THE ACCESSIBILITY TO SOCIAL ASSISTANCE BY PERSONS LIVING WITH HIV/AIDS IN THE VULINDLELA AREA.

By

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Submitted in fulfilment of the requirements for the Degree in Master of Social Work (MSW) AT THE University of KwaZulu-Natal.

Supervisor: M.I Kasiram
Date Submitted: November 2008

DECLARATION

I, Maloney Lindiwe Mtembu. declare that

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- Submitted in fulfilment of the requirements of the degree of Masters in the School of Social Work, University of KwaZulu-Natal, Howard College.

- As the candidate's Supervisor I have approved this dissertation/thesis for submission

November 2008

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1.10 Operational Definitions

The operation definitions of concepts central to this study are listed below:

Access: - Access can be defined as a means of approaching or entering a place and an opportunity or a right to use someone or approach somebody. Accessibility is the time effort and cost, in brief the ease, with which a good, a service or a facility can be reached or used (Mitra, 2005: 23).

Acquired Immunodeficiency Syndrome (AIDS):- A disease of the human immune system that is caused by infection with HIV and characterized by the reduction of the numbers of CD4-bearing helper T- cells to 20% or less of normal, thereby rendering the subject highly vulnerable to life-threatening opportunistic infections (HIV/AIDS for the province of KZN, 2007).

Affected Person: - A person whose life is changed in any way by HIV and AIDS due to the broader impact of this epidemic (HIV/AIDS for the province of KZN, 2007).

CD4 cell: - A type of T cell involved in Protecting against viral, fungal and protozoal infections (HIV/AIDS for the province of KZN 2007).

Disability Grant: - A disability grant is an income given to people who are physically or mentally disabled, unfit to work and unable to support themselves. You get a permanent disability grant if your disability will continue for more than a year and a temporary disability grant if your disability will continue for a continuous period of not less than six months or for a continuous period of not more than twelve months (http://www.services.gov.za/en-za/applicationfordisabilitygrant.htm24/05/08).

Human Immunodeficiency Virus (HIV): - The virus that weakens the body's immune system, ultimately causing AIDS (HIV/AIDS for the province of KZN, 2007)

Infected person: - A person who is infected with HIV, the virus that causes AIDS (HIV/AIDS for the province of KZN, 2007).

Social Security: - The protection which society provides for its members through a series of public measures:

- To offset the absence or substantial reduction of income from work resulting from various contingencies (notably sickness, maternity, employment injury, unemployment, invalidity, old age and death of the breadwinner);
- To provide people with health care; and to provide benefits for families with children (International Labor Organization, 2000:29 as cited in Triegaardt, undated handout)

Social Assistance: - Social assistance refers to non-contributory and income-tested benefits provided by the state to vulnerable groups unable to provide for their own minimum needs, such as the disabled, the elderly and young children in poor households (Woolard, 2003). For the purposes of this study, the disability grant is the social assistance to which people affected by AIDS are entitled.

Person Living With AIDS: - Refers to a person who is infected with HIV. (HIV/AIDS for the province of KZN, 2007)

ABSRACT

The Social Assistance Act of No. 59 of 1992 was put into place to help in assisting poverty stricken people of South Africa by offering social grants to an aged, disabled person or a war veteran. Due to the devastating effect of HIV/AIDS, people living with HIV/AIDS were entitled to social assistance. However, grave problems exist for this group of persons to access social assistance such as the qualifying criteria for the disability grant being complicated by the medical nature of HIV/AIDS, taking anti-retroviral therapy and problems in the administration procedures. Compounding these, is that rural areas are underdeveloped and lack infrastructure to accommodate adequate service provision.

This study aimed to increase understanding of access to social assistance by people living with HIV/AIDS in the rural area of Vulindlela in KwaZulu-Natal, South Africa. The study researched this by hearing the voices of both the service providers (key informants) and people living with HIV/AIDS (patient respondents) by conducting a qualitative study based on a descriptive research design. Data was collected by means of semi-structured, in depth-interviews for both the service providers as well as patient respondents in this study. Findings revealed that the voices of people living with HIV/AIDS were not heard and further that they were not even aware of their rights and entitlements to social security. In fact, in many instances people died without having had any access to their grants whilst others had to wait months before receiving their grants. Findings emphasized the need for education, training and retraining for service providers, recipients and educational institutions as HIV/AIDS poses a major challenge in our society and as it is an ever changing phenomenon.

Using an ecosystemic frame of reference, recommendations were multi-fold and included better networking and collaboration amongst the different bodies that are involved in grant administration and revisiting qualifying criteria. Other recommendations included strategies to deal with corruption, the development of pressure and lobbying groups and staff shortages. Given the time it takes to plan and implement changes and given the life threatening nature of HIV and AIDS, a key recommendation was for a newly introduced grant exclusively for the people living with the virus, to lessen the burden of meeting qualifying criteria and thus give dignity to and improve life quality.

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CHAPTER ONE

1. INTRODUCTION AND METHODOLOGY

1. 1 Introduction and Rationale for the Study

This study was conducted in the rural area of Vulindlela in the province of KwaZulu-Natal, South Africa. Vulindlela is affected by the Human Immune Virus and Acquired Immunodeficiency Syndrome (thereafter referred to as HIV/AIDS) pandemic (Health Systems Trust, 2005). The escalating numbers of people infected with HIV/AIDS in Vulindlela is increasing their vulnerability to poverty.

From the researcher's observations and discussions with HIV/AIDS patients, community members and staff of local clinics and organizations, the high levels of poverty, particularly related to the increasing number of people affected or infected by HIV/AIDS in the area, appeared to be their main concern.

The patients' and 'communities' immediate solution to their problem of poverty was to obtain a social grant. Section 27 (1c) of the South African Constitution (1996) protects the rights of everyone to access appropriate social assistance, if they are unable to support themselves and their dependants (Patel, 2005:124). HIV/AIDS patients are entitled to a means tested disability grant if they meet the qualifying criteria. Based on the researcher's informal conversations with the community, the main difficulty they were experiencing was in accessing the disability grant. According to community members, they were encountering barriers to access in both the formal and informal systems. Informal systems play an important role in rural communities, for example, the need to use a community member as a scribe to fill in application forms (Mhone, 2004). Hardy (2005) is of the opinion that people infected and affected with HIV/AIDS are discriminated and stigmatized by the people in their communities. He further maintains that this makes access to the social grant system difficult, particularly in rural communities.

Difficulties were also experienced in accessing the disability grant through the formal systems. The qualifying criteria for the disability grant are complicated by the medical nature of HIV/AIDS. More recently, access to anti-retrovirals complicates the medical status of HIV/AIDS patients who qualify for the disability grant (Hardy, 2005). There were also problems in the administration procedures and social security system which pose an added burden to sick patients (Ministry of Social welfare, 1997). Households in rural areas face further barriers to accessing the formal system, due to underdevelopment and lack of infrastructure and services in these areas.

This study aimed to increase the understanding of access to social assistance by people living with HIV/AIDS in an area disadvantaged by spatial location, racial composition of the population and poverty. People infected by HIV/AIDS are stigmatized and discriminated against because of the nature of the illness. It was hoped that the findings of the study may contribute to improving the effectiveness and efficiency of the social security system. In addition it should assist the social security system to become more user friendly and address the challenges experienced by HIV/AIDS patients in accessing the system, whilst maintaining the dignity of the recipients. It was also expected to contribute to ensuring that people with HIV/AIDS attain their right to social assistance in order to maintain their quality of life.

The knowledge gained from this study will be of value to policy makers, persons involved in the delivery of social assistance to communities, people infected and affected by HIV/ AIDS and human rights activists.

1.2 PROBLEM STATEMENT

Vulindlela is a poor rural community, with few resources and a high rate of poverty. The increasing number of people with HIV/AIDS in this community is contributing to further economic strains on the people of this community. People infected by HIV/AIDS were experiencing various problems, in accessing the disability grant. The study sought to understand the experiences and challenges of persons with HIV/AIDS in accessing the disability grant. It further sought to attain recommendations from various stakeholders in overcoming these challenges and strengthening the system.

Limited empirical studies exist to address this problem in rural areas. This study intended to bridge this knowledge gap.

1.3 RESEARCH OBJECTIVES

The main objective of this study was to explore and understand the accessibility of social assistance by persons living with HIV/AIDS in the Vulindlela area:

The study specifically sought to establish the following, through the qualitative research method:

- To identify the significant role players both in the formal and the informal systems involved in the delivery of social assistance.

- To understand the partnerships and co-ordination that exists between the above-mentioned formal and informal systems.

- To hear the voices of community members living with HIV/AIDS and the challenges they face in accessing the social security system.

- To identify the difficulties experienced by the persons involved in the social security delivery system in the application process of the disability grant of persons infected with HIV/AIDS.

1.4 RESEARCH QUESTIONS

The research study sought to answer the following questions:

- Who are the significant role players both in the formal and the informal systems involved in the delivery of social assistance in Vulindlela?

- What are the experiences and challenges of persons infected with HIV/AIDS in accessing social assistance in Vulindlela?

- What are the difficulties experienced by the persons involved in the social security delivery system in the application process of the disability grant of persons infected with HIV/AIDS?

- What are the recommendations of the various stakeholders in overcoming these challenges and strengthening the system?

1.5 THEORETICAL FRAMEWORK

This study was guided by the ecosystems theory which was chosen as it allows one to view access to social security holistically. It also allows one to consider HIV/AIDS and social security as part of a larger system. "Problems do not characteristically have 'simple' or linear solutions but must be understood as manifestations of a wider system" (Ife, 2002:41). According to Bronfenbrenner (as cited in Berk, 1998:23) "ecosystems theory views the person as developing within a complex system of relationships affected by multiple levels of the surrounding environment. The surrounding environment consists of the following systems: the physiological, intrapersonal, interpersonal, family/small group, community, cultural, and national. To be effective human service providers, we need a conceptual framework that allows us to view the person within the total gestalt (organized whole) of his/her situation, that is the person-in-situation gestalt. As human service professionals we are concerned with what happens at the interface of the individual and the environment". "The environment consists of both the natural geographical environment that impacts on the development, psychological and social functioning of individuals as well as systems (such as family, the economic, educational, religious and political systems) that influence human development and behavior" (Bronfenbrenner as cited in Berk, 1998:23)

"From an ecosystems perspective, development is the progressive mutual accommodation between an active growing human being and the changing properties of the immediate settings in which the developing person lives, as this process is affected by relations between these settings and by the larger context in which these settings are embedded" (Bronfenbrenner as cited in Berk, 1998)
Brim and Bronfenbrenner (cited in Ashford, et al, and 2001:106) identified four categories, or levels of systems that are useful: "microsystems, mesosystem, exosystem and macrosystem. Microsystems represent any system that involves face-to-face or direct contact among the system participants. The mesosystem refers to a network of personal settings in which we live our lives". The exosystem in Bronfenbrenner's scheme refers to "the larger institution of society that influences our personal systems. This includes institutions like government agencies in which we do not directly work but that have profound effects on our lives. Exosystems are considered to be any of the systems in which an individual is not directly involved. Lastly, the macrosystem represents the larger sub cultural and cultural context in which the microsystem, mesosystem and exosystem are located". "This system has the most pervasive level of influence on social activities" (Ashford, et al, 2001:107). Within the ecosystems model all relationships are bi-directional and reciprocal.

This model is considered appropriate for this study, as an overview of the literature cites all the above mentioned systems as important when people with HIV/AIDS are accessing the disability grant. With specific reference to HIV/AIDS, Nkwe-Mabua (2000:5) is of the opinion that the ecological-systems theory helps to understand how the different systems in society interact and affect one another, in the process of providing for the needs of people with AIDS. In South Africa there were rapid changes and transformation of the social security system after democracy in 1994. According to Ife (2002: 41), “a principle of the ecosystems approach, holism, values organic change, bringing change to one part of system while not ignoring the remainders of the system”. This is an important point to consider in the transformation of the social security system. The environment is made up of various formal and informal systems which are involved in the process of application and attainment of the disability grant. The successful attainment of the disability grant is dependent on the bi-directional and reciprocal relationships of the various systems. The research attempted to identify, understand the partnerships and co-ordination among these various systems in order to answer the research questions and ultimately to bring about better service delivery. Cloete (cited in Du Toit & Van der Waldt, 1999:16) considers co-ordination very important to ensure that every separate activity is undertaken with the purpose of achieving an objective and must be brought into line with every other such activity.

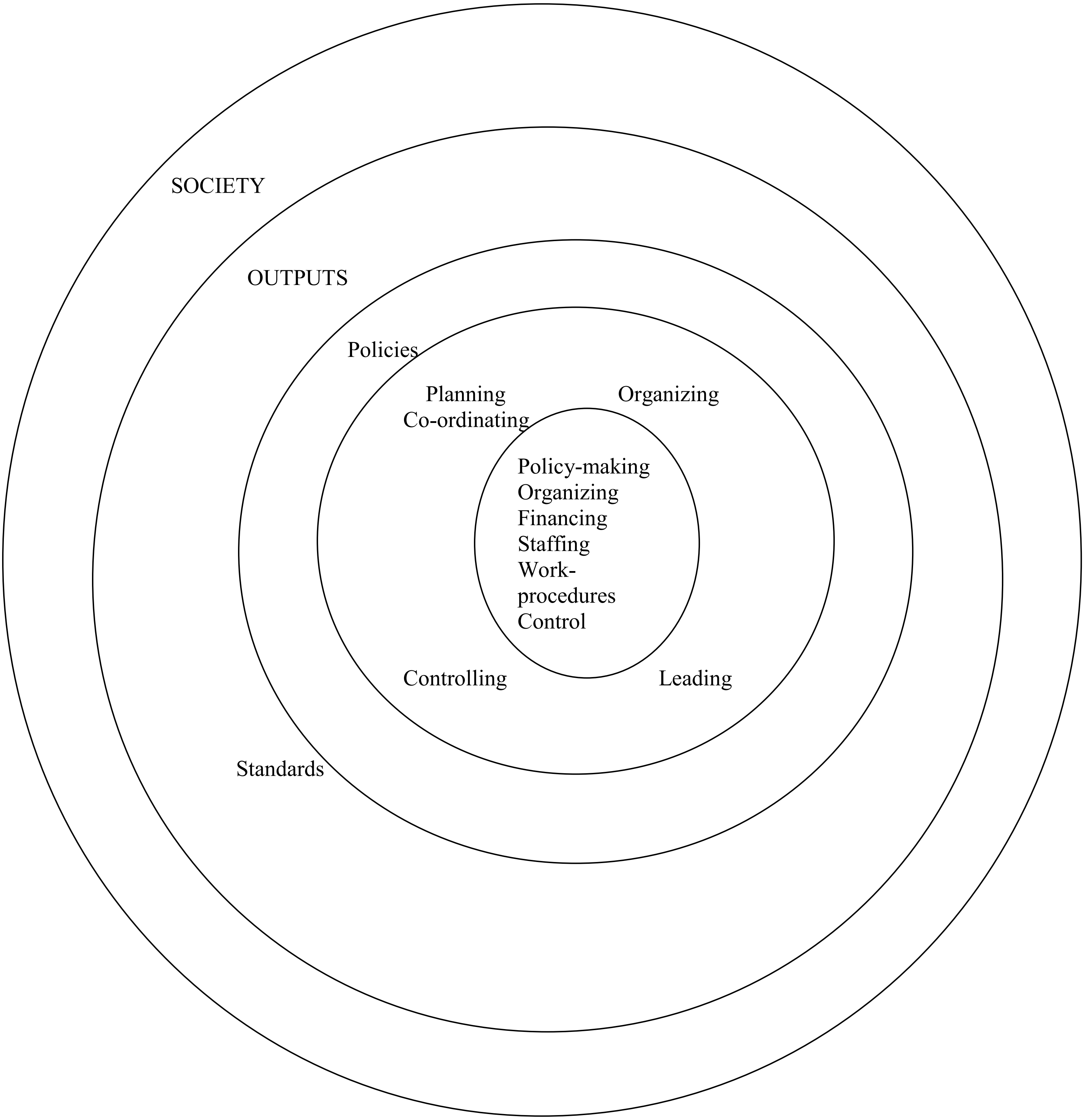
Change, reconstruction and development of society were largely driven by national policies at a macro-level. Socio-political factors have a direct/indirect bearing on social security provisioning in South Africa (Mpedi & Darimont, 2007). Also, challenges in access to social security have been documented right from national level (macro) to the micro system. According to Bronfenbrenner (cited in Whitaker, Schinker and Gilchrist, 1986 as cited in Mohanlall, 1998:8), “human development is a process where individuals and their environment have a mutual influence on one another”. Kazak (cited in Sancho, 1994 as cited in Mohanlall, 1998:8) noted that “social ecology refers to the relationship between the developing human being and the context in which the individual is actively involved”. “This ecological orientation moves away from linearity and emphasizes the wholeness, interdependence and complimentarity of living organisms” (Germain and Gitterman, 1980 as cited in Mohanlall, 1998:8). This perspective is relevant to the study for several reasons. Although a medical phenomenon, HIV/AIDS impacts on society at various levels. “At a micro level, the syndrome is seen to impact on individuals and their families” (Mohanlall, 1998:8). At a mezzo level the researcher identified the different service providers responsible for delivery of services in the research area for people living with HIV/AIDS. On a macro level, the national global impact of HIV/AIDS reveals a spread of the syndrome to all countries in the world. “The magnitude of the HIV/AIDS epidemic as a global phenomenon serves to highlight the need for an effective and urgent response to all levels of society” (Mohanlall, 1998:9).

Also guiding the study was an interesting administrative, management service delivery model developed by Du Toit & Van der Walt (1999:18). It is useful to the study as it illustrates the interplay of processes that are involved in the delivery of social grants to recipients. There might be challenges in any one of these processes which affect accessibility to social assistance in Vulindlela. This model consists of six generic processes that had relevance for the study:

1. Policy-making: the purpose of a policy is to reveal the intention of the government to achieve specific objectives in particular ways.
2. Organizing: which entails establishing structures, each responsible for a particular functional area, grouping some functional activities within specific structures.
3. Financing: which entails obtaining, allocating, spending and controlling public finances.
4. Personnel provision and staffing: which involves performing several other functions for making personnel available to and placing them in suitable positions and developing them.
5. Determination of work procedures: which involves drafting specific instructions to be followed to carry out certain actions. These instructions are found in legislation and regulations arising from legislation.
6. Control: which is exercised to ensure that all administrative and functional functions are carried out effectively and efficiently to achieve objectives.

On another level, the practice of public management entails carrying out a number of basic management functions: planning, organizing, leading, controlling and co-ordinating.

Figure 1: An administrative management model (adapted from Du Toit and van der Walt, 1999:18)



There are also administrative / management regulators which serve as guidelines for giving guidance and control (Du Toit & Van der Walt, 1999:16). They include policies, Acts, procedures and standards. These shape the outputs which become the final products and services to users. The importance of the wholeness of the system, co-ordination and reciprocity between the systems are depicted overleaf in the diagram illustrating the model.

1.6 RESEARCH METHODOLOGY

1.6.1 Research Method

This study used a qualitative research method. The objective of qualitative research is to promote better self understanding and increase insight into human conditions. The researcher tries to understand ways in which different individuals make sense of their lives (Van der Merwe as cited in Garbers, 1996). Rubin and Babbie (1997:272) maintain that the aim of qualitative research is to describe and understand events within concrete and natural contexts. Appreciating context was relevant to this research study as it provided an opportunity to understand how policy makers and service providers perceive the extent and nature of the AIDS virus. In addition, the people of Vulindlela were allowed opportunity to share their understanding, experiences and challenges in accessing social security. This led to a better understanding of disadvantage based on location inequality, race, poverty, gender and illness characterized by stigma and discrimination.

1.6.2 Research design

The purpose of descriptive studies is to describe that which exists as accurately and clearly as possible. Examples would include an in-depth description of a specific individual or group (Van der Merwe as cited in Garbers, 1996:287). A descriptive research design was used in this study.

The principle objective of this descriptive design was accurate description to reveal potential relationships between variables with an emphasis on validity and reliability. In this study, the researcher focused on people living with HIV/AIDS, their experiences in accessing social grants, and for various stakeholders to describe the variables and relationships that exist in grant access with a view to strengthening them. The descriptive component also aimed at understanding who the significant role players were in service delivery and, what protocols and procedures existed for people to qualify for the disability grant.

1.6.3 Sampling strategy

Sampling entails making decisions about who will be participants in the research study. The sample should be representative of the population being studied. Terre Blanche and Durrheim (1999 as cited in Nkwe-Mabua, 2000:31) state that representative samples are particularly important to describe surveys in that they are used to accurately estimate properties of populations.

The study comprised of two sample groups:

- *Sample One*: were people infected with HIV/AIDS
- *Sample Two*: were key informants involved in the delivery of social assistance in the area

Sample one was made up of people infected with HIV/AIDS. The initial intent of the researcher was to identify people living with HIV/AIDS through snowballing but this process was considered ethically incorrect as people may have been coerced into participating without adequate knowledge of the study. Instead the Vulindlela Clinic of Centre for the AIDS Programme of Research in South Africa (CAPRISA) was selected as the site for securing respondents. This allowed for the purpose of the study to be carefully explained by both the researcher and other medical staff before respondents agreed to participate. As the study was qualitative, this site allowed for tapping into the whole process of accessibility to the grant from both the perspective of the service recipient and service provider. Further, the Clinic receives referrals from several clinics in the area e.g. Songonzima clinic, Mpumuza clinic Mafakatini Clinic, East Street clinic adding to the representativeness of the sample.

All respondents were over the age of eighteen years as this is the minimum age for eligibility to the disability grant. Both persons already in receipt of the disability grant and those in the process of applying for the grant were included in the study. The people already in receipt of the grant had received it for more than one year. This inclusion criterion ensured that the difficulties experienced by patients who were in receipt of a temporary grant were captured.

In this study, the number of respondents in the sample was determined until saturation point was reached, in order to gather as much in-depth information as possible. In qualitative research, to explore diversity, you need to reach what is known as saturation point in terms of your findings; for example, you go on interviewing or collecting information as long as you keep discovering new information. When you find that you are not obtaining any new data or the new information is negligible, you are assumed to have reached saturation point (Kumar, 2005:165). Finally, in sample one 31 respondents were interviewed.

Sample two was determined by the use of purposive sampling. The primary consideration in purposive sampling is the judgment of the researcher as to who can provide the best information in order to achieve objectives of the study. The researcher only goes to those people who are likely to have the required information and will be willing to share it (Kumar, 2005:179).

The key informants (sample 2) were identified by the respondents in the study and from an overview of relevant policy documents. Key informants used in the social security delivery systems were:

- The medical officer employed by the KwaZulu-Natal Department of Social Welfare and Population Development
- A senior official from the department of social security (KwaZulu-Natal Department of Social Welfare and Population Development)
- An official from the department of South African Social Security Agency (KwaZulu-Natal Department of Social Welfare and Population Development)
- Social Worker from the department of social services (KwaZulu-Natal Department of Social Welfare and Population Development)
- An "Induna" who had been identified from these sectors as being integral to service delivery.

A total of five respondents formed Sample Two.

1.6.4 Method of data collection

Data was collected using qualitative data collection techniques. Data was collected from July to August 2006. Qualitative research uses a small sample frame with the intention of collecting information rich data, in order to thoroughly explore respondents being studied. Semi-structured, in-depth interviews were used in this study with both sample groups. According to Taylor and Bogdan (as cited in Kumar, 2005:124) in-depth interviewing is 'face- to-face encounters between the researcher and informants directed towards understanding informants' perspectives on their lives, experiences, or situations as expressed in their own words'. In this research, the researcher was engaged in the in-depth interviews with people living with HIV/AIDS and the service providers. This allowed the researcher to capture emotions and experiences of the respondents in detail. Also very little is known about this area, thus requiring in-depth exploration.

The major advantages of using interviews include the following:
Interviews have a high response rate and in this study, nobody refused to participate. Interviews allowed for some flexibility pertaining to the order in which questions may be asked and also allowed the interviewer to probe

while the interviewee may ask for clarification. Thus ambiguous questions may be clarified. Interviews enabled the interviewer to observe non-verbal behavior and the reflective behavior of the interviewee as they responded to questions. Interviews also have the advantage that responses are spontaneous. It is also a useful tool when the interviewee has limited writing or reading skills (Nkwe-Mabua, 2000:34). Confidentiality was a key requirement and assured personally through the use of interviews due to the sensitive nature of the illness and eligibility criteria towards disability grant.

Two separate semi-structured interview guides were used for both sample groups (See Appendix one and two).
The accessibility framework as developed by Mitra (2005) and the administrative management service model developed by Du Toit & Van der Waldt (1999) guided the type of data collected.

Themes for in-depth interviews with people infected with HIV/AIDS were:

- Biographical details
- Perceptions and experiences in applying for disability grants: - PROBE: understanding of procedure and qualifying criteria, cultural and social barriers, challenges and strengths of the system, satisfaction with the system, attitude
- Improving access and enhance integrated, sustainable services

Themes for in-depth interviews with key informants were:

- Biographical profile of the organization / sectors they represent
- Services provided by key informant
- Policies and procedures of the organization in accessing social security for people living with HIV/AIDS
- Difficulties encountered in dealing with the application and procedure involved of the disability grant.
- Strengthening and making the system more user friendly

1.6.5 Data analysis

All the data collected was recorded by means of detailed process notes. Initially the researcher was going to use a tape recorder based on approval of the participants. However, due to the fact that respondents feared their status being revealed to the public through tape recording, despite assurances of confidentiality, taping was not used. The qualitative information was categorized into themes and categories guided by the theoretical framework of the study and analyzed.

1.6.6 Reliability and validity

Due to the nature of the study, validity and reliability was strengthened by ensuring a safe, confidential environment for participants to promote honest and open discussion. Validity was also enhanced through consultation with community members and research experts during the process of data collection, analysis of data and interpretation of data.

The themes of the interviews were informed by current literature thereby enhancing validity so that the study explored what it set out to study.

The replicability of a qualitative study is less a concern than is its trustworthiness. Strategies of trustworthiness were applied in this study such as Lincoln and Guba's (1985: 290-327) four dimensions of:

1. Credibility
    - Prolonged engagement in the field
    - Keeping reflective journals
    - Triangulation: different groups of people involved with HIV/AIDS participated in the study (2 sample groups)
    - Peer review: each phase of the research was discussed with peers and co-researchers who were the participants
    - Structural coherence: The research process was logical and followed the theoretical framework discussed earlier.

2. Transferability
    - A dense description of data and thorough sampling was undertaken.
3. Dependability
    - A careful description of the methods of data gathering, data analysis and interpretation.
4. Conformability
    - Ensuring an audit of the entire research process via supervision and consultation
    - Reflexive analysis
    - Triangulation.

1.7 LIMITATIONS OF THE STUDY

- Due to the fact that HIV/AIDS patients are often stigmatized and discriminated against, the respondents might have found it hard to be truthful in revealing personal information about their illness.
- Respondents would have not opened up about their employment status because of the strict qualifying criteria for access to the disability grant and the threat of it being cut.
- Data was collected in isiZulu and converted to English for analysis therefore certain important aspects might have been missed in the translation.
- The participants of the study were patients who were in receipt of medical services from the Clinic. They might have been more empowered and knowledgeable than persons who were not in receipt of such services, possibly prejudicing the data obtained in the study.
- A further shortcoming was that there could have been more people with HIV/AIDS eligible for the disability grant and the study could have missed out on a part of the community that were not accessing the system, because they did not come forward and disclose their status.
- The social security system was in the process of rapid transformation. The pace of change caused information to be outdated very fast,

thereby making interpretation of data against a changing backdrop very challenging.

1.8 ETHICAL CONSIDERATIONS

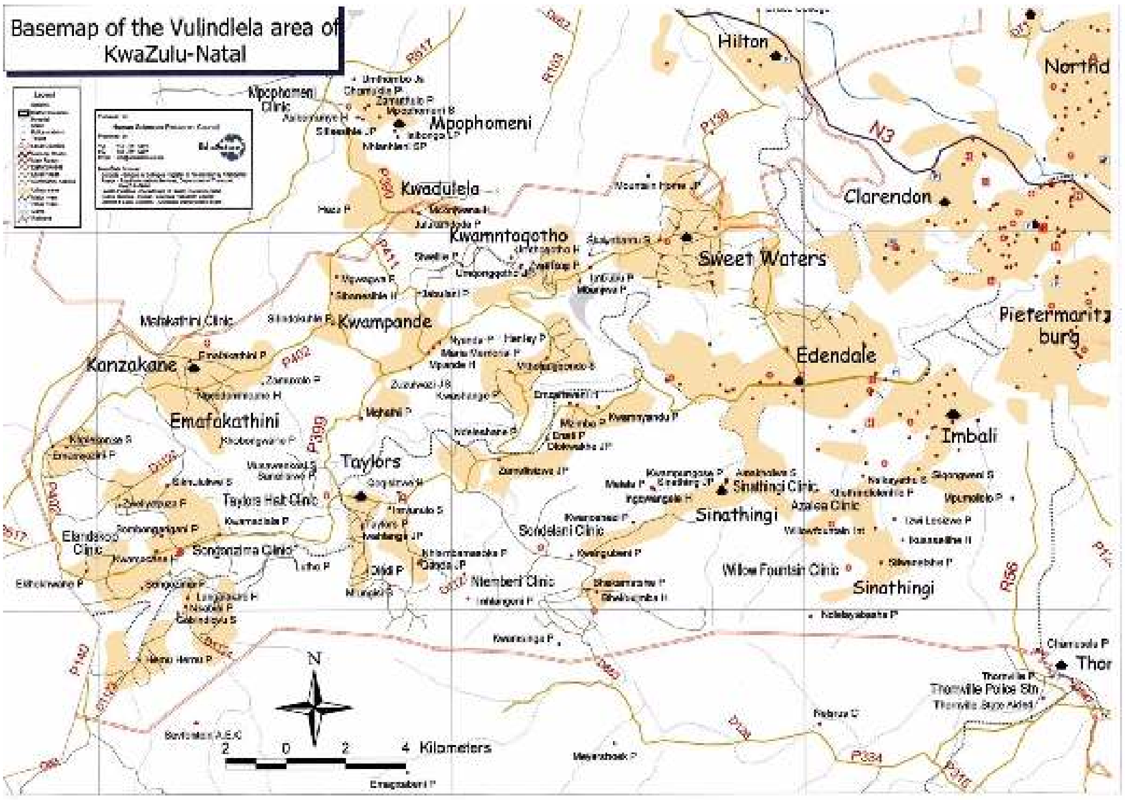
Strict ethical standards and procedures were adhered in the conduct of this study.

- Approval was sought from the University of KwaZulu-Natal Ethics Committee and thereafter the CAPRISA ethics committee.
- To ensure a thorough understanding of the study, before agreeing to participate, letters were written in isiZulu. The signature of a witness was also required as many community members are illiterate in Vulindlela. Informed consent from the patients was then secured (see letter in Appendix).
- All precautions were taken to ensure that no harm was caused to the participants in the study. In fact, where patients required further services, they were referred accordingly.
- Participation was voluntary.
- Participants were allowed to withdraw at any stage without penalty.
- Every effort was made to clarify and ensure that the participants did not have unrealistic expectations from the project.

1.9 THE STUDY AREA

The map that follows depicts the study locale.

Vulindlela



Vulindlela is situated in the UMgungundlovu district municipality in the province of KwaZulu-Natal. It lies just after Howick in Pietermaritzburg. UMgungundlovu has an estimated population of 872 717, and spans approximately 8 941 square kilometers. There is a diverse range of settlements including major urban centers, secondary and local centers as well as semi-rural and rural residential settlements. The area is predominantly agricultural, with urban activities based in the major centers. The district has access to the N3 National Road (UMgungundlovu District Municipality, 2005).

The Vulindlela area contains many different communities and informal settlements with a total population of around 400,000 (Kharsany cited in Smart, 2005:2). There are about 61 500 households in this district (CAPRISA, 2001). Many of the inhabitants live in poverty. There are few employment opportunities in the forestry industry or in the neighboring manufacturing and affluent residential towns (Kharsany cited in Smart, 2005:2).This community is dominated by mostly Black IsiZulu speaking people with a low literacy level.

A survey in Vulindlela, KwaZulu-Natal, conducted by the Centre for the AIDS Programme of Research in South Africa (CAPRISA), found a high rate of teenage pregnancy associated with shockingly high HIV infection rates (Smart, 2005:1). Most people living with HIV/AIDS in Vulindlela are between 15 years and 55 years old. The majority of the population is unemployed. Almost 75% are financially dependent on a family member receiving one or more state social grants (Health Systems Trust, 2005:1)

The socio-economic circumstances of the community are poor. In terms of gender breakdown, 60% are women. Health services are delivered based on the primary health care model. There are several clinics in the district which mainly provide antenatal and family planning services (Kharsany cited in Smart, 2005).

There are several non-governmental organizations currently providing HIV prevention and home-based care services to this community. There are approximately 60 organizations in the area dealing with issues such as youth, women, religion, politics, and housing (CAPRISA, 2001).

Vulindlela can be regarded as a vulnerable community not unlike others in South Africa. Nattrass (2004:4) maintains that the majority of the African population in South Africa has the highest unemployment rate, lowest per capita income and the highest HIV prevalence rates of all racial groups.

1.11 STRUCTURE OF REPORT

This report will consist of five chapters which will cover the following topics:

Chapter One: Introduction and Methodology
Chapters Two and Three: Literature Review
Chapter Four: Results and Discussion
Chapter Five: Conclusion and Recommendations

CHAPTER TWO

LITERATURE REVIEW: UNDERSTANDING HIV/AIDS

2.1 INTRODUCTION

HIV and AIDS is one of the main challenges facing South Africa today. The AIDS pandemic amounts to a socio-economic crisis of significant proportion (Nattrass, 2004:2). According to Nattrass (2004: 3) addressing the dual problem of poverty and AIDS poses major challenges to South African policy makers. As the epidemic of HIV infection threatens to overwhelm South Africa, it is important to understand the basic dynamics in order to deal with them (Gouws & Karim as cited in Karim & Karim, 2005:51).

This chapter will contain part one of the theoretical overview of HIV/AIDS, social security and related issues. The researcher considered it important to include the following broad themes in this chapter:

The impact of HIV/AIDS on society
Prevalence of HIV/AIDS
Overview of illness and progression of illness
The Mutual relationship between poverty and HIV/AIDS
Welfare and AIDS

In this study international as well as local literature was consulted.

The review commences with the impact of HIV/AIDS on our communities.

2.2 IMPACT OF HIV/AIDS ON SOCIETY

It is important to understand the impact of HIV/AIDS as it will guide estimations of needs, planning of services and generally how one responds to the epidemic. However, Barnett & Whiteside (2002, as cited in their book in 2006: 80) warn that the impact of AIDS is still not fully understood, particularly when the long term is considered.

Whiteside, Mattes, Willan & Manning (cited in Poku & Whiteside, 2004:128) has developed a framework which outlines the evolution of the HIV/AIDS epidemic and its consequences (see Table 1). They divide the illness progression into seven stages. Based on the impact and stage of the illness, they then propose responses and possible multi-dimensional interventions from micro-macro levels depending on the stage of the epidemic.

Table 1: The evolutionary stages of HIV/AIDS with responses

Stage	**Epidemiology and prevention**	**Impact and response**
Stage 1 : No one with AIDS identified; some HIV infections	HIV prevalence > 5 percent in high risk groups, targeted prevention	Planning only required
Stage 2: A few cases of AIDS seen by medical services, more people are infected with HIV	HIV prevalence <5 percent in high risk groups, targeted prevention	Impact on medical demand and use of facilities: need to plan for this
Stage 3: Medical services see many with AIDS. Some policy-makers aware of HIV infection and AIDS. The incidence of reported TB cases increases	Prevalence >5 percent in high risk populations. Targeted prevention but general information	Impact still mainly medical but need to begin Human Resource planning and targeted mitigation especially for most vulnerable groups, institutions and sectors
Stage 4: AIDS cases threaten to overwhelm	Prevalence>5 percent in ANC women. Information	Impact now broader – need to start looking at

health services. Widespread general population awareness of HIV/AIDS	available to all, continuing targeting of high risk groups	education sector and all government activities. Private sector plans for impact
Stage 5 : Unusual levels of severe illness and death in 15-50 age group produce coping problems, large number of orphans, loss of key household and community members, TB is a major killer	Prevalence >20 percent in ANC, clinic attendees and has been so for 5 years. Full battery of prevention according to resources	Impact at all levels. Response need to be equally diverse. They may include targeted relief or targeted Anti-Retroviral Therapy
Stage 6: Loss of human resources in specialized roles in production and economic and social reproduction decreases the ability of households, communities, enterprises, and districts to govern, manage, and or provision themselves effectively. Response range from creative and innovative ways of coping to failure of social and economic entries	Prevalence > 15 percent in 15-49 age group and has been so for 5 years. Most cost effective prevention now needs to be focused on key groups and interventions. Efforts to reach those below age 15 or over 15 emphasis on Voluntary Counseling and Testing	This impact requires massive intervention at all levels. The emphasis should be on children in crisis including orphans. Local programmes need to be scaled up and made sustainable perhaps with donor money

As depicted in the stages of illness in Table one, the epidemic comes in successive waves, with the first wave being HIV infection, followed several years later by a wave of opportunistic diseases, and later still by a wave of AIDS illness and then death (Barnett & Whiteside, 2002, cited in Unaids). The final wave affects societies and economies at various levels, from the family and community to the national and international levels. None of the highly affected countries have yet hit “the peak of the third wave nor advanced very far into the fourth”, as one study put it (Bell et al, 2003 as cited in Report on Unaids).

The impact of HIV/AIDS has implications for policy-makers and resource planning (Whiteside, 2004:145). The impact of HIV/AIDS is multi-dimensional, negatively impacting on the lives of individuals, families, communities and national governments. Due to HIV/AIDS, there has been reduced life expectancy, skilled people are mostly affected and poverty is on the rise, as are child headed households since their parents and caregivers are killed by the virus. It is now accepted that while HIV/AIDS is a health problem, it is also a development problem that threatens human welfare, socio-economic advances, productivity, social cohesion, and even national security (The World Bank, 2005). The AIDS pandemic is therefore a biomedical, social, political, economic, and cultural problem. HIV/AIDS affects every member of society and no one is exempt from the impact of the illness.

According to the Social Science Research Council (2005) the impact and consequences of HIV/AIDS on the citizens of countries are putting tremendous strain on national governments. They have to deal with the social, economic & cultural consequences of the disease (Social Science Research Council, 2005). In countries with high levels of HIV/AIDS prevalence, increasing demands on public-sector services such as health, education, and on public administration are being placed (Grant et al., 2004 as cited in Unaids). Additionally, because of loss of employees due to HIV/AIDS, the public administration, health, and education and security sectors have begun to threaten the functioning of these institutions. Concerns are growing about the continuity and quality of public services and governance, with the significant destruction of 'institutional memory' (Grant et al., 2004 as cited in Unaids). This includes the administration of the social security system.

Economic loss to countries is also great. Since HIV/AIDS most frequently strikes adults in the prime of their working years, it poses a threat to the economic growth and development of countries. Adults living with HIV, who would otherwise be generating income, supporting families and contributing to the local and national economies, find themselves losing wages, jobs, savings and eventually their lives (Unaids). Thus, productivity and taxes are lost through deaths of adults in their productive prime. Consumption is reduced, profits are foregone, tax revenue and investments are lost and essential services not delivered. The long illness results in impoverishment of the survivors and many development gains being lost. Whiteside (2004:xvii) agrees that in both males and females, HIV/AIDS impacts most heavily on the most productive sectors of African economies, namely prime-aged adults, thus robbing economies of "scarce skills, depriving children of their parents and the continent of a generation in the prime of their working lives".

It is alarming to note that, (Barnett & Whiteside cited in Unaids) warn that the impact of AIDS is still not fully understood, particularly when the long term is considered, so the worst is possibly yet to come.

It is important that HIV/AIDS is taken seriously as efforts to find an effective vaccine have failed. Anyway, Leonard (2006) is of the opinion that medicine offers less hope in the developing world where most victims are desperately poor with little or no access to the medical care needed to administer and monitor AIDS drugs. Globally, just one in five HIV patients gets the drugs they need, according to a recent report by UNAIDS, the body leading the worldwide battle against the disease (Leonard, 2006). Therefore, the impact and consequences of the disease will still affect societies. This is the reason why the researcher is discussing the prevalence as well as incidence of HIV/AIDS in the following section, so as to bring about a much better understanding of how the virus is affecting our lives.

2.3 PREVALENCE AND INCIDENCE OF HIV/ AIDS

It is important to get information on the prevalence and incidence of HIV and AIDS in order to understand the health impact of a disease within a community and for assessing the need for medical care and for targeting and evaluating interventions (Gouws & Karim as cited in Karim & Karim, 2005:51). The two most fundamental measurements for monitoring trends in an epidemic are prevalence and incidence rates (Gouws & Karim cited in Karim & Karim, 2005:51). Prevalence data provides information on the proportion of individuals in the population who are infected or have the disease at a given point in time. The incidence rate of infection or disease is the frequency of occurrence of new cases of infection of disease at a definite point in time.

2.3.1 Global Statistics

The incidence and prevalence of the AIDS epidemic is on the increase globally. Statistics released by UNAIDS (The Joint United Nations Programme on HIV/AIDS, 2005) show that in November 2005, about 14,000 new people got infected with HIV daily. This figure translates to 4.9 million people annually. According to the Joint United Nations Programme on HIV/AIDS, as of December 2005, 40.3 million people were estimated to be living with HIV/AIDS. Of these, 38 million were adults, 17.5 million were women, and 2.3 million were children under 15. During 2005, AIDS caused the deaths of an estimated 3.1 million people worldwide, including 2.6 million adults and 570,000 children under 15. The overwhelming majority of people with HIV, approximately 95 percent of the global total, now live in the developing world (World Bank, 2005 as cited in Healthywomen.org, 2006)

2.3.2 Africa

It was reported in 2005 that in Africa, nearly 30 million people had the AIDS virus including 3 million children under the age of 15. There are countries in Africa where more than one-third of the adult population carries the infection (The White House, 2003). (The United Nations Population Division cited in Unaids) predicts that Africa will account for nearly three quarters of this difference in 2050, and although life expectancy for the entire continent will have risen to 65.4 years from the current 49.1 years, it will still be almost 12 to17 years less than life expectancy in other regions of the world (Unaids)

It has been estimated by researchers that by 2025 in Africa the AIDS death toll could reach 100 million people. Leonard (2006) is of the opinion that despite more effective medicines, better access to treatment and improved prevention, African deaths alone would exceed 40 million people. Stirling (cited in Leonard, 2006) predicts that Africa will be grappling with AIDS for the next 10, 20, 30 and 50 years to come but still there will be no relief from it.

2.3.3 Sub-Saharan Africa

The HIV/AIDS pandemic has been identified as a major problem area in underdeveloped Sub-Saharan African countries (Dabada cited in Mashologu-Kuse, 2005:380). Sub-Saharan Africa has just over 10% of the world’s population, but is home to more than 60% of all people living with HIV (Joint United Nations Programme on HIV/AIDS, 2005). According to statistics it is estimated that of the 39.5 million people who were living with HIV worldwide in

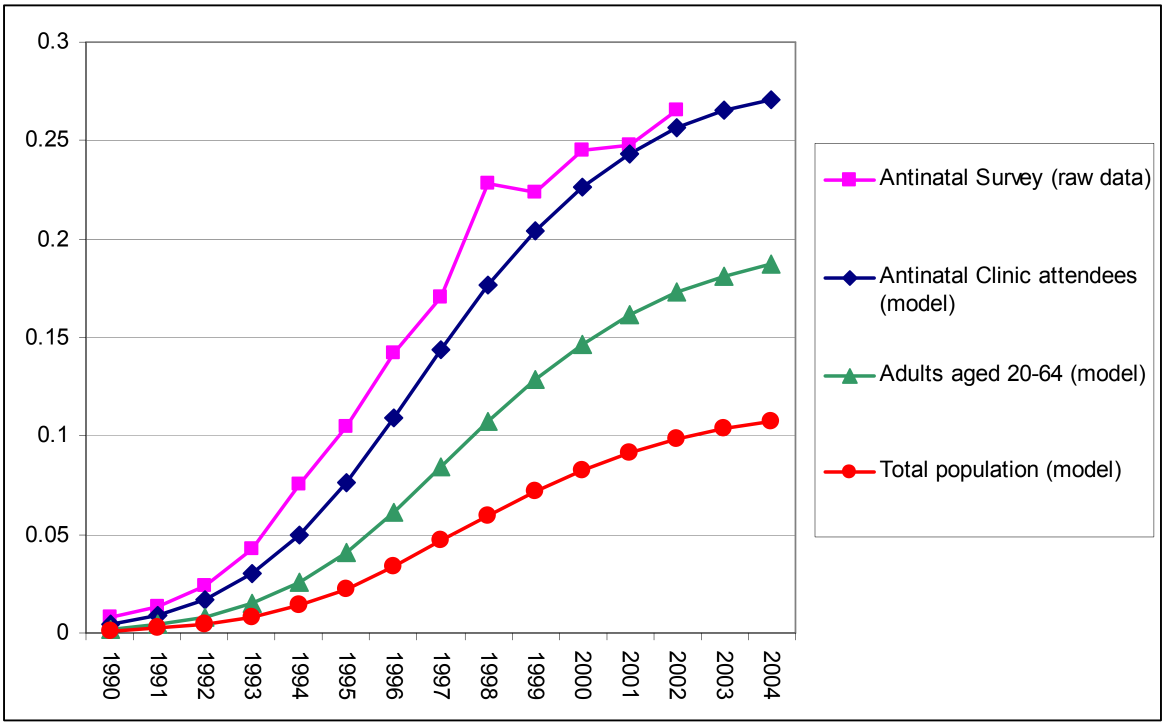
2006, more than 63% are from Sub-Saharan Africa and HIV prevalence is continuing to rise in Southern Africa (The Department of Health, 2007). In Southern Africa the life expectancy is expected to be around 44 years by 2010 (Unaids).

2.3.4 South Africa

South Africa has the highest prevalence of AIDS in Sub-Saharan Africa and this is on the increase (Dabada, 2001 as cited Mashologu-Kuse, 2005:380. About 5.54 million people were estimated to be living with HIV in South Africa in 2005, with 18, 8% of the adult population (aged 15-49) affected. Women are disproportionately affected, accounting for about 55% of HIV positive people. Women in the age group 25-29 years are the worst affected with prevalence rates of up to 40%. For men, the peak is reached at older ages, with an estimated 10% prevalence among men older than 50 years. HIV prevalence among younger women (<20 years) seems to be stabilizing, at about 16% for the past three years (Office of the Premier, 2007).

Nattrass (2004:2) diagrammatically plots (figure1.) trends in the raw HIV prevalence data, based on two important national studies, one is by the South African Actuarial Science Society of South Africa (2002,ASSA- Actuarial Science Society of South Africa, 2004) (ASSA) and the second, the results of a national HIV survey conducted in 2001 by Shisana and Simbayi (2002). The figure below illustrates the HIV prevalence in South Africa from 1990 until 2004.

Figure 1. HIV Prevalence in South Africa



Source: ASSA 2002 Demographic Model (available on www.assa.org.za)

The diagram confirms that HIV rates in South Africa are increasing. It also shows that women are more vulnerable to the HIV pandemic, as the prevalence is above that for the total adult population. Therefore, based on the above studies, the trends in South Africa clearly follow global trends regarding an increase in prevalence the disease.

The Office of the Premier (2007) maintains KwaZulu-Natal has the highest prevalence of HIV/AIDS compared to the national prevalence. By the year 2006, HIV prevalence in KwaZulu-Natal among pregnant women attending public health clinics was 39.1%. This disturbing trend occurs in KwaZulu-Natal (hereafter to be referred to as KZN) in an environment of poverty, unemployment and other socio-economic hardships. The total distribution of KwaZulu-Natal shows that 54% of the population lives in the rural areas, where there is widespread poverty and disease. The rural dwellers are mostly women and children, as the men migrate to urban areas in search of work. These present unique and great challenges in the fight against HIV/AIDS (Office of the Premier, 2007).

According to the information from the National Department of Health, UMgungundlovu, the district in which Vulindlela (locale of study) is located, has the highest prevalence rate of HIV viz. 44% of the population as compared to other districts in KZN (Office of the Premier, 2007).

Now that the extent of pandemic has been discussed, it is important to understand how the virus attacks and destroys the infected person's body. Thus, the researcher proceeds to outlining the stages of the illness in relation to social security access.

2.4 ILLNESS PROGRESSION: CRITERIA FOR DISABILITY GRANT

It is necessary to include a brief medical understanding and progression of the illness as the qualification criteria to the disability grant is based on medical criteria. The World Health Organization (WHO) has a progression framework which is used when assessing eligibility to the disability grant in South Africa. This framework divides the physical symptoms into four stages of the illness. The person becomes progressively more ill at each stage.

The Proposed World Health Organization (WHO) staging system for patients infected with HI /AIDS) is as follows (BMJ. 2002 January 26; 324(7331): 193–197)

Stage 1:

Asymptomatic

Persistent generalized lymphadenopathy

Stage 2:

Weight loss between 5% and 10% of body weight

Minor mucocutaneous manifestations (seborrhoeic. dermatitis, prurigo, fungal nail infections, recurrent oral ulcerations, angular stomatitis)

Herpes zoster within the past five years

Recurrent upper respiratory tract infections (for example, bacterial sinusitis)

And/or

Performance scale 2: symptomatic, normal activity

Stage 3:

Weight loss >10% body weight

Unexplained chronic diarrhea for longer than one month

Unexplained prolonged fever (intermittent or constant) for longer than one month

Oral candidiasis

Oral hairy leukoplakia

Pulmonary tuberculosis within last year

Severe bacterial infections (for example, pneumonia, pyomyositis)

And/or

Performance scale 3: bedridden for less than 50% of the day during the last month

Stage 4 (AIDS):

It is at this stage that the patient is classified as having AIDS.

HIV wasting syndrome*

Pneumocystis carinii pneumonia

Toxoplasmosis of the brain
Cryptosporidiosis with diarrhea for more than one month
Cryptococcus, extrapulmonary
Cytomegalovirus infection of an organ other than liver, spleen, or lymph nodes
Herpes simplex virus infection—mucocutaneous for more than 1 month or visceral of any duration
Progressive multifocal leukoencephalopathy
Any disseminated endemic mycosis
Candidiasis of the oesophagus, trachea, bronchi, or lungs
Atypical mycobacteriosis, disseminated
Non-typhoidal salmonella septicaemia
Extrapulmonary tuberculosis
Lymphoma
Kaposi's sarcoma
HIV encephalopathy†
And/or
Performance scale 4: bedridden for more than 50% of the day during last month

As illustrated in the scale of progression of illness in this chapter earlier, this framework concurs that the epidemic comes in successive waves with the first wave being HIV infection, followed several years later by a wave of opportunistic diseases, and later still by a wave of AIDS illness and then death
(Barnett & Whiteside, as cited in Unaids).
According to Whiteside (2004:1) the estimated median period between infection and the onset of episodes of illness is about eight years and people will be sick for one to two years before they die. Whiteside (2004:128) states that though HIV/AIDS has much in common with other infectious diseases, it also presents a unique challenge, because of the lengthy incubation period between HIV infection and the onset of illness, the factors that impact susceptibility and vulnerability to HIV/AIDS and the rapidity and extent of the epidemic.

Eventually, most people face permanent physical disability and the inability to earn an income for themselves or their family, or provide for the future of their spouses and children after their death (Whiteside, Mattes, Willan, and Manning as cited in Poku and Whiteside, 2004:139). Whiteside (2004:128) argues that since there is no cure, the only way people leave the pool of infection is by dying.

It is interesting to note that the framework classifies the physical symptoms at each stage of the illness. It also includes a level of functioning and performance scale. Many South Africans are between stages 3 and 4, where people are bedridden (Whiteside, Mattes, Willan & Manning, 2004:128 as cited in Poku & Whiteside, (2004). The main cause of HIV/AIDS is poverty and inequality as many women and girl children resort into selling sex in order to survive. Rural people (women) are worst affected as they are left at home by their husbands in search for employment and end up having mistresses that they may infect or are infected by, exacerbating the cycle of infection. Gender thus plays a major role in rural communities with infection rates sky rocketing due to the submissive nature of women and how they infect and are infected.

2.5 HIV/AIDS, GENDER, POVERTY AND INEQUALITY

Butler (2004:68) and van Donk (2002) agree that HIV/AIDS and the accompanying disabilities are a cause of inequality for those living with it and for families and communities. According to Barnett & Whiteside (2002) logical links can be made between HIV and AIDS and inequality. They base their conclusions on evidence of the effect of HIV/AIDS on poverty, employment and other socio-economic variables. Their research point to poor households being more adversely affected by the epidemic and that the epidemic drags these households downwards into deeper poverty, making the already poor poorer.

The World Bank (2005) shares a similar view on inequality and poverty. They note that:

- most people with HIV/AIDS are poor
- HIV/AIDS has a greater economic impact on poor households than on better-off ones because it forces them to draw on their assets to cushion the shock of illness and death; and
- Households with fewer assets are likely to have more difficulty coping than households with more assets (International Fund for Agricultural Development, 2001).

According to the Office of the United Nations High Commissioner for Human Rights, (1996) the countries with the highest incidence and prevalence of HIV/AIDS are not always the poorest. They particularly mention Southern Africa, with the world's highest HIV prevalence and include the most economically developed countries in Sub-Saharan Africa. Generally these countries have higher levels of education, gross domestic products and access to water and sanitation than other parts of the continent. However, they also tend to have greater economic inequality and larger numbers of people living in poverty, both of which have been clearly associated with HIV transmission. In the context of South African history, poverty and inequality are further complicated by race, gender and spatial location. Gender has been known to play a major role in HIV/AIDS transmission.

Gender

HIV/AIDS worsens gender inequality. A number of studies confirm this. Firstly, statistics indicate that women are more susceptible to infection than men. "Younger women in sub-Saharan Africa are infected more often and earlier than men, representing the vulnerability of young women and unequal power relations" (UNAIDS 2006).

Secondly, women bear the greatest burden of the disease, since they are the primary caregivers, with obvious consequences for educational attainment and ability to partake in income-generating activities. The Joint United Nations Programme on HIV/AIDS (UNAIDS, 2006) also highlights findings of various country studies revealing that the heaviest effect of AIDS tends to fall on widows and their family members, and points out that this often stems from “the gender inequality embedded in many cultural traditions”.

It can be concluded that gender plays a significant role in disadvantage, with women disproportionately bearing the burden of poverty, disease, physical labor, and unemployment (Casale & Whiteside, 2006). However poverty is worst in the rural areas, where scarce resources are available only with difficulty.

Poverty

Various definitions of poverty have been proposed. Poverty can be defined as the “inability to attain a minimal standard of living, measured in terms of basic consumption needs or the income required to satisfy them. Poverty is perceived by poor South Africans to include alienation from the community, food insecurity, crowded homes, usage of unsafe and inefficient forms of energy, lack of jobs that are adequately paid and or secured, and fragmentation of the family” (May & Govender, 1998).

Statistics South Africa defines poverty as “the denial of 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-esteem and respect from others” (Mpedi & Kuppan, 2004:226).

Poverty in South Africa is a major issue, (as discussed earlier). The percentage of the province’s households receiving incomes below the poverty line stood at 53% in 2002, up from 45.3% in 1996.

AIDS is a crisis that comes on top of and contributes to existing crises especially in situations of poverty (Whiteside, 2004:1). “What until the early 1990’s was a ‘silent’ epidemic of HIV has now emerged as an inescapably visible AIDS epidemic with devastating effects on communities” (Frohlich, cited in Karim & Karim, 2005:352). HIV/AIDS has transformed the significance of the disease and disability as a cause of poverty and inequality for those living with it and for their families and communities (Butler, 2004:68)

AIDS tends to affect the poor more heavily than other population groups. There is a distinct relationship between poverty and communicable diseases. All factors that predispose people to HIV infection are aggravated by poverty, which "creates an environment of risk” (International Fund for Agricultural Development, 2001). Poverty is a key factor in HIV transmission. Poverty can also accelerate the onset of AIDS and tends to increase the impact of the epidemic.

The relationship between poverty and AIDS can be illustrated by the higher prevalence rates in poorer countries and amongst vulnerable groups, as discussed earlier. According to Stillwaggon cited in Nattrass, 2004:4) “the connection between low income and HIV prevalence has been well established in Africa. Poverty and disease are widespread in Southern Africa and are major factors in the rapid spread of HIV and subsequent opportunistic infections”.

A case study in the Free State shows the adult equivalent per capita income in affected households represents only between 50% and 60% of the level of income in non-affected households. Two thirds of these AIDS-affected households reported a fall in income. Forty four of the respondent households were surviving on less than R1000 a month (South African Council of Churches, 2003). Resources may have to be shared with more dependents, and productive assets are sold off (AIDS Foundation South Africa, 2005).

The relationship between AIDS and poverty is evident in other countries as well. Klavus as cited in Mitra (2005) demonstrates that health care expenditures have a considerable effect on the welfare of households in Finland. He found that the household with a chronically ill individual needs 40% more income to reach the income level of a healthy family.

Erb and Harris-White (2001) also found, based on a village level survey in South India that the direct cost of a chronic illness or impairment, in terms of equipment and treatment, average three months of a person's income.

Whiteside (2004: 130) is of the opinion that the link between poverty and HIV/ AIDS is complicated. He indicates that the effect of illness and death on poverty in households, depends on the number of cases the household experiences; the characteristics of deceased individuals; the households' composition and asset array; community attitudes towards helping needy households; the general availability of resources and the level of life in that community; and the broader resources available for assistance to households. This clearly illustrates how poverty and HIV/AIDS impact on one another therefore, subjecting a person to greater suffering and deprivation.

Spatial location is a typical consequence of inequality in South Africa.The Department of Health (2007), states that people living in rural and informal settlements seem to be at highest risk for HIV infection and AIDS. They state that while the immediate determinant of the spread of HIV relates to behaviors such as unprotected sexual intercourse, multiple sexual partners and some biological factors, the fundamental drivers in South Africa are the more institutional problems of poverty, underdevelopment and low socio-economic status.

The migrant labor system also contributed to the breaking-up of the social support system. Rural communities are at greater risk of exposure to unsafe sexual practices because of the high number migrant workers from these impoverished communities who have to seek work in urban areas away from their families (AIDS Foundation South Africa, 2005). They contract the virus when they are migrating to the cities and at the end of the day they go back to their wives and the virus is passed on.

Rural communities are further disadvantaged as they have limited access to health care and welfare resources. Local organizations find themselves overwhelmed with requests for support whilst losing staff and volunteers to the epidemic (AIDS Foundation South Africa, 2005; HIV/AIDS & Human Development South Africa, 1998). Rural people know little about their rights; therefore, this makes it hard for the infected people to have access to treatment that will assist them (AIDS Foundation South Africa, 2005; HIV/AIDS & Human Development South Africa, 1998). According to the South African Council of Churches (2003) this creates a poverty trap for rural communities which are already facing high levels of poverty and where many households still have unsatisfactory access to education, health care, energy and clean water. These situations are more profound in Black, poor communities. It is therefore important to consider race, when understanding the impact of HIV/AIDS.

Inequality and Race

Poverty in South Africa has strong racial biases nearly 95% of South Africa’s poor are African (Office of the United Nations High Commissioner for Human Rights, 1996).

Africans in South Africa have the highest rate of unemployment and the lowest per capita income (Natrass 2004:4). Therefore it is not surprising that the majority of African people in South Africa have the highest HIV prevalence rates from all racial groups. Segregation and apartheid created distinct racialized sets of economic opportunity and public service entitlement and their effects persist today. Inequality however, is not a Black or White issue. All societies exhibit inequality, regardless of racial politics, and South Africa’s distinct pattern of relative disadvantage therefore should not be attributed solely to a racialized policy history (Butler, 2004:68).

The voices of participants in the ‘Poverty Hearings’ confirmed the direct relationship between HIV infections, human rights violations and underdevelopment. The reason for this is because HIV/AIDS causes people to feel robbed or cheated of their own lives (HIV/AIDS & Human Development South Africa, 1998). People with HIV testified that they experience doubly the consequences of inequality and poverty placed them at greater risk of infection. Once infected, they faced an apparent “conspiracy” on the part of society to keep them poor, because of inability to access health care. Other violations of rights suffered by people with HIV and AIDS included racially based discrimination in employment and education. Clearly racial discrimination has played a major role in HIV/AIDS promotion (HIV / AIDS & Human Development South Africa, 1998).

These findings of inequality are also evident by the high prevalence of the disease in KwaZulu-Natal where over 36% of households live in poverty (Health Economics and HIV/AIDS Research Division (HEARD), 2000 as cited in Wright, 2001:2).

HIV/AIDS and poverty are now mutually reinforcing negative forces in many developing countries (Office of the United Nations Commissioner of Human Rights, 1996). AIDS appears to entrench poverty and increases inequalities at every level, from micro to macro level. The epidemic further undermines efforts at poverty reduction, income and asset distribution, productivity and economic growth. AIDS also appears to adversely affect international development goals, demonstrating its far reaching arm of influence (Barnett & Whiteside, 2002).

About.com has developed a framework illustrating the mutually reinforcing relationship between poverty, inequality and HIV/AIDS.
Cited in About.com: HIV/AIDS 2007

Flow Chart A. shows the mutually reinforcing relationship between poverty, inequality and HIV/AIDS-
Risk of HIV infection
↓

Sexual behavior &
↓
Gender
↓
Inequality
↓
Access to / use of HIV
↓
Prevention measures
↓
Morbidity
↓
&
Mortality
↓

Access to adequate
↓
Nutrition, primary health
↓
Poverty
↓

Care and life prolonging
↓
Treatment
↓
Loss of household income & assets
↓
Diversion of income to health & funerals
↓
School drop out
↓

Burden of care for infected/affected persons
↓
Widow- & orphan hood (loss of security)

This diagram illustrates the flow and relationship links across social and health issues and HIV/AIDS.

Therefore the issue of social assistance becomes critical to comprehensively manage the core aspects of treatment, care and support of people infected and affected by HIV/ AIDS.

CHAPTER THREE
LITERATURE REVIEW: SOCIAL SECURITY

3.1 INTRODUCTION

This chapter continues to provide literature to better understand the topic. This time, in accord with the research field, the need is to determine what literature exists on social security access for those affected and infected by HIV/AIDS. Broad themes (that have several sub themes) covered herein are:

The need for social security
Administrative and bureaucratic procedures
Accessibility barriers
Service delivery initiatives

3.2 THE NEED FOR SOCIAL SECURITY

According to the 2006 Global Report of HIV/AIDS (2006: 81) a determined response in prevention, care, support and treatment is needed to reduce the impact of epidemic. Since HIV/AIDS and poverty are mutually reinforcing, countries have to be aware that poverty alleviation is an important intervention in the control, spread and management of the disease (Report on the Global AIDS Epidemic, 2006 Chapter 4; Spier & Edwards cited in Nkwe-Mabua, 2000:14). Nattrass (2004:3) agrees that given the strong connection between poverty and HIV transmission, anti-poverty measures should be an integral aspect of any AIDS intervention strategy. Given that poverty can lead to HIV/AIDS, safety nets can play a role in the spread and impact of the disease.

Since AIDS threatens the future of society, it must be an important concern to social security administrators (Madavo as cited in Theodore & La Foucade, 2000). According to Bell et al. as cited in the Report on the Global AIDS Epidemic, 2006 Chapter 4) it is important that we manage the problem of HIV/

AIDS as we do not know what is the likely long-term damage, which includes social, economic and psychological aspects. They assert that the social security system is in the ‘future-protecting’ business, meaning that if social security is made accessible, it will greatly benefit the poor.

According to Barr and van der Merwe (cited in Bhorat, 1995:3) since HIV/AIDS is associated with income-loss because of the inability to work, state-provided support mechanisms (including social security) need to be activated. Olivier (2004:26) states that social security should provide the means to certain people to function socially, politically and economically, and ultimately aim at societal solidarity.

Mitra (2005: 13) agrees that poverty reducing safety nets are important since HIV/AIDS patients are more likely to be poor and safety nets are needed to address inequality. Mather et al., as cited in the Report on the Global AIDS Epidemic, (2006 Chapter 8) are of the opinion that since the social and economic impacts of adult deaths from AIDS-related illnesses falls most heavily on the poorer households, many of which are headed by women, development programming, which includes social security, should favour women.

The provision of social security thus has a distinct role to play in mitigating against the spread and impact of the disease.

The most widely accepted definition of social security throughout the world is that of the International Labor Organization (ILO). The ILO defines social security as:

> *“the protection which society provides for its members through a series of public measures, against the economic and social distress that otherwise would be caused by stoppage of substantial reduction of earnings resulting from sickness, maternity, employment injury, unemployment, invalidity, old age and death; the provision of medical care; and the*

> *provision of subsidies for families with children"* (International Labor Organization, as cited in Patel, 2005:123).

It is also argued that social security allows people living with HIV/AIDS to better take care of themselves e.g. affording nutritious food and access to resources. If people receive the disability grant, their confidence is increased along with hope in life (Hardy, 2005). Once a person gets the grant, they see this as their breakthrough from poverty but once it is cut off, they return to the trap of poverty.

It can be argued that the provision of social security as a poverty alleviation strategy in the long run can reduce the costs of treatment of HIV/AIDS patients. UNAIDS as cited in Theodore and La Foucade(2000) states that in the United Republic of Tanzania, the average medical cost per employee that was attributed to HIV/AIDS, more than tripled between 1993 and 1997 (UNAIDS, 2000b). If a similar medical cost impact can be expected in the Caribbean, the expected wage bill impact on Barbados will be in excess of US$ 4 million and in St. Vincent it will be almost US$ 3 million. The fact is that social security schemes have traditionally provided coverage for events related to loss of or reductions in income. In the Caribbean, this coverage is largely dominated by events related to illness, death (including benefits for survivors of members), disability and old age. Given the nature of the impact of HIV/AIDS, it is to be expected that infected social security members and their affected dependents, will make increasing demands on all of these benefit branches. Similarly, with the African nations, on the benefit side, HIV/AIDS is likely to exert increased demands on payment obligations, thus driving up the required total expenditure of social security (Theodore and La Foucade, 2000: 7). Thus poverty with HIV/AIDS will strain and drain social security.

Deprivation, in terms of lack of access to basic social services and economic opportunities, increases vulnerability to HIV and AIDS. Poverty and inequality limit the capacity of millions of South Africans to translate awareness into effective behavior change; rural people find themselves more and more left behind knowledge-wise. "*Gender inequality and abuse of women, with its roots in the multiple burdens imposed on women and their lack of power, even in stable relationships, are major contributors to the spread of HIV infection. High rates of HIV prevalence are also beginning to sustain and deepen underdevelopment"* (Rights of persons affected by with HIV/AIDS as stated in the HIV/AIDS & Human Development South Africa, 1998). These ominous words were uttered in 1998, yet their impact has increased, necessitating multi-layered solution seeking to this pandemic.

The right to access to social security for HIV/AIDS patients also becomes a human rights issue because of the disproportionate incidence and spread of the disease among certain groups (Mann cited in 2006 Report on the global AIDS Epidemic: Chapter 4). It is also apparent that the overwhelming burden of the epidemic today is borne by developing countries, where the disease threatens to reverse vital achievements in human development. As a means of sharing resources in South Africa, social security is becoming even more important in rural communities because, traditional safety nets are breaking down (Poverty Brief, 2002). According to the Committee of Inquiry into a Comprehensive System of Social Security (CICSS) , (2002), the burden of care and support of HIV/AIDS patients is falling on impoverished rural communities, where sick patients return, when they can no longer work or care for themselves.

With the predictions of an increase of AIDS patients moving into stage four of the illness progression scale and the mutual relationship between AIDS and poverty, we can anticipate that social assistance is going to become increasingly important in the spread and prevention of the disease as well as in handling the impact of AIDS in South Africa. Padaychee (2006:392) warns of the dire need to plan, administer and manage the social security system better.

Onwujekw & Uzuchukwu, (cited in Report on the Global AIDS Epidemic, 2006 Chapter 8) state that social assistance is greatly needed for people affected by AIDS. They state there should be pro-poor payment strategies such as payments and exemption of fees for medical services and vouchers for people below a certain income. To understand how social security may be optimally deployed in the fight against the pandemic, the researcher considered it significant to examine the philosophy of social security.

3.3 PHILOSOPHY OF SOCIAL SECURITY IN SOUTH AFRICA

Attacking poverty and deprivation was and remains a priority of the democratic government of South Africa (Reconstruction and Development Programme (RDP), 1994:5). Therefore since HIV/AIDS is associated with poverty, South African patients have a right to social safety nets as it has a poverty alleviation role.

"The goals of social security are to enable the poor, the vulnerable and the excluded of South African society, to secure a better life..." (Procedural Manual, 2003:2). Other goals of social security are *"poverty prevention, poverty alleviation, social compensation, and income distribution"* (White Paper on Social Welfare, 1997 as cited in Wright, 2001). According to Ardington and Lund, 1995; Case and Deaton, (1996) "while the coverage of social insurance is fairly limited due to high unemployment and large informal sector, non-contributory social grants, especially the old age grant, cover millions of people and are widely acknowledged to have contributed to poverty alleviation". Grants are paid to alleviate poverty, fight poverty, share resources, protect against "human damage" (Berghman as cited in Olivier (2004:24) and contribute to the reintegration of the individual into the labor market (Olivier, Smit, Kalula & Mhone, 2004).

Social security, particularly social assistance is one of the strategies that South Africa is using to tackle the spread of AIDS and impact of AIDS on vulnerable groups. In South Africa social welfare includes the right to basic needs such as shelter, food, health care, work opportunities, income security and all those aspects that promote the physical, social and emotional well being of all people. South Africa is in line with international standards in this regard. The President of the International Social Security Association, in his opening address in 2001 at the General assembly stated: “Everyone has a right to be covered by a social security scheme regardless of nationality, race, gender or religion” (Economic Policy Research Institute (EPRI): 10). The social welfare system supports the poor and the vulnerable through direct income support (grants) and welfare services (Reconstruction and Development Programme (RDP), 1995:53).

The South African Constitution (1996) makes provision for social assistance to people without any means. Section 27 (1c) protects the rights of everyone to access social security and appropriate social assistance if they are unable to support themselves and their dependants (Patel, 2005:124). The Constitution supports social assistance as a right in South Africa. The state’s obligation to promote and protect HIV/AIDS-related human rights is defined in existing international treaties. HIV/AIDS-related human rights include the right to life; the right to liberty and security of the person; the right to the highest attainable standard of mental and physical health; the right to social security, assistance and welfare; the right to share in scientific advancement and its benefits; and the right to participate in public and cultural life (Office of the United Nations High Commissioner for Human Rights, 1996).

Clearly, the South African Constitution (1996) makes provision for social assistance to people who cannot support themselves and their dependents. The Bill of Rights in the Constitution (1996) aims at maintaining quality of life. There are safety nets in place to address chronic poverty or transient poverty caused by lifecycle events and economic, social and environmental conditions that effect an individual or household’s earning capacity, therefore these safety nets need to be utilized by the deserving poor (Patel, 2005:124).

Apart from the South Africa Constitution, a vast range of statutory resources provide the framework for social security regulation in South Africa. Social security provision is currently regulated by the Social Assistance Act, 1992 (Act 59 of 1992). This covers a “wide variety of private and public measures that provide cash or in kind benefits in an event of an individual’s earning power permanently ceasing, being interrupted, never developing and secondly in order to maintain children”. In terms of the Social Assistance Act, people who have HIV/AIDS qualify for a non contributory, means tested disability grant.

Therefore as discussed earlier, an extension of coverage of social assistance in South Africa would be of utmost importance and would enhance the capacities of the state to address poverty and inequality through redistributive measures.

However, despite all the rights given to South Africans, Bhorat (1995:6) is skeptical and argues that social security transformation in South Africa will be decided by reference to the neoliberal economic paradigm, and its interaction with the constitution. This stance places responsibility to provide squarely on the shoulders of the individual and family without simultaneous state support. The Report on the Global AIDS Epidemic (2006, Chapter 8) also cautions that in a neoliberal context, it is important to monitor how existing state structures impede or facilitate service delivery.

On the other hand, social security will always be controversial. It is possible that provision of social security could be a form of camouflage by governments to hide conflict in an industrial society or unjust power relations (see Chatterjee, 1996 as cited in Bhorat, 1995:3).

For South Africans, these are pertinent questions in a developing country, hence this study seeked to uncover how best social security safety nets may advantage both the economy and the HIV/AIDS infected and affected.

3.4 THE SOUTH AFRICAN SOCIAL SECURITY SYSTEM

Macro-economic factors have to be understood when discussing social security accessibility as they impact on individuals, families and communities. Among comparable middle-income developing countries, South Africa has one of the worst records in terms of social indictors (health, education, safe water, fertility & inequality). Poverty in South Africa has a strong racial bias with nearly 95% of South Africa's poor being African as discussed earlier.

Social assistance in South Africa represents one of the most significant mechanisms of poverty alleviation and income redistribution. The Report of the Committee of Inquiry into a Comprehensive System of Social Security in South Africa (generally referred to as the "Taylor Report") has estimated that between 20 and 28 million South Africans are currently living in poverty, depending on which poverty line is used (Ministry for Social Development, 2002:29).

South Africa's social security assistance system provides income support in the form of grants to more than 5 million poor South Africans, this not representing all those who deserve the grants. "The largest programme in Rand terms is the State Old Age Pension, which provides grants for more than 1, 9 million poor pensioners. The Child Support Grant has the largest number of beneficiaries, currently providing grants for 2, 2 million children. The Disability Grant is the second largest programme in Rand terms and third largest in terms of number of beneficiaries" (van der Westhuizen & van Zyl, 2002).

Pensions for disability and old age and remittances are the main sources of income for over 40% of the poor (the poorest 40%) and nearly 50% of the ultra poor (poorest 20%). These social transfers reach communities who have otherwise been poorly provided with social services such as education and health. According to van der Berg as cited in Liebenberg & Tilley (1998) barely 50% of the labor force today has formal employment. In this situation, "occupational social insurance can reach at best only half the labor force, leaving the most vulnerable dependent upon various forms of social assistance" (Liebenberg & Tilley, 1998:7).

"The South Africa social security system can be described as atypical for a country of our level of development, as it is more comprehensive in scope than most others in the African continent "(see Guhan, 1994; Gruat, 1990; von Benda-Beckman & Kirsch, 1999 as cited in Bhorat, 1995:6). Only two countries in the region that is Zambia and Zimbabwe have national security systems, whilst Namibia is still underdeveloped and Botswana is still developing the system. South Africa provides a "safety net" pension to people who do not qualify for private pension (Johnson cited in Economic Policy Research Institute (EPRI): 8).

The South African social security system includes free health care to mothers and children under seven years old, a road accident fund, compensation for occupational injuries and diseases, legal aid, disaster relief and other measures. It however, does not match the level of coverage and expenditure achieved in industrialized countries, and is inadequate for the levels of inequality evident in the country, primarily because the qualifying criteria are highly specific and complicated in some cases and therefore exclude most who are in need (Oliver,2000; Republic of South Africa, 2002 as cited in Bhorat,1995:6).

The concept of grants being available for people, who, by reason of disability, are unable to support themselves financially, is a good one. However, disabled people and many non-disabled persons are unable to support themselves because of broader macro-economic factors such as insufficient jobs for South Africans. The disability grant system is greatly stressed because of increased eligibility related to increased numbers of people with AIDS (Swartz &Schneider as cited in Watermeyer, Swartz, Schneider & Priestley, 2006:243). This ideal of accommodating all poor South Africans, is untenable, especially in rural areas. Instead, there is reliance on informal and traditional systems of support as discussed hereunder.

3.5 INFORMAL AND TRADITIONAL SYSTEMS OF SOCIAL SECURITY

Informal and traditional systems are important to this study as access to the disability grant is means tested, preventing many in need from accessing formal social security. In addition, the International Labor Organization (ILO) and South African welfare policy both acknowledge the contribution of private and public supports as safety nets. However, Triegaardt (undated handout) is of the opinion that traditional and informal contributions of citizens which have existed alongside the formal conceptions of social security must also be acknowledged.

These informal and traditional systems appear to have developed in response to the inaccessibility of formal social security systems. They have also developed as a consequence of economic and social hardships. Research on informal systems, particularly in rural areas demonstrate that “informal and traditional systems are based on personal reciprocity, social solidarity, social networks of trust and direct face-to-face interaction between individuals, households and communities” (Ardington & Lund, 1995; Mukuka, Kalikiti & Musenge, 2002 In Triegaardt, undated handout).

Traditional systems of social security tend to exploit women for the benefit of other members of the extended family (Kasente, 2000:39). This implies that there is a general trend to depend heavily on women to care for the children, the sick, old and other members of the household. Thus, with increasing numbers of orphaned and vulnerable children as a result of HIV/AIDS, the burden of care has fallen more on women as community and home-based carers (Triegaardt, undated handout) without adequate compensation, resulting in depletion of energies and spirits.

Kasente (1998:VII) noted that “in Africa, the extended family was an important social security institution, providing support to its members based upon culturally determined patterns of mutual assistance". However, industrialization and urbanization has eroded the significance of the extended family for social security. This paved the way for the poor to transform themselves by developing mutual aid societies, therefore protecting as well as providing more for their families, which includes savings clubs, burial societies, stokvels, food cooperatives and other semi-formal systems. Burial societies and stokvels are more common in urban areas, and they continue to be the most successful means to survive for most families (Molefe, 1996: 177, 178). These informal social security arrangements have ensured the survival of people in adverse conditions. Kasente (1998:39) observes that semi-formal systems of social security are flexible and oriented towards meeting both immediate and future needs. However the risk is of loss of membership if one fails to contribute. The implication is that these systems need support, especially with a view to providing sustainability and protection of members from vulnerability (Triegaardt, undated handout).This may protect people living with HIV/AIDS as they will then always have income even if their grants get cut off, and for them to overcome challenges such as poverty and unemployment.

In the following section the researcher addresses the administrative process that is involved in the application of the disability grant.

3.6 ACCESSIBILITY BARRIERS

"Access can be defined as a means of approaching or entering a place and as an opportunity or a right to use something or approach somebody. Accessibility is the time, effort and cost...the ease, with which a good, a service or a facility can be reached or used" (Mitra, 2005: 23). Mitra (2005: 24) is of the opinion that lack of access is an important contributing factor to poverty given that it limits the opportunities that people have to improve their economic well being. According to Mitra (2004: 26) there is no one solution to enhance the accessibility of safety net delivery and advice centres. Every country needs to devise a set of solutions that is tailored to local conditions, considering existing transport infrastructure, delivery systems, resources, geographic distribution of those who are eligible and existing awareness with respect to disability. One cannot over-emphasize the importance of understanding the socio-cultural context of each country, and in particular attitudes towards persons with disabilities that may act as barriers to their participation in safety nets.

The Global AIDS Epidemic Report (2006, Chapter 8) also calls for examining how existing state structures impede or facilitate service delivery in order to use human resources efficiently and improve human resource planning and development.

Mitra (2005: 36) has developed an interesting Framework for Assessment of Disability Inclusion in Social Safety Nets (SSN). Because of the nature of HIV/AIDS and the eligibility criteria of the disability grants for people infected with AIDS, it would be applicable to this study.

Table: 2 Framework for Assessment of Disability Inclusion in Social Safety Nets (SSN) (Mitra, 2005:36)

Several Dimensions	Relevant Analytic Tools
1. Program Implementation 1a. Physical Accessibility • Accessibility of built environment, including SSN facilities and transport system. • Can social workers go and visit PWD. • Can a family representative apply, enroll and receive benefits on behalf of a PWD. • Are there any geographical	Direct observation and review of Programme's manual of operation. Administrative data on beneficiaries, if available. Analysis of legislative framework.

asymmetries in programme coverage (by region, urban vs. rural) 1.b. Communication & Social Accessibility - Is programme information available in different formats (e.g. Braille) - How does the programme deal with illiteracy among potential and actual beneficiaries? - Is the programme information delivered through different channels besides the government (media, community)? - Do the attitudes of SSN prevent or discourage access to benefits for PWD? - Do some of the SSN staff have disabilities?	Review of existing information materials; semi-structured interviews and focus group discussions with current and potential beneficiaries with disabilities and with programme staff.
2. PROGRAMME DESIGN - Is the cost to apply or collect benefits high for PWD? - Are some of the eligibility conditions difficult to meet for PWD?	Semi-structured interviews and focus group discussions with current and potential beneficiaries with disabilities. Desk review and analysis.
3. PROGRAMME EVALUATION 3a. Programme Coverage	Household data collection and

• What is the proportion of eligibles with disabilities that participate in the programme?	analysis.
• What are the profiles of participants with disabilities compared to non-participants eligibles with disabilities (e.g. demographics characteristics)	Household data collection and analysis.
3b. Programme's Impact on Poverty • What poverty alleviation and reduction impact does the programme have on PWD?	Household data collection and analysis.
3c. Programme's Impact on Inequality • How does this poverty alleviation and reduction impact compare to the one that is for persons without disabilities?	

Mitra (2005) outlines important factors to consider when disabled persons access social grants by disabled people. This could be adapted to suit AIDS patients since they are entitled to the disability grant at stage 4 of the illness with more than fifty percent being bedridden in this stage. This framework was used in the development of themes for interviews conducted in this research. According to Mitra (2005), having a disability creates accessibility challenges that may directly

lead to poverty and exacerbate inequities. The nature of these challenges varies depending on severity and the type of disability (physical, sensory or mental).
It may also involve race and culture (Marcus, Piron & Slaymaker, 2004:10). Inaccessibility may be exaggerated through culturally inappropriate and ritualized, obsolete court procedures and technical, legal language, rather than local tongue all serving to intimidate and exclude. Thus it is clear that staff training, capacitating to deliver services, motivation and incentives are important to provide quality services and improve access to grants (Marcus, Piron & Slaymaker, 2004:10).

Recognizing these concerns, the Department of Health (2007), laudably states that all interventions shall be evidence-based and sensitive to culture, religion, age, gender, language and social circumstances of the people at all times.

3.7 ADMINISTRATIVE PROCESS

"The norms and standards, which have been applied to the grant Administration Process, have been designed according to the 'Batho Pele' principles" (Procedure Manual, 2003: 7)

3.7.1 Grant Application Procedures

The Department of Social welfare has a procedural manual which is aligned with the Social Assistance Act (Act No. 59 of 1992) (Procedural Manual, 2003: 2-2). The purpose of the manual is to:

- To provide uniformity in the Grant Administration Process
- To improve financial management;
- To ensure that the entitled citizens obtain appropriate benefits;
- To improve turnaround time; and
- To improve customer service provision to beneficiaries;

Therefore it can be concluded that there is a will to make the process more accessible and efficient.

3.7.2 Process of Application

It is important to include the application process in the literature review as accessibility may be facilitated or hampered during application.

The process of application is listed below for social security officials to follow:

- Advise the citizen of the qualifying requirements,
- Request documentary proof,
- Capture the application,
- Take a complete set of fingerprints from the applicant,
- Provide a receipt. (Procedural Manual, 2003:2-2)

Once the fingerprints are taken and the beneficiary has provided all the supporting documents, the following steps need to be completed:

Step 1: Capture the applicant's information on the Grant Administration System
Step 2: Print copies of the on line application form
Step 3: The beneficiary must sign both forms
Step 4: You need to sign as a witness
Step 5: Once you have finished questioning/interviewing the applicant must take a complete set of fingerprints. This must be done on a prescribed form. (Procedural Manual, 2003:2-2)

This is the process that all people applying for social assistance must follow in order for them to qualify for the assistance.

3.7.3 Documentation Needed

In order to access the disability grant the following documents are required:

- South African identity document (to prove identity, citizenship and age)
- Proof of income and assets
- Marriage certificate, if you are or were married
- Death certificate, if your husband or wife died

- Proof of disability (medical certificate) (Social Welfare, Chapter 9)

“The welfare officer checks that all the required proof is provided and the information on the application form to assess if the recipient qualifies under the means test. The applicant is then sent to the District Surgeon for a medical examination. All medical records, from other doctors or hospitals are seen by the District Surgeon. The District Surgeon or assessment panel’s report is taken back to the welfare officer. If the person qualifies he/she will be given a receipt” (Social Welfare, Chapter 9)

3.8. CHALLENGES FACING SOCIAL SECURITY SERVICES

The challenge for South Africa is to offer the poor a safety net. A major challenge is the increasing social and economic cost of the HIV/AIDS pandemic because of its impact on spiraling costs to social assistance, social insurance and private savings (Triegaardt, undated handout; Madonsela, 2006).

One of the major achievements in the post-1994 period has been securing constitutional safeguards for the right to social security and social assistance for people in need. Another accomplishment was the amalgamation of 14 different administrative systems inherited from the apartheid era and expanding benefits to children (Triegaardt & Patel, 2005: 140). In 1993, social equity was introduced through the equalization of social grants to all racial groups (Triegaardt, undated handout). Despite the above accomplishments, Mpedi (as cited in Olivier et al., 2004) states that the administration and delivery of services by both social services and assistance and social insurance schemes in South Africa has experienced many problems.

Unilateral Withdrawal of Grants

The unilateral withdrawal of grants by the Department of social development has led to many cases being brought to court. Respondents claim that it is a violation of basic principles and rights to have grants withdrawn without consultation and clarification. The Department's personnel require training, capacity building and information on matters relating to *inter alia*, the basic rights entrenched in the Constitution (Mpedi and Kuppan, 2004:67).

Poor service

Mpedi and Kuppan, 2004:67) also expresses concern that poor people are vulnerable to adverse events and they are often treated badly together with being denied voice and thereby power to make decisions that affect them. Services by administrative personnel have often been described as appalling. This state of affairs can be blamed on *inter alia*, poor customer -service skills and no commitment to serve (Kasiram et al., 2007). Social security officials are often rude and abusive to old-age grant recipients, and pension applications take much time to be processed. It can therefore be concluded that poor service, which is exacerbated by a lack of competent staff and resources, is one of the factors that keeps a sizeable number of prospective social assistance beneficiaries from drawing benefits (Mpedi, 2004:67). This occurs despite the adoption of Batho Pele Principles. Another identified problem is lack of staff or not coping due to high take-up rates of especially the disability and the child support grants (Kasiram et al., 2007). Lack of proper training is clearly a problem as well (van der Westhuizen & van Zyl, 2002).

Poor Infrastructure

Accessibility of services is the second largest problem identified, especially in rural areas in provinces such as the Free State, Northern Cape, Kwa-Zulu Natal and Limpopo. Poor infrastructure creates major obstacles in the delivery of services. "It can be costly for the poor to travel to departmental offices to apply for grants or to pay-points to collect grants. Provinces with vast rural areas struggle to reach grant recipients and the lack of vehicles is a problem in some provinces" (van der Westhuizen & van Zyl, 2002). The pay-points also present problems as it is difficult to meet the national norms and standards with regard to the quality, standard and security at pay-points (van der Westhuizen & van Zyl, 2002).

Eligibility criteria

The eligibility criteria pose a major problem for many grant recipients, so that even if the applicant is terminally ill, if the assessment outcome is negative, the person will not qualify for the grant. "Fifty percent of the respondents indicated that one of the main problems they experience is with the assessment of applications for the disability grant". Problems include lack of medical staff to screen applications, lack of cooperation from Health Departments and medical certificates being sold (van der Westhuizen & van Zyl, 2002). Corruption is a huge concern and identified in the study by Kasiram et al (2007) as mitigating against best service practice.

Corruption

Corruption and fraud are two of the main sources of concern in the provincial social services departments (Poverty and Corruption report, 1997; Kasiram et al., 2007).

These concerns highlight the existence of managerial and administrative flaws in the social security system (Mpedi and Kuppan, 2004:67). Losses to fraud have conservatively been estimated at approximately R1.5 billion per annum or 2.6% of the allocated budget of R56 billion (Significant Progress made in social grants anti-fraud campaign, 2006). The department of social development has implemented a number of initiatives to improve the integrity of the social grants' administrative system, as well as its management, accountability and effectiveness.

Means-testing

Means-testing in the South African social security system has, to date, proved to be a tedious and complex exercise. “The entire means-testing process is time consuming, bureaucratic, open to abuse and creates poverty traps...(that) fail to reach the needy” (Mpedi and Kuppan, 2004:67). There are problems cited in the application of the means test: becoming increasingly discriminatory, administrative delays, corruption and inefficiency, entrenching discrimination and disadvantage (Liebenberg& Tilley, 1998:5). The means test should then not only be based on one indicator, like income/consumption but should be able to define the different facets of poverty by looking at a variety of indicators which capture the living conditions of South Africans (Haarmann, 2000:89).

Financial shortfalls

Poor financial management by provincial social service departments impedes social service delivery. When provincial departments fail to disburse their monthly grants, welfare organizations, individuals and families suffer as a result of the poor management of funds (Mpedi and Kuppan, 2004:67).

Fragmentation of services

Fragmentation of services, already highlighted in 1997, still adversely impacts service delivery in the sense that it creates “a fertile environment for inefficiency and lack of accountability” (Mpedi and Kuppan,, 2004:68).

Many loopholes were created which could be exploited by officials and the public. These include the manual system used in some of the accounting systems, lack of an integrated national ID system and in the labor sector, inadequate records of employment (White paper- Social welfare 1997 chapter 7).

Definition of Disability

According to Hardy (2005) adherence to anti-retrovirals is becoming a problem in desperate households where the disability grant gets withdrawn with the improvement of the health status of the patient. “Other problems we are facing include the problem that some people do not want to get better because while they are ill they have access to disability grants" (Ngcongwane as cited in Daily News Reporters, 2006:3), a sentiment reiterated by the AIDS Law Project deriving from their research (Hardy, 2005). Doctors and patients similarly suggest that some individuals may opt to stop adhering to their antiretroviral therapy in order to increase their viral loads and reduce CD4 cell count therefore re-qualifying for the disability grant (Leclerc-Madlala, 2005; Nattrass, 2006 cited in Nattrass, 2006:9)

The Department acknowledged that there were many challenges arising from the roll-out of anti-retroviral treatment in the public sector, but indicated that persons who might lose their disability grants should ideally be able to access other social assistance programmes, such as the food security programme and child support grants (Hardy, 2005). These programmes not only offer far less support than the disability grant but have access problems of their own (Kasiram et al., 2007).

Marketing and Targeting Social Security Grants

Some of the provinces (KwaZulu-Natal, Limpopo Province and Northern Cape) do not have a separate budget for marketing social security grants and outlining access procedures, communication that is acknowledged as vital to address social security access. Gauteng maintains a number of initiatives to market social security grants that include visits to targeted areas and information dissemination via community radio" (van der Westhuizen & van Zyl, 2002). Other initiatives include the deployment of a sub-director dedicated to customer care and for marketing and information collection. There is also a call centre with a toll-free number to deal with enquiries, establishment of help desks at all the pay-points and targeting impoverished areas, or areas with backlogs (van der Westhuizen & van Zyl, 2002).

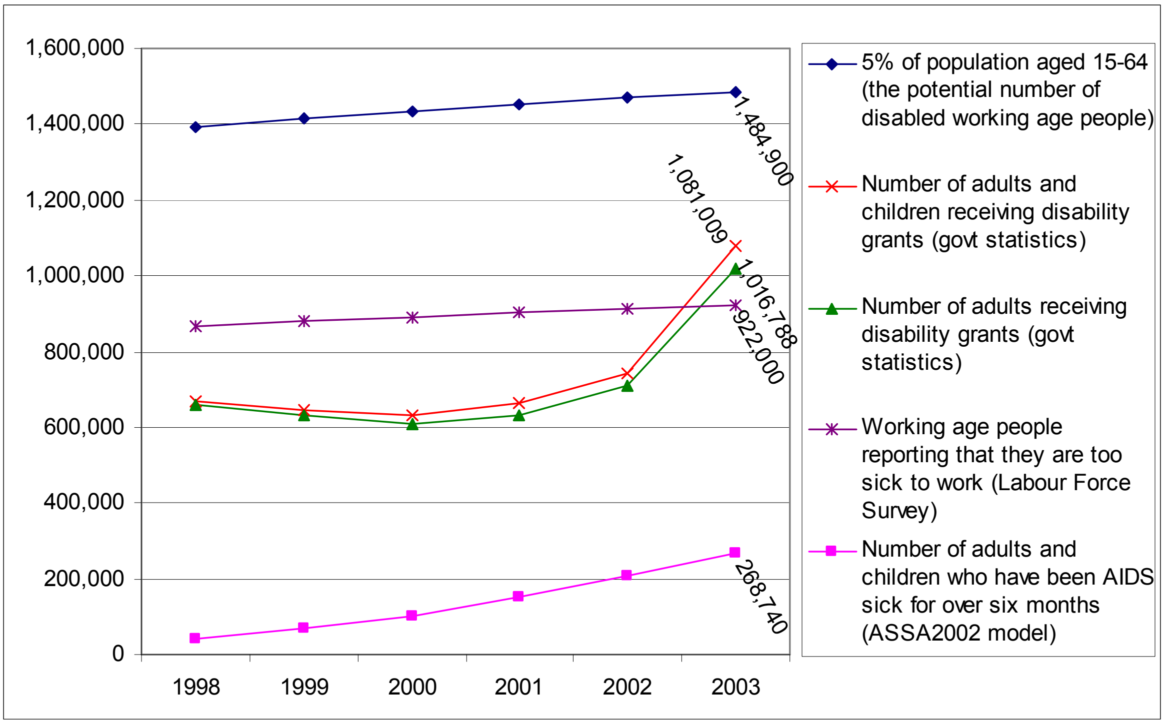
These concerns are discussed in a study report in 2002 by Idasa. Sadly, not much positive change seems to have been forthcoming as the country continues to be plagued by these problems (Kasiram et al., 2007).

However, some improvements brought about by the South African Social Security Agency have been reported.

These are presented alongside a summary of trends in the distribution and access of the disability grant.

2.9.1 Figure 2

Trends in the Number of Disability Grant Recipients



Source: South African Labour Force Survey September 2003 (Statistical News Release P0210, 25 March 04, Pretoria), ASSA2002 Demographic model (available on www.assa.org.za09/07/07). Intergovernmental Fiscal Review 2001, 2003 and 2004.

Nattrass (2004:8) graphically depicts present trends in numbers of disability grant recipients and estimated numbers of people who qualify for a disability grant as a result of being in Stage 4 of AIDS. It is only as a result of a sharp increase (45%) in the number of disability grants awarded in 2003 that the number of disability grant recipients rose above the number of disabled people as estimated in the labor force survey. Perhaps this illustrates that the rise in disability grants is as a result of more people infected with HIV/AIDS. These results point to easier accessibility to the disability grant. However, not much earlier in 2002, it was estimated, that only 43 % of people eligible for grants actually receive them (van der Westhuizen & van Zyl, 2002) and one wonders about the large increase in access over such a short period.

Distance

In South Africa 39% of disability grant beneficiaries live in rural villages. Formal urban or town settlements are occupied by 31% of disability grant beneficiaries, followed by informal urban or town settlements.

Further, a large proportion of disability grant beneficiaries are in the Eastern Cape (59%) and KwaZulu-Natal (27%), living mainly in traditional dwellings or huts. In all provinces, the majority of disability grant beneficiaries live less than half an hour away from their health facility, 42% of disability grant beneficiaries take 15 to 30 minutes to reach their nearest health facility; whilst 16% take 1 to 2 hours or longer to reach their closest health facility. To reach their health facility, they travel mainly by foot or taxi (de Koter, de Waal & Vorstser, 2006). The implication is that if distance and travel can so affect access to health, then it is bound to equally affect access to the grant distribution centre.

The growth pattern of grant receipt reflects that while over 50 000 temporary disability grants had lapsed, a high percentage still make their way to the permanent disability category (Pakade, 2005).

In Limpopo, Mpumalanga, North-West, Northern Cape and Western Cape provinces, the proportion of female take-up rates were lower than the male take-up rates. The take-up rate of males suffering from a disability in the Western Cape (54.1 per cent) was the overall highest take-up rate for both men and women across the nine provinces. The eligibility criteria for accessing the grant are important, and in the next section the researcher discusses the criteria for eligibility. Some of these have already been alluded to, so this section provides a summary of eligibility criteria as opposed to the previous discussion on specific barriers to access.

3.9 SUMMARY: ELIGIBILITY CRITERIA FOR THE DISABILITY GRANT IN SOUTH AFRICA

As specified in the Social Assistance Act (Act 59 of 1992/Act 13 of 2004) "individuals are eligible for a disability grant if they pass a means test and if, as a result of mental or physical disability, they are unable to provide for themselves through employment or professional activity".

Employment

The grant is designed for working-aged adults with the expectation that those who are capable of working should not be eligible (Richter, 2006). The applicant may not refuse treatment which may improve his or her condition. In other words, "the grant is not designed to compensate people for their disabilities, but rather to compensate them for the impact of their disability on earning potential. That people may be able and desire to work, but unable to find it, is irrelevant to the legislation (it seems) the rapid take-up of disability grants between 2001 and 2004 was facilitated by institutional changes to the grant awarding process and by sympathy on the part of at least some decision-makers towards using the grant to provide poverty relief for applicants" (Nattrass, 2006:3).

Means Test

Disability grant in South Africa is subject to means testing, that evaluates the income and assets of the person applying for assistance in order to determine whether the person's means are below a specified minimum (Mpedi & Kuppan, 2004: 223). The purpose of the means test is a poverty analysis with a clear separation of those in need from those not in need of support.

The means test is determined by taking into account:

- any money earned from any kind of work
- money received from a private pension fund

- money received from rental from lodgers in the applicant's house, even if lodgers are members of the pensioner's family
- the value of the house owned by the person who is applying for the grant, if such applicant does not live in the house
- money earned from growing crops or owning livestock

Degree of impairment

Officials from the Department of Social Development are mandated to include in their assessment / record the following criteria in assessing grant eligibility:

- When first diagnosed and current symptoms
- General physical condition
- Body mass index (BMI) or degree of weight loss over period of time
- Any current/opportunistic infection.
- Describe the specific details of each CD4 count and viral loads, where available.

In the absence of significant impairment as a result of opportunistic or recurrent infections, the CD4 count is essential. A disability grant is only considered where the CD4 count is below 200.

There is a "disability grant for medically diagnosed 'disabled' people over the age of 18 in South Africa" (Oliver & Kalula, 2004:39). Those with chronic illness who do not meet the strict medically based criteria discussed above are denied access to the disability grant.

The use of predominantly medical criteria for social assistance has been criticized for various reasons. Donahue cited by Economic Policy Research institute (EPRI), (2002:6) suggests helping those who are in poverty before being struck with the worst effects of AIDS as is done in South Africa at stage 4 of the illness. Donahue is also of the opinion that "by providing assistance earlier, they are often able to slow their economic descent and buy themselves enough time to devise adequate coping strategies". Lund (2006:163) shares a similar view, criticizing the blood-count threshold as far too "objective" to determine eligibility.

"A person with an AIDS-related illness needs food to remain well nourished to keep the blood count high; poor persons will find the disability grant an indispensable source of income to keep healthy; yet for eligibility for the disability grant, the blood count is already so low that the person is well on the way to death" (Lund, 2006:163).

Degree of disablement must also conform to the departmental definition of disability, contained in the Social Assistance Act of 1992 (Act No. 59 of 1992) and according to Poggenpoel & Oliver (2002), is judged solely on the person's inability to work. This understanding is not sensitive to the context in which disabled people function.

It is argued from a developmental welfare framework, that there needs to be a move away from the focus on what disabled people *cannot* do; more emphasis should be placed on what can be done to fully incorporate the active participation of the disabled into the workforce and into other activities (Poggenpoel & Oliver, 2002).

This brings us to consider why grant recipients may resort to cheating, and poor ARV adherence for the sake of retaining the grant.

3.10 ANTIRETROVIRALS AND ACCESS TO THE DISABILITY GRANT

There is now a further complication with the rollout of Antiretrovirals (ARVs). In highly developed countries, "antiretroviral drugs have largely altered the AIDS prognosis from certain death to a manageable chronic illness" (Leonard, 2006). Since the disability grant is the only way that poor households are able to access social security for people of working age, the rollout of ARVs poses unacceptable dilemmas for them. When the patients start to take their medication, it improves their immune system, therefore making them feel better. "The person who was obtaining a disability grant loses the grant immediately as he/she gets well. Thus this makes them ineligible for the disability grant. Disability grant recipients are now faced with a choice between income and health. Those who try to maintain the grant by discontinuing their treatment long enough to get the grant reinstated, and then going back unto treatment, not only undermine their own health but also will contribute to the growth of resistant strains of the virus" (Nattrass, 2004:6). Thus eligibility criteria to qualify for the disability grant pose a challenge for accessibility and future progression of the disease.

The question of whether the South African people are being denied their rights is now pertinent. The Report on the Global AIDS Epidemic (2006 Chapter 8) emphasizes that it is essential that social assistance service delivery efforts be based on human rights. The report states that AIDS mitigation programming needs to be built on rights-based processes. Section 33 of the Constitution contains the fundamental right to administrative justice (Oliver, Khoza, van Rensburg & Klinck, 2004: 151).

South Africa has adopted a developmental approach to service delivery. For service delivery, the focus is on populations at risk and the most socially disadvantaged. According to Patel (2005:158) this is seriously undermined when disability grants cannot be accessed or retained after access.
The Batho Pele Principles should guide service delivery in this regard.

3.11 BATHO PELE

All public institutions have to abide by the Batho Pele principles that apply to social security and hence to this study. Batho Pele 'meaning people first' is the name given to the Government's initiative to improve the delivery of public service.

The key themes contained in the principles to be practiced by officials of all public service institutions are (Procedural Manual 2003:2):

“Consultation; Service Standards; Access; Courtesy; Information; Openness and transparency; Redress; Value for Money; Encouraging Innovation and Rewarding Excellence; Customer Impact; Leadership and Strategic Direction”.
Clearly these themes suggest that people are entitled to receive optimal services. However, this research study was designed to uncover large scale gaps in service delivery, making the Batho Pele Principles an ideal, rather than a reality.

A further initiative to effecting rights-based service delivery is “Operation Isidima”, (consistent with Batho Pele principles) by the Department of Social Development to ensure that Section 2 of the Constitution of the Republic of South Africa, 1996 (Act 108 of 1996) is given effect (South African Government information, 2006). It aims to among other things: reduce the application and processing time for grants to 21 days; enhance human resource capacity to a ratio of 1:1000; upgrade pay and service points; enhance communication by uniform messaging; standardize the application process and deploy dedicated fraud prevention/detection teams (South African Government information, 2006).

The aim is for people infected with HIV/AIDS to have equal rights, and not to face stigma and discrimination, in attempting to live positively with AIDS. In the next section the researcher discusses stigma and discrimination as negatively impacting people living with HIV/AIDS.

3.12 STIGMA AND DISCRIMINATION

The prevalence of misinformation about AIDS in South Africa has not only hampered efforts to increase access to treatment, but has also created a climate of confusion in which prejudice towards people living with HIV thrives (HIV and AIDS in South Africa, 2006).

In some cases it may be impossible for the patients to comply with the instructions they have been given if they have not disclosed their status to family, friends and possibly employers. Further, it may be necessary for pills to be taken during times of travel or when privacy is impossible to achieve (Preston-Whyte, 2006:369). The existence of stigma is well known to most health providers, but they are often unsure and untrained on how to deal with it.

Stigma has been a pervasive dimension of HIV/AIDS and is an “insidious complicated phenomenon that feeds upon and reinforces and produces already present inequalities in class, race, gender and sexuality” that may also negatively affect infection rates (Whiteside 2004:71). The stigma brought about by HIV/AIDS could be the very cause of people not being able to access social security in the first place. “Responding to AIDS with blame or abuse towards people living with AIDS simply forces the epidemic underground, creating the ideal conditions for HIV to spread. The only way of making progress against the epidemic is to replace shame with solidarity, and fear with hope” (Piot, as cited in Karim & Karim, 2005:354).

Grieving becomes affected as “perverted or suspended” when death to AIDS is experienced as euphemisms replace the actual such as: ‘intsholongwane’ (virus); ‘hlengiwe vilakazi’ (HIV); ‘ugcunsula’ (sexual transmitted infection (STIs); ‘ubhubhane’ (the destroyer). It is also common for people to refer to AIDS deaths as the consequence of tuberculosis (TB), ‘of being weak’, of ‘losing strength’ and of bewitchment” (Frohlich as cited in Karim & Karim, 2005:357).

HIV and AIDS deny hundreds of thousands of people the chance of reaching their full potential (Report on the Global AIDS Epidemic, 2006 chapter 4). “Stigma induces discrimination, which induces violations of rights which in turn legitimize stigma” (Frohlich as cited in Karim & Karim, 2005:354-355).

Stigmatization, isolation and potential loss of self-esteem disadvantage patients as early diagnosis and induction into health care promise benefits to the individual and society with productivity, reduced hospitalization costs and decreased transmission being further benefits.

“In addition, keeping HIV a secret is very likely to hinder a person’s ability to develop effective coping strategies, in order to get proper assistance on time, leaving them all the more vulnerable to fear, anger and depression as well as self blame” (Frohlich as cited in Karim & Karim, 2005:355).

Within the family and the community, women are significantly more likely to experience discrimination than men, including ridicule and harassment, physical assault and being forced out of their homes” (Paxton et al. as cited in Report on the Global AIDS Epidemic, 2006 Chapter 4). A recent city study in India found that while almost 90% of the HIV-positive women were infected by their husbands, they faced more stigma and discrimination than men and were often blamed for their husband’s illnesses (International Labor Organization as cited in Report on the Global AIDS Epidemic, 2006 Chapter 4). Thus accessibility to the disability grant might have a strong gender component.

According to the White Paper on Social Welfrare WPSW 1997:85), “the combination of material, social and emotional stresses caused by stigmatization and discrimination make it extremely difficult for people with HIV/AIDS to mobilize effectively” and view their situation as a “public problem” that the government should address. Thus, questioning accessibility becomes minimal (Whiteside, Mattes, Willan & Manning as cited in Poku & Whiteside, 2004:133-134).

The HIV & AIDS and Sexually Transmitted Infections (STIs) Strategic Plan For South Africa (2007), “also emphasizes that stigma and discrimination based on fear and misinformation as well as disrespect for human rights shall be addressed. This priority area seeks to mainstream these in order to ensure conscious implementation programmes to address them”. The aim is creating an appropriate social environment for acceptance and openness for people living with HIV (HIV & AIDS and STIs Strategic Plan for South Africa-2011).

Despite all these challenges, many AIDS patients are still managing to access the disability grant. What facilitates this access is thus the next section in this review.

3.13 SERVICE DELIVERY INITIATIVES

South African Social Security Agency (SASSA)

The researcher interviewed the Acting grant administration manager in July, 2006 to learn that in 2004, the Social Security Act was established to administer grants, with SASSA being established in 2007 to give teeth to the Act. SASSA came about to address challenges faced by the different provinces, in relation to fraud, lack of uniformity and lack of staff which led to applications not being processed appropriately.

SASSA mainly deals with the management, administration and payment of social grants (South African Government information, 2006). Uniform norms and standards that will apply countrywide that adhere to the Batho Pele principles are created by The Social Assistance Act, 2004.

SASSA's objectives as stipulated in the Government Gazzette are:
efficient and effective management, administration and payment of social assistance; serving as an agent for the prospective administration and payment of social security; and rendering services relating to such payments (Government Gazette, 2004).

SASSA has reported some success as cited in a completed pilot project in three offices in the Western Cape, Eastern Cape and Mpumalanga regions and achieved an average of between 1 and 3 days turnaround in these offices" (Report on the Study Tour by the Portfolio Committee on Social Development to Australia, 2006).

An Enhanced Payment Model: **“**A national grant payment model has reportedly been developed which will ensure uniform processes across all regions. The model is said to be developed in consultation with other stakeholders such as National Treasury and will be published with a view to implement before the end of 2006/07 Financial year” (Report on the Study Tour by the Portfolio Committee on Social Development to Australia, 2006). To this end, SASSA has also “signed a draft Memorandum of Understanding with the Banking Association of South Africa to encourage more grant beneficiaries to receive their grant payments via the banks” (Report on the Study Tour by the Portfolio Committee on Social Development to Australia, 2006).

Further, SASSA is said to have developed an “optimal service delivery infrastructure network to support service delivery through the optimal provision of access points or applications and the payments of social grants”. SASSA is reportedly procuring about 40 mobile service units to enhance service delivery efforts in rural areas (Report on the Study Tour by the Portfolio Committee on Social Development to Australia, 2006).

Fraud too is being addressed by SASSA.The Agency is investigating problems such as illegitimate beneficiaries and corrupt databases and have reported use of a fraud unit and a fraud hotline (Report on the Study Tour by the Portfolio Committee on Social Development to Australia, 2006).

An enhanced service model needs to address the concern of limited pay points, vehicles and competent staff, captured in the tables that follow.

Table 4: Number of pay points per province

Free State	200
Gauteng	148 cash pay points (servicing 300 000 beneficiaries) and potentially every bank branch (serving 200 000 beneficiaries)
KwaZulu-Natal	>2 000 (including post offices used as pay points)
Limpompo Province	>2 000 (more than 80% unsheltered)
North West Province	1 4000
Northern Cape	207 cash pay points (excluding electronic banking)
Western Cape	293 (excluding electronic banking)

Source: (Van der Westhuizen & van Zyl, 2002)

Table 5: Vehicles the provincial department of social development has access to, to transport people to pay points

Free State	The private contractor uses 32 vehicles to disburse pensions (department does not transport people to pay points)
Gauteng	The private contractor follows payment routes (department does not transport people to pay points)
KwaZulu-Natal	The contractor has 44 mobile payment teams
Limpompo Province	Payment of social grants has been outsourced
North West Province	59 vehicles

Northern Cape	(9 per one team)
Western Cape	Department does not transport people to pay points

Source: (Van der Westhuizen & van Zyl, 2002)

Table 6: Staff involved in the preparation and carrying out of social security payments

Free State	350 (222 permanent)
Gauteng	N/A (certain aspects of the process have been outsourced
KwaZulu-Natal	750 administrative staff payment contractor employs 308 (including 176 security guards) Total = 1058 (excluding other support staff employed by payment contractor, as well as payment staff employed by post offices
Limpompo Province	Accurate numbers not available
North West Province	+/- 300
Northern Cape	113
Western Cape	A head-office core of 20 employees. Private contractor employs 22 permanent employees, 120 contract workers and 110 security guards.

Source: (Van der Westhuizen & van Zyl, 2002)

These records show that SASSA has begun to introduce change.
However much is still necessary (multi-layered approach in accord with the ecosystemic model) to cater for everyone in need. To this end, the Basic Income Grant was viewed as a possible additional mechanism in the fight against HIV/AIDS and poverty alleviation.

3.14 BASIC INCOME GRANT

The introduction of the basic income grant (BIG) is being proposed to offer solutions in overcoming some of the barriers to access of the disability grant, discussed above.

It is proposed that BIG, a social grant of R100 a month be given to every South African to assist people living with HIV/AIDS and their families (Taylor Committee, 2002). This is important to maintain the health of people living with HIV/AIDS. It will also reduce the need for children to drop out of school, and diminish the burden on households that take care of AIDS orphans. BIG can also help break the vicious cycle of HIV/AIDS and poverty and reverse the trend of the HIV/AIDS crisis in South Africa" (South African Council of Churches, 2003). BIG may "close the poverty gap by 74%…reducing to zero the number of poor South Africans excluded from the social security system" (Waging War on Poverty).

BIG could enhance the provisions of the South African constitution "by not only giving people the right to life but also the means to live it" (Waging War on Poverty).

Further, BIG may be administratively efficient since no means test, employment status, nor additional government resources will be needed (Nattrass, 2006). In addition, corruption would be less likely to surface especially if monies are paid directly into bank accounts (Waging War on Poverty)

3.15 CONCLUSION

The literature review over the last two chapters highlighted the major socio-economic consequences of HIV and AIDS to individuals, families and communities. The provision of a disability grant is regarded as a human right in South Africa, but many are denied access owing to variegated factors, viewed within an ecosystemic perspective. Alongside these barriers to access, was discussed service delivery initiatives that have implications for the topic under study.

In the next chapter, the researcher reports on the findings against this literature backdrop, to lend direction to the conclusions and recommendations that follow at the conclusion of this report.

CHAPTER FOUR

RESULTS AND DISCUSSION

4 INTRODUCTION

This chapter presents the results and discussions of the study. Data was collected using a qualitative method of data collection. The findings of the research will be presented in terms of broad themes that emerged during the conduct of the study. Data from both samples are presented alongside each other as it was apparent that key informants illuminated responses from the sample of 31 infected persons.

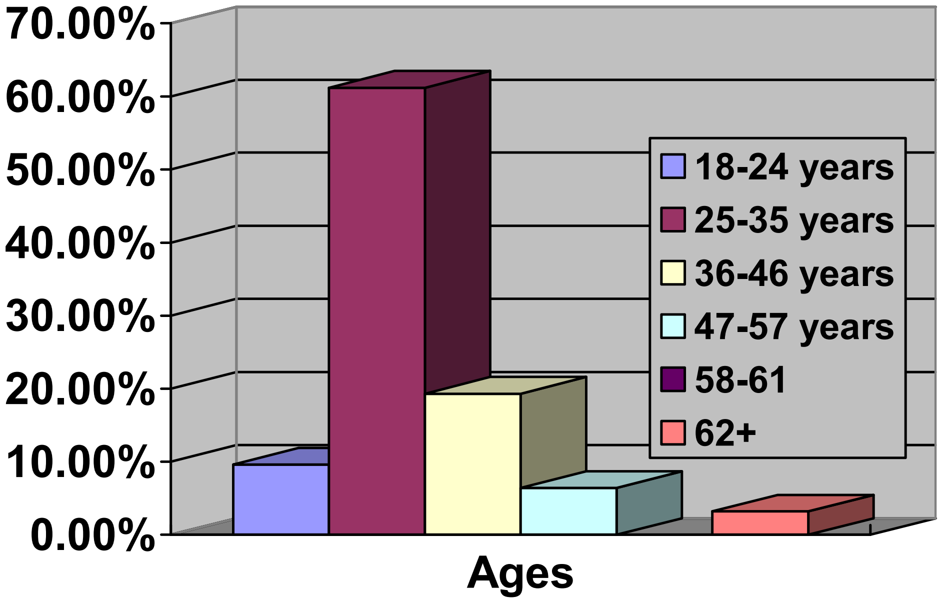
Data was collected using qualitative data collection techniques with fieldwork being undertaken from July to August 2006. Semi-structured, in-depth interviews were used in this study with two sample groups*:* sample one (N=31) were patients infected with HIV/AIDS and sample two were key informants involved in the delivery of social assistance in the area of Vulindlela.

The researcher commences with an analysis of participants' age.

.1 SAMPLE CHARACTERISTICS

<u>**Age range**</u>

Figure 3 Age range of the participants



According to figure 3, 80% of the respondents were between the ages of 25 and 46 years, with the majority (60%) being in the 25 to 35 year category. This age group according to the normal life cycle is usually in their most productive working years. These results are consistent with another study discussed in the literature review by the Health Systems Trust (2005:1) which found that most people living with HIV/AIDS in Vulindlela are between the ages of 15 years and 55 years old. With the younger population being the most affected, it is also a concern that it is females that face the greatest disadvantage, discussed hereunder.

Gender

Figure 4 Gender of participants

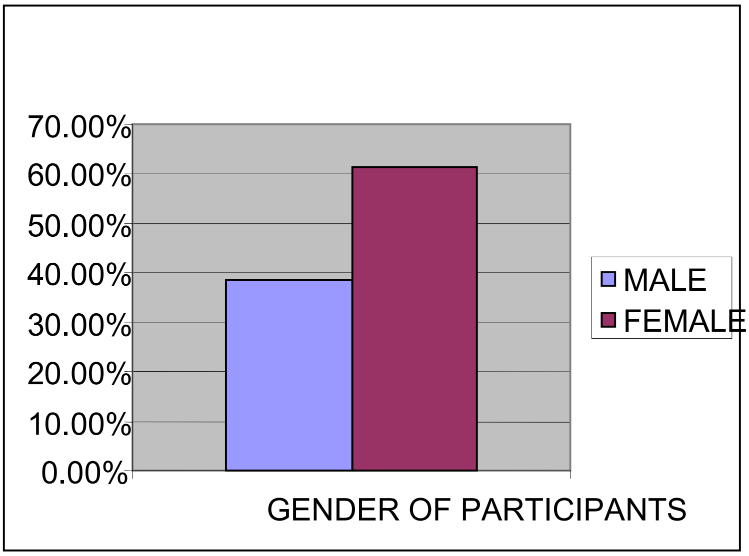


Figure 4 illustrates that more females (61.2%) than males (38.7%) were the patient respondents in this study. This could be, as discussed in the literature review, that women are disproportionately affected by HIV/AIDS. According to the Department of Health (2007), women account for about 55% of HIV-positive people. The risk of becoming infected with HIV during unprotected vaginal intercourse is between two and four times higher for women than for men, a finding borne out in this study. Women are also more vulnerable to Sexually Transmitted Infections (STIs), and an untreated STI in either partner multiplies the risk of HIV transmission by 300-400% (International Fund Agricultural Development, 2001). It is possible then that the female sample was also affected with STIs that predisposed them to greater HIV risk.

Another reason for having more women in this sample could be that women are over represented in the rural areas (Mhone, 2004:4). According to Kharsany cited in Smart (2005) 60% of the population in Vulindlela is made up of women. Being in a rural predominantly black area, places one at a great disadvantage, with women being worse off as they face the burden of accusation (even if married) that they are the ones bringing the virus into the family.

Marital Status

Regarding marital status, in this study 61.2% (N=19) of the patient respondents were single, 6 (19.3%) were living together with their partners, whilst 5 (16.1%) of them were legally married and 3.2% (N=1) was legally divorced.

It is important to note that most of the respondents from the study might still be single because as discussed earlier, 60% of them were young, in the age range of between 25-35 years and still in the phase of considering permanency in their relationships. Interestingly 12.9% (N=5) of the patient respondents had broken relationships with their partner after discovering their positive status, this group again being females. This is possibly because of rural living where women hardly have a voice, perhaps in saying that they were not responsible for bringing the virus into the relationship!

Level of education was also analyzed as people in rural areas are known to have a low level of education, rendering them more vulnerable to the disease.

Level of Education

Level of education can also influence accessibility to the disability grant. It can be anticipated that the higher the education level, the greater the likelihood of having more knowledge about rights and access to the various grants available.

In this study 48.3% (N=15) of the patient respondents had primary school education; 25.8% (N=8) had left school after grade 10 and 25.8% (N=8) had matriculated. These results are contrary to the general trend of HIV positive persons having a lower educational level discussed in the literature review.

The higher level of education in this sample could be attributed to the sample being fairly young and thus having more access to school, especially post

1994 when educational opportunities were deliberately addressed in South Africa. Also, education is now compulsory until sixteen years old. Another possible reason could be because the people who are coming forward for treatment might be the more educated and they have more knowledge about the grants that are available. The patient sample was also skewed in that they were all receiving treatment from the clinic.

However, according to the Head of Social Services in the area:

"Most people here are uneducated, but they do have the councilors who inform them of their rights and what they should do then people come to us".
This information reveals that people in the area benefit from council educators and those systems exist in this community to ensure that the community is educated on social issues and resources. One must note that this view is from a service provider who may be biased in his/her opinion of service provision and its benefits.

Another possibility for the educational trend amongst patient respondents in this study could be because of migration trends as discussed by Mhone, (2004:4) whereby once respondents contract the disease, they return to a rural area, as discussed below.

Migration patterns

61.2% (N=19) of the patient respondents in the study were living in urban areas but had returned to Vulindlela once they required care and support and could not look after themselves. The International Fund for Agricultural Development, (2001) also found that "persons living with HIV/AIDS often return to their village of origin when they fall ill".

This migration back to rural communities is stressful as they are under resourced in terms of access to HIV/AIDS information, scarcity of social support, health services and employment opportunities. Thus the migration trend is important to planners who would want to ensure that rural areas can cope with administering social security to increasing numbers of people. From an ecosystems perspective, it is apparent that burden of care is increased by a variety of factors in this regard, viz. poor families, unemployment, lack of access to the disability grant and poor infrastructural community and national support that cannot keep pace with demand for various care initiatives.

Employment

Employment is a determinant of access to the disability grant. Thus employment history and opportunity for work was researched in this study.

Most patient respondents in the study were unemployed even before being diagnosed with HIV, and were living in poverty stricken circumstances. This trend reflects the similar high levels of unemployment in South Africa and in the District. Poverty is often described as the “greatest co-factor in the global incidence of AIDS” (Spier & Edwards, 1990 as cited in Nkwe-Mabua, 2000:14). Thus, ideally, the respondents would qualify/have access to the grant if based on the means-test.

Clearly, in this study as cited by other authors, most of the respondents were unemployed even before they started on ARV’s (Piot, as cited in Karim & Karim, 2005:354). Almost 13% (N=4) were in temporary employment and indicated that this was due to the fact that they had taken their medication and had recovered sufficiently to go back and look for job,

These respondents may be considered courageous since they were informed of the likelihood that once their CD 4 count increases, then their grants would be cut-off, making permanent income a far fetched possibility. Clearly, the extent of poverty in the area of Vulindlela forces people even if very ill, to get up and fend for their families. Most of the respondents from the study revealed that they were breadwinners and had to look at other means to support their families in order to survive:

"If I just let go just because I'm suffering with this virus, how are my children going to survive, if I do not support them as the head of the household, they would resort to all kinds of criminal activities"

One respondent surprisingly had just been employed:
"After discovering my status, I sought of ways of making it for my little brother and I since there's only two of us now as our parents died of this disease a long time ago".

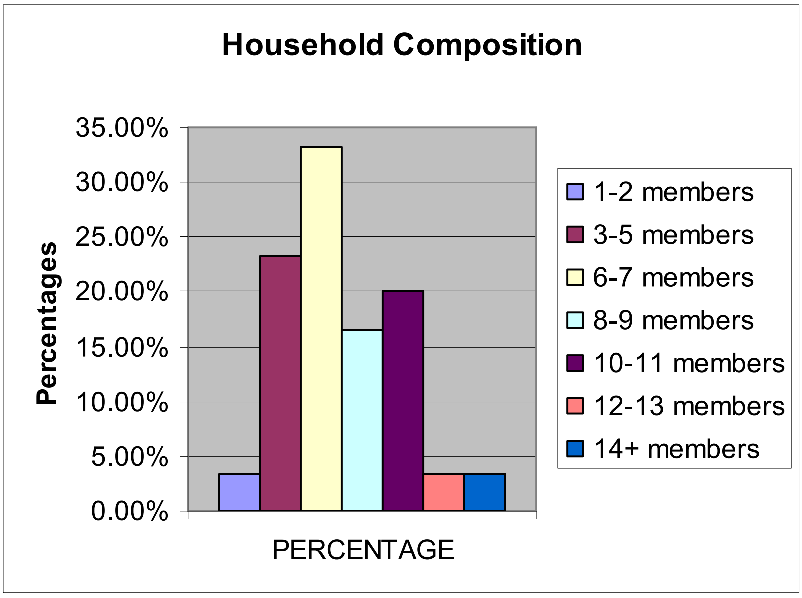
As many as 70.9% (N=22) patient respondents reported to have never worked at all; 6.4% (N=2) respondents were selling chickens and 19.3% (N=6) respondents were self employed (selling fruits and vegetables, building houses or selling sweets or chickens).

The high rate of unemployment is not surprising since the criteria to qualify for the disability grant includes that of being unable to work. For this reason the respondents might have been reluctant to reveal their status. Also, the fact that the CD4 count has to be below 200, means that they are fairly ill and incapacitated and are unable to work as discussed in the progression of illness cycle in the literature review (Whiteside, Mattes, Willan & Manning (cited in Poku & Whiteside, 2004:128).

Most respondents also felt as though they had let their families down or failed them, because of not working at all. They felt guilty that their illness contributed to their family's already existing burden of poverty. This implies that the definition of inability to work as a qualifying criterion for the disability grant could have negative effects on those able to work even though not to their full capacity. Further burden was placed by the fact that due to the disease taking so many lives at once, many families felt afraid, helpless and overwhelmed. From the ecosystems framework that underpins this study, it is apparent how employment and lack thereof together with policy and procedures for accessing the grant, together interplay to maintain a status quo that is far from ideal as families and those living with HIV continue to struggle.

Household Composition

Figure 5: Household composition of the patient sample



The majority (N=29) of respondents in the study lived in households of between 3 and 11 members. Such a large household composition "is not uncommon in poor households in South Africa" (Mather et.al. cited in Unaids). This further impacts on the level of poverty in the households. More than half (54% or N=17) of the respondents were the sole breadwinners in their families, with the disability grant being their main source of income. Other social security grants were also the sole means of support for these families (Child care grant, Old Age Pension, and Care dependency Grant). The rest of the few respondents either depended on sisters' or mothers' salaries as exemplified in the following words of respondents:

> *“The grant is the main source of income as we are all not working in my family, and all depend on my mother’s old age pension, and my children’s grant”.*

> *“ My grand father’s old age grant is the main source of income and it’s the only money we are dependent on, without this grant I do not think we would had made it so far, we would starve”.*

> *“My mother’s old age grant, that is the main source of income, so I assist my mother with my grant and the money that I get from building people’s houses, which is at times very scarce here in Vulindlela... if I do not go out there and do manual jobs, my family would not have food at all, so I’d really suffer if I did not have the grant”.*

> *“Yes the disability grant is the main source of income, as I only sell sweets on the streets, my mother also helps out with her salary as well, otherwise there is no other source of income”.*

Social security has become the major and main source of income in most poor households. Nattrass (2006:1) agrees saying: “this is a consequence of South Africa’s high rate of unemployment which leaves people with no other alternatives to poverty relief”. Although the disability grant does bring some relief, quality of life is seriously compromised and good nutrition is only an ideal, especially since the disability grant has to be shared with many others. Very few respondents were spending their disability grant on themselves only; almost half of them used it to support their families, to buy food, for school clothing, furniture, paying for electricity, water and paying for burials.

4.2 LIVING IN HOPE

Despite people living under such difficult circumstances, they still clung to hope with a fighting spirit, saying:

"We are going to live with this virus, we will fight it whatever way we can".

What the researcher witnessed through such statements, was strength and unending fight in the people of Vulindlela. The support they received from the clinic staff was much appreciated, as evidenced in the following quote:

"If you come to the clinic and be with people who understand you and your sickness, you go back home relieved as we discuss our burdens and see each other through".

It was apparent that no matter how serious the influence of the virus, many patient respondents were willing to deal with it positively as none felt they were being punished by God for their sins but instead, they were grateful that they were given a second chance to re-live their lives properly and to be with their families. Such comments are heartfelt and suggest belief in a Higher Order that many seek solace from in the absence of other more tangible sources of support as discussed by Kasiram (2006).

4.3 KNOWLEDGE OF GRANT

Almost all the patient respondents had knowledge that they qualify for the grant. However, two did not know the procedure regarding access. Of these, 58% (N=18) respondents received the information from doctors at the clinics. The fact that residents are informed by their doctors that they can apply for the disability grant shows the importance of a primary health care service in rural areas, headed by a doctor. Other sources of information were nurses, counselors and community workers. Only 12.9% (N=4) respondents found out from friends and family, perhaps because of the stigma associated with HIV/AIDS, a view also discussed by Piot, as cited in Karim & Karim (2005:354).

These similarities were also found from the sample of key informants in social security/welfare who were also asked similar questions. An official added that they too play a role in knowledge dissemination by running awareness campaigns

"When we do the campaigns we also market ourselves and services we render to the community".

So, respondents mainly applied for grants after they had found out from their doctors that they qualified when their CD4 counts were below 200. Other respondents received the grant because they suffered from other health related illnesses like stroke, TB, diabetes and pneumonia which are opportunistic illnesses linked to HIV/AIDS.

Most respondents had a very good knowledge of their CD4 counts; only a few had no recollection because the virus had affected their mental capacities at the time of their diagnosis, while others were still to apply for the grant. Here's what was said by patient respondents in this regard:

"I knew I qualify for the disability grant because my CD4 count was 18 which made me to qualify as I was told once it gets below 200, I would qualify".

"I knew because my CD4 count was 115 which made me to qualify.

"I did not even know about the grant, as to how do I qualify".

However, social security officials questioned about respondents' knowledge of access requirements, offered a different view from patient respondents, saying that CD4 count hardly played a role in qualifying them for the grant:

"There is discrepancy when it comes to disablement and CD4 count, because a person might have a very low CD4 count of about 111 but the person would not present any symptoms like opportunistic infections and the like. Due to that he she may be denied the grant because of physical appearance…the virus has not yet disabled the person… yet the person is dying… by the time the person finally qualifies it is too late, or the person has already died"

A doctor questioned as part of this study, stated that it was fairly easy to access the grant on the grounds of opportunistic illness. This is reflected in the following quote:

"It is easy to access the grant when the disease is progressing because there will be visible signs for example thrush or rash... if you have illness that qualifies you to get the grant"

Clearly, from an ecosystems perspective, various factors interplay to create problems, in this case, CD4 counts that do not always ensure that a grant is received, doctors who may advise differently only for respondents then to be refused the grant and social security officials who understand that refusal on CD4 grounds is common where no outward physical appearance of illness is manifest.

4.4 KNOWLEDGE OF DOCUMENTATION

Most (93.3%) patient respondents had full knowledge of what was needed by the Department of Social Development to access grants. They correctly identified the following:

- ✓ a copy of their files,
- ✓ the Doctor's letter,

- ✓ ID Document,
- ✓ proof of Correct Address,
- ✓ addresses of their Chief, Induna, Councilor and Pastor and
- ✓ their ARV report.

The reason for the proof of residence or confirmation of residence in a rural area was, according to officials, to determine whether the applicant really resided in that area. This helped to speed up the application process.

Only 2 respondents had no idea of how to apply for the grant, this evidenced in the interview with a grant administration manager:

> "*People do have full knowledge of the grants … (but) do not have knowledge of ... the administration requirements".*

The reason why these two respondents did not apply for the grant may have been fear of being identified in the community as having HIV/AIDS. Fifteen respondents had received the grant after a long waiting period and 12 were still awaiting the outcome of their application (despite a SASSA official indicating that applications now only take one day). Two had their grants cut-off due to their CD4 having increased and one was told to reapply, and people living with HIV/AIDS felt betrayed by the system.

4.5 PROCESSES FOLLOWED AND DIFFICULTIES EXPERIENCED

The process that had to be followed in applying for the grant was generally regarded as simple but problems were apparent with one respondent complaining that it was very hard to get hold of the local authorities.

Service providers maintained that they tried to better service delivery for people in Vulindlela, but patient respondents discussed problems that were experienced. These problems were identified by the sample with HIV/AIDS and included the following:

> *"Yes I had difficulties having to travel to my councilor's place not getting him first time around and having to travel to my church minister and all for addresses. It took me from March to June just running around"*
>
> *"..Not being able to get the grant in the 3 months that they had promised me, but I had to wait for 9 months".* This could be due to the fact that these application processes were done before March 2006 when the one day application initiative commenced.

One Induna himself seemed not to understand his facilitative role in supplying an address and said:

> *"In most cases I face problems when people come with the forms that do not state quite clearly what their problem is, and in grant application forms, there is no space provided for me to put in date stamp to certify clearly".*
>
> However, he clarified that:
>
> *"Yes I assist the grant applicants, with the letters stating that I know the applicant and they reside within my area and certify that; I also add in my address and full names".*

So he was able to supply the required information when prompted.

There seems to be a discrepancy in as far as the understanding of the waiting period is concerned because when the researcher interviewed the social security staff, they maintained it only takes one day for a person to apply whilst the sample of respondents with HIV/AIDS said that it took longer than that. More than anything, the latter sample complained of not being informed of new changes, neither were the roles of the local authorities clearly outlined. In fact, the sample of HIV/AIDS respondents added that they did not see the need for local authorities. It seems that this response was either prompted by their frustration or that they genuinely did not see these officials as performing any meaningful role in alleviating their problems of accessing the grant. From an ecosystems view, at a microsystemic level, the impact of officials' tardiness has far reaching consequences on trust and rapport between service recipients and service providers.

4.6 TIME LAPSE SINCE APPLICATION

Generally respondents indicated that they waited for about 3 months or less before receiving the grant. Some even waited only one month! This is encouraged by the Batho Pele Principles which were previously outlined in the literature (Procedural Manual, 2003:2).
A few respondents indicated that they were had waited for more than 3 months for the grant:

> *"I had to wait six months full, and only got R 6 020, which I think was not enough for me".*
>
> *"I have been waiting for five full months and I am still waiting as it is not out as yet. I went again in July and they further told me to come back in August"*
>
> .

These experiences are not in keeping with the new proposed application process introduced by SASSA as outlined by a senior clerk:

"Before when there was still a three month waiting period for a person to get the approval for the grant, we used to give clients food parcels, but since change came about, where you find out there and then if you qualify, we no longer give out food parcels" .

This is not the case for several people as they had to wait longer than 8 months to get their grants. Although the general trend was for the waiting period to be less than 8 months, the few who still had to wait beyond this time period when they are vulnerable and indeed when receiving the grant becomes a life and death matter, suggests the need for Batho Pele principles to be put into action with greater commitment.

4.7 DISCOVERING ONE'S STATUS

This theme was explored with patient respondents to discover whether the timing of discovering one's status affected the grant application or receipt. Most respondents discovered their status when they went to the clinic for other reasons e.g.

"I first got to know last year September as I went for my pregnancy test".

"I discovered last year November when I got very sick with TB and I went to the clinic and the also tested me for HIV and they told me I was HIV positive".

"I first discovered last year September when I was diagnosed with pneumonia and I came to Mafakatini Clinic for an HIV test and I was told the test was positive"

This translates to a significant time loss when CD4 counts could have been lower than 200 and allowed for an earlier grant application, should the respondent have known his/her status as was identified by Barnett & Whiteside cited in Unaids). One of the objectives of this study was to understand the partnerships and co-ordination between formal and informal systems of care. From the results,

it is evident that co-ordination between care services was a problem, resulting in delays in grant application and receipt, as discussed by Madonsela (2006).

4.8 ASSISTANCE FOR PATIENTS THAT DO NOT QUALIFY

Service providers were questioned as to whether they offer further services or make referrals if the need arises when applicants do not qualify for the grant. They said:

> *"(we may refer to) social welfare"* (doctor)
>
> *"the clients are told they can make an appeal, and the process is explained to them"* (senior admin clerk)

It is surprising that social workers are not consulted, seemingly because their role and functions are not accepted or known.

These responses also point to large service gaps that cannot be filled by referral alone, as individuals and families left without any visible means of support have to survive. It is not enough that referral occurs, with patients having to go from one possible source to another when they are sick. An ecosystems model of understanding calls for integration of services, where impacts of various services may be jointly appraised and developed.

4.9 APPEALS / COMPLAINTS

As discussed in the literature review, the option to appeal or complain to the relevant authority is part of the process.

Only two respondents said they complained and this is what they said:

"Yes, I did ask from the security guard... why my grant was cut-off within less than three months that I had received it. The guard advised me to go to the Department of Social Welfare for enquiry, so I went and I was told to reapply".

”Yes I did complain I was told to go to the Dept of Social Welfare office in Town to room 5 to the personnel who works with the appeals and I was told to reapply”.

Most did not complain to anyone as they thought it was the way things work and that they were supposed to wait this long as exemplified in the following comment:;

“My neighbor told me it could take me the whole year for my application to be processed as that is what happened to her husband”.

> This was despite having been told by the Department that it will only take three months, and not questioning when this time period had expired. This shows that often, rural people are unaware of their rights or are reluctant to confront the authorities.

Said a key informant in verifying this:

“Very few people who come here have knowledge of their rights, as their level of education is nil… unless they have been informed by their local Izinduna, then the will tell you who informed them” (doctor)

The next section focuses on records regarding results of applications.

As regards statistics and figures of grants recipients people rejected, Departmental officials were asked what records existed of grant applications. They informed that:

“*Yes we do keep all statistics; if a person’s application is approved they get the results the same day of application. If rejected they are informed by a* *written letter stating that you can make an appeal within 90 days. That was administered by the MEC in the past but now it is going to be administered by Minister Skweyiya. Other rejected critical cases are referred to Development, which links them with different projects like gardening, sewing etc"* (Acting grant administrator)

"Yes we do keep statistics of all our clients for every month" (senior clerk).

People living with HIV/AIDS usually experience periods when they are unable to make applications themselves. Thus respondents were questioned about this. No respondents used a proxy at all, with a senior clerk confirming this.

Besides not using or knowing about a proxy, respondents may have faced other challenges in accessing or during the receipt of the grants. These are explored in the next section.

4.10 CHALLENGES

The Effects of Anti-retroviral therapy on the illness

Respondents, having been selected from the clinic, were already on ARVs. Surprisingly, most had been on ARVs long enough for them to have become better, yet their CD4 counts remained below 200. A possible reason for this finding is that they may have cheated by not taking their medication rigorously in order to prevent their grants from getting cut-off.

Another possibility is the fear of reapplying which is known to be stressful and long. This is borne out by the finding that those on ARVs were still waiting for their grants for as long as 17 to 21 months. Not taking ARVs as they should be taken undoes the benefits of ARV's, which costs the country a lot of money. Hardy (2005) too acknowledges challenges from offering ARVs and suggests that persons who lose their disability grants should at least be able to access other social assistance programmes, such as the food security programme and child support grants. However, it is difficult to see how these alternative social assistance programmes will comprehensively and adequately cover the needs of people living with HIV who have no immediate prospect of employment, and who have lost their disability grants because of health being temporarily improved due to ARVs treatment. Perhaps though, some food aid will make a dent in their dire circumstances. One official at the department and another senior clerk confirmed the need for food aid but indicated that this was no longer offered because of the expectation that grants would be processed in a short space of time.

Another difficulty facing respondents was transport.

Transport difficulties

All respondents complained of the long distance they had to travel and high costs of transport. Some had to spend as much as R20 rand a day, money that could have been used for food. Said respondents:

> *"…it costs me R25 a day to travel to the Department of Social Welfare".*
>
> *"…it costs R20 per day to get to the Dept of Social Welfare, it's too far and I'm not even working so I have to borrow people's money which I can't even pay back since I'm still waiting for the grant".*

Compounding this problem was traveling when they were too ill.
This situation calls into question the promised government vehicles to transport people to different pay points discussed earlier (Van der Westhuizen & van Zyl, 2002). So, what are these vehicles utilized for if not for the poor public?

These responses from the sample affected by HIV/AIDS are contrary to the response of representatives from the Department of Social Welfare who maintained that they attend to those people they know experience difficulty by going to patients' homes to ascertain living conditions and help where possible. The despair of respondents may also be attributed to lack of knowledge regarding resources such as vehicle access which is a relatively new initiative on the part of government (Van der Westhuizen & van Zyl, 2002)

Securing documents

A major challenge to securing the grant was in respect of documentation. Almost half of the patient respondents experienced a hassle-free application process with all their applications being processed smoothly, but the rest had problems related to long waiting periods and difficulties with documentation. Said a patient respondent in clarifying difficulties experienced:

"I forwarded my file with all my details to the Department of Social Welfare, but unfortunately as I was in the process of application I happened to loose my ID Book, so this is delaying my application as I have to apply for my ID first before I continue with the Disability Grant, meanwhile my family is suffering."

A key informant also explains the situation as follows:

"Barriers that exist in foster care grants (are in relation to) fraudulent activities from the social security side that translate to documentation requirements not being fulfilled". (Head social services)

This problem of fraud and corruption is linked to documentation here but it is discussed again later in the analysis where it was specifically questioned as an area of concern.

Language

Language may pose a challenge to grant applicants. However, this study did not present such results. Respondents had no language problem as the majority of the officials at the Department speak isiZulu. Even when completing forms in English, they were assisted by officials.

"The fact that people are desperate they do make means to come to the department for application, but they face no language barrier since we are all IsiZulu speakers…" (acting grant administration manager).

This sets a good standard for the Department of Social Welfare as they were able to reach their community members.

<u>Corruption</u>

Corruption and fraud are critical concerns for social service departments. "The two concerns clearly highlight the existence of managerial and administrative flaws in social security system" (Mpedi, 2004:67 cited in Olivier 2004).

When patient respondents were asked if they were ever asked to bribe officials, not one claimed to have faced this problem. Only one lady indicated that at a pay point once, an official asked her for money to buy a cold drink. Another respondent said that although it had never happened to him, he had heard of cases where the person was asked to give the official half of the money the person received:

"*Say If you got R3000, then you will have to give the official R1500 as a token of your appreciation for his/ her assistance and nobody has ever questioned that"!*

Key informants provided a different picture. A doctor mentioned having difficulties with fraudulent clients, because as much as the blame is put on the personnel from the Department, clients can also manipulate their application process, providing *"fake information".* He said:

"…we do experience some problems with patients who buy fake CD4 counts from other doctors"

"..you (may) find that when you ask him/her as to which medication they are on, they will tell you something else, ask them how many times they have to take the medication they do not know, they have never had the test before, then you know they were out to get the grant ".

A key informant from the SAPS unit was asked how fraud and corruption was managed. The answer was referral to a special investigating unit and an internal auditor. One wonders about what gets lost during this referral process and how evidence and communication would contaminate the facts. This area, being a burdensome concern, needs joint efforts at problem solving since it impacts individuals, families, communities and the state (ecosystems perspective).

Discrimination from the community

Patient respondents mentioned that they had no problems like discrimination or labeling from the Department officials. But at the community level, they faced tremendous stigma. They are called all kind of names such as: "*Abantu abanesifo esibulalayo*" (Killer Disease carriers).

One community doctor was also viewed as discriminatory. A male patient respondent clarified that he endured humility at the hands of this doctor saying:

"I went to the clinic for the doctor's letter to take to the Department of Social Development, but the doctor insulted me, saying 'Are you happy now that you are HIV positive and you're probably lying that you are positive' without assisting me and I left the Clinic and went to (another) clinic where I was assisted".

This is disturbing as the expectation is for a professional to be sensitive and caring rather than accusatory and insulting.

Twenty two respondents stated that they had no social or cultural barriers as discriminatory, possibly because they had not disclosed their status to their families due to the fear. Others (N=9) were disowned by family as exemplified in the following quotes:

“My son discriminates against me especially if my tooth brush was in the same holder/container as his- he will throw it away”

“… my father kicked me out saying I must look after myself and stay with my girlfriend. Now my community discriminates against me because I’m HIV positive and I think my family had something to do with it.”

“My in-laws were discriminating against me, causing trouble for me even in the community so I had to move out of my husband’s home after my husband’s death- I had to move to my own house with my children”.

Officials presented different information to this question. They had not witnessed nor had discrimination reported to them. This could be attributed to officials not being seen as facilitative. Officials said the following in justifying why patients did not experience discrimination:

“…we have Sweet Waters Drop in Centre where people are enlightened more about HIV/AIDS, we have activities running there such as Dram AID” (Head of social services)

“The community has support of HIV-positive clients as others give advice to HIV positive clients to come and apply for the grant” (senior administrative clerk)

Clearly, a wide gap exists between views of service users and service providers. It seems that the means of knowledge support to the people of

Vulindlela as outlined by the Head of Social Services were not adequately outlined or advertised for there to have been any significant benefits experienced. A bottom up approach does not seem to have been used with consultation and partnerships between the two groups.

Cultural barriers

When questioned on cultural barriers that could have affected the grant application or receipt, Department staff maintained that this was not a problem:-

"I have not experienced any cultural barriers in this community and at the Department, since they come to us, desperately needing the money so they do not find it difficult to talk to me as a doctor" (doctor)

"There are no cultural barriers at all" (Head social services)

4.11 OFFICIALS AND THEIR WORKLOAD

Key informants presented workload as a challenge in processing grant applications. One worker could be doing the load meant for more people, resulting in burnout and ultimately not helping the poor. Social service professionals were most affected by this. They said the following:-

"Lots of social workers vacate the place because of work load" (Head of social services)

"We have a very heavy work load but we always manage as people's needs come first" (senior administrative clerk)

"..We do want to run support groups for people with HIV/AIDS but because we are short staffed it becomes impossible to do it...staff faces the challenge

of carrying more than 300 case loads per person, this further delayed service delivery in the area of Vulindlela." (Social services)

Clearly, workload not only delays the processing of applications, but also prevents service providers from intervening meaningfully in patients' lives, that is also discussed by Kasiram et al. (2003)

4.12 FEARS OF HAVING THE GRANT CUT-OFF

Because this was so real for patient respondents, they were asked about fears in this respect. Most respondents feared for their families. Although some family members discriminated the infected member, when it comes to grant consumption or benefiting from the grant, they forget they ever discriminated against the recipient or that he/she has HIV/AIDS. Such is the short term memory of need and poverty. Others expressed that since they are on ARVs, they were supposed to have a balanced diet, which was going to be hard if their grant got cut-off. Even the process of re-application creates a fear for the respondents, because they know that by the time they go to the Department, their CD4 count will be high, which will mean being refused the grant, a common experience of patients on ARVs. They said:

> *"I will suffer a lot and my family will battle as before, as we had been saved by the grant for even stable diet; as I'm now on ARVs since the doctor explained to me I need to eat nutritious food now"* (fear for family's needs and patient nutrition).
>
> *"I fear ...not being able to support my family, will not be able to even put bread on the table as there is no one who is working at home, and the heavy load will fall on my mother's shoulders yet with the grant we are able to manage".*

> *“I fear that my children will have to travel long distance on foot, as now with the grant I am able to transport them and even put food on the table”.*

Clearly, the main factor affecting these rural families is poverty; therefore the grant is seen as a means of poverty alleviation. “Given the strong connection between poverty and HIV transmission, it would seem, at the very least, that anti-poverty measures should be an integral aspect of any AIDS intervention strategy” (Nattrass, 2004:3; Barnett & Whiteside, 2002). The ecosystems perspective is again useful in understanding the interconnectedness across the various levels of poverty, HIV transmission and individual and family health.

4.13 OTHERS AFFECTED IN THE FAMILY

Twelve respondents had family members who were also infected and receiving a grant, whilst as in their own case, others have had their grants cut-off. Further issues they raised were similar to their own experiences including that of the CD4 count being low and not allowing grant access as well as them keeping their status a secret.

Patient respondents who were also getting the grants together with another family member that was infected, expressed how helpful it was if two or more members of the same household received the grant. The driving concern was evidently more the poverty and family comfort than having a positive status. Said respondents:

“Yes, my younger sister is infected, but her CD4 count is still high so she is not on ARVs as yet”.

“Yes, my younger sister is positive with HIV/AIDS, she also used to get the grant but it has been cut-off”

“Yes my older sister is infected, but she no longer takes her ARVs for she fears her grants being cu-off”.

These responses show how overriding the concern to rise above their poverty is when compared to having a life threatening illness.

A huge burden was again that of discrimination and resultant shame. Had there been adequate support systems in the area, to educate, build self esteem and self awareness, these burdens would not have been so heavy to carry. Multiple layers of support and care (following an ecosystems perspective) are again indicated.

4.14 LOSING PEOPLE TO HIV/AIDS

Most respondents did not openly acknowledge that they had anyone else in the family who was infected, possibly due to the fact that HIV/AIDS especially in rural areas is treated as a disease of sinners or people who cannot commit to one sexual partner. So people decide to keep information about status to themselves. It may be only after death, that the family learns of their member's status or during the last moments when the person decides to come back home from the city for care. Some patient respondents said that they had lost more than one of their family members to AIDS, this contributing to the burden of care as more and more households are becoming female-headed, pensioner-headed or child-headed.

These were some of the comments made by the respondents;

> *"Yes, my ex-girlfriend, who kept it a secret from me but her sisters, told me after her funeral".*
>
> *"Yes, my husband he passed away last year in May".*
>
> *."Yes my younger brother, he passed away last year February and he disclosed of his status before he passed away"*

Having a family member dying of HIV/AIDS was frightening. The worst is knowing you are also going to die; and many think of HIV/AIDS as a life sentence. They start preparing for the unknown (Kasiram et al., 2003).

The objective of hearing the voices of community members as to the challenges they face in accessing the social security system was clearly understood during the conduct of this study. However, it was disappointing to learn that in some instances, service providers were not always involved in actively supporting their service recipients in their fight against HIV/AIDS. Indeed, there were a multiplicity of factors that contributed to this state not the least of which were policies and procedures that could not be easily and rapidly translated into action, family and societal discrimination and fraud and corruption, all suggesting the need for adopting a holistic view with many role players to problem solve (ecosystems perspective).

4.15 ROLE PLAYED BY SERVICE PROVIDERS

According to policy, many role players are involved in the social security system, since poverty is viewed as multi-dimensional. Thus it was important to ascertain the degree of cooperation that existed across these service systems as well as their knowledge of their own role and function.

Relationship between health and welfare

Said a doctor about the relationship that exists between the health sector and service providers from welfare:
"Their relation is based on the fact that when a person is sick with HIV/AIDS that person is assessed by the medical Doctor and then referred to welfare for grant application where the person's details will be processed the same day and they get the result if they qualify for the grant or not, they no longer have to wait 3 months like before" (doctor).

Although the doctor clearly seems to understand the referral process, recipients of service did not. Not even one of the respondents knew about this. The knowledge could have saved patients many trips, time and money.

A service provider from welfare did not share the view of the health professional saying:

“There is not much of a relationship at the present moment, but there is a proposed integrated plan which stipulates that we must work together to promote service delivery” (Head- social services)

Poorly coordinated services clearly exist despite structures being put in place to address this problem as clearly outlined in the (Procedural Manual, 2003). Not only do these responses suggest poor co-ordination but also opposing views by both sets of providers. Open communication is the first step towards better co-ordination and is strongly indicated from these responses.

The role of the social worker in advocacy was also unclear

“Our role is not at all clear in our Department, but if we hear of any fraud that is going on in our department, we advise the client to open a case at the police station and we report the case to the superiors of social security” (Head social services).

Because social workers do not appear to have a clear understanding of their role they intervened by way of reporting/referring matters relating to fraud. The acting grant administrator mentioned the fact already mentioned earlier, that they report the fraudulent matter to their special investigating unit. The doctor mentioned that if they come across fraud they report to SAPS immediately. Fraud remains a huge concern that needs a multiple approach using ecosystems theory.

Relations with SASSA

"SASSA has no social workers. Social workers refer cases of people who need all kinds of grants, but we deal with foster care grants especially, not other grants e.g. disability grant" (Head social services)

This statement suggests that social workers are mostly involved with foster care grant assistance and that they do not monitor grant fraud and the like. With grant access and fraud being such a problem today, this role could well be included even if it means working alongside other service officials who would deal with the criminality of the problem.

The role of the Doctor

"*To do the clinical assessment test, check how much is the CD4 count of the patient. If it is below 200, it is the stage at which the person is liable for treatment, but due to the fact that if a person is suffering from HIV/AIDS, opportunistic infections make the illness worse. The Doctor writes a recommendation letter stating that a person is eligible for the grant due to the illness. This letter will state that the patient will get a temporary grant which is one year or a permanent grant which is five years" (*doctor).

It would be ideal in this case if there could be inclusion of social services since the grant is not permanent, and for recommendations for some kind of relief aid as these individuals, families and communities are living in dire poverty. Again policies regarding these services need multiple role player planning (ecosystems perspective).

The role of Administration clerk

SASSA as the main office that deals with only the grant administration clearly stated their role and what happens before the client comes to them as follows:

> *"We refer the client to our Department's Doctor. This is done to verify the medical details of patients as they are referred by various clinics and hospitals. They are given a date by which they must come to see the Department's doctor where the patient is asked of the medication he/she is on, medical certificate from the previous doctor, and the doctor will interview and examine the client as he fills the medical certificate. Our role at the administration office begins right after the doctor has performed medical examination with the client. Just after seeing the doctor the client will make an application. Should the results from the doctor state the client deserves the grant, we will then ask for his/her appropriate documents and we process the application, capture data and approval is granted or rejection"* (senior admin clerk).

This is according to what was mentioned in the literature that grant approval is medically based (South African Government information, 2006). This is not appropriate as it takes a long while for patients to meet all the required criteria. It is at times too late for the person and they die before getting the grant.

The social service official was also asked what other relief programmes are available for poverty alleviation e.g. food parcels. The response was:

"there used to be social relief whereby the person will be given food vouchers to go and shop at a particular shop for food to support their families, but since people get the result of their application that same day, there is no longer a waiting period. Even in the drop-in Centers for orphans of HIV/AIDS that we as the department fund, food parcels are not directly there. The Sweet waters Drop in Centre is funded by us, so that the orphans can get food in the mornings when they are going to school, and afternoon when they

are going home; we also provide for parents who are sick with the illness, give them counseling and we refer them for grant application. There is not much of a role that we play with people living with HIV/AIDS as we focus mostly on children as they become orphaned by AIDS". (Head social services).

Clearly interim relief is no longer offered despite the fact that the waiting period has not really changed for many applicants. So policy has changed before practice realities were properly assessed. Only the drop-in centre seems to be offering some form of relief. This is the government's way of trying to best deal with issues of HIV/AIDS and poverty, to make the system effective and efficient. Unfortunately as discussed earlier, the main people for whom these services are devised are not aware of supportive structures in the form of relief aid and do not even know that their children could benefit in some small way.

4.16 VIEWS OF KEY INFORMANTS ON THE DISABILITY GRANT

Key informants were questioned about the general value of the grant, taking into consideration that it is often temporary and short term. Obviously the grant plays a big role in the lives of people living with HIV/AIDS, despite this grant being temporary. The key informants had these views about the disability grant:

"People with HIV/AIDS do not qualify for the grant since they are not disabled at all. If they could coupons, food parcels no one will complain that the Government is not delivering, as most of the times the money is not solely used for the sick person's needs but for the entire household. If the social relief grants could be brought back, it would fight with the real problem in hand which is poverty, rather than giving people short term relief in Disability Grants" (doctor).

“The problem with HIV/AIDS is that even if you have HIV it does not mean you are totally disabled, as you can still work” (senior admin clerk)

“People might be HIV positive but that does not mean they are sick to death or disabled which makes it hard for them, because the only grant available for them is the disability grant” (Head social services)

Clearly, these officials also appreciated the “catch-22” situation that patients with HIV/AIDS are in. When dealing with terminally ill patients (even through life expectancy may be extended for a while as in the case of HIV/AIDS patients) it is easy to be sympathetic and feel their pain.

The Doctors being the ones, who do clinical procedures on patients, seem to acutely experience the pain of their patients as it is challenging and emotionally draining to work with people living with HIV/AIDS. This is cited in the following opinions:

“As an individual you do have a sympathetic nature as there are cases that deeply touch your heart in grant application. Then you can give the grant for six months for the critical cases in a social nature, for poor individual to maintain a living” (doctor)

*“Since the Doctor is the one dealing with the applicants directly, it’s his decision that we follow (his lead in granting the assistance)” (*Acting grant administrator)

“All the matters are dealt with by the doctor so we can’t say we have any sympathetic nature that we show since if the person’s CD4 count does not allow him/her to receive the grant we cannot change that” (senior admin clerk).

So what health officials are seeing does not seem to mesh with what they have to offer to patients, in this instance a letter that positively directs the grant. This is difficult for service providers who are human and they may be tempted to adjust their diagnoses and prognoses to better serve their patients. Is this then corruption or heartfelt service? And if this practice becomes common, can it in itself become corruptible by unscrupulous officials who want to make money out of the situation?

The researcher also learnt with surprise that assessment panels assessing grant applicants/applications were no longer used as outlined in (Procedural Manual, 2003) document. This was explored further.

Assessment panels

It is sad to note that the assessment panels are no longer in existence as this body had professionals from all fields to determine the feasibility of the grant application. Key informants stated the following about this panel's role and service not being required any longer:

> *"I arrived at the time when they had been phased out; I have no knowledge of them at all" (*Acting grant administrator).

> *"I came in at the time when the assessment panels had been phased out. It had two offices here at the department them they went"* (senior admin clerk).

These comments show that grant administrators seemed to have no real knowledge about the possible role that could be played by such a panel to better assess grant applications. It seems that their comments were narrow in that they did not state anything to suggest the re-instatement of the panel, a concern given that application processes are fraught with so many problems.

A further development in families and in social security is that in many cases, grant recipients are receiving more than one grant in one household.
This was explored with key informants to ascertain their views. When the Acting grants administrator was interviewed this is what he said:

> *"Definitely you find that in other households people get more then R4000, from foster care grant, child support grant, disability and old age pension for instance"(*Acting grant administrator).

If families can "earn" as much as R4000 in social security, then the state needs to examine how best to manage their resources. This is especially so because in some instances, families are completely bereft of any form of social security or food aid. It may be helpful for the family, but there is a possibility that the applications and thus access have been doctored? Clearly, these concerns and issues need close examination by a team of role players and should be ongoing and regular (ecosystems approach).

The researcher elicited responses from key informants regarding how best they saw grants being processed and managed. The following were the recommendations made by service providers in the area of Vulindlela as there seemed to be many discrepancies when dealing with grant applications:

> *"If people with HIV/AIDS could be given food vouchers like they do in America, instead of being given a grant that will be cut-off once the CD4 count increases and it can save millions of rand for our country" (Medical doctor)*

> *"Once you start on Antiretroviral therapy you need a balanced diet, but immediately after the grant gets cut-off, a client can no longer afford that, so at least once the person starts on Antiretrovirals, they should get the*

> *grant for life as they are on medication that requires them to have stable diet"* (Senior admin clerk)
>
> *"Due to the fact that there is high unemployment level, if people could continue getting the grant even after their CD4 count has increased, it would be better for them to maintain the standard of living health wise especially"* (Head social services).

These comments made by service providers suggest the need for better co-ordination and increased access to services for the rural poor. One person who can link up these different departments is being sidelined in the current scenario. The Chief plays a major role in the rural area and if he is made to be in the center of the application process (as he knows the area he leads), lots of people living with HIV/AIDS would greatly benefit. He may be able to accurately assess need and who requires better nutrition, thereby bridging the gap that exists between patients and service officials. This could also give them a chance to get to know what service officials offer and relay this information to users as the current problem of lack of knowledge prevents many from accessing social security timeously.

If people know they have support from those in charge, they will have courage to face the virus, stop cheating on their medication, and thereby live a quality life instead of premature dying because of not adhering to the treatment.

4.17 SUMMARY AND CONCLUSIONS

The following conclusions and preliminary may be reached from the results of the study:

- Working together and in a coordinated fashion, by different service bodies, could bring about trust and efficient services.
- If service recipients are informed timeously of changes that have been newly introduced, delays that were experienced could be avoided.
- Clear guidelines outlining the application process should be disseminated to all people.
- All service providers should actively practice the Batho Pele Principles to ensure improved services.
- Service delivery should be humane and be equitable, not discriminatory.
- There is also a great need to use a bottom up approach in addressing the needs of poor people as they are easily intimidated by staff personnel.

Chapter FIVE

5 CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

This chapter deals with the conclusions and recommendations arising from the analysis of the qualitative data in the previous chapter.

The reader is reminded of the main objective of this study being to explore and understand the accessibility of social assistance by persons living with HIV/AIDS in the Vulindlela area.
The research study sought to answer the following questions:

- Who are the significant role players both in the formal and the informal systems involved in the delivery of social assistance in Vulindlela?

- What are the experiences and challenges of persons infected with HIV/AIDS in accessing social assistance in Vulindlela?

- What are the difficulties experienced by the persons involved in the social security delivery system in the application process of the disability grant of persons infected with HIV/AIDS?

- What are the recommendations of the various stakeholders in overcoming these challenges and strengthening the system?

These questions form the basis for the structure of this final chapter. The questions are converted to themes and are used to present a summary of the main findings. Recommendations in respect of this study are presented at the end of the chapter and are set in accord with the theory underpinning of an ecosystems perspective.

Using a qualitative research design, this study aimed to discover the meaning and contexts attributed to the questions posed to respondents, through the research tool, the interview. Two sample groups were used viz. patient respondents who were questioned about their experience of accessing the grant and the second group, key informants involved in service delivery, to illuminate and contextualize the findings from the first sample of respondents.

5.2 SIGNIFICANT ROLE PLAYERS BOTH FORMAL AND INFORMAL SYSTEMS INVOLVED IN SOCIAL ASSISTANCE IN VULINDLELA

Considering the ecosystemic framework, many systems were involved in the delivery of social assistance in Vulindlela.

The social grant recipient who accessed the disability grant by him/herself was at the core of the system. The system also consisted of other role players who were interdependent on one another, but the results of the study pointed to a critical role player in the delivery of social assistance being the government of South Africa. The government has stipulated access to social assistance as a right as pronounced in the Constitution of the Republic of South Africa (1996) and that South Africans have a right to administrative justice.

Policies at a macro level shaped access to the social assistance to people affected with AIDS in South Africa. National policies set out the philosophical basis, qualifying criteria, for the amount and procedures that needed to be followed on application, along with the rights of recipients and resource allocations. Such policies were the White Paper of Social Welfare (1997) and the Batho Pele principles (1997). These policies were legislated into the Social Assistance Act (1992). People infected with AIDS were eligible for a disability grant in terms of The Social Assistance Act (1992). The National Department of Social Development was responsible for resource allocations for social assistance and setting of policy guidelines. The National Department of Social Development had also developed procedure manuals for employees working in social security.

Manuals were also developed for service users. This was a national effort to make social assistance more accessible to communities. In terms of the framework for accessibility to disability grants as developed by Mitra (2005) this is a positive step in that there are efforts to ensure communication is clear and understood by people. This responsibility was devolved to provincial departments of Social Development/Welfare. The people of Vulindlela accessed the disability grant at district level where offices were set up. At the district level they deal with administration and delivery of the grants. Results pointed to there being good interaction between the district offices and the community.

Medical doctors appeared to be another major role player in the determining whether or not people qualified for the grant. This was not surprising because the eligibility to the disability grant is based on medical progression of the illness (BMJ. 2002 January 26; 324(7331): 193–197)

Medical doctors and nurses at local clinics played a big part in educating respondent patients about the grant. This is expected since HIV/AIDS is a medical illness and patients' first point of contact is with medical personnel. Also since there are clear criteria (CD4 count), for accessing the disability grant, the doctors know when to refer patients to the Department of Social Development for grant applications. It can also be concluded that the primary health care system in Vulindlela is fairly efficient in making people aware of access to social assistance.

It was noteworthy that the respondents did not mention district surgeons although they are listed in the procedural manual (2003) as key role players. Instead a doctor has now been employed by the Department of Social Welfare to determine respondents' eligibility to the disability grant. The intention of this was to ensure better co-ordination in the system. As discussed by Cloete (cited in Du Toit & Van Der Waldt, 1999:16), co-ordination is essential especially when considering the different systems that need to work in synchrony as per ecosystems theory. It is also important to note that there was no mention of assessment panels in determining eligibility to the disability grant. There was very little contact between the Department of Health and Welfare in this study, although interaction between district offices and the community was good. The latter good interaction is nullified by poor coordination between the two Departments.

Although the Department of Social Development sent clients to Induna (area chief) in the application process, their role was not formalized. The role of the Induna could be critical as a local solution to fill in gaps that exist in the application process.

According to the framework developed by Mitra (2005) the proper use of proxies is important in determining accessibility to the grant. Proxies are recognized as important in South Africa, especially with disabled or ill people. However, they were not used by respondents in this study, possibly because of desperation to access their money themselves and distrust/suspicion that someone else may abuse their monies.

There was limited contact with social workers in the application process since the proposed introduction of SASSA (South Africa Social Security Agency), the regulating body that was set up to serve as watchdog and streamline applications. This could have negative consequences in improving grant access, since in many cases patients had temporary grants and they will have no other recourse to support should their disability grants get cut off. An additional problem was the provision of social relief or food vouchers being withdrawn whilst application outcomes were awaited. The rationale for the withdrawal was because applications did not take long now, but the reality of the situation was that long waiting periods were still experienced, leaving people destitute in the absence of no support.

The non governmental organizations and community based organizations were in the area. However they seemed to play a limited role in informal assistance, in possibly bringing relief for the HIV/AIDS orphans or placing sick adults in community based organizations, together with ensuring that children carry on with their education. Clearly, informal structures need bolstering to help with making some difference in the lives of all persons infected or affected by HIV/AIDS. In addition, it seems that the Basic Income Grant (BIG) could be a possible complementary/supplementary provision to help alleviate poverty and problems related to managing child headed households.

All the stake holders were involved in policy planning but surprisingly, they worked independently instead of co-operatively for improved service delivery. However, policies and procedures regarding organizing, financing, staffing, work protocol are all still in the process of being implemented. So problems with implementation still need to be anticipated, reported where implementation has occurred, and then strategies set for addressing them.
Clearly then, in accord with an ecosystems perspective, many role players are involved in the delivery of social assistance in Vulindlela, all of which not necessarily interacting smoothly with each other; in fact sometimes even in competition with each other.

5.3 EXPERIENCES AND CHALLENGES IN ACCESSING SOCIAL ASSISTANCE

The challenges that persons infected with HIV/AIDS experience is located at many levels of the ecosystem, ranging from individual to macro level.

As discussed in the literature review and found in this study, the qualifying criteria for the disability grant is complicated by the nature of the illness. People are usually unable to work even before their CD4 count is below 200 and need money to ensure good health. Accessibility is also determined only on medical grounds which ignore the context in which people live. Poverty in the rural area of Vulindlela is a major concern especially since the area has a high rate of unemployment; people are living in large households, and these households are supported by the people living with HIV/AIDS who also happened to be breadwinners. This made it very difficult to maintain a healthy standard of living, aggravated by the presence of

HIV/AIDS. This study found that the grant was the main source of income and shared with all family members who live in poverty stricken circumstances. Therefore the conclusion is that social assistance is not accessible to infected persons living with AIDS, a core ingredient that needs multiple role players planning if the HIV/AIDS pandemic is to be meaningfully addressed.

It was clearly established that respondents were in a dilemma about use of Antiretroviral (ARV's) as most people were taken off the grant if their conditions improved, leaving them with no other income. This was a serious problem in the light of high unemployment rates in Vulindlela. So care of the patient was seriously compromised when ARV's were adjusted to suit living circumstances and hardship rather than manage the illness per se.

It was also established that the application process was very long and tedious. Patient respondents complained that policies were forever changing and that change was not filtered to grass roots levels, to the people. There were also other practical problems to the application process. People had to travel longer distances to the area of service only to discover that the department had stopped attending to people as they only help a certain number per day; or finding that they did not meet the qualifying criteria adequately after traveling distances and spending time and money to meet access requirements. Pay points were also far away from the service areas, and if they happened to discover that their grant had been cut off, they had to make another costly trip to air their complaints on time. Transport appeared to be their major challenge and since they lived in a rural area which was far from the city centre, most had to wake up at dawn, to join queues early so as to be in the list of those that would be attended that day. Furthermore the transport cost was unbearable, costing as much as R20 or more per day. For an unemployed and sickly person, with a debilitating illness, this adds to the stress of living positively and indeed surviving under such conditions.

Having the relevant documentation was another obstacle to access along with knowledge of what to bring when applying for the disability grant. The suggestion for large scale education is clearly indicated.

A clear and disconcerting finding was that despite government officials being supposedly guided by Batho Pele principles of courtesy, openness and honesty and value for person, this was not consistently practiced. The burden to the patient under such challenging circumstances, is almost too difficult to bear and flies against the country's constitution.

An important finding that presented a challenge to access was corruption. The representative from SASSA mentioned that they have an anti-fraud unit that deals with all those officials who have been defrauding the system, but amazingly the practice continues unabated. Again, from an ecosystems perspective, all influences need to work in synchrony in order for there to be any measurable effect. And if SASSA is not working in coordination with other providers, then they will continue to work in isolation and not address the corruption problem as it truly exits in practice.

Fear of discrimination and stigma was also a challenge in accessing the disability grant. Only a quarter of respondents had disclosed their status to their families. This truly shows how little our communities are informed about HIV/AIDS. It is one of the reasons why most people decide to keep their status to themselves because of stigma and labeling attached to the disease and the fear that they will be treated as outcasts in their society. Other service providers made it difficult for people applying for the disability, treating them with disdain as per the experience of one of the respondents who faced undue scrutiny at the hands of a professional person who was supposed to support and build the person's self worthiness, not annihilate his dignity.

On the flip side, the disability grant encouraged fraud to a certain extent, as maintained by the medical officer, *“people even bought false blood”*, due to living in poverty caused by the high unemployment rate. They went to their private General Practitioners and asked to be given HIV positive people’s blood so as to obtain a disability grant and maintain a decent standard of living. People did not even take into consideration the danger they were putting themselves into, such as spilt messes on open wounds etc as they were preoccupied by issues of survival in behaving in this manner. It is no wonder then that some patients are maltreated or treated with disdain as discussed earlier, given these behaviours to “beat” the system.

Cultural barriers also served as challenges to accessing the grant in some instances as respondents complained of being discriminated against for belonging to a specific cultural group when they went to collect their medication or to apply for the disability grant. However, they persisted in their efforts to collect medication/the grant as poverty dictated behavior.

Access with regard to language and literacy was not a problem. Officials were helpful, as were formal application forms covering IsiZulu to cater for clientele coming from this service group.

During the process of the study, the social security system was experiencing quick and constant change. It was difficult for officials of the social security system and for people infected with AIDS to keep pace with this. This constant change poses an undeniable problem to access with suggestions for proper and timeous planning that adopts a long term view.

Therefore an ecosystems perspective is clearly useful in involving all role players aiming at communicating improvement in service standards.

5.4 DIFFICULTIES EXPERIENCED BY SOCIAL SECURITY DELIVERY INFORMANTS

Service providers complained of various things that challenged effective service delivery and access to grants by clients.

The expansion and transformation of SASSA posed a major challenge for service providers as they were in an area with very limited resources and lack of professionally trained staff. The shortage of staff greatly affected proper service delivery, with many social workers vacating the Department because of the stressful conditions they worked under. This placed a burden on remaining social workers to cope under trying conditions. This further stressed managers and other administrators who had limited time to both train their staff quickly and put into practice the newly introduced systems for grant application.

Vulindlela being in a rural area was disadvantaged in many ways. Historically there is great lack of infrastructure in rural areas. This made it hard for the officials to reach out to the rural poor people as part of the requirements to help families by understanding their circumstances through home visits.

For the key informants the major challenge was in assisting the new applicants as most of them had no idea on what to bring when applying for the disability grant or any grant; important things like birth certificates, marriage or divorce certificates, death certificate were reported by the senior administration clerk to be very important, but most clients went to apply without these documents or they had left them in another town. This lengthened the application process unduly and exacerbated the poverty status of the family. For those who brought all documents, the application process was easier and faster. This proves that the Batho Pele principle which is Encouraging Innovation and Rewarding Excellence as outlined in the literature review is being respected to a degree and followed by the government departments. So it is apparent from this that Batho Pele principles being practiced is dependent on clients as well, again demonstrating the ecosystems perspective of effect of individual or microsystem on mezzo or macro system (application office and governmental policy). It would be ideal if the same respect could be paid to all principles of Batho Pele, given that all role players are appropriately and concurrently effectively involved.

The medical officer seemed to have been the main source of information and assistance during the grant application, as most patient respondents stated that the medical officer was also the one to attend to problems such as falsified blood results and re-initiate the application process correctly. Sympathetic officials could have perpetuated corruption in an effort to help poverty stricken patients, but such practices only lengthen an already complicated application process.

On the other hand, there seemed to be lack of service delivery on the side of key informants/officials as noted in the findings as some respondents waited over three months before receiving their grants. The lack of service delivery could have been caused by the separation of two departments involved in service provision viz. Health and Welfare. Ideally the two should work together harmoniously as their services complement and supplement each other. Welfare is there to provide for the poor and vulnerable, give them skills and advice regarding services that people need whilst Health stipulates proper medical treatment and advice on proper procedure and qualifying criteria for the disability grant. Together, working in tandem, they ought to ensure relief at a variety of levels, health and well being of the individual and family.

There was also a clear lack of **co-ordination** regarding services that negatively affected access (a significant consideration in ecosystems theory). People leave their place of birth due to low employment opportunities in the rural areas. Migration as a result of poverty forced a lot of people to go to urban areas in search of jobs and a better life. Some people then ended up contracting the virus in the city, only to return to the rural areas which had no resources, further burdening their poor families and under resourced communities.

Vulindlela has a high rate of HIV/AIDS as stated in the literature and this makes it hard for the Department of Social Welfare Population and Development to attend to each case properly. Being understaffed also disfavours the Department. During the conduct of this study, it was found that there were many people who still had not had accessed their grants and many had even died without ever receiving it. One wonders how many people must suffer/die before the disability grant becomes more readily accessible and available for the people living with HIV/AIDS.

As of April 2006, the three month waiting period was declared non existent. Key informants reported that from then, the applicant would get the results the same day of being checked by the doctor. They would hear from social security officials of whether or not the grant was approved and that he/she can appeal the decision within 90 days. However, frustration with this arrangement not working in practice left many without relief, requiring urgent problem solving by officials and policy makers alike.

5.5 RECOMMENDATIONS OF STAKEHOLDERS IN OVERCOMING CHALLENGES

Both sets of respondents were asked what recommendations they had for better access to the grant.
Almost all the key informants from different departments suggested that food vouchers be reinstated as this would assist in most vulnerable households.

The key informants also recommended providing the Basic Income Grant (BIG) to alleviate poverty in the area. The disability grant then can be utilized directly by the infected person as in many instances it is evident that the disability grant is used to cater for the whole family, not the infected person’s needs. This may also deal with the problem of stigma when accessing the disability grant.

If people with HIV/AIDS could be given food vouchers as is done in America, instead of being given a grant which gets cut-off once the CD4 count increases, this could save millions of rands for our country.

Access to the disability grant should not be cut off once the infected person is better with proper administration of antiretroviral therapy. In fact once persons start ARV's, they should get the grant for life, this being a lifelong disease and because they are on medication that requires them to enjoy a wholesome diet. It was also recommended that due to the fact that there is high unemployment in the area, people should continue getting the grant even after their CD4 count has increased, because the chances of getting employment whilst being vulnerable to opportunistic disease, was limited.

For quick and effective service standards, it was suggested by the key informants that there should be better networking between local and traditional leaders and the Departments. Then people would not have to actively seek assistance as there will be clear information all round. This suggests the adoption of an ecosystems perspective, one where the contributing role of all systemic influences are recognized and addressed where dysfunction and dissonance prevail.

Recommendations by researcher

The researcher has set out the recommendations in accord with the ecosystems perspective because this helped with theoretically grounding the study.

- ✓ **Respect and recognition:** It could be recommended at a micro level that the people living with HIV/AIDS, be acknowledged and treated with respect and recognition of their right to self determination. This needs to be achieved during individual contacts; when people get individual attention they feel important and empowered. In this way they would be in a position to reveal their status to significant others/officials and enjoy better and timely assistance than at present.

- ✓ **Stigma and discrimination**: This needs to be dealt with as a separate issue as people living with HIV/AIDS were found to experience great difficulty even in living in their own homes and/or communities with their children being subjected to persecution and sometimes active harm. All three social work methods should be together used to break the back of this trend. Casework is very necessary to change unhealthy attitudes and behaviors; group work needs to be educative and therapeutic and community work is also essential.

- ✓ **Ignorance and knowledge regarding services/resources:** The Department needs to advertise their services to get public attention and for the people to start utilizing services to which they are entitled. Further, more direct lines of communications should be made publicly available. For better service delivery of the rural deserving poor we need networking and positive co-operation between all the stakeholders.

  At a macro level, mass media to deal with ignorance and provide knowledge about rights and responsibilities relating to HIV/AIDS should prove very useful. To this end, local newspapers, television and even door-to-door visits (used in political campaigning) may be critical.

- ✓ **Education and training:** At micro, mezzo and macro levels, service providers and recipients need to be taught through education, training and retraining about the ever changing knowledge and advancements related to HIV and AIDS, to be fully informed of all changes. This has implications for educational institutions and service providers who have to keep themselves updated in order to impart this knowledge effectively. It is also a reality that education must needs be imparted in a manner that is novel and creative, so the search should continually be for innovative teaching and learning methods. Education through group work support is important as this could allow people living with HIV/AIDS to have hope, develop trust and their dignity protected in the course of knowledge giving and receiving.

- ✓ **Therapeutic casework and group work**: Group work support will positively empower as well as encourage people living with HIV/AIDS to first accept their status and then learn to live positively with it. Further, it has potential for significant others too to enlighten them and overcome stereotyping. If people living with HIV/AIDS are supported and encouraged to go for treatment and therapy, there would be lesser numbers of HIV/AIDS deaths in our country as a whole.

- ✓ **Therapeutic Family Intervention**: Family therapy would help persons living with HIV/AIDS feel comfortable enough to discuss their status openly with loved ones so as to get proper attention and assistance. As family therapy encourages open lines of communication, understanding, support and mutual assistance will be better assured from immediate family members. The most important contribution of family therapy will be developing greater bonds amongst family members, increase sensitivity and provide opportunity for discussion of fears, anxieties, hopes and dreams. In this manner family members learn how to protect their members from discrimination, exclusion and harm.

- ✓ **Pressure and support groups:** At a mezzo level, since people living with HIV/AIDS meet each other at hospitals or clinics regularly they could come together not only to provide support to each other but also to exchange ideas that would positively impact their lives such as learning beadwork as an income generation past time. The latter suggestion is made to deal with the problem of unemployment both in the area as well as with HIV affected persons. They could also together brainstorm for improved service delivery, possible sheltered employment opportunities as well as act as a pressure group with a voice to make changes that positively affect them. A disappointing finding was that many client respondents confirmed their status very late, retrieved documentation essential for grant access late or never and reapplied when instead they could have appealed grant refusal decisions. Clearly, poor, naïve people suffering from HIV/AIDS need organizing to benefit from a variety of interventions that aim at education alongside therapy to empower them and better grant access.

- ✓ **Neighbourhood involvement**: At the exosystemic level, it is important to harness the support of the community to help deal with problems related to access since neither the person with HIV/AIDS, nor his/her family can constantly give time and effort to deal with problems of service delivery. Such involvement will traditionally be the role of the social worker to ensure community social work services, but could just as easily be driven by informal supports such as by the traditional community leader. Formalizing traditional supports seems to be a useful strategy given the enormity of HIV/AIDS and the many role players needed to comprehensively address it (ecosystems perspective). Such involvement has the added benefit of vicarious education and thereby stigma and discrimination may be easily overcome. Clearly, community work of this nature has to occur alongside other strategies mentioned earlier such as group work, casework and even education and training.

- ✓ **Medical support:** People living with HIV/AIDS had knowledge on how exactly to access grants only because they were assisted by the medical doctor after going for testing. This needs to be formalized as a supportive service and medical personnel afforded more time and recognition for providing this service. The Department of Health needs to accept this crucial role and responsibility and provide training on how best to impart information to their patients.

Further, the challenge was regarding accepting the medical definition of disability; this needs to be revisited not only by medical personnel but also other team members (in accord with an ecosystems perspective) to include impairment exacerbated by poverty, prejudice and social exclusion.

- ✓ **Complementary and supplementary services:** Living with the virus often renders patients incapable of working and being constantly fatigued, with CD4 counts being such that grants could be withdrawn. Several possibilities exist to support patients- to have food vouchers instead of grants or food vouchers to supplement the grant. Another important service and duty that was necessary but absent was to advise and refer patient respondents who were still on the waiting list for social relief, and to drop-in centres or other non-governmental organizations to plan for the future care of orphaned children in case the parents die. Networking and effective teaming is clearly necessary and in accord with ecosystems theory that confirms the need for all systemic players to function harmoniously together, recognizing the value of all contributions.

  Further, service excellence would be assured if there were mobile offices in the rural area of Vulindlela, to bring services closer to the people.

- ✓ **Dealing with corruption**: Corruption was a major concern both in respect of professionals and people living with HIV/AIDS when accessing the grant. This is degrading for professional people who were sworn in to provide better services to the poor and who were supposed to promote and protect the dignity of the community they serve. Several ways are suggested to curb this tendency. One way in which people living with HIV/AIDS find harmony, peace, support, love and acceptance is through accepting God, because this is where they will not be judged, labeled or discriminated against. This self same spiritual system of support could be used to help them appreciate that corruption is wrong and indeed criminal. Another is to ensure that SASSA works more efficiently to prevent corruption although this requires that the body works together with policy makers to work at reviewing qualifying criteria that discriminate HIV/AIDS persons unjustly. A further suggestion is for cameras to be installed at all centres where applications are made, although the sensitive nature of HIV/AIDS may need for this to be thoroughly negotiated in order that no rights are infringed. Networking (a core ingredient of ecosystems theory) then is crucial in ensuring that all involved role players are satisfied with actions that may curb corrupt behaviour.

- ✓ **Staff shortages**: More people are living with HIV/AIDS than with any other life threatening disease that service providers deal with. This makes it hard for them to deal with heavy work loads. Ensuring that there is enough staff to assist people living with HIV/AIDS is an important task that the Department should deal with to better service the rural poor. Perhaps, there also needs to be a programme on staff self care to facilitate coping with heavy, difficult or sensitive workloads.

- ✓ **Policy development**: At the macro level, HIV/AIDS is recognized as a global phenomenon that is increasingly threatening life. It should be dealt with holistically and by all service providers at policy level to better the lives of people in our society. Being globally connected allows for global exchange and collaboration to plan and intervene better changing the devastating effect of this pandemic. Then these exchanges should ideally result in workshopping of ideas to arrive at best options. Even then these options should be regularly evaluated (such as in the case of the Batho Pele principles) to assess how they must be adjusted to keep pace with changing trends and circumstances. People possess rights; they should exercise this right for improved standards of assistance that would uplift them from the dire poverty they experience.

A further suggestion for macro level involvement is for HIV/AIDS to be viewed in relation to poverty and unemployment. These need to be deliberated at all systemic levels for joint problem solving.

- ✓ **Research:** There is a need for more research to increase understanding of the pandemic and facilitate appropriate prevention and care programmes. This study was qualitative, on only one aspect of HIV/AIDS, grant access of persons affected by the virus, with a small select sample from a specific location.

  More studies are necessary to uncover the multi-faceted nature of the pandemic; mixed research methodologies are necessary to quantify and qualitatively explore and describe meanings attributed to so many aspects of the pandemic; larger samples are necessary to allow for generalization and longitudinal studies essential to trace developments and effects of the changing face of the pandemic.

Lastly, the researcher believes that since HIV/AIDS is a chronic illness, affecting so many South Africans, and pervading a new democracy that is struggling to survive the pressures of such like as corruption and political power plays, that the answer may not lie in changing access conditions regarding the disability grant to help persons with AIDS. Rather the answer may lie in a newly introduced grant exclusively for the people living with the virus, to lessen the burden of meeting qualifying criteria and thus give dignity to and improve life quality.

Appendix One

Themes for in-depth interviews with people infected with HIV/AIDS

Biographical details

What are your perceptions and experiences in as far as applying for disability grants: - PROBE: understanding of procedure and qualifying criteria, cultural and social barriers, challenges and strengths of the system, satisfaction with the system.

What can be done to improve access and enhance integrated, sustainable services?

Appendix Two

Themes for in-depth interviews with key informants

Biographical profile of the organization / sectors they represent

Services provided by key informant

Policies and procedures of the organization in accessing social security for people living with HIV/AIDS?

Difficulties they encounter in dealing with the application and procedure involved of the disability grant.

How can the system be strengthen, and made more user friendly?

APPENDIX THREE

INTERVIEW GUIDE

Biographical information:

BIOLOGICAL DETAILS

1. Age

18-24 years	
25-35 years	
36-46 years	
47-57 years	
58-61	
62+	

2. GENDER

MALE	
FEMALE	

3. MARITAL STATUS

SINGLE	MARRIED	DIVORCED	SEPARATED	LIVING TOGETHER	WIDOWED	OTHER

4. HIGHEST LEVEL OF EDUCATION

NEVER STUDIED	
GRADE FOUR	
GRADE SEVEN	
GRADE TEN	
MATRICULATED	
TERTIARY (SPECIFY)	

5. RELIGION

SHEMBE
ZION

CHRISTIAN, SPECIFY
OTHER

6. OCCUPATION

TEMPORARY EMPLOYMENT	
FULL TIME EMPLOYMENT	
PUBLIC WORKS PROGRAMMES	
NOT EMPLOYED	
OTHER	

7.SOURCE OF INCOME

EMPLOYMENT	
SOCIAL SECURITY	
CHILDREN'S GRANT	
SELF EMPLOYED	
OTHER	

8. TYPE OF EMPLOYMENENT, (SPECIFY WHAT YOU ACTUALLY DO?)

9. HOUSEHOLD COMPOSITION

NUMBERS IN HOUSEHOLD

1-2	3-5	6-7	8-9	10-11	12-13	14+	OTHER

9. WHEN DID YOU FIRST GET TO KNOW THAT YOU ARE HIV POSITIVE? PROVIDE DETAILS………………………………………………………………………………
…………………………………………………………………………………………
…………………………………………………………………………………………
…………………………………………………………………………………………

10. HOW LONG SINCE YO HAVE BEEN ON ARVs?

11. WHEN DID YOU STOP WORKING DUE TO THE ILLNESS?EXPLAIN……………………………………………………………
…………………………………………………………………………………………
…………………………………………………………………………………………
……………………………………………………………………………………….....

12. HAVE YOU APPLIED FOR THE DISABILITY GRANT? IF YES PLEASE PROVIDE DETAILS, IF NO PLEASE STATE WHY?..
...
...
...

13. WHAT GRANT DID YOU APPLY FOR?

14. HOW DID YOU FIND OUT ABOUT THE DISABILITY GRANT?EXPLAIN………………………………………………………………
…………………………………………………………………………………
…………………………………………………………………………………
…………………………………………………………………………………

15. HOW DID YOU KNOW YOU QUALIFY FOR THE DISABILITY GRANT? GIVE DETAILS………………………………………………………………………
…………………………………………………………………………………
…………………………………………………………………………………
…………………………………………………………………………………

16. WHAT DIFFICULTIES/CHALLENGES DO YOU FACE WITH APPLYING FOR A DISABILITY GRANT?EXPLAIN………………………………………………………………
…………………………………………………………………………………
…………………………………………………………………………………
………………………………………………………………………………...

17.WHAT WAS THE PROCEDURE THAT YOU HAD TO FOLLOW IN ORDER TO QUALIFY FOR THE DISABILITY GRANT?GIVE DETAILS………………………………………………………………………
…………………………………………………………………………………
…………………………………………………………………………………
…………………………………………………………………………………

18. HOW LONG HAVE YOU WAITED FOR THE DISABILITY GRANT?EXPLAIN………………………………………………………………
…………………………………………………………………………………
…………………………………………………………………………………
………………………………………………………………………………..

19. IS THERE ANYBODY THAT YOU COMPLAINED TO REGARDING THE PERIOD YOU HAD TO WAIT?IF YES PLEASE PROVIDE DETAILS, IF NO STATE………………………………………………………………………
…………………………………………………………………………………
…………………………………………………………………………………
…………………………………………………………………………………

20. DID YOU GET ANY ASSISTANCE FROM YOUR DOCTOR OR CLINIC FOR APPLYING? PLEASE EXPLAIN………………………………………………………………………
…………………………………………………………………………………
…………………………………………………………………………………
…………………………………………………………………………………

21. IS THIS THE FIRST TIME YOU ARE APPLYING FOR THE DISABILITY GRANT? IF YES PLEASE PROVIDE DETAILS, IF NO STATE………………………………………………………………………………
………………………………………………………………………………
………………………………………………………………………………
………………………………………………………………………………

22. IF YOU HAVE HAD YOUR GRANT FOR MORE THAN SIX MONTHS DID YOU REAPPLY? PLEASE PROVIDE DETAILS…………………………………………………………………………
………………………………………………………………………………
………………………………………………………………………………
………………………………………………………………………………

23. WHAT ARE YOUR FEARS OF HAVING YOUR GRANT CUT-OFF?EXPLAIN……………………………………………………………………
………………………………………………………………………………
………………………………………………………………………………
………………………………………………………………………………

24. IS IT FEASIBLE FOR YOU TO GO TO THE RELEVANT DEPARTMENTS TO APPLY? IF YES PLEASE PROVIDE DETAILS, IF NO STATE………………………………………………………………………………
………………………………………………………………………………
………………………………………………………………………………
………………………………………………………………………………

25. ARE YOU THE BREAD WINNER IN THE FAMILY? IF YES PLEASE PROVIDE DETAILS, IF NO STATE………………………………………………………………………………
………………………………………………………………………………
………………………………………………………………………………
………………………………………………………………………………

26. IS THE GRANT THE MAIN SOURCE OF INCOME IN THE FAMILY?EXPLAIN………………………………………………………………
………………………………………………………………………………
………………………………………………………………………………
………………………………………………………………………………

27. NUMBER OF DEPENDENTS IN THE HOUSEHOLD?PROVIDE DEATIALS…………………………………………………………………………
………………………………………………………………………………
………………………………………………………………………………
………………………………………………………………………………

28. IS THERE ANYBODY ELSE IN THE FAMILY WHO IS INFECTED? IF YES PLEASE PROVIDE DETAILS, IF NO STATE………………………………………………………………………………

………………………………………………………………………………………
………………………………………………………………………………………
………………………………………………………………………………………

29. HAVE YOU LOST ANYONE CLOSE TO YOU DUE TO HIV/AIDS? PROVIDE DETAILS………………………………………………………………………
………………………………………………………………………………………
………………………………………………………………………………………
………………………………………………………………………………………
………………………………………………………………………………………
………………………………………………………………………………………

30. DO YOU HAVE ANY RECOMMENDATIONS TO HELP OTHERS THROUGH APPLYING FOR THE DISABILITY GRANT?

Appendix Four

INFORMED CONSENT FORM-K I

PROJECT TITTLE:

THE ACCESSIBILITY TO SOCIAL ASSISTANCE BY PERSONS LIVING WITH HIV/AIDS IN THE VULINDLELA AREA.

Statement of the project's aims

The study aims to assess the difficulties and challenges experienced by people with HIV/AIDS in the rural area of Vulindlela in accessing social assistance.

I am a registered Masters student in the School of Social Work and Community Development at the University Of KwaZulu Natal. I am currently in the process of undertaking research for my dissertation. Dr Neeta Gathiram telephone no.031-2607932 from the above mentioned University is the University supervisor for my dissertation. (*This is now changed as my ex supervisor has left the University).*

My research questions are as follows:
Who are the significant role players both in the formal and the informal systems involved in the delivery of social assistance in Vulindlela?

What are the experiences and challenges of persons infected with HIV/AIDS in accessing social assistance in Vulindlela?

What are the difficulties experienced by persons involved in the social security delivery system in the procedure and the approval of the disability grant for people with HIV/AIDS?

What are the recommendations of the various stakeholders in overcoming these challenges and strengthening the system?

You have been identified as a key informant to meet the aims of the study. To obtain this information you have been chosen to participate in an interview. The interview will be approximately an hour. All information that will be obtained will be treated with the strictest of confidence. After the completion of the project, all your information will be kept in locked place to ensure no one has access to it. There will be no payment or reimbursement of any kind for your participation in this study. As a voluntary participant, you have the right to withdraw from the study at any time without being prejudiced.

I…………………………………………………… ………………………………
(Full names) hereby confirm that I understand the content of this document and the nature of the research project, and I consent to participate in the project.

I understand that I am at liberty to withdraw from the project at anytime, should I so desire.

Please print you name and sign to confirm your participation in this study

Name: ____
Contact No: ____
Organization: ____
Signature: ____
Date: ____

Signature of Witness: (1) _________________________________Date:

:(2) _________________________________Date:

Appendix Five

INFORMED CONSENT FORM- Patient-Respondents

PROJECT TITTLE:

THE ACCESSIBILITY TO SOCIAL ASSISTANCE BY PERSONS LIVING WITH HIV/AIDS IN THE VULINDLELA AREA

Statement of the project's aims

The study aims to assess the difficulties and challenges experienced by people with HIV/AIDS in the rural area of Vulindlela in accessing social security.

I am a registered Masters student in the School of Social Work and Community Development at the University Of KwaZulu Natal. I am currently in the process of undertaking research for my dissertation. The research focuses on the challenges and experiences of people with HIV/AIDS in accessing disability grants. Dr Neeta Gathiram telephone no.031-2607932 from the above mentioned University is the University supervisor for my dissertation. (*This is now changed as my ex supervisor has left the University).*

My research questions are as follows

Who are the significant role players both in the formal and the informal systems involved in the delivery of social assistance in Vulindlela?

What are the experiences and challenges of persons infected with HIV/AIDS in accessing social assistance in Vulindlela?

What are the difficulties experienced by persons involved in the social security delivery system in the procedure and the approval of the disability grant for people with HIV/AIDS?

What are the recommendations of the various stakeholders in overcoming these challenges and strengthening the system?

You have been identified as a key informant to meet the aims of the study. To obtain this information you have been chosen to participate in an interview. The interview will be approximately an hour. All information that will be obtained will be treated with the strictest of confidence. After the completion of the project, all your information will be kept in locked place to ensure no one has access to it. There will be no payment or reimbursement of any kind for your participation in this study. As a voluntary participant, you have the right to withdraw from the study at any time without being prejudiced.

I………………………………… …… … …………………………… ……………... (Full names) hereby confirm that I understand the content of this document and the nature of the research project, and I consent to participate in the project.

I understand that I am at liberty to withdraw from the project at anytime, should I so desire

Please print you name and sign to confirm your participation in this study

Name: ____

Signature: ____

Date: ____

Signature of Witness: (1) _________________________________Date:

:(2) __________________________________Date

Appendix Six

The Chief Director
Department of Social Welfare
P/Bag X1724
Pietermaritzburg
3200

Attention: Dr Mqadi

Re: Placement for Research

I am a registered Masters student in the School of Social Work and Community Development at the University Of KwaZulu Natal. I am currently in the process of undertaking research for my dissertation. Dr Neeta Gathiram telephone no.031-2607932 from the above mentioned University is the University supervisor for my dissertation. (*This is now changed as my ex supervisor has left the University).*

The title of my research is "The Accessibility to Social Assistance by Persons Living with HIV/AIDS in the Vulindlela Area".

Statement of the project's aims

The study aims to assess the difficulties and challenges experienced by people with HIV/AIDS in the rural area of Vulindlela in accessing social assistance.

My research questions are as follows:

Who are the significant role players both in the formal and the informal systems involved in the delivery of social assistance in Vulindlela? What are the experiences and challenges of persons infected with HIV/AIDS in accessing social assistance in Vulindlela? What are the difficulties experienced by persons involved in the social security delivery system in the procedure and the approval of the disability grant for people with HIV/AIDS? And what are the recommendations of the various stakeholders in overcoming these challenges and strengthening the system?

To answer my research questions I need to interview 3 staff members from the Vulindlela Department of Social Welfare Population and Development. The categories of staff that are pertinent to my study are a Social worker, a Medical Doctor and a representative from Social Security with your permission.

I will appreciate it if my request got your immediate attention. I intend completing my dissertation immediately, which has been stipulated by my bursars.

Should there be any queries please do not hesitate to contact me on this no. 0834640610.

Yours faithfully
Maloney Lindiwe Mtembu (Miss)

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