receive. To achieve this, participants must have the personal resources and skills, organizational capability and the appropriate level of political access to participate (Beresford and Croft, 1993:51). These authors emphasize the two key components, namely access and support. Participants need to be offered support and skills to enable them to take part in the initiatives aimed at empowering them. When people are not supported to participate, it would be a challenge for them to make full use of any opportunities that are provided by the external institution (Beresford and Croft, 1993:59). It is further indicated by Beresford and Croft (1993) that there are elements which are crucial in participatory initiatives, such as self-confidence, assertiveness, self-esteem and expectations. When these are low, it is difficult for people to make choices and control of their lives.

To illustrate this point, Beresford and Croft (1993) states: "A self help group of people with HIV and AIDS reiterated the relationship between people being able to take control of their lives and services. People are encouraged to be involved all the time. The gain of this way of working is that it gives people confidence. We are in business of empowering people after they are diagnosed with HIV and AIDS. We are giving them back control over their lives."

Public participation often has tangible financial benefits as well. In a study of the relationship between participation and the effectiveness of interventions designed to reduce poverty, Hoddinot *et al*. (2001:1) found that increasing participation increased the labour intensity of projects and lowered the cost of

creating employment for poor individuals, without creating cost over-runs on the projects.

According to Menike (1993), an empowering approach to participation views poor people as co-producers with authority and control over decisions and resources - particularly financial resources that are then devolved to the lowest appropriate level. Inclusion of poor people and other traditionally excluded groups is also critical in priority setting and budget formation at the national level to ensure that limited public resources are used to build on local knowledge and priorities, and to demonstrate commitment to change. Participatory decision-making is not always harmonious and decisions may be contested and therefore conflict management strategies need to be in place to manage disagreement. Participation of poor people in planning is regarded as the most important aspect in development projects because the inputs of the poor sustain the projects.

Swanepoel (1997:2-13) indicates that the principles that govern the best practice in participatory development are those discussed below, namely human orientation, empowerment, accountability, local organization capability, ownership, social learning, and collective action. Sustainability, which is also identified by this author as a cornerstone of participatory development practice, has been discussed in Section 3.3.2 under sustainable development.

Human orientation

According to Bruwer (1995:25), holistic approaches embrace people being set free from poverty by increasing their choices. Human orientation refers to development which is about people and not about abstract things, and where people's capabilities are recognised and enhanced. Through this principle justice and equality are emphasised. According to Rahman (1993:207) human orientation is also a process of self-development through community development projects, and it cannot be given to people from external sources. This author emphasises the need for development to be aimed at developing people's creativity as they attempt to fulfil their socio-economic and cultural needs. It should furthermore be recognised that people's creativity and needs

are ever changing and therefore newer collective action is always sought. The scale of development projects should be in line with the capacity of the participants so that they can manage and sustain the project themselves.

Empowerment

Menike (1993:181) states that authentic participation of the poor in initiatives aimed at improving their lives for better generates significant empowerment. Empowerment can therefore be viewed as a process of enabling people to elicit and increase the ability they have and to influence decisions that affect their lives and those of future generations. This author further states that the poor lack power to improve their living conditions, but they do not want things to be imposed on them otherwise they will not actively participate and sustain the empowerment initiative. According to Narayan (2002:14) empowerment is the expansion of choices and action. It means increasing one's authority and control over the resources and decisions that affect one's life. As people exercise real choices, they gain increased control over their lives. Successful efforts to empower poor people, increasing their freedom of choices and action in different contexts often share four elements, namely access to information, inclusion and participation, accountability and local organizational capacity. These are discussed in more detail further down.

Accountability

Narayan (2002:22) and Theron (2005:124) both emphasised that public officials must be held accountable for their policies and actions that affect the well being of citizens. Accountability for public resources at all levels can be ensured through transparent fiscal management and by offering users a choice in services. At the community level, for example, this includes giving poor groups choice and the funds to purchase technical assistance from government. When poor people can hold providers accountable, control and power shift to them.

Local organizational capital

Narayan (2002:22) states that local organizational capacity refers to the ability of people to work together, organise themselves and mobilize resources to solve problems of common interest. Poor people turn to each other for support and strength to solve their everyday problems. Local organisational capacity is a key to development effectiveness. Organised communities are more likely to have their voices heard and their demands met than communities that are not organized (Narayan, 2002).

Ownership

According to Swanepoel (1997:8), the community or action group tends to have a sense of ownership when programmes or projects are relevant to them. Ownership develops when the need that the project is aimed at is a need experienced by the community and when their terms of reference are embraced in the project. Ownership should be facilitated through allowing time for the process to evolve naturally and for collective decision-making to take place. The management of projects, including finances, should be driven by the participants from the beginning with the guidance of change agent (Swanepoel, 1997).

Social learning

According to Bandura (2009:1) social learning is a process which people learn to model their behaviour because they have motivation, have the ability to reproduce the behaviour and are able to keep record of what they have learned. People's environment causes them to behave in certain ways. Social learning suggests a combination of social and psychological factors influencing behaviour. Social learning is mutual and participants learn from each other. The change agent also learns from local people and this instils new self-regard that empowers.

Learning in development is often a collective process that recognises and builds on prior knowledge. Social learning puts people first and should primarily build on enhancing community capability (Swanepoel, 1997:9).

Community capabilities can be promoted through social capital. Field (2005:4) indicates that the term social capital is generally used to refer to resources that people derive from their relationships with each other and from having a mutual goal. People can use their social capital or social networks to gain access to skills and knowledge needed to improve their lives in a variety of ways.

Collective action

Swanepoel (1997:32-35) states that every development project requires collective action aimed at achieving a common goal. People would share a common problem, a common heritage and culture, and would have a common purpose and take part in common activities. Swanepoel (1997:32-35) regards the participants of the collective action as an action group that shares common concerns and then come together to take action regarding their shared situation. Collective action promotes participation via the implementation of collective tasks and the collective management of addressing the identified needs.

As stated above, different researchers (Swanepoel, 1997 and Davids *et al.,* 2005) highlight that communities will actively participate in the planning and implementation of development projects only if such projects are relevant to their needs and they are able to understand know how they will benefit from the project. As discussed above, participatory development therefore involves factors such as culture, self-reliance, satisfaction of basic needs and sustainability. Theron *et al.* (2007:5) states that successful "grassroots level participation in development depends on a corps of effective change agents who will ensure that beneficiaries of development are placed at the centre of the initiatives they promote". This author discusses the general challenges of participatory development. Development workers historically approached the community with plans that have been ready made within the government bureaucracy, and they then just consult with the beneficiaries. This is a negative factor that might cause reluctance on the part of communities to participate in the projects, as the projects are not addressing their felt needs.

Change agents often lack the proper skills to plan *with* the participants, and therefore plan *for* them.

Poor people understand their felt need better than a change agent can. Therefore, they can do better to change their situation if they are provided with support and resources by government and business. They can also draw on their social capital and indigenous knowledge (Swanepoel, 1997).

The following case study of an income generating project of women from Moganyaka community in Limpopo Province, illustrates a successful initiative of participatory development (Mavalela, 1999:41-68). The project involved 28 unemployed women. The women had a common problem (poverty) and initiated a bakery project called *Phela o phedise***,** meaning "live and let others live". The women used their indigenous knowledge with the support from the development worker and the local chief. They explored the use of local resources, for example they used a mud-built-oven and it was operated with fire wood that they collected locally. Fundraising was done to buy ingredients for bread making. The local community was the main supporters of the project as they were buying the bread fresh from the bakery. The women were fully aware that for the project to develop to a stage where they could get a wage, a long time would be needed but that ultimately it would reward them. At a later stage, the Department of Health and Welfare became involved and they built a proper bakery and bought advanced equipment. The project was managed *with* members, not *for* them. This built courage, confidence and recognition for the participants.

According to Theron (2005:120) public participation is a component of the process of human growth and development. Human development could be achieved by allowing people to make decisions and determine their own destiny and be self sufficient. Chambers (1983) as cited by Theron (2005:121) states that the public participation process is important as it encourages a bottom-up approach rather than a top-down approach. A top-down approach is viewed as depriving people from being creative and taking ownership of their own initiatives.

Rust (2008b:11-13) discusses the advantages of the top-down and bottom-up approaches to sustainable development. This author cites Sachs *et al*. (2002:51) in this discussion which comes to the conclusion that a completely top-down approach is not sustainable over the long term as it "does not empower people and organisations by transferring skills through involving them in all aspects of the project and as such is a dependency-creating approach". However, Rust (2008b:12) cautions against also not ignoring the few benefits of a top-down approach, such as ease of project management in certain instances, the mobilization of external resources, and the fact that such an approach is often already entrenched and accepted in local communities via the role of traditional leaders and village elders. Rust and Hanise (2008:225) consequently state that the preferred approach would be to merge the bottom-up approach (giving people voice and developing empowering, sustainable community-based solutions) and the top-down approach (providing improved project management while leveraging external resources to achieve a … desired outcome)".

In South Africa, public participation offers valuable opportunities to rectify the inequalities of the past. It improves the chance of achieving sustainable development. Effective and authentic public participation leads to an expectation that transformation in the system will take place, with such transformation being the building blocks of development (Theron, 2005:119).

Theron (2005) discusses key components of effective public participation. There is a need to identify the action group or stakeholders in the public participation process carefully. Therefore, the facilitator of development should be re-skilled to act as a change agent by engaging the action group at all stages of planning and implementation. The role of the change agent should be clarified in the process and the meaning of the concept public participation should be explained.

An inter-disciplinary public participation team that includes the change agent as well as the community stakeholders who have indigenous knowledge and skills,

should be effectively engaged so that all involved can have a common understanding and work towards achieving a common goal of empowerment.

Beresford and Croft (1993:60-61) also highlights key elements to effective participation, as discussed below.

Resources

Public participation, like any other policy, has its own implications for resources. The resources required are human resources, material, time, space, skills and support, all of which have financial implications. In terms of time, the change agent should move at the pace of the participants as they have their own rhythm of empowerment and they understand their priorities, constraints, wishes and needs (Beresford and Croft, 1993:60-61).

However, excluding people from participating in the public participation process has its own implications as it results in inappropriate services and therefore wasteful expenditure.

Access to information

As it is stipulated in the Batho Pele principles, communities need access to information at service points and in languages which they understand. Poor people are able to take effective action when they have the relevant information, presented in a format which they can easily understand and interpret. This information should be timely disseminated in their language and through group discussion and debates. In most development projects, the need for information disclosure and dissemination is underestimated. The information that is regarded as relevant includes rules and rights to basic government services, financial services, market prices and private sector performance. Government institutions need to institute ways of effectively responding to poor people's needs (needs analysis), so that they may prioritise and jointly with the private sector and the communities involved, fulfil the communities' preferences (Beresford and Croft, 1993:60-61).

Training

Beresford and Croft (1993:60-61) indicates that communities need to be empowered with skills and ideas, but facilitators should not forget to incorporate the valuable indigenous knowledge these communities possess. Assumptions that people cannot participate often ignore the contribution training can make, but making people's participation conditional on training can also be discriminatory.

Research and evaluation

According to Beresford and Croft (1993:60-61), public participation demands some form of research as it is not sufficient to rely on the professional perspective of the change agents. Evaluation should include participants' own assessment of the initiatives to involve them. Their perception of participation may vary from those of the change agent. The participants know what it feels like, what they want from it and how best it can be improved to meet their identified needs. It is important that research reflects the values, priorities and interest of the participants.

Equal access and opportunities

Theron (2005:111-130) and Beresford and Croft (1993:73) indicate that participants need to have equal access to the services and opportunities. Public participation implies that people should have equal access in three overlapping spheres, namely mainstream life, support services, and arrangement for participation. It should be noted that even though it is highly emphasized that all should have access, women are still discriminated against compared to men as they are culturally burdened with caring for sick family members and by household chores, which restricts the time women have available for participation (Beresford and Croft,1993:73).

According to the World Bank (2000:10) participation can be designed to give voice to socially excluded groups such as women. Many women in Tanzania

indicated in a study on AIDS, conducted by the TANESA NGO (World Bank (2000:10) that they were fearful of and ashamed of discussing AIDS openly. They also highlighted that the burden of fetching water and firewood in the field exposes them to sexual aggression and rape (World Bank, 2000:10). This is an example of how participatory methodology, if implemented well, can empower vulnerable groups such as women by uncovering topics that are difficult to talk about.

Related to the above discussion on the keys to effective participation, the World Bank (2000:9) states the following principles for community empowerment.

- Development projects must be participatory and needs driven in nature. Projects should include both the socially excluded and elites.

- Development must emphasize institutional change and enhance transparency and promote a change of negative attitudes.

- Community-driven projects empower communities by giving them untied funds which allow them to chose their own priorities and implement their own programmes. However, where there are no local funds, it is better to start on a small scale and grow gradually.

- Local communities need to be assisted with technical and managerial support on demand.

- The local communities should also be held accountable, not only the local and central governments, and the development workers.

3.4 The role of the change agent

Change agents can play an important role in participatory development, but they need to learn to play an advocacy role, an enabler, mediator and organiser rather than imposing projects on people (Laderchi, 2001:4 and Theron, 2008:12). Theron (2008:9) states that the change agent should understand the value of the social capital in the community as it is an asset

that the community acquires through the social networks they develop and maintain with other community members. The change agent should therefore embrace what is available within the community and integrate the local indigenous knowledge into projects to further the aims of development.

Theron (2008:11) highlights that the change agent should not adopt a "know all approach", but should be a partner with the beneficiaries as they must have a sense of ownership and develop strategies to deal with their problems.

Theron (2008:15) indicates that for development to thrive, change agents should adopt a participatory development approach where beneficiaries become role players, and not spectators. The approach includes aspects such as the following:

- changing from a top–down approach to a bottom-up approach;
- changing from a blue-print approach to a social learning approach;
- changing from a control style to a release style;
- changing from a formalised approach to an incremental approach;
- changing from viewing participation as a cost to viewing participation as a benefit, and
- changing from a rigid approach to a flexible approach.

It should be noted that the community developer (change agents) should have the attitude of learning from the economically disadvantaged community member.

According to Mavalela (1999:35, citing Rahman, 1993:157) "professional knowledge has as much to take from the local knowledge and wisdom as other way round and this mutual enrichment is possible only in relation of equality between the two knowledge streams and not in a presupposition of superiority of one over the other".

3.5 Conclusion

Poverty is a major socio-economic problem around the world. In South Africa, there are high levels of poverty, and this needs urgent attention from the relevant stakeholders to ensure a better life for all South African citizens, including people infected with and affected by AIDS. This could be achieved through participatory development were the resources of the community becomes available for development and the community becomes self-reliant in the end.

The change agent needs to work within the community's frame of reference to promote self-reliance and ownership of development initiatives. Although the change agent learns from the community, sharing her/his own skills and knowledge also plays a vital role in the development process – a process of mutual learning is therefore needed.

CHAPTER 4: FACTORS RELATED TO THE LIVING EXPERIENCES OF PLWAs THAT COULD INFLUENCE NON-PARTICIPATION IN DEVELOPMENT PROJECTS

4.1 Introduction to the chapter

In the previous chapter HIV/AIDS was discussed in relation to development and poverty. In particular, as participation is fundamental to this study, attention was given to the importance of participation in development initiatives. In this chapter, the theme of participation is taken further via an exploration of the living experiences of PLWAs and how these relate to development projects. Whereas the focus in the previous chapter was mostly on aspects of development and participation in general, the focus in this chapter shifts to factors related to HIV/AIDS in particular.

The experiences of PLWAs and women living with HIV/AIDS will be discussed, as well as how these experiences relate to their participation or not in development projects. Issues that are discussed in this chapter include socio-economic and biological factors, as well as cultural beliefs, gender implications, stigma, lack of resources and discrimination. All of these factors can potentially impact on the level of participation of poor women living with HIV/AIDS in development projects, but people are different and from unique family backgrounds and socialised differently, and therefore no generalisations can be made.

A discussion of self-help groups and AIDS-focused development projects is lastly presented to understand the factors that make such projects successful.

4.2 Biological factors

Literature shows that biological factors also have an influence on how PLWAs will participate, or not participate, in development projects. According to Pratt (1995:72) it is probable that most individuals infected with HIV will eventually develop some form of ill health as a result of infection. This acute illness is characterised by lethargy and malaise, headache, fever, joint pains,

tenderness and pain in the muscles, and diarrhoea. Individuals may also develop a variety of self-limiting, neurological manifestations of acute HIV infections, for example, atypical, aseptic meningitis and acute encephalitis (Deacon, 2005:38). AIDS can further contribute to malnutrition by reducing appetite and also interfering with absorption of nutrients and making additional demands on the body's nutritional status (Gillespie and Kadiyala, 2005).

AIDS is a very painful chronic disease. The virus tends to destroy the immune system of the infected person. As the body loses its immunity, the PLWA tends to become sick and to lose strength. Some PLWAs become bedridden and cannot do anything for themselves.

These severe symptoms might contribute to the inability of PLWAs to participate fully in development projects, particularly if such projects involve hard labour like making a food garden.

4.3 Social factors

In literature, a number of social factors are highlighted that might be behind the non-participation of poor women living with HIV/AIDS in development projects. In trying to design projects to encourage participation and obtain the maximum possible benefit to PLWAs, an exploration and understanding of these factors become important. These social factors are briefly discussed below

4.3.1 Cultural beliefs

Cultural and belief systems have a great impact in people's daily lives and can therefore influence people's participation in development projects aimed at empowering PLWAs. For instance, because of these cultural beliefs, people might not be willing to openly admit their health status by working on a project designed to assist PLWAs.

According to Deacon (2005:57), the terrors, silences and stigma associated with the symptoms of the diseases decimating communities throughout the country in the wake of the HIV/AIDS pandemic, make sense if understood in

terms of their witchcraft connotations. No one wants to publicize the fact that they have been cursed. Such publicity would not only be embarrassing, but is dangerous. The researcher suggests that further research may show that the HIV/ AIDS epidemic in black townships and villages is likely to stimulate suspicions of sorcery, fear of witchcraft, and a general sense of spiritual insecurity as more and more people die at an early age of painful, debilitating and incurable infections that resonate with indigenous categories of interpretation broadly classified under consequences of witchcraft. Believing in witches provides people with perceived meaning and potential answers that science cannot give.

For instance, people who believe in witchcraft as the cause of the illness find it difficult to believe the virus theory. Therefore, people's belief systems could put them at risk of HIV infections (Ntsieni, 2005:28). According to Van Dyk (2001, as cited in Ntsieni, 2005:29) there are reports in Africa that witchcraft is believed to be the cause of transmission and AIDS.

Diverse cultures play an important role in how people respond to issues of life, and therefore there are many myths surrounding HIV/AIDS. One example, with dire consequences for young women in Africa, is that sex with a virgin might cure the disease (Meel, 2003 and Karabo, 2009).

4.3.2 Gender implications

As discussed in Chapter 3, gender inequality is a major driving cause behind the spread of HIV. This inequality often overlaps with cultural, social, economic and political inequalities between men and women. The roles and attributes assigned by society to men and women affect females from protecting themselves against HIV infection (Van Rensburg, 2004:287).

According to Pratt (1995:176) women are both socially and culturally vulnerable to HIV/AIDS because they are in most cases economically dependent on men. Women are expected to be passive and submissive in their sexual relationships, which are mostly controlled by the men. They lack the skills and confidence to discuss sexual behaviour with their partners, and have little bargaining power within their sexual relationships. This sexual

subordination of women makes it impossible for them to protect themselves from sexually transmitted HIV infections.

Furthermore, the burden of caring for AIDS victims in households falls heavily on girls and women (UN, 2004:68) – on top of their general responsibilities of caring for the family. Caring for terminally ill patients might force women to become house bound.

The UN (2004:66) indicates that inequality in access to credit, employment, education and information all make women more vulnerable to the negative impacts of HIV/AIDS. The UN further reports that the stigma of the disease may inhibit widows from seeking community and extended family support, which are vital safety nets in rural areas.

Garcia-Moreno (1997:302) argues that while in Africa HIV has been dominantly linked to heterosexual relationships, with the disease therefore equally affecting men and women, the role of women as transmitters of the disease (for instance via prostitution) is often highlighted at the expense of women's role as sufferers of the disease. The mother-to-child infection mechanism of the disease further strengthens this perception.

From the above, the following might be deduced about women's participation in the projects:

- women might not want to risk losing financial support from the men by admitting their health status by working on HIV/AIDS-related projects, as the men might withdraw their support from women living with HIV/AIDS;
- women carry heavy burdens for childcare and caring for the ill at home and may not have the time to participate in projects, and
- because of gender discrimination, women may not have the necessary confidence to take part in such projects. This lack of confidence might also be made worse by a sense of shame because of women's

perceived role as transmitters of the disease, as well as the general stigma attached to the disease.

4.3.3 Lack of social support

Sherr *et al*. (1996:47) argue that although few studies have demonstrated a casual relationship between support and health, there is ample evidence that various aspects of social support and health are positively associated. Good social support either promotes health or offers some protection from illness. For people with chronic illnesses there is a positive association between the support and the psychological resources which help the individual cope with illness. There is also evidence, however, that diagnosis of a chronic illness may eliminate the existing support and that those with a poor prognosis may receive the least support.

Furthermore, Field (2005:4) highlights that strong relationship in communities could work to the detriment of those with HIV/AIDS. People use their social capital to access skills and knowledge in a variety of ways. This knowledge may be a valuable source for the human development necessary for achieving sustainable livelihoods. Human development generates opportunity for economic appropriation, using social capital resource for their own benefit, therefore reinforcing the disadvantages of other community members (Kilpatrick *et al*., 2001).

According to Altman (1994:37-43) support services cover a wide area, ranging from the immediate and obvious needs of counselling those who are newly diagnosed to providing home care once they become sick. Support for those already infected and preventative education, are both very important. To meet these two goals requires not just the provision of services, but constant advocacy and interaction with government, health providers, and potential donors. Many people in developing countries particularly have noted that caring for someone with AIDS can become a very strong motive for behavioural change. Support becomes imperative for empowering people with AIDS to take control of their own situation. These support networks end up establishing groups and or movements of PLWAs. The movements are very

important to provide support to the affected and the infected, as AIDS has a severe effect on people who have no resources to deal with it. These people are in most cases unable to tap into traditional sources for emotional, physical and financial help, and as a result rely on community-based and voluntary services for assistance. This can be seen in most of the local clinics all over the country, where the PLWAs rely wholly on the non-government organisations for support. In general the whole population needs to be made aware of HIV/AIDS and be encouraged to support those who are either infected or affected (Altman, 1994:37-43).

Jackson (1992:188) is of the opinion that people with HIV and their families are part of the general public, and are exposed to negative media coverage, prejudiced ideas, false beliefs and judgemental values, just as much as anyone else. Their own responses to the knowledge of their infection will be affected by their previous levels of understanding and attitudes, which may be highly negative.

According to Jackson (1992:236) greater understanding and awareness should remove irrational fears, and lead to supportive attitudes from society towards infected people. They will for instance not be feared as a source of infection through social contact. For PLWAs to be accepted and supported, they should no longer feel that they need to keep their diagnosis a secret, and should be able to openly access support services for PLWAs. Often those people who tend to accept and give support to PLWAs are the members of support groups for people affected by the virus (Jackson, 1992:236).

4.3.4 Stigma, self stigmatisation and expected stigmatisation

According to Pryor and Reeder (1993:231) stigma is defined as a pattern of prejudice, discounting, and discrediting that an individual experiences as a result of others' judgements about her/his personal characteristics or group membership. HIV/AIDS-related stigma results from the way in which AIDS presents as a disease. For example, the disease can disfigure one's appearance and impair one's ability for social interaction. Furthermore, because of its communicability, it is characterised as a dreaded disease.

Stigma has had profound consequences for people with HIV/AIDS. Individuals perceived to be infected with HIV have been fired from their jobs, driven from their homes and socially isolated. PLWAs are more negatively evaluated than people who suffer from other diseases. It is known that people living with HIV/ AIDS are judged as being promiscuous or immoral, and as a result they may experience varying kinds and degrees of discrimination and a loss of status (for example being excluded from a religious community). This form of discrimination is a direct consequence of stigmatisation that results in negative consequences for PLWAs (Deacon, 2005: 38).

The stigma attached to HIV/AIDS may be one of the reasons why PLWAs do not fully participate in food garden projects. They may feel that other people might not want to buy products, for example vegetables, from PWLAs as they might be scared that the products could also be infected.

Steele and Aronson (1995, cited in Deacon, 2005:34) argue that since people know how society stigmatises them, they react by either conforming to, or resisting against this. According to Deacon (2005:34) conforming involves self-stigmatisation, which means accepting society's negative judgement on one's own identity as HIV-positive. This is psychologically damaging because it reduces the self esteem of the stigmatised person. Therefore the infected person tends to withdraw from public life and does not want to participate in any activity that will expose his/her status. This has further negative consequences on public health programmes because people may be reluctant to be tested, to disclose their status, and to seek treatment. They may also be unwilling to participate in therapeutic programmes such as support groups.

According to Soskolne, Stein and Gibson (2003, as cited in Deacon, 2005:34-35) hiding or revealing a previously hidden stigma causes greater psychological distress than revealing a stigma that has not been, or cannot be hidden. People who try to hide their status experience greater anxiety than those who reveal it. In an effort to resist self-stigmatisation, people living with HIV/AIDS may develop a very positive identity that leaves no room for dealing with illness and distress. The decision by many people living with HIV/AIDS to

adopt a strongly positive identity can be influenced not only by the psychological need to evade anxiety about their condition, but also by social factors. These social factors include the extreme negativity projected by society onto people living with HIV/AIDS. It requires a wide-spread promotion of a positive HIV identity by strong individuals as an attempt to minimise the perceived threat of HIV-positive people to society by emphasising that HIV-positive people can take care of themselves.

Deacon (2005:35) further indicates that levels of expected stigmatisation and discrimination materially affect the self esteem and behaviour of PLWAs. Fife and Wright (2000, cited by Deacon, 2005:35) suggest that individuals' perception of stigma accounts for the significant differences seen in the impact of an illness on them. Some research suggests that levels of stigma perceived by PLWAs tend to be higher than the actual levels of stigma (Deacon, 2005:35).

It is further also argued by Deacon (2005:38) that certain kinds of discrimination, such as the loss of the right to medical aid, pension and life insurance benefits, and opportunities for education, have been based on lower expected contributions to society by PLWAs and higher expected burdens on the family or the public purse. Such discrimination has been challenged because it violates the human rights of PLWAs. It is difficult for people who face all the issues associated with being HIV positive to also play a role in confronting these attitudes. To do so can both empower them and help change social attitudes. In general, some PLWAs have tended to see themselves as having a role to play in the larger AIDS struggle, particularly as educators.

Altman (1994:62) suggests that there is a need to discuss and open up spaces for defending PLWAs. There is a particular need for an urgent social compromise to avoid the continuation of the situation. The strugglers can unite and form civil organisations, calling society as a whole and the discriminated segments in particular for comprehensive debate, in order to preserve individual freedom and to ensure every citizen's rights (Altman, 1994:62).

4.4 Economic factors

4.4.1 Introduction

In Chapter 3, the linkages between HIV/AIDS and poverty were discussed in general. In this section, more specific aspects of economic deprivation are discussed in relation to how these might impact on the ability of PLWAs to participate fully in development projects.

To lend context to this discussion, Lawson (1997:4) states that research in other countries has shown that HIV/AIDS has had the most severe effect on families and households of poor communities, which have then experienced reduced ability to pay for basics like food, housing and services. Research in African countries has shown that the impact of HIV/AIDS on poor families in both rural and urban areas is:

- loss of income;
- productive labour diverted to care for the sick;
- food reserves or savings diverted on health care and funeral costs;
- reduced educational opportunities as children are withdrawn from school; and
- reduced level of nutrition, and in some cases serious malnutrition.

4.4.2 Unemployment

Natrass (2004:130) indicates that the rise in unemployment has resulted in a significant increase in poverty, particularly between 1999 and 2002. Unemployment rates are especially high among the youth, who constitute the bulk of those devastated by HIV/AIDS. As such HIV/AIDS has a significant socio-economic impact as it mostly affects the economically active individuals (Lawson 1997:4). Data provided by Steinberg *et al*. (2009:304) supports this statement as it shows that the proportion of all new HIV infections between 1995-2010 are concentrated in the following age groups: 15-19 (25%), 20-24 (15%) and 25-29 (10%).

Nattrass (2003:7) discusses how the South African path to economic growth has become increasingly skills intensive, which means that as HIV/AIDS constrains the ability of people to access education, it becomes even more difficult for the unemployed to find work. Being employed is furthermore often a way for PLWAs to access treatment via the wellness programmes offered by many companies and therefore unemployment also constrains treatment options for PLWAs.

As poverty and HIV/AIDS are linked, the social implications of the disease in areas with high unemployment are obvious (Mboyi *et al*., 2005:13). As discussed in Chapter 3, one of the manifestations of poverty is not having physical assets, such as land, the means to work the land, or the means to start a self-employment business. Therefore unemployed PLWAs, who are mostly from poor communities, are not able to create their own employment either. Therefore, these people rely on pensioners, transfers from employed family members and (increasingly) on disability grants to survive (Nattrass, 2003:8).

In addition to these societal impacts of HIV/AIDS in relation to unemployment, being unemployed also has psychological effects. A study completed at Rutgers University (John J. Heldrich Center for Workforce Development, 2009) shows how the majority of unemployed people experience anxiety, helplessness, depression, stress and sleeping problems. For PLWAs these psychological effects of unemployment come on top of the emotional distress caused by the disease itself.

4.4.3 Social grants

The government is offering disability grants to people infected by HIV. Those who are eligible for these grants are those whose CD4 count is below 200 (the CD4 count of a healthy person is over 600). According to Natrass (2004:128), the problem with this scenario, however, is that the loss of a disability grant may have serious financial and other implications for people living with AIDS. Welfare transfers, like pensions and disability grants, are important components of household income particularly for households at the

bottom end of the income distribution. It is thus to be expected that for many PLWAs, the disability grant has always been a source of great relief.

On one level it is entirely appropriate that a person should lose the disability grant once he/she starts to enjoy better health as a result of Highly Active Antiretroviral Therapy (HAART). It is reported (Natrass, 2004;21 and Stepaniak, 2007:1) that some PLWAs compromise their own health by not taking antiretroviral medication because they want their CD4 count to be low enough to continue benefiting from the disability grants. They are forced into this situation by the unemployment rate in the country, as they do not think that they will ever find employment. This is a sad situation as their quality of life does not improve and their health keeps on deteriorating, because the grant, while it is better than nothing, does not enable them to obtain nourishing food.

Furthermore Natrass (2004:131) argues that South Africa has a high rate of unemployment and formal employment has declined steadily for over a decade. Therefore, unemployed people who have their health restored by HAART may find themselves in a very difficult position within the labour market. Those who previously have had access to a disability grant may find themselves without an income to support themselves. They could thus face a terrible choice: not to take antiretroviral and keep the disability grant for the short time they have left to live, or take the antiretroviral, live longer but without an income. Such a choice could result in many people “yo-yoing “ between disability grants and AIDS treatment, resulting in the treatment regime being far less effective and more conducive to drug resistance.

4.5 Development and empowerment projects

4.5.1 Introduction

In this section, the types of projects that are initiated to assist PLWAs are discussed. In particular, self-help groups and integrating HIV/AIDS work with development work are discussed. Examples of successful projects are given to extract lessons for this study.

4.5.2 Self-help groups

According to Jackson (1992:136), self-help groups have proven to be effective in empowering people living with HIV/AIDS. Self-help networks have become important pressure groups to promote self-reliance.

An example is the Mashambanzou Organization in Harare that has initiated a multi-purpose centre for income-generating projects for people living with HIV/AIDS, as well as for training and support work. The projects run at the centre involve sewing and knitting groups that also provide a forum for discussion and mutual support.

Another success story cited by Jackson (1992:136) is The AIDS Support Organisation (TASO) in Uganda, with many branches around the country, that has gainfully employed PLWAs. Their motto is “Live positively with AIDS”. Another example of such a project is the Choice Organisation attached to the Tzaneen Municipality which attempts to work with organisations to encourage viable and sustainable development projects in the local communities (Mboyi *et al*., 2005:13).

These authors report that the Choice Organisation has collaborated with HIV-positive people in the villages to develop a chicken production business, and also supports clinics in establishing vegetable gardens. Equally important is the empowerment achieved as a result of the valuable role played by this organisation in their local communities. Women played a leading role in initiating poverty alleviation projects and spoke with pride of the visible impact of their work. Especially notable was the commitment to voluntarism among these women, despite their need for material compensation. In addition, communities are provided with valuable skills to improve self-sufficiency in addressing AIDS and other health problems. The skills also provide them with prospects of an accredited career path (Strebel, 2004:25)

4.5.3 Integrating HIV/AIDS work with sustainable development projects

According to Lawson (1997:55-58) HIV/AIDS is a development issue rather than purely a health issue. Therefore, NGOs in developing countries have begun to integrate HIV/AIDS into sustainable development projects. In developing countries, holistic AIDS and development programmes have begun to emerge along these lines. One example is Acord in Uganda which is a rural development programme that aims to promote sustainability and income-generating activities by strengthening community initiatives. The programme has an integral AIDS component that provides counselling support, and education and training (Lawson, 1997:57).

In South Africa there are several NGOs that have begun to integrate AIDS work with income-generating projects. For example, the Simunye Support Group in Tembisa is doing bead work. Lawson (1997:58) states that the Pietermaritzburg AIDS Action group which works in the informal settlements in the Pietermaritzburg area, uses development projects such as brick making and sewing as an entry into AIDS education. The success of these projects tends to rely on the development workers, and they have not always been successful. One problem with these projects is that they may not always be suitable to the needs of young PLWAs. Mercy Maluleke of National Association for People Living with AIDS (NAPWA) (cited by Lawson, 1997:58) says:

> "At my age I wouldn't want to be making dollies or embroidering cloths. I would do it because there was nothing else and the organisation may be saying to me, "this is how we can help you with income generation". But there's nothing that really comes out of that. You find that young women who are HIV positive don't want to do knitting; they want to enter competitions for Miss Durban and things like that. If organisations can start doing things about teenage women then it would motivate them to get off street and stop them from infecting more young boys and elderly."

This statement shows that the development projects have to be established in consultation with the PLWAs and not imposed on them. This will increase participation and also lead to ownership of the projects.

According to DeJong (2003:23-25), the success of the projects depends on sustainability. Sustainability in its broadest sense focuses on strengthening local initiatives and sustaining community ownership of programmes. It is possible that increased local responses to HIV/AIDS would break down social barriers and reduce stigma. In this sense a virtuous cycle could be created where increased coverage generates more demand for further local responses and thus the programme in question becomes more effective.

If an income-generating project is not successful, PLWAs will also not want to participate in the project. According to Ghigudi (1991:3, as cited by Mavalela, 1999:24) the factors that might constrain the success of women's income-generating projects are the following:

- the scale of the enterprises is often too small and funding inadequate, for instance 20 women sharing one sewing machine to make clothes;
- projects are limited to women's traditional activities such as baking and sewing, which means that they lack diversity to respond to market needs;
- women combine their project work with their domestic responsibilities;
- women tend to be apologetic about making money and find it hard to get rid of people who are not making a contribution to the project;
- women do not take risks;
- women tend to copy other income-generating projects instead of designing a new project for a specific market need;
- women lack access to resources such as credit, training, and information, and

- donor organisations favour larger development projects over women's small income-generating projects.

4.6 Conclusions

It was shown that self-help groups and sustainable development projects have the potential to support PLWAs, in particular to increase their self reliance and self esteem. It is for this reason that it is important to encourage maximum participation. In this chapter the reasons that might hinder participation, as presented in literature, have been discussed from a social, economic and biological perspective. Furthermore, those aspects that would help a project to be successful were discussed. In the next chapter a study is described to do empirical research on a particular project to investigate the non-participation of poor women living with HIV/AIDS in the project.

CHAPTER 5: RESEARCH DESIGN AND DESCRIPTION OF THE CASE STUDY

5.1 Introduction

The purpose of this chapter is twofold, namely to:

- provide information on the research paradigms and methodologies used in the research, and
- describe the specific case study and the samples investigated in the empirical part of the project.

In certain aspects this chapter is therefore an elaboration of certain aspects that were touched upon in Chapter 1. Additional information, such as interview schedules and consent forms is included in the appendices to this study.

5.2 Research paradigms applied in this study

5.2.1 Applied research

This study is applied research, which is defined by Monette *et al*. (1994:6) as research focusing on solving problems in practice. A research study is designed based on the assumption that some group or society as a whole will gain specific benefit from the research. In this study, HIV-infected patients will benefit from the findings, as the study will focus on the experiences of PLWAs, as well the factors that are de-motivating them from participating in the projects aimed at alleviating their plight. This information can then be used to adapt social work practices and projects to better suit the needs of the participants.

5.2.2 Phenomenological research

The research has a phenomenological basis. According to Fouché (2002:273), a phenomenological study is aimed at understanding and interpreting the meaning that subjects give to their everyday lives. Creswell (1998, as cited by Fouché, 2002:273) regards a phenomenological study as a

study that describes the meaning that experiences of a phenomenon, topic or concept has for various individuals. It is for this reason that Strydom (1998: 30) emphasises that researchers should make a thorough study and become sensitively aware beforehand of the values, norms, and climate which exist in a community before any research project can commence at all.

Rich information was obtained from the participants that facilitate understanding of their circumstances and the lack of participation in the development projects. In this way, the researcher was able to uncover the meanings that the research participants attach to their everyday lives.

5.2.3 Feminist action research

The third paradigm used in this research links to the phenomenological nature of the study. The study namely also gives expression to feminist action research (Weiner, 2003:3). This means that this study can be described as follows:

- It is grounded in women's experiences;
- it is concerned with issues that matter to women;
- it is non-exploitative;
- it gives a voice to women, and
- it gives value to women's lived realities.

5.2.4 Qualitative research

A qualitative approach was used in this study. According to Schurink (1998:241), a qualitative research approach is aimed at understanding social life and the meaning that people attach to everyday life. Qualitative research is descriptive in nature, as opposed to quantitative research which is aimed at testing predictive and cause-effect hypotheses about social reality (De Vos *et al*., 2005:75). The concepts are converted into operational definitions and results appear as numbers and are frequently reported in graphs and tables (De Vos *et al*., 2005:75).

Creswell (1998:142) states that qualitative research increases the depth of the study (and therefore the length of the report) as it is personal, familiar and friendly. The participants' own language is used to understand their real world. Quantitative research, on the other hand, is about testing predictive and cause- effect hypotheses about social reality.

Qualitative research is differentiated by the method of data collection, processing and analysis and the style of communication of findings. The method used is flexible and unstructured. When conducting qualitative research, the researcher identifies themes and describes the findings rather than subjecting the data to statistical procedures (Kumar, 2005:12).

5.3 Research methodologies and tools

5.3.1 Participant observation

Participant observation, as a qualitative social science research technique, may be described as a form of subjective sociology as it involves getting to know the people being investigated. This is done by entering the context being researched and participating, either openly or secretly, in that context. It differs from "direct observation" in that the researcher takes part in the activity (Social Research Methods Knowledge Base, 2009.) The difficulty lies in being able to participate in a group while still being able to use the insight and understanding of a sociological observer (Sociology Central, 2009).

The researcher, as a social worker working with the PLWAs, was in the ideal position to be a participant observer.

5.3.2 Interviews

Interviews are a well-known technique in social science research. The advantages of this research methodology are that the interviewer can explain questions if necessary, and can also ask a respondent for clarification of his or her answer. The most important disadvantages of this technique are that it is resource intensive and that the interviewer may be able to influence the outcome of the answer (Babbie, 1989:245).

An interview schedule (see Annexure 1) was used to collect data from the participants. An interview schedule consists of a list of specific questions prepared by the researcher to use when interviewing participants. According to Peil (1995:71) an interview schedule usually produces satisfactory results as it allows for a personal approach. The researcher ensured that questions were understandable. The researcher also made sure that the questions were answered in full by using follow-up questions.

With regard to the questions on the interview schedule, the researcher focussed on a broad exploration of the social, economic and physical factors that might impact on the participation of poor women living with HIV/AIDS in the food garden projects (as discussed in Chapters 3 and 4 of this study).

Subjects were interviewed individually during their support group meetings at the clinics around Tembisa and their responses were recorded by using field notes.

According to Bless and Higson-Smith (2000:155), a pilot study is conducted prior to a larger piece of research to determine whether the methodology, sampling instruments and analysis are adequate and appropriate. According to Strydom (2002), the purpose of the pilot study is to improve the success and effectiveness of the investigation. Space must be allowed on the schedule during interview for criticism or comments by the respondent. The researcher must carefully consider those comments during the main investigation.

The researcher selected two (2) participants to participate in the pilot study, to check whether the interview schedule would generate the necessary information to answer the research question. These two respondents were not part of the survey. This exercise helped the researcher to make the necessary changes, based on what the participants indicated as problematic during the pilot testing. The major change was on rephrasing the questions, to make them understandable to the participants by not using any jargon.

5.4 Data collection and analysis procedures

5.4.1 Data collection

The researcher collected data by asking questions on the schedule and recording the responses of the participants.

To ensure privacy, the interviews took place in the office of the researcher. Each interview lasted approximately 30 minutes. The interviews were spread over three (3) days because the researcher had to attend to her normal responsibilities in between interviews. The interviews took place during September 2007.

5.4.2 Data analysis

According to De Vos (1998:203), data analysis means the categorising, ordering, manipulating and summarising of data to obtain answers to research questions. Interpretation takes the results of analysis, and makes inferences pertinent to the research relations. The researcher used words to analyse and interpret the data.

The collected data were analysed by extracting themes and interpreting what the participants said. A detailed account of how the participants responded to the questions in the interview schedule is provided in text form, due to the qualitative nature of the study.

5.5 Ethical issues

According to De Vos *et al.* (2005:57) *ethics* is defined as a set of moral principles which is suggested by individuals and groups that govern behavioural expectation about the most correct conduct towards participants. The researcher is obliged to respect the ethical rights of participants. The ethical aspects that are relevant in this study are discussed below.

5.5.1 Harm to subjects

In this study the researcher ensured that there would be no physical or emotional harm, even though the research topic was sensitive. According to

Strydom (2002:64) emotional harm to participants might be more difficult to determine than the physical harm which is visible. Strydom (2002:64) further argues that the participants should be thoroughly informed beforehand about the potential impact of the investigation. The participants were informed about the potential emotional harm, to allow them to withdraw if they felt they could not manage to withstand the challenge.

5.5.2 Informed consent

Emphasis under this aspect of *informed consent* is placed on accurate and complete information so that subjects will fully comprehend the investigation and consequently be able to make a voluntary, thoroughly reasoned decision about their possible participation (Strydom, 2002:65). Written consent was obtained from the participants before the commencement of the interviews, after they had been provided with all the necessary information pertaining to the study (see Annexure 2 for the consent form used).

5.5.3 Deception of subjects

Strydom (2002:66) describes deception of participants as deliberately misrepresenting facts in order to make another person believe what is not true, and violating the respect to which every person is entitled. The researcher ensured that she was honest concerning every procedure and all the information that she gave to the participants.

5.5.4 Violation of privacy and confidentiality

Confidentiality refers to agreements between persons that limit other people's access to private information (De Vos *et al*., 2002:67). The privacy of information revealed by the participants in this study was always respected. The privacy of the respondent about information revealed would have been violated if apparatus like tape recorders, videos and cameras were used without the consent of the subjects. The participants were given the assurance that the information that they gave would only be used for research purposes and this was be adhered to. The names of participants will also not be published or made known to the public.

5.5.5 Publication of the research findings

Strydom (2002:71) indicates that participants must be informed about the findings of the study and this will reassure them that they are being acknowledged and recognised. The findings of this study will be available in a form of a thesis, which will be available on the University of Stellenbosch's website, and its usage will be encouraged for further research projects. A manuscript will be prepared from the findings of this study and sent for publication in a professional journal. The participants will be informed about the findings, so that they know how the information they have provided was used, specifically that the findings have to improve the projects to facilitate their participation.

5.5.6 Restoration of subjects

According to Strydom (2002:73) a debriefing session is necessary after completion of the data collection session. During debriefing sessions after the study, subjects have the opportunity to work through their experience and its consequences. This is one way in which the researcher can assist participants and minimise harm. The researcher held debriefing sessions with the participants, to rectify any misperception which might have arisen during the data collection phase. This was also aimed at restoring the participants' emotional state.

5.6 The research population, sampling and sample description

5.6.1 Population

According to Grinnell (1993:134), a population is the totality of persons, events, organisational units, case records or other sampling units with which the research problem is concerned. The population at the time of the study was all people living with HIV/AIDS registered at the Tembisa Main Clinic (56 persons) and the Winnie Mandela Clinic (62 persons). These numbers are not static because everyday people are being diagnosed with HIV/AIDS and added to the register. The majority of those registered were women. Some of these patients participated in support groups at these clinics.

5.6.2 Sampling method

A sample is defined by De Vos (1998:191) as the element of the population considered for actual inclusion in the study. The sample is being studied in an effort to understand the population from which it was drawn. Larger samples make it possible to draw more accurate conclusions and make more accurate predictions.

The researcher used a purposive sampling method from the non-probability sampling procedure. De Vos (1998:198) indicated that this type of sample is based entirely on the judgement of the researcher, in that a sample is composed of elements which contain the greatest number of characteristics, representative of typical attributes of the population. Bless and Higson-Smith (1995:95) explain purposive sampling as a sampling method based on the judgement of a researcher regarding the characteristics of a representative sample.

For the purpose of this study the researcher selected a sample of 20 respondents who were willing to participate. The sample therefore represented 17 % of the population of all PLWAs registered at the two clinics as shown in Figure 5.1. The researcher selected the subjects based on their HIV/AIDS status and they were all women.

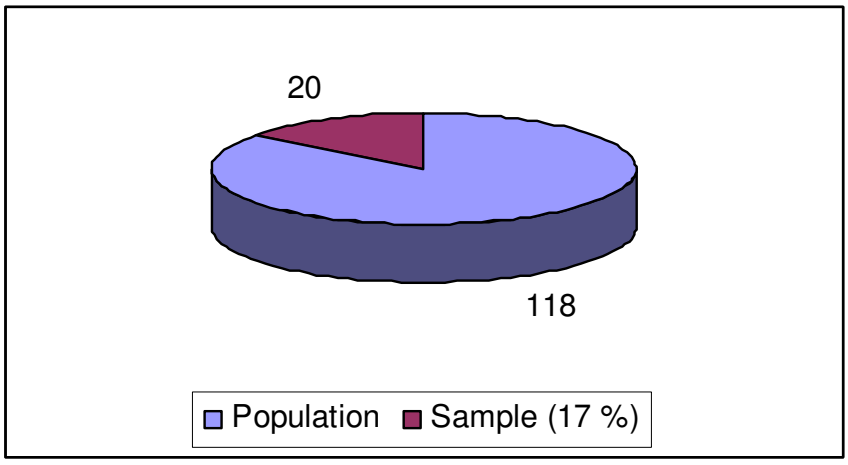

Figure 5.1: Sample as a percentage of the population

Source: Compiled by author, 2009

5.6.3 Demographic description of the sample

It was important to have a clear picture regarding the demographic information of the participants as this could have influenced how they would have participated in development projects. The demographic information is presented in Table 5.1 regarding age, marital status, educational employment, and employment.

Table 5.1: Age distribution of the participants in the study (also see Figure 5.2)

Age distribution	**Number of participants**	**Percentage (%)**
22-30	5	25
31-40	12	60
41-50	3	15
Total	**20**	**100**

Source: Compiled by author, 2009

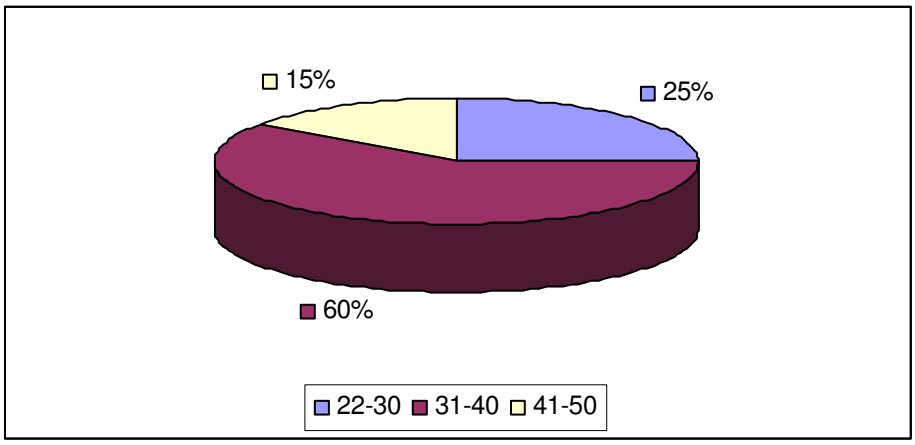

Figure 5.2: Age distribution of the participants in the study

Source: Compiled by author, 2009

Table 5.2: Marital status of the participants in the study (also see Figure 5.3)

Marital status	**Number of participants**	**Percentage (%)**
Single	11	55
Widowed	3	15
Married	3	15
Separated	2	10
Divorced	1	5
Total	**20**	**100**

Source: Compiled by author, 2009

The information in Figure 5.2 reflects a high percentage (80%) of families headed by single parents, who could be finding it very difficult to fend for the needs of their family members. Single parents also have less support than those who live with a partner. Kruger (1996:1) supports the above findings that single headed families are likely to experience a higher level of poverty. According to this author, when a high proportion of the nation‘s children are brought up in such circumstances, the future of the nation is bleak (Kruger, 1996:1).

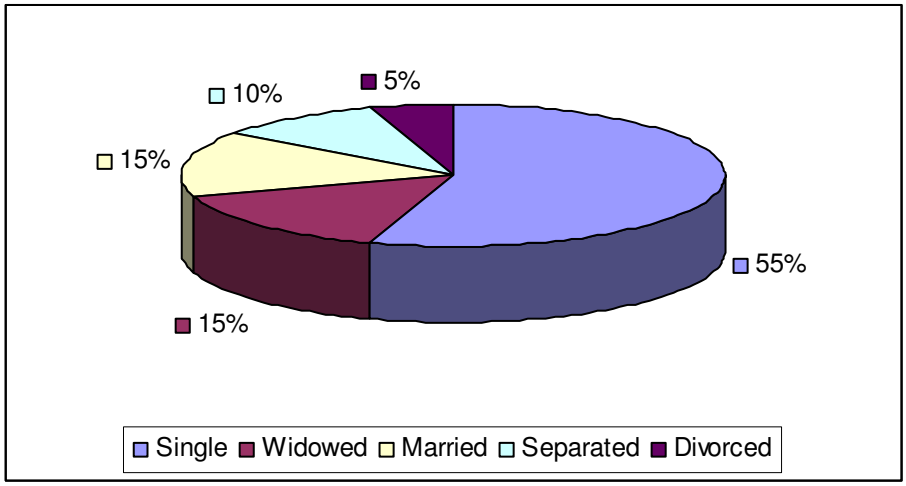

Figure 5.3: Marital status of the participants in the study

Source: Compiled by author, 2009

Table 5.3: Education level of the participants in the study (also see Figure 5.4)

Education level	**Number of participants**	**Percentage (%)**
Up to primary school	10	50
Up to secondary school	10	50
Total	**20**	**100**

Source: Compiled by author, 2009

The information in Table 5.3 shows that none of the participants had a tertiary qualification, with a full 50 % only having attended primary school. Therefore, if they were to find employment, they are likely to occupy lower positions. This situation increases the likelihood that they would experience poverty as they would not be able to meet their basic needs with the low wage that would be offered for their positions.

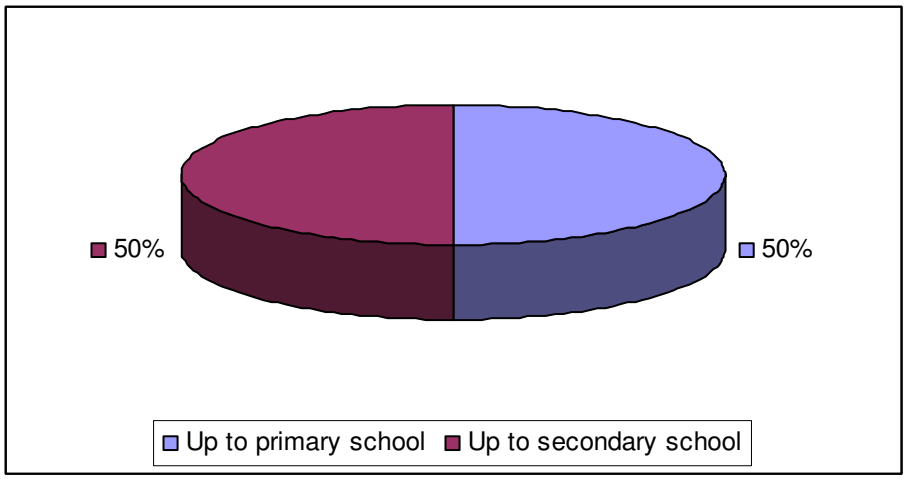

Figure 5.4: Education level of the participants in the study

Source: Compiled by author, 2009

Table 5.4: Employment status of the participants in the study

Education level	**Number of participants**	**Percentage (%)**
Unemployed	20	100
Employed	0	0
Total	**20**	**100**

Source: Compiled by author, 2009

All of the participants in this study were unemployed (See figure 5.4). They were mostly relying on the help of relatives to make ends meet, while a few relied on social grants. These results support the information about the high level and effects of unemployment discussed in Chapters 3 and 4 of this study.

5.7 Description of the case study

The case study involved food garden projects at two clinics in Tembisa. Information on these two clinics is given below. Information on how the projects were planned is also given.

5.7.1 Winnie Mandela Clinic

The Winnie Mandela clinic is situated in the informal settlement of Tembisa (Ekurhuleni Municipality). The services rendered are: Primary Health Care (PHC), Voluntary Counseling Testing (VCT), Wellness clinic, Antiretroviral down referrals, Expanded programme immunization (EPI), Integrated Management of Childhood Illness (IMCI), Reproductive Health , Mental Health Services, Dental Clinic, Antenatal Clinic (ANC),and Youth-friendly Services (see Photograph 1).

The clinic serves 6 500 patients per month. The clinic has 30 staff members**:** Professional nurses (10), Staff Nurses (2), Pharmacist (1), Assistant Pharmacist (1), Medical Doctors (3 locums), Dentist (1), Dental Assistant nurse (1), Social Workers (2), Cleaners (3), Administration Clerks (3), Health Promoter (1), Lay Counsellors (2) and Nutritionist (1).

The closest public transport for patients to the clinic is mini-bus taxis. There is no alternative transport to the clinic, and the railway station is very far from the clinic.

During the study, there were no projects operating except the food garden project which never thrived. The women prepared the ground and never planted anything. When the researcher returned in 2009 to the clinic to observe progress with the project, it was impressive to see the clinic back yard surrounded by a food garden (see Photograph 5.2), which was different from the poor beginnings of the project.

Photograph 5.1: Services rendered by the Winnie Mandela Clinic

Source: By author, 2009

Photograph 5.2: Vegetable garden being tended by unemployed woman at the Winnie Mandela Clinic, two years after the study

Source: By author, 2009

5.7.2 Tembisa Main Clinic

The Tembisa Main Clinic is situated in the Township of Tembisa (Ekurhuleni Municipality), five (5) kilometers from the Winnie Mandela Clinic. It renders the same services as the latter clinic in the informal settlement. The clinic serves about 7 000 patients per month, and has 36 staff members representing the same type of skills as those offered at the Winnie Mandela Clinic in the informal settlement. Whereas the medical doctors at the Winnie Mandela Clinic were locums, the Main Clinic employs one full-time doctor.

As in the case of the Winnie Mandela Clinic, the closest public transport for patients to the clinic is mini-bus taxis, with the railway station being very far from the clinic and no alternative transport being available.

During the study, there was a food gardening project that produced vegetables but not enough to sell. The soup kitchen that used to operate is no longer operational as the volunteers did not get further funding from the provincial authority, which was the main sponsor. The volunteers also did not get any assistance from the private sector.

5.7.3 How the food garden projects were planned

The researcher, in her capacity as a social worker, was expected to develop empowerment projects as part of fulfilling job requirements. The researcher started a support group of people living with HIV/AIDS. The purpose of this group was to give support to people experiencing common problems related to the disease.

As the sessions of the support group continued, the researcher encouraged the group to start a vegetable garden as a way of alleviating poverty. The reason for encouraging the participants to make a food garden was that vegetable seeds are relatively inexpensive, and the space/ground and water were already available at the clinic free of charge. The following aspects were addressed in planning the food garden projects:

- *A place to work:* The researcher identified a space at the clinic which was previously used by other patients for a food garden and was unused at the time.

- *A committee to run a project:* A committee consisting of a chairperson, secretary and treasurer, was elected from the 14 participants in the project. The participants did not understanding their roles. The researcher as the facilitator was playing a leading role and tried to educate the whole group about the roles of committee members so that in future they should be empowered to perform such roles.

- *Equipment and material:* The participants volunteered to bring the basic gardening tools such as forks. The researcher volunteered to buy seeds. Future plans were to network with food foundations, and the Department of Agriculture (both local and provincial) to ask for assistance with further skills development and support with material as the participants only had their indigenous knowledge on which to rely.

- *Marketing:* The participants agreed to consume the products and to sell some to the local communities if they produced more than they could consume.

- *Profit:* The participants did not expect any profit in the beginning as the project was just starting and their priority was to produce vegetables for their own consumption. Making a profit was the long-term plan.

- *Bank account:* Opening a bank account was a future plan, as the participants did not have any funds at the beginning of the project.

- *Record keeping:* The researcher was keeping the minutes of the support group, but the participants were not confident enough to keep records of their sessions.

5.8 Concluding remarks

In this chapter the research design was discussed and the research sample was described in terms of demographic information such as age, education and marital status. The clinics where the food garden projects took place, were described, and the way in which these projects were planned, was also described.

In the next chapter the results of the empirical research will be presented and analyzed to shed light on the factors that play a role in the non-participation of the poor women living with HIV/AIDS in the food garden projects.

CHAPTER 6: PRESENTATION AND ANALYSIS OF RESEARCH RESULTS

6.1 Introduction

In this chapter the researcher presents the data collected from the participants by way of interviews as well as participant observation. The data collected is also analysed. The empirical findings are integrated with the literature findings in an attempt to verify these findings.

Since this study was qualitative in nature, the findings are presented in the form of descriptions and discussions. Some of the responses that the participants gave are presented *verbatim*, to confirm their views. The findings are presented according to the different themes in the interview schedule (Annexure 1).

The chapter concludes with a summary of the results and analysis of the data collected.

6.2 Results from participant observation

By acting as a participant observer in her role as social worker working with the PLWAs, the researcher made the following observations about the participants in the study, as well as the research population:

- Despite the stigma attached to HIV/AIDS and submissive gender roles, the participants were confident and open in their interactions with the researcher. The reason for this is thought to be that the researcher had built up a long-standing relationship with the participants through her work as a social worker at the clinics.

- The researcher has observed that the population of this study is from different cultural backgrounds and have been socialised differently. This is

apparent from their dress code (e.g. the distinctive Tsonga piece of clothing named a “motjeka”) and their languages (namely Zulu and Tswana). These diverse cultural backgrounds can influence the manner in which people respond to the development projects that are established in their neighbourhoods. People can be seen as not interested in participating, whereas in fact they do have their reasons. For instance, according to the Batswana culture, a widow is not allowed to socialize with the rest of the community until she has completed a year of mourning and has been traditionally cleansed.

- The researcher has observed that most of the patients infected with HIV/AIDS are living in shacks in the informal settlement which are characterized by appalling conditions, without adequate sanitation and clean water. Some patients live in the township but in crowded and unhealthy conditions such as up to 10 family members sharing a four-roomed house. Most of these people come from rural areas and are living in these conditions in the hope of finding employment in the urban area.

- From home visits the researcher has observed that in poverty-stricken environments the conditions are such that people might be apathetic and be reluctant to participate in development projects that would improve their life. In working with PLWAs, the researcher was left with the impression that many poor people prefer handouts, rather than working. The researcher has observed that if women are sick and being exposed to chronic diseases they are likely to be reluctant to participate in developmental projects, since their priority might be with their health conditions. This might be one of the reasons why they are content with accepting handouts.

- The researcher has observed that there are many child-headed households and they are struggling to make ends meet. Many parents die due to HIV/AIDS, leaving behind dependent children. These children leave school at an early age to look after siblings or the terminally ill parents. Poverty becomes a vicious cycle because these children will

grow up to be poor adults, as they never get a chance to complete their education. These examples illustrate how HIV/AIDS can lead to absolute poverty or aggravate already existing poverty levels. For instance, often these children are dependent on help from their grannies who have to use their meagre old-age grants to help, thereby aggravating their own levels of poverty.

- The researcher observed that some of the research population travelled on foot to the clinic. This indicates either a lack of transport or, more likely, the fact that they are too poor to afford the minibus taxi fees.

- The researcher has observed from the support groups she has facilitated that people with a common problem are likely to be open with each other about their problem and to learn coping skills from other members. This gives them a sense of belonging and a feeling that they are not alone, and they gain a sense of purpose by assisting the fellow members in the support group.

- The researcher has observed that most clinics in Gauteng use separate consulting rooms for TB and HIV/AIDS patients. Some patients feel stigmatised and do not want to be seen in those rooms because they regard them as HIV rooms and see this as shaming them. The researcher believes that if all patients could be seen in primary health care rooms, this would reduce the stigma and would encourage the community to come for TB and HIV testing without feeling any intimidation. This could gradually eliminate the negative attitude towards HIV/AIDS and encourage people to participate openly in development projects, without fearing to be stigmatised.

- The researcher observed the unethical practices of the informal business vendors operating close to the clinics and selling the PLWAs what they claimed to be vitamins to boost their immune systems. In some cases, the cost associated with these vitamins was as high as R400, thereby

compromising the PLWA's ability to buy nutritious food as recommended by the medical practitioners.

- From discussions with the primary health care nurses, as well as with their patients, the researcher has observed that some patients do not want to take their HIV/AIDS medication as they want to qualify for a grant. In one instance, a person who came for testing was very upset to learn that he was not HIV-positive as he wanted to receive a grant.

6.3 Results from interviews

The data collected during the interviews is presented and discussed in the following sections. To lend context to this discussion, the responses are presented according to the questions that were used in the interview schedule given in Annexure 1. Where relevant, the responses are discussed against the background of literature surveyed for this study.

6.3.1 Social factors

Question 5: Would you like to share your social challenges as a person living with HIV and AIDS?

The participants gave a variety of responses, and some of these responses are given below:

"I have been rejected by my sister who is the closest family to me, since my parents have passed away."

"I thought of committing suicide because there is no life when someone is infected by HIV, but just torture and humiliation, my friends were making jokes about my condition. They said I'm a living corpse, so they did not want to be associated with me. I was also rejected by my family and relatives."

"*People gossip about my status, they believe that I was promiscuous and deserve HIV. This has affected my emotions and my self-esteem leading me to isolate myself from the public."*

"I'm living with fear of death, worried about leaving my kids behind, since their father left me for another woman and left me being HIV positive."

"My family never uses the utensils, (e.g. cups, cutlery) that I use. They believe that I will infect them with the virus."

"I was raped because the perpetrator wanted to know what does a person living with HIV taste like".

"*I engaged in prostitution so that I can get money to buy food and I was not using condoms as my clients refused it".*

In the above responses it is possible to detect a negative progression in the social effects of the disease. The revelation of their HIV-status leads to gossip, leading to humiliation and rejection by social groups. When the PLWAs have been rejected and deserted, the door is left open for prostitution as a survival strategy, thereby causing the PLWAs to live in constant fear of death as they would have been made aware of the danger of multiple infections.

The above challenges faced by PLWAs are confirmed by Mboyi *et al.* (2005:8) who state that fear of stigma and discrimination has been raised as a major barrier to dealing with the epidemic in the community. The stigma, isolation, and the lack of family and societal support make them unwilling to participate in community projects, as the projects themselves are labelled. This might be one of the reasons that hinder the PLWAs from participating in the development projects that are specifically established for them, as they will be easily identified as infected by HIV, hence they would be stigmatised, which would have an adverse impact on their social life.

It is therefore important to establish projects in such a manner that the PLWAs can avoid being labelled – possibly by opening these projects up to all people who are affected by poverty, so that the projects would be for all and not only for a specific group, namely PLWAs.

Question 6: Have you experienced any form of discrimination since you were diagnosed with HIV/AIDS?

Respondents indicated that they are experiencing different forms of discrimination, as is confirmed by the following responses:

"*I have experienced discrimination from the community and from my family since I was diagnosed with HIV. My opinion is never taken seriously; people say the HIV virus has run to my head, meaning that I'm crazy."*

"My family did not want to share same utensils with me. They thought I would infect them with HIV. I believe that as long as people are sexually active and not using condoms, they are likely to be exposed to HIV and not by sharing utensils with an infected person. "

"I was excluded from joining a burial society because they believed that I would soon die with AIDS and they cannot take a risk because my contributions will still be minimal by the time I die."

"I tried to sell fried fish, sheep and chicken feet as a way of generating some income for my family, but people did not buy from me because they were scared to be infected by food prepared by a person living with AIDS."

"My friends no longer associate with me because of my HIV status. They gossip about me and I feel rejected."

The responses given by the participants illustrate the discrimination to which PLWAs are exposed in their daily lives. This might be another reason why people living with HIV/AIDS are reluctant to participate in projects due to the discrimination that they experience within their families and communities – they might be expecting the same form of discrimination when taking part in the projects. Bendix (1996:593) agrees with the participants that discrimination occurs when someone treats another person differently and usually unfairly. Stigma and discrimination remain key barriers to accessing voluntary counselling, care and support services. The opportunity to encourage individuals to practise safer sex is thereby lost, which results in the

continued spread of HIV/AIDS. It also precludes sick patients from seeking treatment (Furber, 2004, cited by Mboyi, *et al.* 2005: 8).

It is evident from the findings regarding discrimination that PWLAs are experiencing some form of stigma in their communities, and this can lead to them isolating themselves. Deacon (2005:35) agrees with the findings that discrimination materially affects the esteem and behaviour of PLWAs, for example when they are being treated as being "crazy" and when people do not buy food from them or share their utensils. It should be noted that stigma has had a profound consequences for PLWAs. They have been dismissed from jobs, and have been socially isolated and driven from their homes (Pryor and Reeder, 1993). Stigma also has direct economic consequences, such as when the patient is not allowed to join a burial society, leading to significant funeral costs falling to the family when the person passes on. As a result they will not be motivated to participate in the development projects for fear of further stigmatisation.

It is again evident that working to reduce stigma through community education programmes would be a significant factor in assisting PLWAs.

Question 7: What local belief/cultural factors are you aware of concerning HIV and AIDS in your community?

The local community members have different belief systems which affect daily living. This is evident in the perceptions they have concerning HIV/AIDS, as shown by the following responses:

"*People believe that HIV and AIDS is a disease that I got from a widower (makgome). I don't really know how and from whom I got it because I used to have three partners prior to my current partner and was not using condoms."*

"*Other people believe that I was bewitched (sejeso). They believe that I was given some poisonous muthi, and now I am reacting to it"*

"Some people blame me that I got infected because I was promiscuous and this result in me withdrawing from interacting with the public"

From the above statements of the respondents, one can draw the conclusion that local beliefs are instrumental in shaping the way the community reacts to PLWAs. Deacon (2005:57) confirms the above findings that the HIV/AIDS epidemic is likely to stimulate suspicions of sorcery, fear of witchcraft and a general sense of spiritual insecurity as more and more people die at an early age. The treatment that PLWAs receive from their communities, based on the cultural beliefs can be seen to be influencing their willingness to participate in development projects. There is a need to increase effort to raise awareness among all communities regarding HIV/AIDS, to ensure that everybody is able to differentiate between myths and facts. This could go a long way towards dispelling the stigma attached to HIV, hence making life easier for PLWAs within their communities, and making it more likely that they would openly participate in development projects.

Question 8: What form of support are you receiving as a person living with HIV and AIDS?

It is evident from the following responses that there are those who are receiving support from their immediate environment as well as those who do not receive any support. The responses given by participants are as follows.

"I stay with my parents, my two children and my six siblings in a four roomed house. We survive with the old age pension that my parents receive and it feeds eleven family members."

"Nobody cares about me and my children's welfare. I do not have a support system; I am a shame to my family because of my HIV status".

"I'm staying with my boyfriend; he is renting a back room which is used as both a kitchen and a bedroom. We are sharing this room with my three children, as my family rejected me because of my status and I had to leave with my children."

"My family supports me completely (emotionally, financially). I receive my social grant and my three sisters and my mother, who is a pensioner, are there for me."

"I live with my two children in a shack and we survive on a child support grant that amounts to R400 per month. Their father deserted us and my family is rejecting me."

People living with HIV/ AIDS indicated that they need psychological, emotional and financial support from their families, friends and society at large. It is evident in the literature review that good social support promotes better health, or offers some protection from illness. There is a positive relationship between support and psychological resources and this helps individuals to cope with social challenges and illness (Sherr *et al*., 1996:47). Support has an impact, and can encourage PLWAs to participate in developmental projects, rather than being blamed, isolated, and rejected by the community.

The above responses confirm that people living with HIV/AIDS receive varying degrees of support, but are mostly all experiencing poverty because of the disease. Few receive support from their immediate social environment, and what support is received, varies from assistance from parents who receive old-age grants, to boyfriends, and child support grants. The researcher considers the theory of Maslow's hierarchy of needs (Smith, 2002 and Egan, 2002) relevant here. People namely have a need to belong (family, friends and society at large), specifically in this context where people are experiencing difficulties. Therefore PLWAs need continuous support to cope with the challenges of the epidemic. Support depends on the closeness of the relationship. Those who are likely to support PWLAs are family members, partners, friends, church groups, and health care workers. The support they receive, would encourage them to participate actively in development projects, hence the quality of their lives would be improved. Support is needed for PLWAs to feel accepted for who they are and not what they are suffering from, and it can only be attained by dealing with all the misconceptions and myths that are attached to HIV/AIDS.

Question 9: Do you think people living with HIV and AIDS are experiencing poverty?

The research data indicates that participants are experiencing poverty and that it has affected their lives significantly. This is confirmed by the following responses:

"*I am unemployed, single and engage in prostitution so that I can feed my children."*

"I stayed in an abusive relationship and practised unsafe sex for the sake of financial maintenance from my partner."

"On a daily basis I need basic food to survive and cannot afford to participate in projects that take time to thrive."

"I cannot afford to buy basic food recommended by the medical practitioners so as to improve my health status."

"I do not have proper shelter; I stay in a shack which is cold in winter and hot in summer. It does not have adequate facilities such as a toilet, electricity and running water".

"I am a prostitute and my clients refuse to use condoms even though I disclose my HIV status, but I am forced to go on with the trade for me to earn a living. One of my clients said that he cannot eat a banana with its peel on (meaning he cannot have sex with plastic on, it will reduce the pleasure). Even though I am aware that I am at risk of re-infection, I have no other option but to continue, as I have no other source of income."

These respondents clearly indicated that they suffer greatly from poverty, to the degree that their life styles are reduced to living in shacks, abusive relationships, unemployment, prostitution to meet basic needs, and increased risk of multiple HIV infections. People resort to risky actions to alleviate the immediate circumstances they find themselves in, that is, to get money to buy food. Strebel (2004:54) agrees with the above findings that the HIV/AIDS epidemic cannot be addressed in isolation from broader social issues

especially poverty, as they are interrelated. HIV/AIDS is a social development issue, which requires a reduction in the stigma of AIDS-related initiatives and an increase in community capacity. The development projects could help in alleviating poverty if they could be taken seriously by all parties involved. This could restore the financial independence that is needed by PLWAs, and would result in them not having to engage in risky behaviour for the sake of meeting basic needs such as food.

6.3.2 Economic factors

Question 8: Are there funds available for development projects?

Respondents who participated in projects such as food gardens and bead work indicated that there was no funding available for the projects. Respondents were expected to seek donations to start up the projects, without any professional assistance in the process. It is important to note that if the financial support is not adequate, then the projects do not thrive, hence not meeting the goal for which they were established. The government usually gives funding to projects that are already in existence and doing well, leaving out those that are still in a planning phase, because their survival cannot be guaranteed. This might be another factor that de-motivates some PLWAs to continue participating in projects. Some of the respondents' responses are presented below:

"I'm experiencing poverty and cannot be expected to look for donations on an empty stomach, to fund the project. If the project was giving me something back, maybe I would be eager to participate, instead of looking for donations for the project to survive."

"Projects without funding are a useless exercise because they take time to thrive and this leaves us with nothing to eat."

"I need formal employment so that I can get a fixed wage every month and be able to meet my needs. Seeing that the project that I was involved in did not meet my needs, I had to quit and try something else. The other worry for me regarding the project was that I was expected to raise funds to help in the

running of the project. How can I be expected to raise funds for the project that does not give me anything in return, while I do not have money to meet my everyday needs?"

These responses show that the majority of participants are more concerned about immediate bread and butter issues than about future developments in the projects. No project can survive without funding, therefore projects will collapse if sufficient and reliable funding for the projects is not obtained. Participants end up losing motivation to participate in projects aimed at uplifting them because these projects do not promise immediate benefits – in fact, in some cases the participants are expected to raise funds to get the projects off the ground. Chambers (1983:106) as cited by Davids *et al.* (2005) agrees with the findings that if the community does not have resources it will not be enthusiastic about continuing with projects, especially when these projects encounter problems in obtaining resources.

The aspect of a reliable income, such as would flow from formal employment, was also raised by the participants. Therefore, not only is there a need for income from the projects to motivate participants to be involved, but this income should be sustainable so that participants can rely on it.

For development projects to be sustainable there has to be enough resources, and this will encourage people to participate. Sufficient resources can also encourage ownership of the project, which is an important factor in ensuring the success thereof. It would be beneficial if all professionals engaged in these projects could play a leading role in fund raising, to motivate PLWAs to participate fully. This would enhance the chances of success of the project, and create the perception on the part of the participants that they will be gaining something from participating in the project.

Question 9: Do these projects meet your needs/expectations?

Projects take time to develop. The projects did not really meet the immediate needs of the participants due to the lack of resources. The fact that the projects were not suitable and were not helping in meeting their needs, is confirmed by the following responses:

"A food garden is suitable for the aged, not my age, I am only 32 years and cannot be seen working in the garden whilst my peers are earning better salaries somewhere. I'm interested in projects that will empower me for future competition in the open labour market."

"I participated in the project because I was receiving food parcels from the clinic. I had to leave the project immediately when the food parcels dried out. I felt that I did not benefit at all from the project and this made me leave."

To ensure that projects meet the need of the PLWAs, the projects should be undertaken in consultation with the participants. This will encourage maximum participation and a sense of ownership, as the participants will influence the process of the project to meet their needs and hence increase the chance of success. Lawson (1997:55-58) agrees with the findings that the projects may not be suitable for the needs of young PLWAs. The researcher is of the opinion that this may be one factor that hinders PLWAs from participating in development projects aimed at uplifting their standard of living, as it has been established that the majority of PLWAs are still young.

Therefore a top-down approach to planning the projects is not recommended, as it limits participation. In contrast, a bottom-up approach offers valuable opportunities to rectify inequalities and it improves the chances of the projects being sustainable (Meyer and Theron, 2000:10). Burkey (1993: 56) confirms that active participation is essential because it builds self-confidence, pride, creativity and co-operation and results in people becoming empowered.

Question 10: Did you participate in the planning phase of these projects?

In response to the above statement participants had the following to say.

"I participated in the planning phase of the project because the project started as a support group that led to income generating projects (bead work)."

"I was never involved in the planning phase of the project, everything was tailor made by the facilitator."

"I did join the bead work and food garden projects while they were already operating, and I do not know how they came to exist."

"I just joined the existing bead work project because I was desperate to make money. No money was generated from this project because the treasurer used the money for her own benefit. I was never involved in the planning phase."

"The development worker just imposed the idea of a food garden on us, she never explored with us if we are interested or not. I was not involved in its planning."

Swanepoel (1997:2) argues that planning should be a participatory, learning and collective effort, aimed at meeting the identified need. Often participants are passive and the development worker comes up with a readymade plan that she/he wants to implement in the community. This has led to many projects collapsing and communities losing interest in participating in developmental projects in general. Swanepoel (1997:2) further confirms that the opposite of planning is doing things as they come up, that is being reactive, hence the failure of most projects. If the participants could be part of the planning phase, they would be able to develop that sense of ownership, which is so crucial in the success of development projects.

From these responses it can be deduced that the participants were not fully involved in the planning of the projects, and hence, that there was not a real sense of ownership. In most cases, the participants just joined already existing projects. The response indicating lack of trust in the treasurer of the project (namely that she used the money for her own benefit) and also indicates a lack of shared ownership of and responsibility for the project.

Question 11: What financial problems do you have in relation to your medical treatment and other needs?

The majority of participants indicated that they are experiencing financial problems as they are unemployed and struggling to make ends meet. The rise in unemployment has resulted in a significant increase in poverty between

1999-2002 (Natrass, 2004:131). Those who are already on anti-retroviral treatment struggle with transport fees to travel to the Masakhane ART Centre at Tembisa Hospital. The other challenge was obtaining appropriate food before taking medication. The responses of participants are as follows.

"I do not receive a social grant which makes it difficult for me to meet my needs. As you know I have to travel to the clinic to access treatment, and without any source of income, this is a nightmare."

"My grant has been suspended because my CD4 count is above 200, with devastating results for me. At least with the grant I was able to buy food and address some of my needs. Even though it was not enough, it was better than now."

"I defaulted on treatment so that my CD4 could drop, for me to qualify for a disability grant. I know this is detrimental to my health, but I had to do it so that I could get a grant. You also know that there are no jobs outside for everybody, so the best thing is to get a grant so that I could have something to eat."

The findings of this study confirm that PLWAs compromise their own health to obtain some means of survival. This is a drawback for the Department of Health which has as primary goals firstly to reduce the number of new infections of HIV, and secondly, to improve the health status of people living with HIV/AIDS (Department of Health and Welfare, 2002:30). Defaulting treatment results in developing resistance to treatment and leads to the terminal stage and eventually to death. Many families are headed by children who have been left by parents who died of AIDS-related illnesses. Some families are headed by older persons who survive on social grants and have to take care of orphans whose parents have died of AIDS. The researcher believes that if the development projects could be of such a nature that they help PLWAs to meet their financial needs, then there would be no need for any person to put his/her life at risk by not taking the necessary medication just to qualify for the social grant. The income from the projects must be of

such a nature that the people become motivated to participate in the projects and make to them successful.

Question 12: What initiatives have you undertaken to empower yourself and to improve your socio-economic status?

The majority of participants have tried to improve their socio-economic status, without any success and this has affected their confidence. Some tried to open fast-food outlets but could not gain support from their communities due to the stigma attached to HIV. Some tried to sell handcrafts but could not go further. Their responses are as follows.

"I *have tried to sell chicken feet but the business is slow because most people are selling the same product. The worst thing is that people prefer to buy from those that they do not know their HIV status and my business suffered the most. I can only attribute the failure of my business to the stigma attached to HIV and AIDS".*

"I have tried to sell fried fish and sheep feet (ditlhakwana) but people were not supporting my business because they know about my status. They think they will be infected by food prepared by PLWA."

"In my efforts to make a living I tried to sell vegetables but due to the high costs that I incurred in buying stock I could not manage. Another contributing factor is the fact that most people are unemployed, and hence they are unable to afford to buy from the street vendors. Instead they prefer to go to the market and buy better produce at a reasonable cost. As a result my business suffered and I could not afford to sustain it."

"My efforts of finding a job have not been successful and this makes it tough to survive without any source of income."

"I'm interested in quick money as a prostitute because I cannot survive without food. There are no jobs and I cannot afford to start a business, and prostitution was found to be the best option"

The findings show that participants do try to empower themselves financially, but due to the high rate of unemployment and the stigma attached to HIV/AIDS they are not succeeding. Some of them are therefore resorting to risky behaviour patterns such as transactional sex to get some money for their daily survival. As it has already been indicated earlier, development projects would be the answer to the current problem, where PLWAs would be able to work and get some money to meet their needs. It would also help to address the issue of HIV stigma in communities, so that HIV-positive people would find themselves accepted within their communities. The researcher believes that this would facilitate the process of having their small businesses supported by their communities.

The fact that the responses indicated that the PLWAs have tried to empower themselves socio-economically shows that they have the desire to help themselves and the willingness to work. Therefore an unwillingness to work and a preference for living on handouts are not the reasons why the PLWAs do not participate fully in the development projects.

6.3.3 Biological factors

Question 13: How would you describe your health status in relation to your involvement in community activities, including the developmental projects?

The majority of participants indicated that their physical well-being changed daily, and could not always be predicted. This could be another factor that leads to reluctance to participate in the projects. Due to the fact that their physical health is seriously affected, as they are not eating well, they do not find anything to motivate them to fully participate in the development projects. Their responses to confirm this are as follows:

"I'm not interested in participating in projects that require hard labour and which take time to reward. Remember life is about money and good health, I'm not well and I don't think it is worth the effort to be still involved in the project that does not give me anything back."

"My body is aching most of the time and it's difficult to be fully functional, as a result I cannot sacrifice by participating in the project that does not promise anything."

"HIV and AIDS is a painful condition and require the body to rest and be cared for. I often feel dizzy and feel like sleeping all the time. I also believe that because I do not eat well my body cannot keep up with the demands at the project, so I had better leave and just concentrate on my health."

"I have accepted my status but sometimes I have mood swings that make me want to withdraw from the public and be alone. I believe if the project was promising some financial reward I would be able to sacrifice and participate fully, as finding a job is a dream that I think will never be realized. I also feel OK when I am alone at home because mingling with people is stressful due to the stigma and discrimination that we PLWAs experience."

From these responses it is clear that the physical condition of the PLWAs is a factor in their lack of interest in the projects. This is aggravated by the fact that the projects do not reward them and that as the projects are specifically for PLWAs their participation in the projects could result in the participants being stigmatised. The researcher has also observed that even those who look healthy do not want to participate in projects, and this could be attributed to the stigma. Pratt (1995:72) confirms the finding that most individuals infected with HIV develop some form of ill health as a result of infections. Pratt (1995:72) further confirms that the acute phase of the illness is characterised by painful muscles, diarrhoea, and fatigue that can make a person sleep most of the time. This might also lead to the withdrawal by the PLWAs from the projects because of ill-health and lack of external incentive to keep them participating.

6.4 Summary of findings from the interviews and participant observation

The aim of the study was to investigate the living experiences of poor women living with HIV/AIDS to determine which factors resulted in their non-

participation in development projects set up to empower them socio-economically.

With regard to the living experiences of poor women living with HIV/AIDS, the picture that emerges is one of a cycle of deprivation. The various aspects such as poverty, health, unemployment, and social stigmatisation interact with and reinforce each other.

This cycle of deprivation can be illustrated as follows: Poverty is high and all the respondents were unemployed. This resulted in some of the women engaging in risky behaviour. Firstly, some women engaged in prostitution to earn an income to meet their basic needs, thereby putting themselves at risk of multiple HIV infections, as well as putting their clients at risk of contracting the HIV virus. Secondly, some stopped taking their medication to allow their health to deteriorate to the point where they qualify for a grant. Furthermore, because of high levels of poverty, PLWAs cannot afford the nutritious food necessary to help them fight the disease, and they also often live in unsanitary conditions that are not conducive to improving their health. Because of the results of ill-health (for example an aching body and extreme fatigue), the PLWAs are not able to fully participate in projects that might raise their standard of living.

Another important aspect of the cycle of deprivation is the stigma attached to HIV/AIDS. Because of the stigma, the poor women are reluctant to take part in projects that might improve their standard of living. The stigma also results in people not coming forward for testing and counselling. Furthermore, the stigma results in PLWAs often being rejected by their families, thereby causing a lack of support, both financially and emotionally. Support from family, friends and the community has been identified as a factor that could help PLWAs cope with the disease and so their health suffers further. Furthermore, because of the stigma associated with HIV/AIDS people living with the disease find it difficult to start traditional small businesses such as selling food, thereby adding to their economic hardship. The stigma also results in people being fired from their jobs and excluded from benefits such

as joining a burial society. This illustrates how the various factors are linked and how they influence each other.

With regard to the specific factors that impact on the non-participation of poor women living with HIV/AIDS, the following was found:

- Stigma is a very significant factor. PLWAs experience rejection from family, friends and the community and so they do not want to take part in projects that have been specifically designed for PLWAs. Taking part in such projects would show others that they are living with HIV/AIDS – the projects themselves become stigmatised in effect.

- Furthermore, because of the stigmatisation they experience, PLWAs find it easier and safer to withdraw and stay at home than to move out and take part in community development projects as they have come to expect rejection and they therefore become self-stigmatised.

- Cultural beliefs around HIV/AIDS lend support to the stigma associated with PLWAs. There is a need to break down the stigma by education to make communities aware of the real facts so that they do not believe in for instance curses and witchcraft. The sense of spiritual unease that communities experience related to HIV/AIDS will also decrease if they can be educated, and this will make life much easier for the PLWAs.

- Because of the importance of stigma, development and social workers have to run projects in such a way as to reduce the likelihood of stigmatisation. For instance, development projects should be set up for all people suffering from poverty, and not just for PLWAs. Furthermore, at the clinics, all patients should be seen in the same rooms, instead of putting PLWAs in separate rooms where everybody can see them going in to the HIV rooms.

- Because of the high level of economic deprivation, PLWAs will only be motivated to participate in projects that can promise immediate benefits to them. Not only do the PLWAs need the benefits to be immediate, but they also need a sustainable and reliable income. Therefore, if the projects

cannot meet these needs, the PLWAs are unlikely to participate in them. The projects discussed in this study were not able to provide the participants with an immediate and sustainable income.

- The projects discussed in this study were also not supported with resources from government. The participants were expected to raise funds for the projects themselves. Government support is mostly not available for projects in the initial phases. Therefore, the participants did not have confidence that the projects would ultimately be a success and hence they did not participate fully.

- The majority of the PLWAs are relatively young and therefore the nature of the typical projects (food gardens and bead work) is not suitable for them – which also influences their motivation to participate.

- The planning of projects was mostly done in a top-down manner. The participants therefore did not experience a feeling of ownership and pride in the projects which impacted on their motivation to participate in the projects, especially when the projects experienced difficulties. Because they were not sufficiently involved in the planning of the projects, the projects were also not tailored to meet their felt needs, thereby further decreasing their motivation to participate fully.

- The physical condition of the respondents significantly impacts on their motivation to participate in development projects. PLWAs experience severe ill-health such as an aching body, nausea and fatigue and are therefore often too ill to participate in projects, especially if these involve hard labour and they have to walk long distances to the projects. If the projects are delivering benefits to them, they might still try to make the sacrifice to participate. However, the projects discussed in this study did not deliver an income, and were thought to increase the likelihood of stigmatisation, so there was very little incentive for the PLWAs to participate in these projects.

- Most of the PLWAs have tried to improve their own standard of living by trying to set up small businesses or looking for employment. They did not

have much success because of stigmatisation and the unavailability of employment. This result shows that PLWAs are willing to work and do not just depend on handouts. The reasons why they do not participate in development projects are therefore not because they are apathetic, but rather as the projects do not result in real socio-economic benefits for them.

- Whereas the projects discussed in this study did not lead to economic benefit for the participants, thereby impacting on their motivation to participate, the support groups provided an environment where they could share common problems with each other. Being able to help each other in this environment increased their own sense of self worth.

In the following chapter, the above aspects will be used to formulate recommendations to increase the participation of PLWAs in development projects.

CHAPTER 7: CONCLUSIONS AND RECOMMENDATIONS

7.1 Introduction

The findings of this study are presented in this chapter. To lend context to this presentation, the research question is revisited. Then, the results of the interviews and the participatory observation are discussed, based on the literature review presented in Chapters 3 and 4. Thereafter, as the role of the change agent, in this case the researcher, is fundamental in development projects, a self-reflexive review of the role of the researcher in the projects under discussion is presented.

The chapter is concluded with recommendations for improving the participation of PLWAs in development projects.

7.2 The research question investigated in this study

It was the aim of the researcher to answer the following question:

What factors contribute to the non-participation of poor women living with HIV/ AIDS in food garden projects aimed at empowering them socially and economically?

The objectives of the study were therefore to:

- Provide a broad overview of the link between HIV/AIDS, poverty and development;
- explore requirements for successful participation in general;
- explore the experiences of poor women living with HIV/AIDS in general and especially the factors that hinder them from participating in empowerment projects such as the food gardens, and
- formulate recommendations to address the factors that de-motivate HIV patients from participating in empowerment projects such as the food gardens, so as to facilitate and promote participation.

7.3 A discussion of the findings of this study

The findings of this study highlighted several factors such as discrimination, social challenges, financial challenges, biological factors, and cultural factors that influence non-participation of PLWAs in development projects, such as the food gardens under investigation in this study.

In this section, the findings of the study, as reported in Chapter 6, are discussed based on the literature surveyed for this study. To lend context to this discussion, the findings in Chapter 6 are repeated here (shaded italics).

7.3.1 The cycle of deprivation

With regard to the living experiences of poor women living with HIV/AIDS, the picture that emerges is one of a cycle of deprivation. The various aspects such as poverty, health, unemployment, and social stigmatisation interact with and reinforce each other.

This cycle of deprivation can be illustrated as follows: Poverty is high and all the respondents were unemployed. This results in some of the women engaging in risky behaviour. Firstly, some women engage in prostitution to earn an income to meet their basic needs, thereby putting themselves at risk of multiple HIV infections, as well as putting their clients at risk of contracting the HIV virus. Secondly, some stop taking their medication to allow their health to deteriorate to the point where they qualify for a grant. Furthermore, because of high levels of poverty, PLWAs cannot afford the nutritious food necessary to help them fight the disease, and they also often live in unsanitary conditions that are not conducive to improving their health. Furthermore, they are experiencing financial problems in relation to medical treatment. Because of the results of ill-health for example an aching body and extreme fatigue, the PLWAs are not able to fully participate in projects that might raise their standard of living.

From the literature discussed, it is clear that it would be difficult to make progress if HIV/AIDS is viewed in isolation from its social, economic and political context. HIV/AIDS must be viewed as a problem of poverty and

development. All of the manifestations of poverty, such as lack of basic needs and powerlessness, interact with each other, making it very difficult for the poor to escape the poverty trap. Therefore, reaching the MDG targets, specifically with regard to eradicating poverty and hunger, universal primary education, gender equality, child mortality, HIV/AIDS and other diseases, would facilitate progress.

As discussed in Chapter 3, the human development paradigm holds advantages for addressing the problems related to HIV/AIDS. In particular, the human development approach recognises and increases people's capabilities. It is a holistic approach that embraces the whole person, and therefore goes beyond the current service-based community-orientated activities such as skills development – thereby encouraging self-reliance and boosting self- esteem.

The sustainable development approach has the advantage that it also recognises the interaction between various aspects, rather than focusing on for instance economic growth, employment creation or poverty alleviation. Therefore, as HIV/AIDS involves a cycle of deprivation, as shown above, a sustainable development approach is needed in addressing the epidemic. Sustainable development furthermore enforces a long-term perspective, and therefore it is closely related to self-reliance. If the project can continue even after development workers have left the scene, this would show that empowerment and human development have been achieved.

7.3.2 Stigma related to HIV/AIDS

Another important aspect of the cycle of deprivation is the stigma attached to HIV/AIDS. This leads to a lack of support which contributes to poor women living with HIV/AIDS being reluctant to take part in projects that might improve their standard of living. The stigma also results in people not coming forward for testing and counselling. Furthermore, the stigma results in PLWAs often being rejected by their families, thereby causing a lack of support, both financially and emotionally. Support from family, friends and the community

has been identified as a factor that could help PLWAs cope with the disease and so, in the absence of this needed support, their health suffers further.

Furthermore, because of the stigma associated with HIV/AIDS people living with the disease find it difficult to start traditional small businesses such as selling food, thereby adding to their economic hardship. The stigma also results in people being fired from their jobs and being excluded from benefits such as joining a burial society. This illustrates how the various factors are linked and how they influence each other.

Stigma is a very significant factor influencing the non-participation of PLWAs in development projects. PLWAs experience rejection from family, friends and the community and so they do not want to take part in projects that have been specifically designed for PLWAs. Taking part in such projects would show others that they are living with HIV/AIDS – the projects themselves become stigmatised in effect.

Furthermore, because of the stigmatisation they experience, PLWAs find it easier and safer to withdraw and stay at home than to move out and take part in community development projects as they have come to expect rejection and they therefore become self-stigmatised.

Cultural beliefs around HIV/AIDS lend support to the stigma associated with PLWAs. There is a need to break down the stigma by education to make communities aware of the real facts so that they do not believe in for instance curses and witchcraft. The sense of spiritual unease that communities experience related to HIV/AIDS will also decrease if they can be educated, and this will make life much easier for the PLWAs.

Because of the importance of stigma, development and social workers have to run projects in such a way as to reduce the likelihood of further stigmatisation of those taking part in the projects. For instance, development projects should be set up for all people suffering from poverty, and not just for PLWAs. Furthermore, at the clinics, all patients should be consulted in the same rooms, instead of putting PLWAs in separate rooms where everybody can see them going in to the "HIV rooms".

As literature indicates, the way HIV/AIDS presents as a disease (for example disfigurement), as well as the fact that it is communicable can lead to stigmatisation. Another factor leading to stigmatisation are myths and cultural beliefs surrounding HIV/AIDS, with particular emphasis on witchcraft, which leads to a sense spiritual unease. Stigmatisation should be dismantled through education and awareness programmes in communities.

Stigma has a profound effect on PLWAs, as discussed above. It is also very stressful for PLWAs to try and keep their status hidden for fear of being stigmatised, causing high levels of anxiety. This emotional distress can also further affect their health negatively.

As can be seen from the findings discussed above, there is also a high level of self-stigmatisation among the PLWAs which leads to them isolating themselves and not participating fully in the development projects and support groups provided for them. Interaction with an appropriately educated and sensitised community can go a long way towards easing this self-inflicted stigma. As quoted in the literature there is a need to discuss the epidemic and open up spaces for defending PLWAs.

7.3.3 Economic rewards expected from development projects

Because of the high level of economic deprivation, PLWAs will only be motivated to participate in projects that can promise immediate benefits to them. Not only do the PLWAs need the benefits to be immediate, but they also need a sustainable and reliable income. Therefore, if the projects cannot meet these needs, the PLWAs are unlikely to participate in them. The projects discussed in this thesis were not able to provide the participants with an immediate and sustainable income.

The projects discussed in this thesis were also not supported with resources from government. The participants were expected to raise funds for the projects themselves. Government support is not available for projects in the initial phases. Therefore, the participants did not have confidence that the projects would ultimately be a success and hence they did not participate fully.

As the literature indicates, even though there are a number of NGOs that have started to integrate income-generating development projects such as brick making and sewing, these have not all be equally successful. The reason for this is that government and the private sector do not want to fund projects that are still in their infancy, and rather support large well-established projects.

However, literature highlights other reasons why such projects are often not successful. Relevant to this study, is the fact that women often copy other income-generating projects instead of designing a new project for a specific market need. Therefore, projects tend to rely on women's traditional skills such as sewing, baking, and bead work, leading to a too high supply of the same kinds of services and products in the market. Furthermore, women do not have access to the resources needed such as credit, training and information.

Often, the development agents who are trying to put these income-generating projects into place, also do not have adequate business skills to ensure profitability. For instance, the training of social workers does not include business and financial skills. It might be helpful if social workers address this skills gap by linking up with NGOs and municipalities and projects they are initiating.

7.3.4 Suitability of projects for younger PLWAs

The majority of the PLWAs are relatively young and therefore the nature of the typical projects (food gardens and bead work) is not suitable for them – which also influences their motivation to participate.

Statistics show that unemployment rates are especially high among the youth, who constitute the bulk of those devastated by HIV/AIDS. Literature furthermore indicates that the fact that development projects for PLWAs are not always suitable to the needs of young people is a significant factor leading to the collapse of the projects. There is a particular need for projects targeted at teenaged female PLWAs to stop the cycle of HIV-infection and deprivation of women.

7.3.5 Lack of participatory planning of projects

The planning of projects was mostly done in a top-down manner. The participants therefore did not experience a feeling of ownership and pride in the projects, which impacted on their motivation to participate in the projects, especially when the projects experienced difficulties. Because they were not sufficiently involved in the planning of the projects, the projects were also not tailored to meet their felt needs, thereby further decreasing their motivation to participate fully.

According to literature, local organizational capital is important in ensuring effective participation and development effectiveness. A sense of ownership results when people participate fully and when the projects are relevant to their needs. Participation also leads to social learning, also of the change agent, which is empowering for the communities.

Literature indicates that the following is needed for effective participation: resources (which the projects under consideration did not have, as discussed), access to information and training (which would indicate a need for business skills on the part of the change agent, or networking with NGOs or municipal staff responsible for local economic development, who could provide the skills).

One of the stumbling blocks to participation is how the change agent approaches the project. Many change agents and development workers approach the community with plans that have been readymade within the government bureaucracy, and they then just consult with the beneficiaries. This might lead to the projects not addressing the felt needs of the intended beneficiaries.

Literature consulted shows that the change agent should understand the value of the social capital and indigenous knowledge in the community and should therefore embrace what is available within the community and integrate project plans with the local indigenous knowledge. The change agent should not adopt a “know all approach”, but should be a partner with the beneficiaries as they must have a sense ownership and develop strategies to

deal with their problems. This means that the change agent should not be too controlling and should not play too strong a leadership role, but should allow the project to develop incrementally.

7.3.6 Physical condition of PLWAs hindering their participation

The physical condition of the respondents significantly impacts on their motivation to participate in development projects. PLWAs experience severe ill-health such as an aching body, nausea and fatigue and are therefore often too ill to participate in projects, especially if these involve hard labour and they have to walk long distances to the projects. If the projects are delivering benefits to them, they might still try to make the sacrifice to participate. However, the projects discussed in this thesis did not deliver an income, and were thought to increase the likelihood of stigmatisation, so there was very little incentive for the PLWAs to participate in these projects.

Literature shows that of the physical manifestations of HIV/AIDS, malaise and lethargy are probable factors impacting on the motivation of patients to take part in development projects. In addition, PLWAs are likely to be weak and not able to undertake hard physical work. Another factor in this regard is that one of the symptoms of HIV/AIDS is reduced appetite and absorption of nutrients, making additional demands on the bodies of the already weakened PLWAs.

The projects under consideration in this study were food gardens that involved hard physical labour. Furthermore, some of the PLWAs had to walk to the projects as they could not afford minibus-taxi transport and the railway station was very far from the clinics.

7.3.7 PLWAs' efforts to uplift their standard of living

Most of the PLWAs have tried to improve their own standard of living by trying to set up small businesses or looking for employment. They did not have much success because of stigmatisation and the unavailability of employment. This result shows that PLWAs are willing to work and do not just depend on handouts. The reasons why they do not participate in

development projects are therefore not because they are apathetic, but rather as the projects do not result in real socio-economic benefits for them.

As stated in the literature consulted, self-reliance and a sense of ownership of projects are important results of the human development approach. Furthermore, people should not be passive spectators of their development, but should take initiative and have a role to play in actions aimed at uplifting their standard of living. Therefore, actions by PLWAs aimed at improving their standard of living, for instance starting a small business or looking for employment, are positive signs of human development.

However, as stated in literature, and found in this study, the level of deprivation faced by the PLWAs (for instance in terms of stigma, poverty, unemployment, ill-health and lack of access to services) is often overwhelming. It is therefore very difficult for the PLWAs to "uplift themselves" and it could be for this reason that some of them seem to be content to depend fully on social grants, even if these are not sufficient.

While the social grants are a source of great relief to the PLWAs, they are not permanent and are therefore not a sustainable form of income. When the health of PLWAs improve and they lose the grants, they are often forced back into deeper poverty as they cannot find employment or start self-employment businesses. As a result literature indicates that some PLWAs stop taking their medicine to be able to access the grant again. This situation is wasteful in terms of government funding, as it increases resistance to the medication. Furthermore, such PLWAs are never completely lifted out of their dire situation, but need government intervention again and again, thereby utilising resources that could have been used to help other PLWAs.

7.3.8 Social value of the support groups and projects

Whereas the projects discussed in this thesis did not lead to economic benefit for the participants, thereby impacting on their motivation to participate, the support groups provided an environment where they could share common problems with each other. Being able to help each other in this environment increased their own sense of self worth.

As literature indicates, HIV/AIDS patient are depended on chemicals (medication) with few or no internal resources to cope with the devastating illness. Therefore group work provides a venue in which patients are able to discuss aspects such as their fear of dying, rejection, and stigma. These issues are addressed within the powerful healing currents of the group process. It is reported that patients described these meetings as “information sharing”, “getting in touch”, and “reinforcement for life and relaxation”.

The role of the group facilitator is crucial in determining the success of the group process. For instance, in this study it was found that even though the women taking part have mostly been socialised in submissive gender roles, they were confident in the group setting. This was in part attributed to the fact that they had built up a relationship of trust with the facilitator.

Therefore, as literature indicates, the success of the projects under consideration should not only be judged on economic grounds. The support groups and the projects have the potential to provide other important aspects of social benefit to the PLWAs. It is for this reason, that PLWAs should be encouraged to participate fully in projects, and that projects should be designed such that they motivate participants to participate.

7.4 A self-reflexive discussion of the role of the researcher as change agent in the projects under consideration

After the completion of the study, the researcher was able to reflect on her role in the projects under discussion, particularly as regards participation of the PLWAs. These are her conclusions in that regard:

- The research was a learning experience for the researcher specifically with regard to the need to include participants in the planning of projects. She realised that she approached the PLWAs with a blue-print for a project and did not create sufficient opportunity for them to participate in the planning of the project.

- The researcher followed a top-down approach which resulted from the tendency of researchers to think that they know everything since they

are professionals. This attitude does not acknowledge the local skills and information which are positive and important resources for development.

- Furthermore, the researcher approached the project with preconceived ideas about what is best for the PLWAs without really assessing if her project idea would address their felt needs. For instance, she did not brainstorm with the participants about what kind of project would be suitable in consideration of their ages.

- Whereas the intention of the researcher to assist the PLWAs to uplift their standard of living was good, the planning and implementation of the project was poor from a development perspective as it did not allow the participants to be the drives of their own development, thereby not reaping the benefits of a human development approach.

- Furthermore, the researcher (as a social worker) does not have the necessary business and financial skills to manage a successful income-generating project.

- Finally, because of a very high case load, the researcher did not have sufficient time to attend to the projects under discussion or to facilitate more of the much-needed support groups. As stated in this study, two social workers had the responsibility for 7 000 people.

7.5 Recommendations for improving the participation of PLWAs in development projects

The recommendations listed below are based on the findings of this study as discussed in this chapter, as well as in Chapter 6.

- Measures to address the HIV/AIDS epidemic and its effects, should be integrated with development and poverty alleviation projects as HIV/AIDS is a holistic problem related to development, and not just a health problem. This will begin to break the cycle of deprivation faced by the PLWAs,

thereby creating a climate that is more conducive to participation and thus unlocking all the benefits of participation.

- Development planning policies should adopt a human development approach, as this will encourage a sense of independence and self-esteem, as well as reduce dependency on handouts.

- The community needs to be continuously educated about HIV/AIDS to eliminate the myths they have about the condition. Awareness campaigns should also be implemented to attack the stigmatisation related to HIV/AIDS. Furthermore, the effectiveness of existing campaigns about stigmatisation should be investigated as they do not seem to be having the desired effect.

- Development projects must be inclusive of all people suffering from poverty, and should not only focus on PLWAs. This would prevent the projects themselves being branded as HIV/AIDS projects, and those who participate in them being further stigmatised.

- To further break down stigmatisation, PLWAs should be consulted in the same room as the other patients.

- There is a need for support services (for example legal counselling) to help PLWAs who have been discriminated against on the basis of their health status such as being dismissed from a job or excluded from benefits.

- The community and families should be encouraged by politicians, church leaders, NGOs, health workers, and community workers to support PLWAs to cope with the disease and accept their condition. This will help reduce the stigma, discrimination, and enhance their self-esteem.

- Government departments should make available seed funding for small development projects that are in the initial stages. The size of the fund does not have to be large, but it is important that the grass-roots development or social worker is able to access this seed funding easily without too much “red tape”.

- Government should put in place policies that would provide an incentive to the private sector to support the kind of development projects discussed in this study as part of their corporate social responsibility.

- Social and development workers should be able to access advice and information via for instance development agencies, NGOs and banks, free of charge, to ensure that the projects are designed to meet market needs, and not just a duplication of other projects.

- Skills training and income-generating projects need to be carefully marketed and subjected to quality control to ensure their viability and sustainability.

- In designing projects, the use of non-traditional skills that go beyond for instance baking and sewing, should be investigated.

- Linked to the need to use non-traditional skills in income-generating projects, there should be an exploration of ways in which to make the development projects more interesting to young PLWAs, especially teenage women.

- Successful income-generating projects should be advertised to create confidence on the part of the PLWAs that their own projects could also be successful.

- Projects need to be designed and implemented in a participatory manner. As the literature emphasises, projects should be carried out in consultation with the participants so as to promote ownership and maximum participation and choice in the type of projects as many literature .This could be encouraged by making any effective participation a condition of funding for the project. Social and development workers should also be sent on training courses in participatory approaches.

- The importance of participatory approaches to development should be emphasised at all training institutions for instance at universities. The orientation of change agents should start at that level already.

- Government should capacitate their change agents with the necessary skills to manage income-generating development projects in the communities to avoid so-called “white elephant” projects. In particular, the training of social workers should be adapted to equip them with these kinds of skills as they are often expected to play the role of development change agent. Social workers should also learn to network more with NGOs and municipalities.

- The ratio of social workers to patients should also be increased at the clinics as the responsibilities of social workers, within the context of the HIV/AIDS epidemic, have increased significantly both in size and nature.

- As PLWAs are often too ill to participate in the development projects and cannot travel long distances as they do not have money for transport, backyard food gardens should be encouraged in communities as they have the potential to improve food security and the health status of PLWAs, without incurring extra transport costs.

- To encourage the participation of those PLWAs who are too ill to do physical labour, less physically demanding options should be explored for income-generating projects.

- Disability grants should not be immediately and fully suspended when people’s CD4 counts improve above 200, because it becomes a worthless exercise to give treatment and people default for the sake of grants. The government should explore options to address this situation. For instance, conducting a means test, making continued support for PLWAs with a CD4 count higher than 200 conditional on their participation in appropriate development projects, and designing flexible exit programmes.

- Development projects should not only be viewed from an economic perspective as they also have social benefits, much as the support groups have. Therefore, projects should be designed in such a way that the potential social benefits of these projects are maximised, for instance making products in a support group set up.

7.6 Concluding remarks

In this study, the underlying reasons for the generally low level of participation of poor women living with HIV/AIDS in empowerment projects were investigated within the context of poverty alleviation and participatory development.

The picture that emerged had many facets and the reasons for non-participation were found to be due to a number of different factors, such as the cycle of deprivation suffered by poor women, the stigma still clinging to PLWAs, expected economic rewards, inappropriate nature of projects for younger PLWAs, the lack of sufficient participatory planning, and the poor health and weakness of PLWAs.

When the researcher reflected on her own role in setting up empowerment projects for PLWAs, the importance of participatory planning and management of such projects became even more apparent. This experience instilled in the researcher a greater appreciation of the need for 'planning with' rather than 'planning for' in projects aimed at improving the socio-economic status of PLWAs.

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ANNEXURE 1: INTERVIEW SCHEDULE

TOPIC OF RESEARCH:

Factors contributing to non-participation of people living with HIV and AIDS in sustainable development projects

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A. IDENTIFICATION (PERSONAL PARTICULARS)

1. Age : 21-30,31-40,41,41-50

2. Marital status: Single, Married, Separated, and divorced.

3. Educational status : Primary grade 1- grade 7
   : Post-primary grade 8 – 12
4. Occupation : Specify (e.g. plumber)

Specify –
Unemployed –

B. SOCIAL FACTORS

5. Would you like to share your social challenges as a person living with HIV and AIDS?
6. Have you experienced any form of discrimination since you were diagnosed with HIV and AIDS?
7. What local belief /cultural factors are you aware of concerning HIV and AIDS in your community?
8. What form of support are you receiving as a person living with HIV and AIDS?
9. Do you think people living with HIV and AIDS are experiencing poverty
   (a) If yes, how has poverty affected your life? Elaborate----------
   (b) If your answer is no, give reasons----------

C. ECONOMIC FACTORS

8. Are there funds available for the development projects? Explain
9. Do these projects meet your needs/expectations?
10. Did you participate from the planning phase of these projects?
11. What financial problems do you have in relation to your medical treatment and other needs?
12. What initiatives have you undertaken to empower yourself and improve your socio-economic status?

D. PHYSICAL/BIOLOGICAL FACTORS

13. How would you explain your health status in relation to your involvement in community activities, including the development projects?

ANNEXURE 2: CONSENT FORM

Factors influencing non-participation of people living with HIV and AIDS in sustainable development projects

Name: _____

Address: _____

I hereby declare that the purpose of the study has been discussed with me and that I understand and agree to participate voluntarily.

I understand that my confidentiality will be respected and my personal information will not be disclosed without my permission.

My signature implies informed consent to participate in the study.

_____ _____

Signature Date