

Assessing Learning Needs of KwaZulu-Natal Paralegals for Managing HIV/AIDS

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DECLARATION

I, Sandile Sithole, declare that this is my own, unaided work. It is being submitted for the requirements of the degree of Masters of Social Science (Community Development), at the University of KwaZulu-Natal (Formerly the University of Natal, Durban). It has not been submitted for any degree or examination in any other university.

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~~Signature~~

A handwritten signature in black ink, appearing to read 'S. Sithole', written over a horizontal line that has been crossed out with multiple parallel lines.

Date: 13 February 2004

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Abstract

The Constitution of South Africa outlines the way in which the country should be run and lays down *different levels of government and their powers*. Most importantly it sets out a list of human rights in the Bill of Rights. These rights belong equally to all individuals. Stigmatization and discrimination of people on the basis of their HIV status is a violation of their basic human rights.

In South Africa a person can have his or her rights upheld in court if they are violated or *threatened by an individual or institution (whether the state, private company or any other organization)*. Enforcing the rights of people living with HIV/AIDS and/or their families, as well as countering and redressing discriminatory action, is a matter of accessing existing procedural, *institutional or other resources that comprise the societal gains of democracy*. However, the biggest challenge currently has to do with ordinary people's lack of awareness about their rights, and this pertains particularly to those millions of South Africans living with HIV/AIDS.

This study sets out to examine the knowledge levels of para-legals currently advocating for the rights of people living with HIV/AIDS and/or their families in KwaZulu Natal. With an infection rate estimated to be in the region of 36% of the adult population, it is essential that providers of legal advise and advocacy in this province have sound grasp of HIV/AIDS issues.

It should be noted that this study attempts to move beyond a documentation of knowledge by *exploring what such para-legals perceive their actual needs for more effective management of HIV/AIDS to be*. The study seeks to make recommendations towards a better and more relevant training of para-legals, one that is needs-driven and more attuned to the context and lived realities of the people whom they seek to serve.

Dissertation Summary

The study consists of five chapters as follows:

- Chapter 1 is an orientation to the study that provides a context for the study as well as rationale for assessing learning needs of KwaZulu-Natal para-legals for managing HIV/AIDS.
- Chapter 2 focuses on materials and documents on the subject of HIV/AIDS, legal and human rights related issues. It emerged that HIV/AIDS is a complex issue that requires timely and integrated intervention strategies.
- Chapter 3 outlines the methodology used to collect data that would be analysed to assess the learning needs of KwaZulu-Natal para-legals for managing HIV/AIDS. This study was triangulated through usage of focus groups, questionnaires and reviews of written documents.
- Chapter 4 provides the findings of para-legals said needs regarding knowledge for managing HIV/AIDS in their respective communities. These included training about how to provide counselling to people living with HIV/AIDS and /or their families; the need for awareness-raising workshops and campaigns to prevent further spread and motivation towards care, support and treatment of people living with HIV/AIDS and/or their families and training regarding how to establish local networks of stakeholders and role-players to ensure a concerted and co-ordinated attack on the problems to address HIV/AIDS issues.
- Chapter 5 provides a summary of findings and then offers recommendations and conclusion. The summary suggests three areas of prime importance in managing HIV/AIDS in KwaZulu-Natal. These are individual counselling, community workshops to raise awareness and campaigns, and training on forming networks or coalitions at local community level. Recommendations are that, integrated approaches should be used to effectively manage HIV/AIDS. Two such crucial approaches are a regional and local community approach. The strategies should be multi-pronged and look at communications frameworks that will respond positively towards reducing the spread, effects and impacts of HIV/AIDS to people living with HIV/AIDS and/or their families.

- Finally, the references and appendices of relevant information to the study, including the focus group questions and programme followed, questionnaires used during data collection from practicing para-legals and a map of CLRDC Paralegal Offices and/or Resource Centres and the CLRDC Diploma in Para-legal Studies Course Content Outline.

CHAPTER 1

ORIENTATION TO THE STUDY

1. INTRODUCTION

This study is in essence an assessment of para-legals' learning needs required for managing HIV/AIDS in rural communities of KwaZulu-Natal.

The HIV/AIDS pandemic has multi-faceted causes and impacts but discrimination against sufferers of disease is in no way helping to curb it. Notions of human rights and the law are regarded as significant forces for decreasing vulnerabilities of individuals and communities suffering from the impact of the disease. However, international and national frameworks are often too distant from the realities of communities. It is for this reason para-legals are viewed as community conduit to justice. In the light of this fact, the researcher wishes to explore whether indeed para-legals are adequately equipped to advocate for the human rights of people living with HIV/AIDS and/or their families.

What is a paralegal?

By definition, a paralegal (also known as a legal assistant) is a person qualified through education, training or work experience to perform substantive legal work requiring knowledge of legal concepts and is customarily but not exclusively, performed by a lawyer. A paralegal may be retained or employed by a lawyer, law office, government agency or non-governmental agency and may be authorized by administrative, statutory or court authority to perform this work.

This study concerns itself with both student and practicing para-legals' learning needs required by them in order to effectively manage HIV/AIDS. Some para-legals are responsible for assisting disadvantaged rural citizens by resolving their law-related problems and facilitating human rights' educational events. Para-legals can play a pivotal role in educating communities about their human rights and addressing issues of HIV/AIDS-related discrimination.

The study aims to reveal knowledge levels, attitudes and perceptions of HIV/AIDS held by both types of para-legals. Issues around prevention, transmission, and HIV risk factors will be the most important themes being explored.

Para-legals can make meaningful contributions towards managing HIV/AIDS in their respective local rural communities in KwaZulu-Natal. Often they are the only resource for accessing information due to lack of libraries and other resource centres. The study will help inform a learning programme design that will empower para-legals to make a meaningful contribution towards advocating and protecting legal and human rights of people living with HIV/AIDS and/or their families.

These people continue to suffer from various forms of discrimination, stigma and ostracism based on their health condition and/or status. Often human rights are actually violated due to discrimination and victimization. Human rights organizations, such as the **Community Law and Rural Development Centre (CLRDC)**, play an important role in bringing such issues to the fore and contributing towards addressing them at community level. This study aims to discover what rural based para-legals identify as their required learning needs for making a meaningful contribution towards managing HIV/AIDS in KwaZulu-Natal.

1.1 BACKGROUND AND CONTEXT

It is a known fact that the HIV/AIDS pandemic is at crisis level in KwaZulu-Natal. The prevalence of HIV/AIDS poses a threat to the social, economic and political situation in South Africa given the fact that KwaZulu-Natal is the second most populated province, after Gauteng. The epidemic is growing with alarming speed in KwaZulu-Natal. Therefore, intervention programmes and/or strategies that will equip service providers to deal with HIV/AIDS issues are critical.

The CLRDC is a non-partisan, non-profit organization incorporated as a Section 21 company (company not for gain). CLRDC promotes a human rights culture through education and training in rural communities. Its projects include workshops on democracy and governance, provision of access to justice, capacity building for rural community structures, gender awareness and HIV/AIDS training and support.

This study is based on the CLRDC's most recent objective of training para-legals around the challenges presented by HIV/AIDS. The CLRDC has a pool of over 110 Para-legals and over 300 paralegal committees, enabling it to make a meaningful contribution to awareness raising and education and training with regards to HIV/AIDS issues.

Formerly known as the Community Law Centre (CLC), the CLRDC began working in rural communities in KwaZulu-Natal and parts of the Eastern Cape because of the very limited access to legal, human rights and democracy education in rural communities. Another motivating factor was the mounting political repression and in South Africa that violated people's basic rights. Prior to 1989, the only legal facilities available to rural dwellers were the local Magistrates' Courts and these were often ineffective and not easily accessible since they were situated far from the communities. They did not offer education, but only featured education after the fact.

Community-based legal advice and education is essentially the only option for ordinary people to access justice. The CLRDC began working in five pilot communities and gradually increased the number of communities to 67 with over 70 functioning advice offices. These are staffed by 110 para-legals who are approximately 60% female and 40% male.

The CLRDC has a broad training curriculum for its student para-legals pursuing a Diploma in Paralegal Studies (accredited by the University of Natal, Faculty of Law) and others already in practice as para-legals in rural communities. Those in practice participate in the CLRDC's annual programme entitled "Continued Legal Education" (CLE). This provides practicing para-legals with an opportunity to learn new changes in law as well as other CLRDC programmes. This, it is intended that this study will benefit all learners in the CLRDC programme and the organisation itself.

1.2 RATIONALE AND PURPOSE

The study aims to assess the learning needs of a core group of student para-legals and those already practicing in rural-based advice offices and/or resource centres for managing HIV/AIDS.

The study will address learners' (para-legals) needs and those of the educators and employers (CLRDC). (Para-legals are employed by various institutions to provide services to indigent communities.) These institutions all have their own mission and objectives and depend on donor funding to further these. This study intends to enable the CLRDC to integrate the question of HIV/AIDS into its human rights' programmes, thus enhancing its potential to attract more funding. Likewise, the demand for its services from clients is expected to increase.

This study is relevant to the researcher's current field of study in Community Development and is of use to the organisation where the researcher is currently employed. The results will also be useful in a real

situation of programme development. The CLRDC will use the information gathered to develop a human rights-based HIV/AIDS programme to help para-legals towards managing HIV/AIDS in their respective communities.

The CLRDC is one of the most sophisticated and influential NGOs in KwaZulu-Natal because of its multifaceted education and training programmes and grassroots involvement. It has established sound relations with both traditional authorities and communities at grassroots level as well as local government structures over the past thirteen years. It has also established over 70 community-based paralegal offices, some of which are currently converted to community resource centres.

Para-legal offices are managed by paralegal committees, within which the CLRDC has built capacity to spearhead their own development. These committees organize local community workshops facilitated by para-legals. Because they are supported by the powers that be they serve to empower the community. The CLRDC provides support and evaluation services to both para-legals and paralegal committees.

The CLRDC has established an infrastructure whereby information is easily accessible to community members. This includes print material, education and training on issues of HIV/AIDS. The CLRDC has not yet developed a programme that responds to the needs of its partner communities to venture into HIV/AIDS advocacy. In all of its education and training programmes, be they for traditional leaders, para-legals, paralegal committees or local government, there is always a demand for HIV/AIDS programmes.

Para-legals are the nearest local resource by which rural communities can access to justice, democracy and good governance. Para-legals have been trained in a myriad of legal and community developmental subjects (i.e. social transformation issues) that enables them to simultaneously resolve individual matters and to run educational workshops to empower the broader community.

In the past, para-legals did not receive adequate training for dealing effectively with HIV/AIDS-related matters. Para-legals end up referring HIV/AIDS related cases to home-based care workers even though they ought to have provided assistance themselves. Without adequate training, para-legals cannot respond to the community's need for their intervention on HIV/AIDS, human rights and law-related matters.

It ought to be noted that the study is based on Queeney's (1995: 199) theory, which suggests that: "careful educational needs assessment is a first step to develop intervention strategies that are relevant. Although the results of any needs assessment are usually imprecise and rarely point with certainty towards specific action, they are helpful to inform programme design. The needs assessment helps the educator to collect information relative to the learners' strengths. The next step is for an educator to review the data and to develop opportunities to act on the strengths and perhaps improve any potential areas of weakness".

1.3 THE SIGNIFICANCE OF THE STUDY

The study will investigate the learning needs of para-legals on human rights- based HIV/AIDS issues with the intent of making training meaningful. The researcher has vast experience in community development and his intensive training on HIV/AIDS at postgraduate level will contribute significantly in assessing learning needs of Kwa-Zulu-Natal para-legals for managing HIV/AIDS. The study will also equip the researcher with advanced skills and knowledge to handle HIV/AIDS capacity building programmes for government planners and other sectors in KwaZulu-Natal.

The study will provide insights regarding the learning needs of para-legals on matters of HIV/AIDS at local community level. In the light of the researcher being conscious of community development approaches that exist, any developmental intervention must address an identified need by the beneficiaries and the present study is seen to provide this aspect. The experience the researcher brings to the study will also be helpful in determining the learning needs of para-legals for managing HIV/AIDS in KwaZulu-Natal.

This study is therefore significant on the following basis:

Firstly, the study will reveal the experiences of practitioners in Education, Training and Development (ETD) in working with rural communities, providing multi-faceted education and training programmes that include among others; aspects of law and capacity building rural community structures.

Secondly, the study will contribute significantly to ETD Practitioners in developing skills and knowledge in development facilitation and management through postgraduate studies in community development. The study will also reveal principles of community development that are "a people-centred and people-driven process". In other words, it means that the development

initiative introduced by the development practitioner must address people's needs. The intervention strategy in this process thus begins with a "needs assessment" also commonly referred to as a "needs analysis".

Thirdly, the study is applicable to real life situations. The outcome of the study will help to inform the design of a learning programme that will respond to the needs of para-legals for managing HIV/AIDS in their respective local communities in rural areas of KwaZulu Natal.

Fourthly, participants in the study will be the same people who will benefit from the study and the learning programme that will be designed and who will then ultimately respond to their clientele needs for intervention in managing HIV/AIDS in their communities.

Fifthly, one of the fundamental principles of development is "people's participation" from the planning stages of any developmental initiative. The learning programme that will be developed out of the study will be a result of the participants' identified learning needs. This can be qualified by Boyle's (1981: 95 - 96) arguments where he highlights the reasons for involvement of people in needs identification and assessment. He states that the reasons provide three basic premises for support for the concept of citizens' involvement in programme development as follows:

- 'More accurate decisions about the relevant needs and opportunities for which continuing education programmes will be reached when clientele are involved in making those decisions. It is believed that people, when provided with the real facts of the situation, will identify their most critical problems.'
- 'The involvement of clientele representatives will speed up the process of change. It is assumed that those who are involved will aid in diffusing and legitimizing subsequent educational programmes.'
- 'Involvement in programme development is a learning experience. Participants should be better informed and better prepared for active leadership in a process of change'.

Goody and Kozoll (1995: 3) further confirmed Boyle's argument by acknowledging that the facilitator or educator must bring together the various players and resources in the planning process.

Goody, Kozzoll and Boyle's argument implies that the study will apply constructivism as explained by Gravett (2001). According to Gravett, constructivism is based on an assumption that learning is a process of constructing meaning and a process of knowledge construction. The process entails that learners arrive at meaning by selecting their own knowledge rather than being recipients and storages of knowledge. This process occurs through both individual and societal activity. Through this process, learners bring in their accumulated baggage of assumptions, motives, intentions and previous knowledge to the learning situation. This forms a framework that envelope the immediate situation and determines the course and quality of learning that may take place.

Lastly, the study will help the para-legals to identify their learning needs while at the same time providing CLRDC an opportunity to expand its services. Therefore, the study will be beneficial to the para-legals, the communities and the CLRDC. It should be noted that there is a dwindling of financial support from donors to NGOs. Major funding has currently shifted towards support for HIV/AIDS-related programmes. The CLRDC will benefit from the study, as it will assist the organisation to integrate HIV/AIDS into its programmes while at the same time not shifting from its core business.

1.4 THE RESEARCH QUESTIONS

The research questions will consist of specific questions that will lead back to the main research question. The main research question would be:

What are the learning needs of para-legals to advocate for the rights of those affected and/or infected by HIV/AIDS in rural communities in KwaZulu-Natal?

Specific questions that elaborate on this main question are:

- 1.4.1 What are the levels of knowledge of para-legals towards HIV/AIDS transmission, spread, prevention and risk factors?
- 1.4.2 How do para-legals understand HIV/AIDS related stigma and discrimination?
- 1.4.3 What do para-legals suggest as their current learning needs with regards to HIV/AIDS?

- 1.4.4 How do para-legals think they can contribute towards prevention of the spread of HIV/AIDS in their respective rural communities?
- 1.4.5 In what ways can para-legals contribute towards the care and support of people affected and/or infected by HIV/AIDS?

The researcher will develop and ask specific questions related to the study to assess the para-legals' understanding of HIV/AIDS-related stigma and discrimination. The aims of the questions will be to assess the para-legals' levels of awareness about HIV/AIDS-related discrimination and the stigma attached to it as a legal and human rights issue.

Questions to determine the levels of knowledge, attitudes and perceptions of para-legals towards HIV/AIDS transmission, spread and prevention would be asked. Other questions will relate to the lobbying and advocacy role that can be played by para-legals at community or grassroots level.

The question as to how para-legals can contribute towards managing HIV/AIDS in rural areas will be explored. The overall aim will be to assess whether para-legals are equipped to play the role of advocating for the rights of people living with HIV/AIDS.

1.5 RESEARCH METHODS

The researcher will use qualitative methods consisting of three tools: focus groups, questionnaires and Literature Reviews. Chapter three of this document describes the methodology and the following discussion explains the qualitative tools utilised.

1.5.1 Focus Group

Focus group interviewing is a group discussion generally involving eight to twelve participants from similar backgrounds or experiences to discuss specific topic of interest in qualitative research. For the purposes of this study, a focus group will be predominantly female since the current CLRDC student intake is ten females and only one male. Therefore, gender biased responses may be expected.

Para-legals on the CLRDC Diploma Course in Para-legal Studies are readily available and the venue that will be used is the CLRDC training facilities that are conveniently accessible to the researcher and the

para-legals. The researcher will be assisted by two facilitators to run the focus group sessions. A half-a-day programme will be designed by the researcher to collect the required information based on the research questions mentioned earlier on in section 1.4 of this document.

1.5.2 Questionnaires

Due to time constraints, the researcher prefers to use questionnaires for collect data from practicing para-legals.

Questionnaires will be e-mailed to those CLRDC para-legals currently practicing in rural community-based advice and resources centres. The para-legals consist of five females and seven males. Written questionnaires will be used for gathering opinions, attitudes, preferences and perceptions of the para-legals. Question formats will vary and will include open-ended and closed questions.

Open-ended questions relating to their basic knowledge and understanding of HIV/AIDS issues will be asked. These will relate to awareness, prevention, treatment, care and support for people affected and/or infected by HIV/AIDS. Specific questions about their learning needs will be included.

1.5.3 Literature Reviews

The researcher will glean information from a variety of written materials: annual reports, books, journals and curriculum reviews found at CLRDC.

1.6 ETHICAL CONSIDERATIONS

The subject of HIV/AIDS is a very sensitive one and should be addressed carefully. The researcher will thus be considerate of ethical issues related to HIV/AIDS; in particular, the right of people to confidentiality and privacy. Questionnaires shall be treated with confidentiality to protect individual paralegal's views, perceptions and understanding of HIV/AIDS issues and all information gathered will be handled with care.

Para-legals' consent to participation in the study shall be sought prior to the conducting of focus group sessions. Responding to questionnaires and participation shall be voluntary in both instances. The researcher shall exercise sensitivity in all questions so as to avoid possible problems that might arise from

participation in the study. Focus groups will not pose any problem since the researcher will be directly involved in collecting data. Questionnaires on the other hand, will be submitted to the research supervisor for prior scrutiny.

1.7 DATA ANALYSIS AND INTERPRETATION

All data collected will be thoroughly analysed by the researcher to identify commonalities, differing opinions, perceptions, knowledge levels and gaps. The final outcome of the study will be a result of an interactive process of collecting-analysing-collecting-analysing, rather than in a simple and linear direction.

1.8 OUTLINE OF CHAPTERS

Chapter 1: Orientation to the study

Chapter 2: Literature Review

Chapter 3: Methodology

Chapter 4: Research Findings and Data Analysis

Chapter 5: Summary and Recommendations and Conclusion

References

Appendices

1.9 DELIMITATION OF THE STUDY

The study will target a sample of twenty-one respondents. These will be broken down as follows. Eleven para-legals participating in the CLRDC Diploma course in Paralegal Studies will form part of the focus groups and ten para-legals already practicing in rural-based advice and/or resource centres in KwaZulu-Natal will be targeted to respond to questionnaires that will be administered electronically.

CHAPTER 2

LITERATURE REVIEW

2. INTRODUCTION

This chapter reviews written documents on HIV/AIDS in relation to its link to human rights and legal issues. It provides conceptual definitions and responds to some questions on the spread of HIV/AIDS, particularly in South Africa and other countries. Characteristics of the epidemic and important forces or factors that contribute to the spread of HIV/AIDS are highlighted. It provides insights on the devastating socio-economic impacts of HIV/AIDS. HIV/AIDS as a human rights issue is also addressed together with how gender relations influence the spread of HIV/AIDS.

2.1 DEFINITIONS OF TERMS

This section defines the terms used in the study:

Needs assessment in general, means the determination and identification of needs and the hierarchy of their importance. As Queeney (1995:1 - 2) suggests; “needs assessment is a decision- making tool for continuing educators, used in identifying the educational activities or programmes that should be offered to best meet the clients (i.e. learners and rural communities as recipients of the services provided by Para-legals) and society’s educational needs.”

Needs assessment is also defined as “a process for identifying the gaps or discrepancies between what actually is and what ought to be” (Queeney, 1995:5). It should be noted that educational needs change continuously, and the principle of life-long learning and education is a key to adult and continuing education. This also applies to learners in the workplace environment.

Other definitions of terms used in the study are as follows:

- HIV stands for Human Immuno-Deficiency Virus.
- AIDS stands for Acquired Immune Deficiency Syndrome.

- Acquired means that you can get infected with it.
- Immuno-deficiency means a weakness in the body's system that fights disease.
- Syndrome means a group of health problems that make up a disease. AIDS is a stage where a person who has been infected with HIV becomes terminally ill.
- A virus called HIV causes AIDS. If a person gets the virus the body will try to fight the infection. It will make "antibodies" which are special molecules that are supposed to fight HIV.
- When an infected person gets a blood test for HIV, the test looks for characteristic antibodies. If the person has them in his/her blood it means that he/she has the infection. People with HIV antibodies are termed "HIV positive".

It should be noted that being HIV-positive or having the HIV disease is not the same as having AIDS. Many people who are HIV positive, who can live long without getting seriously ill, do not have AIDS yet. As the HIV disease progresses, it slowly wears down the immune system. This means that viruses, parasites, fungi and bacteria that usually do not cause problems, can make you very sick because the immune system is damaged. These kinds of diseases are called "opportunistic infections".

An infected person can live long and develop AIDS at a later stage. An infection is commonly acquired from an infected person. The blood and vaginal fluids, semen, and breast milk of people infected with HIV have enough viruses to infect other people who come into contact with them. The most common modes of HIV transmission are:

- Having sex with an infected person;
- Sharing needles (shooting drugs) with someone infected; and
- Being born when their mother is infected, or drinking the breast milk of an infected woman.

In the past, some people became infected through transfusion of infected blood, but currently blood supply is carefully screened and the risk is extremely low.

At the moment, there is no documentation of cases of HIV being transmitted by tears, sweat or saliva but it is possible to get infected through oral sex or in some rare cases, deep kissing, if there are sores or ulcers in the mouth or if gums are bleeding.

HIV/AIDS is a global pandemic. The disease is currently hitting hard in poverty stricken countries and communities. In Africa most countries are impoverished and therefore the rate of the disease is high as compared to western countries. According to Kebaabetswe and Norr (Essex and Mboup et al, 2002: 517 – 518) poverty contributes to HIV transmission throughout Africa and serves as a barrier to sexual behavioural change. This is a result of economic barriers and pressures that force women and young girls to resort to sex work. Furthermore, some impoverished parents enlist adolescent daughters into sex work to earn money for the family. This will be explained in further detail in section 2.6.1.

South Africa has recently emerged from an era of international isolation and political conflict into a new democratic era. This came at the same time as the disease became prevalent in the country. HIV/AIDS has thus become the most important issue in South Africa. The question that still has to be answered is why HIV/AIDS has become such an issue in South Africa? The next section tries to provide insights as to the reasons.

2.2 REASONS FOR HIV/AIDS TO BECOME SUCH AN ISSUE IN SOUTH AFRICA

The severity of HIV/AIDS in South Africa is explained in Whiteside and Sunter (2000: 58 - 67). The two authors begin by asking two questions that are important in understanding HIV/AIDS in South Africa. Why has HIV spread so rapidly in South Africa? and why will the impact be so severe?

These authors state that in South Africa the population is both particularly susceptible and particularly vulnerable to the impact of HIV/AIDS. Susceptibility is defined as the chance of an individual becoming infected. Susceptibility is said to be a consequence of the kind of milieu that one lives and works in and would include environmental, infra-structural, cultural, economic and social factors. These make certain segments of the society vulnerable, as the effects of the disease are more or less likely to increase deaths and illnesses.

They further state that the high susceptibility of people to the spread of HIV and vulnerability to the impact of AIDS differs among segments of the society. There are some that are particularly susceptible and vulnerable. In South Africa, the highest infection rate is now in the age bracket between 15 and 49.

The situation is frightening when one considers that approximately 60 % of the population falls within this age category. It implies that the latest AIDS disease has a potential to devastate social, economic and most importantly, human resources development. However, a study conducted in 1998 revealed that data that are representative of the general adult population in the most sexually active years (ages 15 – 49) are hard to gather. [World Health Organization (WHO) Program on AIDS, unpublished field guidelines cited in Essex, Mboup et.al, 2002: 282]

The demographic impact is already felt, especially by the black population where AIDS-related deaths and numbers of people living with HIV increases rapidly. The social and economic impacts are not yet as severely felt compared to this demographic impact.

According to Leclerc-Madlala (2000) people in the province of KwaZulu Natal in South Africa have been “dying like flies” since the early 1990’s. She further states that in mid-2000, KwaZulu-Natal had an estimated adult HIV+ seroprevalence of between 30% and 40%. The epidemic of HIV infection has since matured into an epidemic of AIDS- related morbidity and death. The province is leading the way in term of numbers of people dying of AIDS and a rapidly growing generation of AIDS orphans.

Whiteside and Sunter (2000:59) state that South Africa had a late start to HIV take off. The apartheid’s legacy was a fertile environment for the rapid spread of the disease. The periods mentioned by Whiteside and Sunter are confirmed by Leclerc-Madlala’s argument on the early experiences of HIV in South Africa. The early 1990’s in South Africa was the period when the process of transition began. The unbanning of political organizations, return of detainees and those that were in exile, lifting of mandatory economic sanctions, the beginning of multi-party negotiations and ultimately the end of political violence. The democratic era that ensued came up with many challenges; amongst them, the opening of “flood-gates” for refugees from other African states ravaged by political conflict and the import and export of goods to and from South Africa through road transport. This raises a question of whether there are linkages between poverty and HIV/AIDS when considering the socio-economic imbalances that the apartheid system caused.

The spread of HIV is attributed to the main mode of transmission; that is, sex. South Africa is perceived to have a high level of sexual activity, including the types of sex or the range of partners people have (i.e. casual or commercial sex, multiple partners and same sex partners). [Whiteside and Sunter (2000:60)]

It is however, also necessary to look at significant and contributing factors to the spread of HIV/AIDS that are influenced by global trends. The next section provides an overview of the HIV/AIDS situation particularly in Africa since there is a lot to learn from for the benefit of South Africa. This will assist in determining which intervention strategies will be necessary to deal with the HIV/AIDS pandemic.

2.3 SIGNIFICANT AND IMPORTANT FACTORS FOR UNDERSTANDING THE HIV/AIDS EPIDEMIC IN AFRICA

HIV is a pandemic in Africa. It is regarded as “an immense human and social tragedy”, with potential to devastate the workforce productivity and economic stability in many nations (ILO Report on AIDS, 2000).

A UNAIDS published report of The United Nations Special Session held in June 2001, revealed shocking statistics of the HIV/AIDS situation in Africa. These will be helpful in developing an understanding of the forces and factors that drive the incidence of the pandemic in Africa. It revealed that:

- The total number of Africans living with HIV/AIDS is now 25,3 million. In eight African countries, at least 15 percent of adults are infected. In these countries, AIDS will claim the lives of around a third of today’s 15-year olds.
- During the year 2000, millions of Africans infected in earlier years began falling ill, and 2,4 million people died of HIV-related causes compared with 2,3 million in 1999.
- Africa is home to nearly 70 % of adults and 80% of children living with HIV/AIDS in the world, and has buried three quarters of the more than 20 million worldwide who have died of AIDS since the epidemic began.
- Infection rates in young African women are far higher than in young men, with rates in teenage girls in some countries five times higher than in teenage boys. Among young people in their early twenties, the rates were three times higher in women.
- In Africa, women’s peak of infection rate occurs at earlier ages than in men. This will be explained further in another section covering factors associated with women’s vulnerability and those associated with men’s vulnerability.

- A recent study estimated that in 1997, public health spending for AIDS alone already exceeded 2 % of Gross Domestic Product (GDP) in 7 of 16 African countries sampled which is a staggering figure in nations where total health spending accounts for 3,5% of GDP.
- Studies on the economic impact in South Africa predict that the GDP is expected to be 17% lower by 2010 than it would have been without AIDS. It will also wipe out US\$22 billion from the economy.
- In Botswana, AIDS related expenditure consumes 20% of the government budget and reduces spending intended for the poorest by 13%. Furthermore, a shocking 35.8% of adults are now infected with HIV, while in South Africa, 19.9% are infected, up from 12.9% just two years ago. The adult HIV prevalence rate in Botswana has more than tripled since 1992, when it was estimated at 10%. Life expectancy in Botswana at birth is now estimated to be 44 years instead of 69 without AIDS.
- With a total of 4.2 million people infected, South Africa has the largest number of people living with HIV/AIDS in the world, as well as the world's fastest-growing epidemic. Already, 1 in 4 South African women between the ages 20 - 29 are infected with the virus.
- More than 1 in 4 adults living in Zambian cities are HIV positive, and more than 1 in 7 Zambian adults are infected in the country's rural areas. On the other hand, the percentage of pregnant girls aged 15 - 19 infected with HIV in the capital, Lusaka, has on average dropped by almost half in the last six years.

The percentage of unmarried women who were sexually active fell from 52% to 35% between 1990 and 1996. Furthermore, another study in Zambia showed that in one hospital, deaths among health workers increased 13-fold over a 10 year period from 1980 to 1990, largely because of HIV.

- In Zimbabwe, life expectancy is 43 instead of 65.
- West Africa is relatively less affected, with prevalence rates of under 2% in some countries. However, Côte d'Ivoire is already among the 15 worst affected countries in the world. In Nigeria, by far the most populous country in sub-Saharan Africa, over 2.7 million are infected with HIV.

- By the year 2010, crude death rates in Cameroon will have more than doubled as a result of HIV/AIDS. An estimated 340 000 people in Ghana are currently living with HIV. In North Africa, there is insufficient data, but localized studies in southern Algeria show rates of around 1% in pregnant women attending antenatal clinics. Surveillance sites in both northern and southern Sudan indicate that HIV is spreading among the general population.

In North Africa and the Middle East, there were some 80 000 new infections in the region in 2000. The infection rate in East Africa, once the highest in the continent, hover above those in West Africa but have been exceeded by the rates now being seen in the southern zone.

- The prevalence rate amongst adults in Ethiopia and Kenya has reached double-digit figures and continues to rise.
- Through strong prevention programmes, Uganda has brought its estimated prevalence down to around 8% in 1999 from 14% in the early 1990s. HIV prevalence among 13-19 year old girls has fallen significantly over an eight-year period. The rate in teenage boys is always much lower than in teenage girls since boys are less likely than girls to have partners in the older, more heavily infected age group. The rate in teenage boys has thus remained roughly stable. The percentage of teenage girls who had ever used a condom tripled between 1994 and 1997.
- HIV-positive patients have occupied 39% of the beds in Kenyatta National Hospital in Nairobi, Kenya, and 70% of the beds in Prince Regent Hospital in Bujumbura in Burundi.
- The rate of bed occupancy at Prince Regent Hospital in Bujumbura, Burundi estimated at 70% is an indication of the fact that effects of war have had an impact on the rate of HIV infection in that particular country. This is a significant indicator even for South Africa as we have emerged from many years of political struggle and conflict. Having provided a broad picture in terms of statistical information, it is necessary to look at the characteristics of the HIV/AIDS.

[Statistics cited online at: http://www.un.org/ga/aids/press_kit/fs_Africa.htm]

2.4 CHARACTERISTICS OF THE HIV/AIDS EPIDEMIC

This section covers the characteristics of the HIV/AIDS epidemic. The characteristics relate particularly to the African continent and in particular to the Sub-Saharan region of which South Africa is a significant part that has been the most affected.

Copson (2002) reveals some defining characteristics of the HIV/AIDS epidemic as it pertains to the sub-Saharan region:

- HIV/AIDS, the human immunodeficiency virus that causes AIDS, is spread in Africa primarily by heterosexual contact.
- Sub-Saharan Africa is the only region in which women are infected with HIV at a higher rate than men. This, according to UNAIDS is because women make up an estimated 55% adult population in sub-Saharan Africa, as compared with 47% worldwide.
- Young women are particularly at risk. A United Nations study found girls aged 15 - 19 years to be infected at a rate of 15% to 23%, while infection rates among boys of the same age were 3% to 4%.
- Eastern and Southern Africa have been found to be more severely affected than West Africa, but infection rates in a number of West African countries are starting to escalate. In some Southern African countries, 20% or more of the adult population is infected with HIV and the rate has reached 35.8% in Botswana.
- The South African government released statistics in March 2001 showing that 4.7 million South Africans including 24.5% of adults were infected in 2000. This rate has increased from 22% in 1999.
- The African AIDS epidemic is having a much greater impact on children than is the case in other parts of the world. An estimated 600 000 infants in Africa become infected with HIV each year through mother-to-child transmission, either at birth or through breast-feeding.

These characteristics will be discussed in detail in the next section that looks at the factors contributing to the spread of HIV/AIDS in Africa. The above facts arise from various factors that would need to be identified and explained so as to create a better understanding of the HIV/AIDS situation in Africa.

2.5 CONTRIBUTING FACTORS TO THE SPREAD OF IN AFRICA

This section covers characteristics of the factors contributing to the spread of HIV/AIDS in Africa.

According to Booker and Minter (2002), the spread of HIV/AIDS in Africa is attributed to social and economic conditions, as well as to levels of access to health care services. Furthermore, there are a variety of primary determinants of who lives and who dies as a result of the HIV/AIDS epidemic. The broader societal context includes weak health services, poverty and in particular the insubordinate position of women, significant social factors decisively influence the “acceleration” of transmission that makes a disease an “epidemic” (i.e. widespread) or a “pandemic” (i.e. reaching national or global proportions).

These sentiments are also shared by Copson (2002) who argues that AIDS’ experts emphasize the variety of economic and social factors in explaining Africa’s AIDS epidemic whilst placing blame primarily on the region’s poverty. The social conditions are:

- Those that are associated with poverty that deprived Africa of effective systems of health information, health education and health care. The result is that Africans suffer from higher rates of untreated sexually transmitted infections (STIs) other than AIDS. Such infections increase susceptibility to HIV.
- That African Health Systems are typically unable to provide AIDS counseling, which could help alleviate the spread of the disease.
- That HIV testing is difficult for many Africans to obtain.
- That AIDS treatment is generally available to the elite. This is more relevant in South Africa where government has for a long time been “dragging its feet” on provision of antiretrovirals while people were dying, until recently, where they have decided on a roll-out programme to provide treatment.

It is commonly understood that the most common cause of HIV infection is having unprotected sex with an HIV positive person. Research studies have shown that there are a number of co-factors that predispose certain groups to HIV infection. Vulnerable groups at increased risk of getting infected include:

- Migrant workers
- Armed forces
- Sex workers
- Transport workers
- Women and youth

[Facilitators Manual: A Primary Capacity Development Course for Government Planners, 2001: 68]

Akeroyd (1996: 4) explores the contributing factors and explains how they are being associated with patterns of gender relations, the subordination of women and with social kinship bonds. Reference is also made to male circumcision that is highly significant in accounting for the spread of HIV/AIDS and the location of the main AIDS belt of Eastern and Southern Africa.

South Africa forms part of the developing countries and is therefore highly vulnerable to HIV. The meaning of vulnerability is that HIV does not discriminate between men and women, rich or poor, black or white. All people who are sexually active and who do not practice safe sex can be infected with HIV. However, the conditions under which some people live can put them at greater risk than others. An example would be illiterate people who cannot read printed messages about how to avoid infection with HIV. Women who are poor are more likely to sell their bodies and are therefore more likely to be infected with HIV.

Some of these co-factors have been explained earlier on in this paper. However, to make a coherent argument some will be re-emphasised. The co-factors are the product of political, economical and/or social forces, often beyond any individual person's control. The reality of an apartheid past cannot be ignored in one's assessment of these co-factors.

The transition to democracy in South Africa gave birth to a new context where human rights are enshrined and entrenched in the constitution. It is therefore, befitting not to look at the issue of HIV/AIDS in isolation from a human rights and legal perspective.

2.6 CONTRIBUTING CO-FACTORS AND FORCES

There are eight other contributing co-factors and forces identified that will be discussed here in further detail.

- The status of women
- The Vulnerability of Youth
- Access to health care and health status
- Migrancy
- High levels of mobility
- Social Dislocation and War
- Cultural Barriers and Tradition
- Underdevelopment and Poverty

[Facilitator's Manual: A Primary Capacity Development Course for Government Planners, 2001: 67 - 68]

2.6.1 The Status of Women

In sexual relationships, women have little or no control when it comes to issues of condom usage, monogamy, childbearing and/or family decisions. There is high incidence of rape and violence against women in almost every part of the continent and globally. In Africa, poverty often drives women to have commercial sex (exchange of sex for money). The negotiation of condom use among African women is commonly not within their control.

Many people believe that infection rates among women generally would be far lower if women's rights were widely respected in Africa and if women exercised more power in political and economic affairs.

2.6.2 The Vulnerability of Youth

Many young people in Africa are sexually active but do not have the concomitant life skills to deal with sexual negotiations, particularly around safe sex. Their exposure to drugs, alcohol, early sex, peer pressure and poverty, makes them vulnerable to HIV/AIDS.

Williams, Milligan et al (1998:3) highlights the vulnerability of youth. They state that young people between the ages 10-14 years account for about thirty percent of the world's population, (about a million

people in total) but are by no means a homogenous group. At the lower age range, they consist of pre-teen girls and boys most of whom are not yet sexually active. At the upper end they consist of physically and sexually mature young men and women, virtually all of who have been sexually active for several years and who in most cases have children of their own.

They further state that sexual activity of young people in the same age group is extremely diverse depending on the individual's level of physical, physiological and sexual development and other factors like economic circumstances, family status, religion, cultural beliefs and background as well as levels of education. However, there is one feature common to young people in many parts of the world, which is their potential vulnerability to HIV and other Sexually Transmitted Infections. Sexual abuse, rape especially, during dates and commercial sex or sex favours, often with older men, all have a major contribution to the vulnerability of youth.

A researcher in a UNAIDS Project studying differential infection rates discovered that young women's lives are being cut short through sex which is all too often forced, coerced, or 'bought' with "sugar daddy" (older men) gifts.

Poverty often drives young girls to give sex in exchange for money, gifts, or payment for education. One of the more horrendous urban legends has been the belief that sex with a virgin is a cure for AIDS. This practice certainly makes young women and girls extremely vulnerable. On a very simple level, actual condom usage is particularly challenging for an inexperienced male youth making it highly likely that he will engage in unprotected sex.

2.6.3 Access to Health Care and Health Status

This has been mentioned previously but is re-emphasized here. Sexually Transmitted Infections (STIs) may go untreated due to lack or inaccessibility of facilities. Poor health status, under-nourishment and susceptibility to TB all influence susceptibility to HIV disease and expedite AIDS and death.

According to the HIV/AIDS and Human Development Report, (2000) the most visible and immediate impact of HIV/AIDS is upon the health sector. Some of the important points about this sector include the following:

- There will be an increased demand on health care and AIDS related illnesses. The order of the High Court of South Africa to the government to provide antiretrovirals is a typical example. The lobbying action for provision of antiretrovirals by the Treatment Action Campaign shows that this projection is becoming a reality.
- Increased health expenditure will occur as patients with AIDS related illnesses cost more to treat. Projections for South Africa indicate that HIV/AIDS could potentially consume between 35% and 84% of public health expenditure by 2005.
- Patients with HIV and AIDS related illnesses utilize a large proportion of the resources of tertiary institutions. For example, it is estimated that between 30% and 70% of beds in many hospitals, are filled by HIV/AIDS' patients.

2.6.4 Migrancy

A study by Soskolne and Scharshall (2000) discovered that migrant populations are at great risk for poor health in general and HIV infection in particular. This is due to the impact of the migrant situation on their health, economic transitions and access to health services as well as difficulties faced by the host country in coping with the traditions and practices of immigrants.

They stated that, "migrants create xenophobia, isolation and hostility by the host community. Like other people living with HIV/AIDS, migrants who are HIV-positive are subjected to stigmatization and discrimination, and therefore they hide their HIV status as long as possible, thus making support services unavailable for them."

The study also revealed that AIDS and migration are two of the crucial issues facing the world today. This is based on the findings of WHO in 1999 where it was discovered that almost 34 million people were living with HIV. More than 95% of the infections occurred in developing countries, where poverty, poor health systems and limited resources for prevention and care fuelled the spread of the virus.

Further studies have shown that the incidence of HIV infection is higher among workers who live away from home. This argument is supported by Copson (2002) where he stated that poverty forces large numbers of African men to migrate long distances in search of work, and while away

from home they have multiple sex partners, increasing their risk of infection. Some of these partners may be women who have become commercial sex workers because of poverty and they too are likely to be vulnerable to infection.

Migrant workers may carry the infection back to their wives when they return home. An example is long distance truck drivers and taxi drivers who transport Africans long distances by car or kombi. This is also confirmed in a UNAIDS publication on HIV/AIDS prevention in the workplace, which shows a link between HIV and migration. It states that large-scale legal and illegal migration makes it more difficult to combat transmission and adds to vulnerability. Migrants who are looking for work or escaping political conflicts are often alone and far from their families. They are likely to resort to commercial sex either to make money or for pleasure. This applies to both males and females.

Females will sell sex to make money while males will buy sex for pleasure. Illegal immigrants are afraid of being caught and do not use health services since they feel insecure that they might be arrested if health authorities discover their national identities. Victims of rape will not report the rape to the police for fear of being deported. HIV prevention, therefore, creates a further need for additional cooperation and common strategies on migration and regional development.

2.6.5 High Levels of Mobility

Many men who work away from home for long periods have a culture of purchasing sex from sex workers. In addition, with relevance to South Africa, the country has a well-developed system of transport routes. Its ports and borders are a gateway to many parts of Southern Africa. This has close links to what was argued in the previous section on migrancy. The only difference being that high mobility includes those who are long distance drivers such as taxi and truck drivers.

2.6.6 Social Dislocation and War

Refugees are vulnerable to HIV for the same reasons cited for migrant workers above. Millions of these refugees are displaced within their countries because of war and ethnic tensions.

Furthermore, often soldiers in war situations often have a need for sexual intimacy as a counter balance to the violence they experience. This is exacerbated by the frequent non-availability of condoms, having disposable income, being away from home for long periods of time, the

presence of feelings of vulnerability and their willingness to take risks. Commercial sex workers often gravitate towards military barracks. In addition, refugees are traumatized by war and violence. One of the manifestations of war is an increase in rape as an expression of hostility.

Refugees have minimal access to health and education facilities. Transactional sex is also a factor common amongst the poor and dispossessed who have limited economic means. In such conditions, social norms break down and in the face of personal upheaval the risk of HIV infection appears to be a matter of less concern.

2.6.7 Cultural Barriers and Tradition

It is common knowledge that in many African societies there is still a respect for certain traditions and cultural practices. Some of the practices increase individual vulnerability to HIV.

Typical examples are:

- Resistance to condom usage, which is a barrier to HIV prevention. In African culture women are expected to be submissive to men.
- The practice of *ukungena* (mandatory wife inheritance by a brother-in-law if a women's spouse dies).
- There is a culture of silence around discussing sex and sexuality.

2.6.7 Underdevelopment and Poverty

Parts of Southern Africa are regarded as being the poorest and most underdeveloped in the world. This poverty has a major impact on access to health care and education facilities.

In most of the impoverished communities in these countries there is lack of information around HIV/AIDS or access to condom use.

Women are driven to commercial sex work or transactional sex (where sex is used as means of payment or earning money for school fees, rent, food etc). The strong correlation between education and the empowerment of women means poor women are particularly vulnerable. Lack of recreational facilities may result in young people resorting to sex as a form of recreation.

For people living with HIV, poverty may result in diseases and illnesses such as tuberculosis and malnutrition, and the greater prevalence of other contagious diseases may hasten the progression of their disease. The effect of poverty is multiplied by the vulnerability of women, who face both subtle and violent subjection, oppression and exploitation in many African societies.

The spread of HIV/AIDS in Africa has a micro-macro impact at different levels and sectors of the African society. It is therefore necessary to look at the issue in the context of HIV/AIDS and its devastating effects.

2.7 THE IMPACT OF HIV/AIDS

Some of the impacts of HIV/AIDS have been explained, however, it is necessary to look at their significance.

The HIV/AIDS pandemic is not just a matter of statistics. Its effects are impoverishing people, breaking their hearts, causing violations of human rights and wreaking havoc upon their bodies and spirits. Many people living with HIV/AIDS suffer victimization, isolation and rejection.

AIDS particularly disrupts seasonal labour-intensive agriculture, food processing and family life. Blaming others allows people to deny risk and to avoid taking realistic steps towards protecting themselves and others. AIDS also poses a threat to the survival of millions of people in the third world, where health and social infrastructure weakened by prolonged economic crises cannot bear the burden of the disease. In its second decade, the pandemic is expanding fastest in countries with poor economies, where all economic, political and social mechanisms that keep countries poor interact to produce a context in which AIDS thrives.

International Economic Factors

An epidemic such as HIV/AIDS is a social process, shaped by political, economic and cultural forces. Several economic processes fuel the spread of the epidemic. These include the global economy that relegates Africa to production of agricultural and mineral exports and distorted domestic economies inherited from colonialism. These circumstances result in unfavourable terms of trade, massive foreign debt, landlessness, and unemployment and widening disparities in wealth exacerbated by repressive politicians who siphon wealth from public funds. All these

processes, lead Africans to act out of desperation in ways that promote the spread of the disease, whilst persistent poverty leaves most Africans without access to effective treatment (Brook Grundfest Schoepf, 1999).

AIDS poses the greatest single hindrance to economic development in the world's poorest regions and will dramatically increase global economic disparities with destabilizing consequences for the entire world (Booker and Minter, 2002: 1).

2.7.1 Economic Impact

According to Whiteside and Sunter (2000: 82 - 97), the effect of HIV/AIDS began to be felt in South Africa in 2000. The epidemic is projected to peak around the year 2010. The economic impact will only slowly manifest itself as the number of individual deaths and illnesses accumulate over time. The economic impact will depend on how many people are infected and who they are. This is based on the notion that economics does not value all lives equally but everyone is considered a consumer even if they are not a producer.

The paradox of AIDS is that by killing the economically active age group, employment opportunities for those presently unemployed could become available. AIDS will also reduce the ranks of the unemployed as they fall sick and die. These arguments do not in anyway suggest that AIDS is good for the economy. They merely highlight the complexity of the epidemic.

According to a UNAIDS' Best Practice publication on prevention (2000:17), HIV/AIDS has grave consequences for human and social development. Examples of factors that will impact greatly on a country's ability to raise productivity and private investment are as follows:

- Many employees will have children and spouses who are also infected.
- The death of one or both parents will mean that young people will be forced to work earlier thereby sacrificing their education.
- The sustainability of economic growth in countries like Botswana and South Africa will be threatened in a shrinking consumer market that could result from declines in population growth and re-direction of consumer expenditure into caring for those who are ill.

- HIV/AIDS will dramatically affect the social environment in which all businesses operate, even if 'costs' can be contained. AIDS will have an impact on the morale of populations in the same way as rampant crime has.

These factors have a bearing on the labour force. The biggest challenge for the employers would be how to retain the human resources in a situation where productivity is at stake due to ill-health and growing numbers of deaths. This calls for a great emphasis on the importance of national, local and regional interventions that will help prevent the continued spread of HIV. Co-operation in the form of private-public partnership towards combating HIV/AIDS is therefore essential.

The economic impact of HIV/AIDS is greater than that of other diseases for several reasons. It is necessary to provide a general overview of some of these reasons cited in the Capacity Development for Government Planners, 2001.

- HIV/AIDS hits poor households dramatically and an increased burden is therefore placed on an already over-burdened household. The impact on households is as much as 30% greater than from other illnesses. HIV/AIDS affects the earning capacity of the household at the same time as it is incurring costs in terms of medical care. Quite often there is significant expenditure in search for a 'cure'. Those who buy anti-retroviral and/or other medication can experience severe financial burdens.
- HIV/AIDS is always fatal and often results in disability. Levels of poverty determine health status, diet and ability to treat opportunistic infections.
- HIV/AIDS strikes adults between 25 and 45, so people become ill and die in the years when they are potentially and optimally economically active.
- The death of an adult often means loss of provider, caregiver and nurturer.
- Insurance and medical benefits may be lost and burial/funeral costs are an additional strain on families.
- These and other expenses can result in the sale of assets (such as land), in children having to leave school and perhaps be forced into lowly paid work. They may also turn to crime

or sex work, which results in further social disintegration as previously mentioned.

- The impact on the workplace includes high levels of absenteeism, loss of labour, loss of skilled, trained personnel rising costs of employee benefits, reduced work performance and lower productivity.
- The impact of HIV/AIDS on the markets includes growth in certain areas such as money lending, funeral services and health care and decline in other areas such as consumables especially those bought on credit.
- Though it would be difficult to determine the macro-economic impact, there are certain trends that are likely to emerge as a result. These may include:
 - Reduction of the number of workers available in the economy (human capital) and increased production costs which may reduce international competitiveness.
 - Decrease in public sector, corporate and personal savings due to health care and related HIV/AIDS expenses, which in turn may reduce investment and drive up the cost of capital.
 - A reduction in direct government investment on infrastructure as expenditure on HIV/AIDS increases.
 - The most profound impact is on development as a whole. Increased illness and death and reduced life expectancy will compromise development objectives; affected people, particularly orphans, will have greatly reduced chances of fulfilling their human potential.

2.7.2 Social Impact

According to Whiteside and Sunter (2000), people's interaction in various ways other than economic gives rise to social impacts. Families, public health services and private sector firms currently feel the impact. This calls for rigorous action if the scourge is to be curbed and eradicated.

Studies show that even though the epidemic is more advanced in developing countries, the impact is still at an evolving stage and largely unknown, particularly in South Africa.

South Africa is, however, different to other developing countries because it is more modern, skills-dependent and boasts a technologically advanced economy. The citizens of South Africa get more from the state compared to other countries. What is of concern is that projected impacts of HIV/AIDS in the future a long term, complex and surprising findings. They note the immeasurable consequences of the epidemic.

There are three concepts that are of value in understanding how the epidemic unfolds and how it may have *negative consequences*. They are *civil society*, *social capital* and *socially reproductive labour*.

- **Civil Society**

Civil society refers to that part of society that occupies the space between the individual and the state; and the degree to which there is perceived and acted-upon community of interest in a group or nation. This may include any grouping of people outside the household and the workplace. The extent of civil society helps to determine the economic, social and cultural functioning of the society. Civil society organs may include non-governmental organisations (NGOs), community-based organisations, faith-based organisations and civics.

- **Social Capital**

Social capital is defined by Robert Putman (Whiteside and Sunter, 2000: 94) as “features of social organisation, such as trust, norms and networks, that can improve the efficiency of society by facilitating co-ordinated actions”. Social capital is productive in a sense that it makes possible to achieve ends that would not otherwise be attained by individuals alone. A typical example is a co-operative. *Social capital is in many respects the medium through which individuals operate collectively in order to thrive.*

- **Socially Reproductive Labour**

Socially reproductive labour will be affected, as this is the category at greatest risk of contracting HIV/AIDS. Partners who fall within this category may find themselves engaging in sexual

practices without having tested their HIV status but at the same time wanting to have children. Their performance at work will be affected as they fall sick or they will have to take time off to take care of their sick children who are living with HIV/AIDS.

2.7.3 Psycho-social Impact

HIV/AIDS typically strikes more than one member of the household. The psychological trauma of this is enormous. The burdens of care often falls on the very young or elderly who often have little training in caring for the terminally ill. The impact of watching a parent, child or relative die can be devastating.

Diagnosis and disclosure of HIV status in itself results in major stress for the individual infected. Stress and depression can adversely affect many areas of family life, including school, work performance and family relationships. In order to cope with stress, depression and hopelessness, some people will resort to substance abuse, such as alcohol and drugs. The worst case is when an HIV infected person goes on a spree of infecting others as means of revenge for being infected.

Stigmatization of the disease has several effects: denial of illness, ostracisation by the family or community, not being able to deal with the grieving process properly, and refusal to practice safe sex. "As the illness becomes impossible to conceal, caregivers and all household members are more likely to experience rejection, 'fear of contagion' and anticipatory grief". [Impending Catastrophe, p 9 cited in Facilitators Manual: A Primary Capacity Development Course for Government Planners, 2001:68]

This situation requires strategies that can deal with it as it unfolds.

2.7.4 Children Living with HIV/AIDS

The term 'children living with HIV/AIDS' was developed by the National AIDS and Children Task Team (NACTT) and refers to all those children infected and affected by HIV/AIDS. This includes children who are infected, those vulnerable to infection, and those from households containing members living with HIV/AIDS and to those adversely affected by the epidemic in their communities.

Orphans are the most tragic and long-term legacy of the HIV/AIDS epidemic. Caring for them is one of the greatest challenges South Africa faces. It is projected that by the year 2005 there will be approximately 800 000 orphans under the age of 15. That figure might rise to more than 1,95 million by the year 2010.

The consequences of a generation of AIDS orphans will impact greatly on most spheres of life, (i.e. welfare, public spending, crime and poverty). Many orphans will become street children. Children-headed households or families consisting of children and the elderly means that many children will grow up with minimal parenting, not to mention the stress on children of having to bring up other children.

Orphans have less access to food and education than non-orphans. Some studies show that the death rate among AIDS orphans is 2.5 to 3.5 times higher than for non-orphans. [HIV/AIDS in South Africa: The Impacts and Priorities p15 cited in Facilitators Manual: A Primary Capacity Development Course for Government Planners, 2001: 68]

Lack of healthy adults able to farm the land, produce income and care for the sick makes it necessary to keep children working at home. The trauma that children face after seeing relatives die is further impairing their ability to attain a good education.

According to Elsey (2000: 3), children orphaned by AIDS are the poorest children and are most likely to be pulled out of school to support their foster households. Child-headed households are often least able to pay school expenses and have the greatest need for labour of all siblings at home.

2.7.5 Educational Institutions

The HIV/AIDS and Human Development Report (2000: 42 - 44) revealed that lack of education exacerbates the impact of HIV/AIDS. Generally, people with more education lead healthier, more productive lives. It based this on the following reasons:

- Better-educated people have greater access to education than those who are illiterate or uneducated; they are more likely to make well-informed decisions and act on that information.

- Educated people in general, have better jobs and greater access to money and other resources that can help them support healthier lives.

Contrary to these reasons, the report states that the same resources can be used unwisely, for example, buying alcohol, drugs and sex and to migrate to urban areas where better jobs are available but at the same time infection rates higher. The resources may also be used to encourage behaviours that increase the risk of becoming infected with HIV/AIDS. It concludes that education is an asset when it comes to protection against HIV/AIDS.

The report makes it clear that education and information are fundamental human rights. This means that when children and young people are denied access to basic information, education and skills to deal with HIV/AIDS, (be it for religious values, social mores or cultural preferences) they will be much less empowered to reduce their own risk of infection.

Another study by Elsey (2000: 3) revealed that the number of teachers was expected to decline due to HIV/AIDS. Teachers were expected to be less productive while they were sick. Well teachers would be expected to take large classes. Funds would be tied up in sickness benefits and would not be used for replacement of teachers. In worst affected areas, the number of administrators and managers would fall.

The role of teachers within communities would change as they might be seen as outsiders who have brought HIV/AIDS into the communities. Stigma will also create divisions among pupils and their peers. The resources available for education would be reduced as government funds are channeled towards the increasing cost of HIV/AIDS, thus reducing quality of education children are receiving.

2.7.6 Welfare

The burden of dealing with the impact of HIV/AIDS has fallen largely on the shoulders of the welfare sector that is notoriously under-resourced and faces a series of harsh cutbacks in an attempt to reduce state and provincial deficits.

Of significance is the increased demand for state grants. The instance on a Basic Income Grant for poor unemployed people of South Africa is one such example.

It is obvious that, if an individual is both an economic and social actor, the results of getting infected will clearly be devastating. Whiteside and Sunter, (2000: 84) provide clarifying insights on this issue.

Dealing with the impact of HIV/AIDS, calls for a multi-pronged intervention strategy. It should be noted that examples illustrated in the priority issues provide strategies to reduce the impact of HIV/AIDS. HIV/AIDS is both a public health issue and a human rights concern. In the next section I will shed more light on HIV/AIDS as a Human Rights and Legal Issue.

2.8 HIV/AIDS AS A HUMAN RIGHTS ISSUE

The Centre for Socio-Legal Studies (CSLS) Trainer's Manual (2002) provides valuable facts on the difficulties experienced by people living with HIV/AIDS and/or their families. These would be helpful in developing understanding of HIV/AIDS as a human rights issue. It states that people living with HIV/AIDS have been shunned, discriminated against, assaulted and degraded by individuals and communities. People with this infection find it really difficult to come out into the open, in the face of discrimination and stigmatization. As a result they hide, suffer and die in silence. Without people coming out into the open, it is difficult for public health authorities to do research on the spread of the disease and to assist both those who are infected and everyone else who has the potential to be affected by the disease. Without acceptance of people with HIV/AIDS by society, there will always be non-disclosure and it will be difficult for government institutions and individuals to plan and manage the disease.

It further argues that all over the world, the epidemic of HIV/AIDS is having a profound impact, bringing out the best and worst in people. They trigger the best when individuals group together in solidarity to combat government, community and individual denial, and to offer support and care to people living with HIV/AIDS. They bring out the worst when individuals are ostracized by their loved ones, their family and their communities, and discriminated against individually and institutionally.

Discrimination, degradation, assaults, dehumanization, etc. are all cited in the CSLS manual as important human rights issues, which result from the HIV/AIDS crisis. It is important for people suffering from HIV/AIDS to be respected as equal human beings. (CSLS: 2002, HIV/AIDS, The Law and Human Rights Trainer's Manual)

Furthermore, the very nature of stigma and discrimination is very important to highlight.

2.8.1 Nature of Stigma and Discrimination

The undesirable differences and spoiled identities that HIV/AIDS related stigma cause do not naturally exist but are created by individuals and by communities. Stigmatization describes this act of devaluation. HIV-related stigma builds upon and reinforces existing prejudices. It also plays into and strengthens existing social inequalities especially those of gender, sexuality and race.

Stigma and discrimination play a key role in producing and reproducing relations of power and control. They cause some groups to be devalued and others to feel that they are superior. Ultimately, stigma creates and is reinforced by social inequality.

Prejudiced and stigmatizing thoughts frequently lead people to do and/or not do something that deny services or entitlements to another person. For example, such thoughts may prevent health services being used by people living with HIV/AIDS, or terminate their employment on the grounds of their HIV status. These are acts of discrimination.

Discrimination occurs when a distinction is made against a person that results in their being treated unfairly and unjustly on the basis of their belonging or being perceived to belong to a particular group. Consequences of stigma and HIV/AIDS-related discrimination are that rights of people living with HIV/AIDS and their families are frequently violated. This is simply because they are known or presumed to have HIV/AIDS. This violation of rights hinders the response and increases the negative impact of the epidemic. The next section provides a human rights perspective to issues of stigma and discrimination.

2.8.2 Stigma, Discrimination and Human Rights

The UNAIDS' Opening Up the HIV/AIDS Epidemic, Best Practice Publications (2000: 5), states that:

“Denial causes individuals to refuse to acknowledge that they are threatened by a previously unknown virus which requires them to talk about, and to change, intimate behaviour possibly for

the rest of their lives. Denial also causes communities and nations to refuse to acknowledge the HIV threat and the fact that its causes and consequences will require them to deal with many different and controversial issues highlighted earlier on such as, for example, the nature of cultural norms governing male and female sexuality, the social and economic status of women, sex work, families separated by migrancy, inequalities in health care and education and injecting drug use.”

Denial, stigma, discrimination and secrecy will continue to exist even despite the high prevalence of HIV and AIDS in most communities. These problems are caused factors at individual and community levels that will be further explored in the next section.

According to the UNAIDS Best Practice Publications on Opening up the HIV/AIDS epidemic (2000:9) these are caused by among others:

2.8.2.1 Factors at an Individual Level

At an individual level, people do not want to acknowledge that HIV/AIDS is within their community and that it poses a real threat to them and to their families. Furthermore;

- They themselves may already be infected; and
- They may be transmitting the virus to their sexual or drug injecting partners.

Individuals do not want to be tested for HIV or to disclose their HIV status because of fear that their partners will reject them and that they might be subjected to stigma, discrimination and/or be blamed for infecting others.

A common problem in developing countries such as South Africa is that people know that they will not have access to drugs for treatment which would slow down progression of the disease or alleviate their pain and suffering. Stigma, denial, discrimination and lack of access to care, stem from and lead to a sense of fear and hopelessness and ultimately encourage secrecy about HIV/AIDS.

2.8.2.2 Factors at the Community Level

Poor communities struggle with extremely difficult conditions under which to combat HIV/AIDS.

This is caused by among other reasons:

- Insufficient health care and education services which include insufficient voluntary testing and counseling;
- Insufficient public education campaigns, particularly education targeted to vulnerable groups including young people, women and marginalized groups;
- Insufficient access not only to antiretroviral drugs but also pain reducing drugs and suffering caused by AIDS-related illnesses;
- Insufficient community organization and support, which include lack of social and legal infrastructure to protect people from HIV-related discrimination.

These conditions are exacerbated among marginalized groups in communities. These result in obstacles seriously hampering government and community efforts to prevent the spread of HIV/AIDS and to provide care and support for those affected by HIV/AIDS. Regrettably, these conditions also reinforce denial, secrecy, stigma and discrimination.

Integrated HIV/AIDS prevention, care and support programmes are necessary to overcome these conditions. This argument is based on Girma and Schietinger's (1998 & 2000: 1) motivation for such programmes. These authors define HIV/AIDS "care and support" as an "intervention or set of interventions whose purpose is to mitigate the impact of HIV/AIDS epidemic on individuals, families, communities and nations".

They argue further that care and support activities are broad in nature and are critical to the continued efforts of communities, governments and donors to promote sustainable development. Also, the benefits of care and support are three fold:

- Firstly, care and support mitigate the effects of HIV pandemic on individuals, families, communities and nations, thereby promoting their prospects for sustainable development.

- Secondly, care and support interventions help prevent further HIV/AIDS transmission by enhancing the effectiveness of prevention efforts.
- Thirdly, care and support are rights because they promote access to basic health and welfare consistent with the Universal Declaration of Human Rights, and they are therefore ends in themselves.

In South Africa health and welfare rights are entrenched in the constitution. Section 27.1 of the Constitution (1998: 13) provides that:

- ‘Everyone has a right to have access to health care services, including reproductive health care’;
- ‘Sufficient food and water’; and
- ‘Social security including if they are unable to support themselves and their dependents, appropriate social assistance’.

The forms of stigma and discrimination faced by people living with HIV/AIDS are multiple and complex. Individuals tend to not only be stigmatized and discriminated against because of their HIV status, but also because of what it connotes.

Freedom from discrimination is a fundamental human right founded on principles of natural justice that are universal and perpetual. The basic characteristics of human rights are that they are inherent in individuals because they are human and that they apply to people everywhere.

As stated previously, in South Africa, the Constitution is the most basic and highest law of the country. All laws must be in line with the principles and values that are found in the Constitution. Therefore, any law or conduct that goes against the Constitution is illegal. Discrimination against people living with HIV/AIDS, those assumed to be infected and/or their families is a clear violation of human rights based on the constitution. This means that there are linkages between HIV/AIDS, Human Rights abuses and the law.

It is at the community and national level that HIV/AIDS-related stigma and discrimination are most effectively combated. Communities, community leaders and civil society organs must

advocate for inclusiveness and equality irrespective of HIV status. Issues of inequality also have negative consequences that perpetuate stigmatization and discrimination.

These are some of the major issues for consideration when managing HIV/AIDS based on the fact that HIV/AIDS prevention and care programmes engage a full range of human rights. These are freedoms and entitlements that are invested in each person at birth, which are universal in nature and inalienable. Therefore, managing HIV/AIDS is important to prevent further spread of HIV and to protect human rights of those who are infected with HIV and those who are not. It is therefore necessary to look at the gender dimension that is a social and economic factor that will shed more light on how this contributes to the spread of HIV/AIDS.

2.9 GENDER INEQUALITY AS A CONTRIBUTING FACTOR TO THE SPREAD OF HIV/AIDS

This section looks at the issues of gender inequality and its contribution to the spread of HIV/AIDS. Most arguments are based on the information cited from a paper presented at the XIII International AIDS Conference by Geeta Rao Gupta (2000), International Center for Research on Women.

Gupta began by providing a contextual picture of gender relations and the link to the spread of HIV. She stated that:

“... in patriarchal societies, all women, regardless of their race and class are oppressed, discriminated against and exploited on the basis of their sex. A new form of oppression is presently on the increase, on the basis of HIV infection. Although all HIV-positive people face discrimination, society by and large has chosen to blame women for the rapid spread of HIV/AIDS.” A typical example of this is the incident of December 1, 1998 when Gugu Dlamini was stoned to death by a gang of male youth as a result of her voluntary disclosure of her HIV positive status.

This is also confirmed in a Panos Publication, (1999) which stated that:

“... to understand why and to explain the particular negative impact on women living with HIV/AIDS, their experience needs to be located within patriarchal gender relations. This context can have devastating consequences for both men and women in a long run.”

It would be necessary at this point to provide conceptual definitions commonly used on issues of gender inequality and sexuality issues.

2.9.1 Gender-related Conceptual Definitions

According to the Commission on Gender Equality [CGE (1996:1)], South Africa, gender refers to the socially constructed relationship between men and women, boys and girls. It is about the way people relate to one another within a particular social context. Gender relations are shaped by socio-economic institutions governing labour allocations and resources entitlements, by socio-cultural norms, which define gender identities, and by the scope for representation of gender interests within political and legal institutions. These factors interact to create a specific pattern of gender differentiation and inequality.

Conceptual definitions of gender and sexuality are always difficult to separate, as the two are interlinked when it comes to issues of HIV/AIDS and gender inequality. Gender is not synonymous with sex. It refers to widely shared expectations and norms within a society about appropriate male and female behaviour, characteristics and roles. Gender is a culture specific construct that differentiates women from men by defining the ways in which they interact.

According to the CGE, gender equality refers to the equal access and control over the resources. It is concerned with the promotion of equal opportunities and fair treatment for men and women in personal, social, cultural, political and economic arenas. Gender equality entails meeting women and men's, boys and girls needs in order for them to:

- Compete in the formal and informal labour market;
- Participate fully in civil society; and
- Fulfill their familiar roles adequately.

Their needs are met without being discriminated against because of their gender. It is about elimination of all forms of discrimination and oppression based on gender, race, class, religion, disability or geographic orientation.

The above definitions reflect that there are differences in what women can do or cannot do in one culture as compared to another. This brings us to a point of looking at roles that are associated with men and those with women that also have effects on gender relations.

2.9.2 Roles Associated with Men and Women.

There is always a distinct difference between:

- Women's and men's roles;
- Access to productive resources and decision-making authority.

Men are seen as being responsible for the productive activities outside the home while women are expected to be responsible for reproductive and productive activities within the home.

Women's roles in development indicate that they have less access over and control of productive resources than men-resources such as income, land, credit and education. This has been in the past but still exists. The responsibility of the reproductive role of women brings the issues of gender and sexuality as contributing factors to the spread of HIV/AIDS in the sexual concept to the fore.

2.9.3 Gender Inequality and Sexuality As Contributing Factors

According to Gupta (1998), sexuality is said to be distinct from gender, yet the two are intimately linked. An individual's sexuality is defined by whom one has sex with, in what ways, why, under what circumstances and with what outcomes.

- Sexuality is more than sexual behaviour and it is multi-dimensional and dynamic;

Explicit and implicit rules imposed by society as defined by one's gender; age, economic status, ethnicity and other factors influence one's sexuality.

Gupta also provides four components of sexuality ("Ps" of sexuality) as follows:

- Practices;

- Partners pleasure/pressure/pain;
- Protection; and
- Power

The first two are aspects of behaviour (i.e. how one has sex and with whom) while the others refer to underlying motives. The last 'P' that stands for power, over many years has been discovered to be the most important.

Gupta also highlighted that sexuality is closely related to the other "P", but that the balance of power in sexual interaction determines its outcome. She argued that power plays an important role in decision making.

Power is fundamental to both sexuality and gender. Unequal power balance in gender relations that favour men, translates into an unequal power balance in heterosexual interactions in which male pleasure supercedes female pleasure and men have greater control over women with regard to when, where, and how sex takes place.

The understanding of an individual's sexual behaviour, male or female, necessitates an understanding of gender and sexuality as constructed by an interplay of social, cultural and economic forces that determine the distribution of power.

According to Walsh (2001:1), gender roles and relations powerfully influence the course and impact of the HIV/AIDS epidemic. Gender-related factors shape the extent to which men, women, boys and girls are vulnerable to HIV infection, the ways in which AIDS affects them, and the kinds of responses that are feasible in different communities and societies. This is based on the following factors:

- Gender inequalities are a major force behind the HIV/AIDS epidemic. The difficult attributes and roles associated with being females profoundly affect women's ability to protect themselves against HIV/AIDS and cope with its impact. Reversing the spread of HIV/AIDS therefore demands that women's rights are realized and that women are empowered in all spheres of life.
- Gender-based inequalities overlap with other social, cultural, economic and political

inequalities and thus affect women and men of all ages.

- Gender inequality makes women more vulnerable to being infected with HIV/AIDS compared to men because they lack power and control over their lives.

Vulnerability happens at different levels that need to be highlighted. The next section provides more details about these types.

2.9.4 Types of Vulnerability

Mann and Tarantula (1996), provide three types of vulnerability to HIV/AIDS, These are: personal, programmatic and societal.

2.9.4.1 Personal Vulnerability

This refers to both cognitive and behavioural factors that place people at risk. These include:

- Lack of access to information on HIV/AIDS and sexuality. Many men and women are not exposed to accurate and relevant information.
- Personal characteristics such as individual attitudes towards HIV/AIDS, and perceptions of personal risk. Many women who deny that they are at risk, suffer from the “it will not happen to me” syndrome.
- Lack of personal skills such as the ability to negotiate safer sex.

2.9.4.2 Programmatic Vulnerability

Programmatic vulnerability refers to the contributing factors of HIV/AIDS programmes to reducing or increasing vulnerability. Many programmes, whether run by the government or civil society sector, neglect to integrate an awareness of how gender inequality contributes to the spread of the disease. This factor ought to be there in all phases of the programme from initiation to needs analysis, planning, designing and in implementation and evaluation. Otherwise such programmes will fail to reduce women’s vulnerability.

The major concern in this regard is that many programmes fail to address issues such as whether, and to what extent, women can ensure that their partners use condoms, alternatively, where they cannot, what else they might do to reduce the risk of HIV infection, for example using a female condom.

2.9.4.3 Societal Vulnerability

Societal vulnerability refers to the broader context of women's lives, including the political situation, culture, tradition, gender relations, and attitudes towards sexuality, religious beliefs and poverty.

The power imbalances that define gender relations and sexual interactions affect women's access to use health services and treatment.

According to Walsh (2001:1), gender roles and relations powerfully influence the course and impact of the HIV/AIDS' epidemic. Gender-related factors shape the extent to which men and women experience inequality.

In the case of Voluntary Counseling and Testing (VCT) men feel quite free to do it independently, whereas women feel compelled to negotiate with their partner first, thereby creating a potential barrier. ("If he says no, what next"?)

Women's social and economic vulnerability and gender inequality also lie at the root of their painful experiences in coping with the stigma associated with HIV infection. HIV positive women bear a double burden in a sense that they are infected and they are women.

These facts show that both men and women are vulnerable to HIV/AIDS; however, women are more vulnerable than men. One aspect of culture which affirms women's symbolic inferiority is virginity testing.

According to Leclerc-Madlala (2001: 541), to understand the symbolic value of virginity testing, it is necessary to highlight the political and cultural nature of this practice. In KwaZulu-Natal, the dominant narratives of blame for the HIV/AIDS epidemic among Zulu-speaking people are framed within the common discourse of female sexuality.

What are the factors that contribute to women's increased vulnerability?

2.9.4.4 Factors Associated With Women's Vulnerability

According to Gupta (2000: 5-6) there are six different factors associated with women's vulnerability:

Firstly, there is a culture of silence. This means that women must submit to men.

Secondly, women are expected to be ignorant about sex and passive in sexual relations. This results in women not being informed about risk reduction or, even if informed, makes it difficult for them to be proactive in negotiating safe sex.

Thirdly, there is the traditional norm of virginity preservation for unmarried girls. It increases young women's risk of infection because it restricts their ability to ask for information about sex out of fear that they will be thought to be sexually active. Virginity puts women at risk of rape and sexual coercion in high prevalence countries. This is due to the myth that having sex with a virgin cleans a man of infections. Perhaps this belief arose because of erotic imagery surrounding the innocence and passivity associated with virginity.

- In cultures where virginity is highly valued, research has shown that some young women practice alternative sexual behaviour such as anal sex in order to preserve their virginity not knowing that it puts them at the risk of contracting the same, if not increased the virus. Young boys too, practice sodomy as an alternative to vaginal sex, believing the myth that HIV is only transmitted when you sleep with a female.
- The strong norms of virginity and the culture of silence that surrounds sex and access to treatment services for STIs can be highly stigmatizing for adolescent and adult women.

In many cultures, virginity is considered to be a feminine ideal. Using barriers or non-penetration sex methods (*ukusoma*) as safer options presents a significant dilemma for women. Women remain at risk of contracting HIV because the secreted semen may accidentally penetrate the vagina and she can be infected thus.

A fourth factor is women's economic dependency that increases their vulnerability to HIV/AIDS. The economic vulnerability of women makes it more likely that they will exchange sex for money or favours, less likely that they will succeed in negotiating protection, and less likely they will leave a relationship that they perceive as risky.

Fifthly, male power in the form of violence against women (both directly and indirectly) contributes to women's vulnerability to HIV. Physical assault, violence, and fear of abandonment all act as significant barriers for women who have to:

- Negotiate condom usage,
- Discuss fidelity with their partners or
- Leave relationships that they perceive to be risky.

Another important dynamic of the spread of HIV/AIDS is the relationship between violence, risky behaviour and reproductive health. An inseparable relationship between gender, sexuality and HIV/AIDS exists. Individuals who have been sexually abused are more likely to:

- Engage in unprotected sex
- Have multiple partners,
- Trade sex for money or drugs.

2.9.4.5 Factors Associated With Men's Vulnerability

Gupta (2000: 5 - 7), further provides factors associated with men's vulnerability as follows:

An important question remains how the unequal balance of power in gender relations actually increases men's vulnerability to HIV infection, despite or rather because of their greater power. There are various factors associated with men's vulnerability:

Firstly, men are expected to be more knowledgeable and experienced about sex. This puts them, particularly the young men, at risk of infection because such norms prevent them from seeking information. Fear of admitting their lack of knowledge about sex protection causes them to experiment with sex in unsafe ways and at young age to prove their manhood.

Secondly, it is a commonly held myth that a variety in sexual partners is essential to men's nature as men. This factor seriously challenges the effectiveness of prevention messages that call for fidelity in partnership or reduction in the number of partners.

Thirdly, there is the norm of masculinity; men are socialized to:

- Be sexually dominating over women.
- Be self reliant,
- Not to show emotions and
- Not to seek assistance at times of need or stress.

Lastly, manifestations of traditional notions of masculinity are strongly associated with a wide range of risk-taking behaviour. Emphasis on sexual domination over women as a defining characteristic of malehood contributes to homophobia and stigmatization of men who have sex with men. The fact that sex between male partners is a risky behaviour that contributes to the spread of HIV/AIDS does not help such stigmatization of homosexuals.

A United States' Survey revealed that young men who adhere to traditional views of manhood were more likely to report:

- Substance abuse;
- Violence;
- Delinquency; and
- Unsafe sexual practices.

The United Nations Special Session on HIV/AIDS (2001:1) revealed that men, especially young boys are vulnerable, too. Social norms reinforce their lack of understanding of sexual health issues at the same time celebrating promiscuity. This vulnerability is further increased by the likelihood of engaging in activities such as substance abuse (i.e. alcohol, drugs etc) and opting for types of work that can entail mobility and family disruption (i.e. migrant labour or military).

Expectations of invulnerability associated with being a man runs counter to the expectation that men should protect themselves from potential infection and encourage the denial of risk. Stigma and fear force men to have sex.

2.10 CONCLUSION

There is an increased acknowledgement of the role that gender plays in fueling the HIV/AIDS epidemic. Public discourse on sex and sexuality is still inadequate and needs serious addressing.

The suggested approaches to address the situation cannot succeed unless the programmatic intervention is thoroughly researched to make informed decisions. Civil society can play a meaningful role in fighting HIV/AIDS as lessons from other countries indicates.

Findings from the research studies could be used to develop informed intervention programmes to raise awareness, prevent the spread of HIV/AIDS, advocate for the rights of people living with HIV/AIDS and/or their families, thereby ensuring that they are not discriminated against. Others may lobby government to respond positively towards its obligation to provide access to health care including treatment to minimize AIDS-related deaths.

CHAPTER 3

RESEARCH METHODOLOGY

3. INTRODUCTION

This chapter provides details on the process of data collection that the researcher followed. The researcher used qualitative methods to collect data. The main reason was because “the overall purpose of qualitative research is to achieve an understanding of how people make sense out of their lives, to delineate the process (rather than outcome or product) of meaning-making, and to describe how people interpret what they experience” (Merriam & Simpson, 1995; Motton & Marais, 1994; and Motton, 2001).

The researcher’s assumption was that para-legals would have some knowledge, understanding and opinions around the subject of HIV/AIDS management. Through assessing their learning needs the researcher would be enabled to identify knowledge gaps and strengths. In turn, this would inform a programme design for the training of para-legals.

3.1 Research Method

The data collection strategy for this study was triangulated through the usage of three tools: i) focus groups, ii) questionnaires and iii) Literature Reviews. These tools were used to collect data that would respond to the broad dissertation topic and specific questions outlined in section 1.4 of chapter 1 of this document.

With regards to on designing a qualitative study Maykut and Morehouse (1994) stated that: “the goal of qualitative research methods is rigorous, systematic description of experience. The usage of methods is appropriate when the focus of research is subjective experience and meaning. These are dependent on context and are highly interactive.”

Cafferella (1994:76) identifies some of these methods as including written surveys, key informant interviews, group meetings, review of written material and documents. This study uses an

interactive approach, based on as it is on a legal and human rights perspective of HIV/AIDS pandemic and using similar methodology.

3.2 TARGET GROUP

The target group for the study was two-pronged, consisting firstly of para-legals studying towards a Diploma in Paralegal Studies and secondly those already in practice at rural-based advice offices and/or resource centres.

3.2.1 Student Para-legals

Para-legals studying towards a Diploma in Paralegal Studies consisted of a class of eleven para-legals, ten females and one male.

3.2.2 Practicing Para-legals

Para-legals who are already in practice and who participated in the study were ten in total. They included para-legals who had graduated with a Diploma in Paralegal Studies and those who had successfully completed a theoretical component towards a Diploma qualification. The CLRDC always refers to para-legals according to the groups that they fall when participation in the Diploma. Thus far groups one to eleven have been trained since the CLRDC inception. Each and every training cycle has a class (also referred to as a group) of not less than ten student para-legals in total. The group numbers are also used to categorise para-legals for continued assessment and performance evaluation purposes.

Community profiles of CLRDC Paralegal Offices and/or Resource Centres (refer to Appendix 4 for offices map) and para-legals that were targeted for data collection were as follows:

- **KwaXimba:** KwaXimba is a semi-rural area. The KwaXimba Paralegal Office is situated about 48 km outside Durban in the Nchanga (Nagle Dam) area. It serves a community with a population of about 15 000 and consists of 13 villages. It takes about 25 minutes to get to the office from central Durban. This office is staffed by two para-legals, a group-two and group ten paralegal.

- **KwaNgwanase:** KwaNgwanase is a rural area situated about 500 km outside Durban; 2km from the Mozambican border. The area is under the Tembe Tribal Authority. The KwaNgwanase Paralegal Office serves a population of about 209 086 people in twelve municipal wards. It takes about 5 to 6 hours to get to the office from central Durban. One group seven paralegal staffs this office.
- **Ematheni:** Ematheni is a rural area about 350 km outside Durban, about 30 km outside Nongoma town, under the Ematheni Tribal Authority. The Ematheni Paralegal Office serves a population of about 200 000 people in twelve villages. It takes approximately three and a half hours to get to the office from central Durban. One group seven paralegal staffs the office.
- **Madadeni:** Madadeni is a peri-urban area about 350 km outside Durban in the Midlands region. It is situated about 25 km outside Newcastle. The Madadeni Paralegal Office serves a population of about 250 000 people. It takes approximately three and a half hours to get to the office from central Durban. The office is staffed by two para-legals, one from group seven and the other from group ten.
- **Qiko:** Qiko is a rural area about 90 km outside Durban in the South Coast region. It is situated about 30 km outside Scottburgh. The Qiko Paralegal office serves a population of about 20 000 people in five villages. It takes about one and half hours to get to the office from central Durban. The office is staffed by two para-legals. Both are group two para-legals.
- **Rietvlei:** Rietvlei is a semi-rural area about 250 km outside Durban in the Eastern Cape. It is situated between Umzimkhulu and Kokstad. The Rietvlei Paralegal Office serves a population of about 36 000 people in 3 villages. It takes about 2-3 hours to get to the office from central Durban. Two para-legals staff the office. One paralegal is from group two and the other from group seven.
- **Limehill:** Limehill is a rural area 250 km outside Durban, about 30 km outside Wasbank in the Midlands region. The Limehill Paralegal Office serves a population of about 8 000 people in four villages. It takes about two and half hours to get to the office from central

Durban. Two para-legals staff the office. One is a group seven paralegal and the other a group ten paralegal.

3.3 RESEARCH TOOLS

Three tools were used to collect data as follows: focus groups, questionnaires and Literature Review.

3.3.1 Focus Groups

“Focus groups are particularly useful as an initial step in identifying broad-based areas of interest for learning about a particular target population, obtaining reaction to new ideas, and generating ideas for programme topics, etc. The qualitative nature of data collected requires that it be carefully interpreted based on the fact that results cannot be generalized with confidence among the weaknesses of focus groups”. (Gilmore, Campbell and Becker, 1989: 70 cited in Queeney, 1995: 124).

Focus group interviewing is a group discussion generally involving eight to twelve participants from similar backgrounds or experiences who gather to discuss specific topics of interest. The focus group used in this study consisted of a group of eleven para-legals studying towards a Diploma in Paralegal Studies, and consisted of ten females and one male. The focus group exercise was conducted once. It was a half-day session that lasted for four (4) hours.

The researcher and two assistants facilitated the focus group sessions. The researcher used a tape recorder to capture data from group discussions at plenary. The assistants also took notes and numbered all newsprints from individual group presentations. An audiotape recorder was also used during feedback sessions in plenary and flipcharts were also used by para-legals to present feedback from small group discussion in plenary. Para-legals’ consent was sought before usage of this device and they did not object. The researcher used the information on an audiotape recorder during report compilation on data collected from focus groups to ensure that none of the important points and issues raised was missed out.

Questions for discussion can be found in Appendix 1 whilst the sessions outline can be found in Appendix 2. Questions included open-ended, probing and closed questions, which were carefully

developed and sequenced by the researcher to create lively discussions. An outline of the group sessions was discussed and approved by the researcher's supervisor.

The researcher's assumption of para-legals in focus groups was that, since they were studying towards the Diploma Course, their understanding of HIV/AIDS issues would be basic. This was based on the researcher's understanding of the previous groups of student para-legals who came into the diploma course with very little knowledge of legal and human rights issues. Further information would be gathered through literature reviews and questionnaires.

3.3.2 Questionnaires

Bless and Higson-Smith (2000:109-110) provides some useful pros and cons of using questionnaires. They state that questionnaires **are useful** in data collection because:

- they are easily standardized;
- there is very little training of researchers;
- since respondents are asked to e-mail back filled questionnaires without indicating their name, anonymity is assured and this helps them to be honest in their own answers;
- the most important advantage of using mailed questionnaires is that large coverage of population can be realized with limited time and cost.

Limitations are that:

- it is difficult to interpret subjects' responses;
- it is difficult to ensure that subjects understand questions; and
- the response rate may be low and biased.

Written questionnaires are used for gathering opinions, attitudes, preferences and perceptions. Question formats may be varied and include open-ended, ranging checklist and forced choice. These can be administered through mail or given to individuals or groups to complete. (Caffarella, 1994: 77)

Questionnaires in this study were designed to elicit the information that the researcher deemed necessary for the purposes of the study. Questions were carefully constructed to eliminate the

limitations listed above. The possibility of para-legals' misinterpretation of questions could not be avoided, however, questions were constructed such that they avoided prejudicing para-legals in their responses. The only concern was that the para-legals' responses might be biased towards a legal and a human rights perspective.

Open-ended questions about para-legals' basic knowledge and understanding of HIV/AIDS issues were asked. These related to awareness, prevention, treatment, care and support for people affected and/or infected by HIV/AIDS. Also, specific questions on learning needs were included as a form of further data collection.

Questionnaires were e-mailed to those CLRDC para-legals currently practicing in rural community-based advice offices. The geographical coverage of KwaZulu-Natal province for data collection is reflected on Appendix 4 which shows CLRDC Advice Offices and/or resource centres. Out of the twelve questionnaires sent, those returned came from four females and six males. The para-legals that were targeted for questionnaires covered almost the entire KwaZulu-Natal province. Questionnaires included open-ended questions that were aimed at assessing para-legals understanding of HIV/AIDS stigma and discrimination through responding to question related to cases in Appendix 3.

It should be noted that para-legals who have completed theoretical training of the Diploma course work the same way as those who have graduated. The only exception is that the performance appraisal of those serving practical training is aimed at accreditation purposes. The results of the appraisal are used to determine whether para-legals satisfy the practical requirements to be granted the diploma qualification in Paralegal Studies. The researcher did not draw any distinction between the para-legals who have graduated and those serving the practical component of training. They were all treated the same.

Looking at the CLRDC map (refer to Appendix 4), it should be noted that the province of KwaZulu-Natal was widely covered. The only real limitation was that responses from Rietvlei were not received due to Telkom's delay in installing a telephone line that would enable electronic transmission by e-mail or facsimile possible.

3.3.3 LITERATURE REVIEWS

Review literature is useful for assessment of what has already been written about the area of study. It obviously illuminates what has not been written or has been written in a conceptually or methodologically inadequate way. A review thus offers a synthesis of how the researcher's proposal addresses the 'gaps', silence or weakness in the existing knowledge base.

The researcher can decide to investigate that which has not yet been discovered or explored. Essentially, a review aims to identify limitations in the existing research on a field of study in order to justify the proposed research. (Vithal and Janses, 1997:14 – 16)

The researcher gleaned information from written materials such as: annual reports, books, journals and curriculum reviews. An up-to-date file of written materials that pertain to educational activities of the study provided sources of information in conjunction with other methods. For example:

Course materials from CLRDC and other literature were reviewed to discover more about how these could inform HIV/AIDS intervention programmes and integration of HIV/AIDS training into CLRDC programmes. Journal articles on HIV/AIDS, Human Rights and the Law were reviewed as they provided useful information particularly on gender, sexuality and HIV/AIDS. The journals also provided data for this study as progress could be traced on how the CLRDC gender awareness programmes have responded overtime to gender related discrimination and thus be integrated HIV/AIDS and Human Rights issues.

3.4 CONCLUSION

This chapter provided an outline of the methodology used to collect data. A triangulated method: focus groups, questionnaires and written documents reviews was explained as enabling the researcher to quickly discover some common ground, concerns and areas of future learning amongst the target group.

It can be noted that participants, most of whom were females, were comfortable to work together in the focus group.

CHAPTER 4

RESEARCH FINDINGS AND ANALYSIS

4. INTRODUCTION

This chapter presents the findings on gathered from focus groups and questionnaires data. Data collected was based on assessing learning needs of para-legals for managing HIV/AIDS in local communities.

The researcher's approach to finding out learning needs of para-legals for managing HIV/AIDS was guided by principles of **learning needs assessment**. The study was influenced by Queeney's (1995) suggested approach of learning needs assessment particularly for adult learners. In this instance, the term "adult learners" refers to para-legals.

The study was also guided by constructivist theories. The theory of **constructivism** implies that the study did not follow a linear process but moved back and forth, thereby providing para-legals with an opportunity to construct their own knowledge and state their understanding of HIV/AIDS and human rights related issues. It also provided the researcher with an opportunity to assess their attitude towards HIV/AIDS issues, identifying gaps and discrepancies in knowledge in terms of effectively contributing towards managing HIV/AIDS in KwaZulu-Natal.

4.1 DATA COLLECTED FROM FOCUS GROUP AND FINDINGS

The focus group consisted of eleven student para-legals studying towards a Diploma in Paralegal Studies. The sessions lasted for four hours, commencing at 09h00 and finishing at 13h00. The exercise was divided into four sessions. The sessions involved brainstorming, small group discussions, presentations and discussions in plenary. (Refer to Appendix 1 and 2 for sessions outline).

The first was a brainstorming session in plenary that took about fifteen minutes. The question addressed during this session related to para-legals' understanding of what would constitute the ideal paralegal for managing HIV/AIDS in a local community.

Secondly, there were discussions in two small groups of five and six para-legals. Each group discussed the same questions and presented its input in plenary. The questions discussed were aimed at determining levels of basic knowledge of HIV/AIDS transmission, spread, prevention and risk factors. The third session focused on protection issues. The process was the same as the second session. The session was based on assessing para-legals understanding of HIV/AIDS and STIs prevention methods and practices.

The fourth session in the afternoon was dedicated towards assessment of para-legals reception to playing an advocacy role for the rights of people affected by HIV/AIDS. This covered issues of what they would identify as their learning needs to manage HIV/AIDS. The discussions revolved around issues on how para-legals can contribute towards prevention of the spread of HIV/AIDS, care, treatment and support for people living HIV/AIDS and/or their families. Finally, the last session addressed questions of para-legals' concerns of playing an advocacy role and what they would recommend as remedies towards such concerns.

Following, are actual responses to research questions obtained from focus group discussions and an analysis of the implications of the answers.

4.1.1 Session 1: Qualities of an ideal para-legal for managing HIV/AIDS

Q. What qualities should an ideal paralegal have for managing HIV/AIDS?

The purpose of this question was to assess the level of understanding and their vision of an ideal paralegal who would contribute towards management of HIV/AIDS in a local community.

Such an ideal person would:

- Not discriminate against people;
- Be sympathetic and able to deal with sensitive issues;
- Be able to provide information;
- Be able to provide more information about HIV/AIDS;
- Know the right channels of where to get help;
- Could provide counseling;
- Could empower people;

- Could keep a profile of HIV/AIDS victims so as to have information on who the infected person lives with, who can take care of them and prevent spread to their partners;
- Must have communication skills to deal with the victims and their families;
- Could teach people about their rights in law;
- Could keep information confidential;
- Could network with other local groups and officials;
- Could assist in formation of support groups; and
- Could assist victims in accessing social grants.

The data collected provided a clear picture of what para-legals considered to be necessary qualities of someone who can make a meaningful contribution towards addressing HIV/AIDS, human rights and law-related problems in a local community. Almost all the responses listed above indicated that para-legals understood the advocacy role they could play in managing HIV/AIDS at community level.

Important as they are, however, the responses do not mean that they can transform into action without the requisite training. They provide a basis for the researcher to decide on the areas that a training curriculum should cover. The onus is left on the researcher to decide which areas should be covered.

4.1.2 Session 2: Para-legals' Basic Knowledge, Attitudes and Perceptions Towards HIV/AIDS and STIs.

The purpose of this sub-section of session two was to assess para-legals' basic knowledge, attitudes and perceptions towards HIV/AIDS, other Sexually Transmitted Infections (STIs) awareness and the risk of getting or transmitting these diseases.

Q1. How and where is information about HIV/STIs obtained by para-legals?

The purpose of this question was to assess para-legals basic knowledge of resources available at local level, through the media and other communication channels on HIV/AIDS and STIs.

Para-legals' responses were as follows:

- Through reading posters, billboards, pamphlets, listening to verbal messages and participation in community workshops.
- Local clinics, hospitals, libraries, medical practitioners, the media and all government institutions, non-governmental organisations (NGOs) dealing with HIV/AIDS, eg Love Life, Lifeline, AIDS Training and Information Centre (ATIC) and drop in centres are all sources of information.

The responses indicated that para-legals were clear about a range of local sources of information regarding HIV/AIDS and STIs. These ranged from private and public institutions and the civil society organs.

Mention of non-governmental organisations is an indication that para-legals understand that they themselves can also play a role in dissemination of information about HIV/AIDS at local community level because they too are employed by an NGO.

Q2. How reliable or true do you think the information is from these sources?

The purpose of this question was to assess para-legals' perceptions and attitudes on the reliability of information from their identified sources.

Para-legals' responses included that:

- The information is true and reliable because the sources identified conduct various research studies and case studies to verify their statements.
- The fact that these sources, especially hospitals, are contributing to the prevention of the disease helps to confirm that.

The confidence displayed by para-legals on the reliability of information was convincing as they stated even the processes involved to make conclusions on issues before making them public. This implies that the para-legals' understanding of the information referred to was based on informed decisions after having been researched and verified. Their attitudes and perceptions

showed a fair level of maturity in assessing information for public dissemination that it must have been proven correct.

Q3. What do para-legals know about the spread of STIs and HIV/AIDS?

The purpose of this question was to assess para-legals' level of knowledge about HIV/AIDS transmission and its spread.

Para-legals' responses were as follows:

- In full, STI stands for Sexually Transmitted Infections and HIV, Human Immunodeficiency Virus;
- They are both sexually transmitted through unprotected sexual intercourse;
- STIs (eg syphilis, gonorrhoea, chlamydia and venereal disease) can be cured by injections;
- You get HIV through unprotected sex, blood transfusion and sharing needles.

Para-legals responses stated the full meaning of the STIs and HIV/AIDS acronyms. They then gave an explanation of HIV/AIDS and STIs as outline above. This proved para-legals basic level of knowledge about STIs and HIV. This might be the result of their age and exposure. Their responses confirmed the points covered in section 2.1 of chapter two on definitions of terms. The modes of transmission were listed by para-legals. Section 2.5 in chapter two also covered contributing factors to the spread of HIV, which were confirmed by para-legals' responses. The only omission of their responses was the mother-to-child transmission. It was surprising that, though most of them were women, they did not mention this mode of transmission.

Q4. How do para-legals know if a person is HIV positive?

The purpose of this question was to assess para-legals' understanding of HIV diagnoses and symptoms.

The para-legals' responses were as follows:

- Through blood test results.
- Through symptoms such as weight loss, excessive night sweat and running stomach.
- If the person discloses his/her status after having gone for an HIV test and results came out positive.

Para-legals had lively debates on determining whether a person was HIV positive or not. It was quite interesting to note that para-legals referred to common symptoms of an infected person with HIV. The last point raised about disclosure confirmed the level of knowledge and understanding that only after having tested HIV positive could it be confirmed that the person's disclosed status is true. Section 2.1, mentioned that the HIV test looks for characteristics of antibodies that are determinants of HIV infection. These are the same as those mentioned above by para-legals.

Q5. How do Para-legals think they themselves might become HIV positive?

The purpose of this question was to assess para-legals' perceptions and attitudes towards sexual practices.

- By practicing unprotected sex including oral sex.
- By getting contact with contaminated blood.
- By taking care of an infected person without taking precautions eg using gloves.
- Getting contact with a body of an infected person's eg bleeding, open sources, bodily fluids.

Para-legals were clear of how each person might become HIV positive. Their responses covered most of the modes of transmission. Akeroyd's (1996:4) reference to the important role of unsafe sex was reiterated by para-legals' opinions.

Para-legals did not mention the symptoms of an HIV positive person. The assumption might be that since these questions were answered at the same time they took it for granted that it had been covered in the previous section 4.2.5. The examples listed showed para-legals' understanding that there is no risk of HIV transmission through casual contact.

Q6. What do para-legals know about the risk of getting HIV/AIDS from partners?

The purpose of this question was to assess para-legals' attitudes and perceptions towards safer-sex practices among partners.

The responses were affirmative from both groups.

- If he/she is engaging in unprotected sexual activities or using drugs.
- If he/she is having extra-marital partners.

Para-legals responses indicated that they had an understanding of risky behaviour among partners, which might result in infection with HIV/AIDS, or other STIs if either partner engaged in unprotected sexual practices with other partners or was promiscuous.

Q7. Other than your steady partner do you have casual partners?

Para-legals came up with dissenting viewpoints in response to this question. Some para-legals agreed that they did and some did not have casual partners.

This might have been a sensitive question to respond to openly. Surprisingly, some para-legals indicated they did have casual partners. This raised further questions on sexual behaviour and the risk of getting infected should partners not be using condoms or other protection measures.

Summary on para-legals basic knowledge, perceptions and attitudes towards HIV/AIDS and STIs.

The levels of understanding, knowledge, perceptions and attitudes were thoroughly addressed. The responses covered important points that had also emerged in literature review. Para-legals' knowledge of how HIV/AIDS is transmitted and their understanding of misconceptions about HIV status and symptoms were indicated.

Para-legals identified sources of where and how knowledge on HIV/AIDs could be accessed. The reliability of information was clearly stated to ensure the relevance and accuracy thereof.

Although para-legals showed basic level of understanding, the biggest challenge is the actual behavioural change and practice that contributes to the spread of HIV/AIDS. The risk of transmission may be reduced if contributing factors to the spread are taken into consideration. The issues of gender relations and sexuality as highlighted in section 2.9 of chapter two of this document indicated that there is a need to foster a concerted effort to change of attitudes towards safe sex.

Lessons from other studies further confirmed that unprotected sex was the driving force behind most HIV epidemics. Findings of Gupta (2000) and Walsh (2001), for example, revealed that power in sexual relations is concentrated in men's hands. This results in social attitudes that foster unsafe sex. Knowledge is an important pre-requisite for prevention of HIV transmission. It is also a prerequisite for behavioural change.

Para-legals are a local resource that can channel Information, Education and Communication (IEC) campaigns at local community level that would be aimed at increasing knowledge about HIV, the behaviours that spread it and the ways in which it could be prevented. The success of these campaigns lies with imparting quality information to the grassroots community.

Limitations identified in this section:

Some of the questions asked during this session might have been sensitive to para-legals and therefore responses could not be explored further. It is commonly understood that given the sensitivity of discussing HIV/AIDS issues, it would be impossible for someone to come out openly about having multiple partners. This might result in stigmatization. In small groups individuals were open to discussion and the feedback in plenary showed that some of them had and some did not have casual partners. The groups were also mixed with single and married para-legals.

The limitation of the study in this section was that it did not cover abnormal situations such as perceptions and attitudes towards bigamy, polygamy, prostitution and homosexuality. These are areas that need further study and exploration. The issue of mother-to-child transmission was not covered and neither did para-legals mention it. It showed that there is a knowledge gap in this area. Noting that most para-legals were females, it was expected that it would be raised.

4.1.3 Session 3: Protection Issues and Risk Factors

The purpose of this subsection was to find out how para-legals protect themselves from getting or transmitting HIV and other STIs. This helped the researcher to ascertain para-legals' attitudes and perceptions towards HIV prevention and risk factors.

Questions and responses from para-legals were as follows:

Q1. What are you currently doing to protect yourself from HIV/STIs?

The purpose of this question was to determine para-legals' knowledge, attitudes and perceptions on protection from contracting HIV and STIs.

Paralegal responses were as follows:

- Using condom
- Have one partner only
- Abstinence
- Practicing non-penetrative sex (*ukusoma* - practice by traditional Zulu people to preserve virginity until marriage).

The responses showed that para-legals had knowledge of how HIV/STIs could be prevented. Their responses covered safe sex practices that are in line with messages promoted on prevention of HIV/AIDS and STIs. Cultural practices of protection also came out. The norms of preserving virginity until marriage came out strongly as a possible solution to prevent infection. These responses might be general and not related to what para-legals actually do to protect themselves. This showed that there was a knowledge gap about risk factors. The practice of *ukusoma* was identified as a risky one because there are still high chances of getting infected through this practice if semen enters the vagina despite a lack of penetration.

Para-legals' responses showed that the risk of contracting HIV/AIDS might be reduced if people use condoms or abstain or have sex with one partner only. The only risk factor of having one partner is the faithfulness of the other partner.

The response on virginity testing resulted in much provocation and was argued to show lack of regard for women's human rights. The practice has been proven as a contributing factor associated with women's vulnerability. As para-legals work in predominantly rural settings, they can help the community to develop an understanding of the pros and cons of traditional and western practices that could contribute to or prevent the spread of HIV/AIDS.

Q2. Do you and your sexual partner use male condoms? If so, who initiates usage?

The purpose of this question was to assess para-legals safe sex practices.

Para-legals' responses were affirmative. Both groups' responses agreed on condom usage.

- Either partner initiates.
- There are mixed reactions from both partners. Some male partners feel offended when female partners ask for condom use as they feel that there is lack of trust from the other partner. On the other hand female partners feel insulted because they say it implies that the male partner is suspicious of promiscuity by the female partner to an extent that it may break relationships.
- Women's insistence on condom usage result in a positive attitude to men when the deal is "no condom no sex."
- Men are forced to compromise in response to their desire to have sex.

The responses indicated that there were different views on condom usage. In some instances some para-legals, particularly those who are married, indicated that condom usage required negotiation as it had an effect on the level of trust between spouses and/or partners.

It was clear that awareness programmes for both gender groups were very much necessary. The points raised about some male partners taking offence when female partners initiate or ask for condom usage raises concerns. Behavioural change and women's empowerment needs to be a focus point.

Q3. Who initiates condom use in a relationship?

- Female partners in most of the cases but some males do.
- Both partners.

Again there were different views on initiation of condom usage. The fact that female partners mostly initiate condom use indicated their consciousness of their susceptibility to STIs. The traditional and religious tradition contradicts the concept of a 'right to equality'. It showed that there was still a gap between western and traditional practices. It confirms Leclerc-Madlala's (2001) argument in section 2.9.4.4 in chapter two of this document where she stated that culture plays a role in fueling the spread of HIV/AIDS.

Q4. How often do you use condoms?

- Every time engaging in sex.
- It varies.

The variation was explained as using a condom or not depending on who one slept with. The risk of using it when convenient indicated that some para-legals might be at risk of acquiring HIV or STI if they alternate condom usage.

Q5. Which situation makes you use condoms?

- Fear of getting STIs and HIV.
- Prevention of unnecessary pregnancy.

The responses from para-legals indicated that reasons for condom usage applied to both female and male para-legals and for different reasons.

Q6. What happens when you insist on condom use with your steady partner?

- There is agreement between both partners.
- In most cases either partner asks whether or not there is lack of trust between the partners concerned.

- There is a high risk of getting infected with HIV when either of the partners pretends to be honest while being promiscuous on the other hand.

The indication of the responses pointed to the complexity of the issues of how the disease spreads regardless of how partners are knowledgeable about the risk factors of unprotected sex. The question of trust among partners plays an important role to highlight the risk factors of contracting HIV/AIDS even if you are faithful to your partner.

Q7. How easy is it for para-legals to get male condoms?

They are freely and easily available from hospitals, clinics, public places (i.e. toilets) and other organisations.

Q8. How easy is it for para-legals to get female condoms?

Para-legals responded that female condoms are scarce and expensive. You can only get them from pharmacies.

This raises the question of gender inequality as highlighted in section 2.9.3. If male condoms are freely available why are female condoms are not similarly so?

Summary of Discussion of section 4.1.3, session three on HIV/AIDS and STIs Protection and Risk Factors

The responses provided a general understanding of protection issues against HIV infection and STIs. Para-legals identified protection mechanisms from getting infected with HIV/AIDS and STIs. Para-legals also showed an understanding of the risk factors of practicing unsafe sex. Other areas of concern were condom usage initiation that had an impact on the level of trust between spouses and/or partners. The most important issue identified was the risk that might result in infection should one partner be unfaithful while pretending to be well behaved in front of the other spouse or partner.

The issues of gender and sexuality also came to the fore as it became evident that the spread of HIV/AIDS and STIs is inextricably related to the attitudes, perceptions and behaviour of spouses

and/or sexual partners. Unless issues of gender inequality and sexuality are adequately addressed the spread of HIV/AIDS and STIs will not cease.

Findings of the UNAIDS study (2000) revealed that STIs increase the chance of HIV transmission. Looking at an impact level, STIs can be a proxy measure for the impact of HIV prevention programmes because STIs are like HIV, a marker of unprotected sex with a non-monogamous partner.

The mere fact that some para-legals confirmed that they had casual partners besides steady partners, indicates that the risk of spreading HIV is also present amongst them. The question this raises is how then can para-legals raise awareness amongst the community about the risk of getting STIs and HIV when they themselves are at risk of getting infected?

All aspects of HIV and STIs prevention programmes funnel into a single goal: to reduce the transmission of HIV and other STIs. If programmes are successful in bringing about changes in exposure to HIV and STIs then the incidence will necessarily change as well. Fewer incidences of HIV and STIs will mean a decrease in the spread of HIV.

The gap between knowledge and practice in the area of HIV and STIs prevention indicates that there is a learning need for para-legals as advocates of human rights to promote behavioural change to decrease the spread of HIV/AIDS. This, they cannot do unless they take the lead in setting an example.

4.1.4 Session 4: Para-legals' Further Learning Needs for Managing HIV/AIDS, their Concerns for Advocating for the Rights of People Living with HIV/AIDS and their Recommendations to address their concerns .

The purpose of this section was to identify para-legals perceived learning needs for managing HIV/AIDS in their local communities.

The questions and responses received were as follows:

Q1. What learning needs do para-legals identify as necessary for their effective management of HIV/AIDS?

Para-legals responses were as follows:

- Knowledge as to be able to help people living with HIV/AIDS.
- Counseling skills
- Knowledge of how to access government grants
- Labour Laws and their relation to people living with HIV/AIDS.
- How to network, communication channels to all role-players in fighting HIV/AIDS in local communities.
- Strategies to invite people living with HIV/AIDS to local community workshops.
- How to deal with legal matters concerning PLWHA, for example, human rights related issues.
- How to raise funds for HIV/AIDS programmes.
- Sources of information and other resources such as poverty alleviation programmes for those who cannot afford to support themselves and their families due to illness.
- Conflict resolution skills especially to be able to deal with issues of stigma and discrimination and where their families ostracize victims of HIV/AIDS.

However, in accordance with Queeney's definition (see page 12), para-legals needs were subject to analysis by the researcher to find out whether the identified needs were relevant or not.

Gravett (2001: 18) refers to this as "knowledge construction" in that para-legals' existing knowledge served as an interpretative framework for knowledge construction. It was quite interesting to learn that most of the areas identified as learning needs pointed to the direction of effectively managing HIV/AIDS in local communities.

Para-legals indicated that they needed intensive training on HIV/AIDS issues as to better assist the community. There was acknowledgement that their understanding of HIV/AIDS was limited. The most critical part need was for community-based approaches for addressing the HIV/AIDS.

The issues raised by para-legals on the need for communication strategies at a local level as well as networking confirmed the Spanier and Piot (1999:52-53) findings referring to key areas that must be considered in grappling with HIV/AIDS. It suggested two intervention strategies: a

community approach and regional co-operation. This implied that no one could work in isolation when dealing with HIV/AIDS as it had multiple effects and impacts.

Concerted efforts are essential in dealing with issues of HIV/AIDS. Para-legals mentioned that they would need training on skills and strategies that would help them deal with issues at a local community level. Local approaches acknowledging local dynamics should be considered when dealing with sensitive issues of HIV/AIDS. This was relevant to issues of traditional and modern prevention or protection strategies. The learning needs identified by para-legals pointed out clearly that they should be offered necessary opportunities through education and training on HIV/AIDS. This can make a meaningful contribution towards managing HIV/AIDS in KwaZulu-Natal. Findings from the focus groups validated the information gathered in the literature review.

Q2. What contribution can para-legals make in their respective communities towards prevention of the spread of HIV/AIDS?

The purpose of this question to assess para-legals' level of understanding of how they could contribute towards prevention of the spread of HIV/AIDS.

Para-legals responses of possible contributions were as follows:

- Conduct workshops in their communities to raise awareness.
- Disseminate information about HIV/AIDS to the community, i.e. community meetings and organizing campaigns.
- Show people alternatives to penetrative sex.
- Distribute condoms.

The above responses indicated that para-legals had an understanding of advocacy strategies to deal with HIV/AIDS issues. The activities listed included different strategies that can be used as a model for HIV/AIDS' management at local community level. The strategies listed confirmed Whiteside and Sunter's (2000:84) argument in section 2.7.6 where they stated that dealing with the impact of HIV/AIDS calls for multi-pronged strategies. The suggested strategies confirmed that HIV/AIDS is both a public health and a human rights concern. Usage of lobbying and advocacy strategies are some examples of practical social action that could be used to address the

human rights concern while condom distribution and showing safe sex alternatives can contribute towards prevention of the spread of HIV/AIDS.

Q3. What contribution can para-legals make in their respective communities towards care, support and treatment for people infected and/or affected by HIV/AIDS?

The purpose of this question was to assess para-legals' level of understanding of the role they could play towards addressing issues of care, support and treatment for people infected and/or affected by HIV/AIDS.

The responses from para-legals were that they could do the following:

- Provide counseling (i.e. emotional)
- Home visits.
- Advise victims on applying for disability grant and the importance of medical examination.
- Encourage PLWA to do their own projects such community gardens to get vegetables, making items to sell, writing wills.
- Encourage PLWA to take prescribed medication.
- Encourage them to identify caregivers to look after children when they pass on.
- Encourage caregivers to apply for exemption from school fees for children.
- Encourage caregivers to apply for childcare grant.
- Encourage them to apply for government housing subsidies.
- Encourage PLWA to create memory boxes for their children.
- Assist in filing all legal documents that PLWA will need eg: identity document; marriage certificates; grant applications; and title deeds etc.
- Encourage them to apply for insurance to cover funeral costs.
- Encourage them to join burial clubs and societies.
- Encourage them to talk to their children about HIV/AIDS.
- Speak to the children about HIV/AIDS.
- Help the PLWA to trace their families and/or relatives where they have not stayed together.
- Refer them to places where they can get treatment (eg pharmacies, clinics and doctors).

- Encourage them to get regular assessment from the doctor.
- Encourage people to exercise and eat properly.
- Help them read instructions from the medication and report any side effects from medicines and record expiry dates for medication.
- Encourage them to refuse pre-employment blood tests.
- Help report when any discrimination HIV positive people may suffer.
- Advise that no one is allowed to force them to disclose their HIV/AIDS status.
- Advise that they can refuse an operation done on them without their consent.

The ample responses of how para-legals can contribute to prevention, treatment, care and support confirms that if they could be empowered to deal with some of the issues that they had listed, they could make a significant contribution to manage HIV/AIDS in their respective communities. It confirms Girma and Schietingers' (1998 & 2000) argument that integrated approaches to care and support will enhance the management of HIV/AIDS. How it would be possible for para-legals to engage in all of the above would require further assessment.

Q4. What are para-legals' concerns about playing an advocacy role for the rights of people living HIV/AIDS and/or their families?

The purpose of this question was to find out para-legals concerns on their advocacy role to play for human rights of people living with HIV/AIDS and/or their families.

Para-legals responses included concerns about:

- The effects of HIV/AIDS on the economy and how para-legals would be able to help PLWA.
- Discrimination against PLWA by government officials and other people in the community.
- Doctors disclosing HIV status to the insurance companies.
- How to deal with issues of retaliation for one person infecting another person's relative.
- Conflict between traditional healers and doctors.
- Dealing with issues when people living with HIV/AIDS are being left alone by their families and when their condition becomes critical.

The issues raised as concerns tied in with the devastating impact of HIV on different sectors economically, socially and politically. The effects on the economy are those highlighted in section 2.7.1 of this document.

It is stated that HIV/AIDS would have a devastating effect on the economy. Most of the active labour force will be affected or infected as statistics indicate that the population group of 14-49 years will be hardest hit. This population group includes parents who might also have infected children. The demand for social grants for the disabled, child support and care dependency grants will also increase making it difficult for the government to raise income tax from individuals as more and more will get sick. It also mentioned that all other sectors would get affected since most activities depend on the viability of the country's economy.

Socially, para-legals could play a pivotal role to ensure that people who qualify for social grants actually receive them. They will advise people on how to apply for those grants and also follow up on behalf of clients whose grants would have taken long to come through.

Politically, para-legals could play an important role to mobilize the community with the support of power structures to lobby for favourable government policies to fight the spread of HIV/AIDS. Para-legals could also be helpful in dealing with matters of discrimination by government officials.

Discrimination was viewed as a major concern (as highlighted in sections 2.8.1 and 2.8.2 of this document). Para-legals would have an important role in dealing with these problems. Issues of prejudice and reinforcement of such will be dealt with by para-legals after receiving adequate training.

Para-legals' suggestion of working closely with Chapter Nine Institutions (institutions supporting constitutional democracy in South Africa) indicates that para-legals identified the complexity of issues surrounding HIV/AIDS requiring multi-pronged intervention strategies. These institutions include the Human Rights Commission (HRC), Commission for Gender Equality (CGE) and Public Protector (PP) etc.

These institutions receive complaints on violations of human rights and it is their responsibility to promote, protect and monitor human rights violations in South Africa. As these institutions are

not easily accessible especially to rural communities, para-legals could bridge the gap between the community and these institutions through networking. Para-legals could refer cases and report on them in their respective advice offices and/or resource centres.

The numbers of cases received by each paralegal office and/or resource centre could be reported to the rightful departments within these institutions to keep up to date statistical reports in order to monitor the impact of HIV/AIDS management at local community level. This does not imply disclosure of individual's HIV status and cases will be treated with confidentiality.

Q5. What are para-legals' recommendations to address their concerns?

The purpose of this question was to find out what para-legals' recommendations are in order for them to successfully playing an advocacy role for the rights of people living with HIV/AIDS and/or their families.

Para-legals' responses were as follows:

- Para-legals need to find proper channels to sue the government officials discriminating against PLWA. eg The Public Protector.
- Para-legals can refer some of the cases to social workers.
- Para-legals need to find out about rights in employment and inform people living with HIV/AIDS of these rights.
- Para-legals can pursue actions against doctors disclosing their patients' HIV status.
- Inform people to familiarise themselves with reading insurance contracts before signing.

Elma and Lynton's assertion (1985 in Queeney, 1995: 124) that: "small group interactions provide abundant opportunities for assessment. It is well known from organizational theory that small group dynamics offer unique insights into understanding individual behaviour. This lends itself well to assessment." was proven to be true. The abundant information gathered through focus groups was unbelievable. The para-legals' existing knowledge of HIV/AIDS will serve as an interpretative framework for knowledge construction.

4.1.5 Summary of Focus Group Discussions

Data collected from focus group sessions provided in-depth information around learning needs of student para-legals for managing HIV/AIDS. The information gathered would be useful to inform a design of a learning programme that would be aimed at developing para-legals skills and knowledge to contribute towards managing HIV/AIDS within a local community where they will be practicing on successful completion of the diploma course.

Student para-legals level of knowledge, attitudes and perceptions towards HIV/AIDS transmission and risk factors were revealed. The level of awareness of HIV/AIDS in general was high but the issue of putting knowledge into practice was raised as a concern particularly among sexual partners. Para-legals responded satisfactorily on questions of accessing information and resources at community level.

The problems created by cultural practices and beliefs also came to the fore. The highlight of this was the issue of negotiating safe sex among married couples where relationships got affected as pretence of honesty was raised as a concern.

Student para-legals had a clear vision of characteristics and qualities of a person who could make meaningful contribution to address HIV/AIDS and STIs issues at community level. Even though the questions on stigma and discrimination were not asked, student para-legals brought it up as an important point.

Student para-legals raised counseling skills, conflict resolution, labour laws, networking and training on conducting workshops as their learning needs. The learning needs identified by student para-legals included training on conflict resolution and how to conduct workshops.

These are subjects that form part of the diploma course curriculum. Workshops add impact to the paralegal programme by complementing individual counseling and support with advocacy in the broader community. Local workshops organized and conducted by para-legals are a useful tool to educate, raise-awareness on different aspects of law and human rights. The importance of channeling correct information and knowledge to local grassroots level requires cadres that would be able to do justice to this undertaking. Therefore, para-legals are well positioned to perform

this task of disseminating correct information and imparting useful knowledge at local community level.

From the above it was clear that the learning programme design that would emerge would require intensive HIV/AIDS training, teaching of the labour laws relating to HIV/AIDS and information on how to establish local community networks.

4.2 DATA COLLECTED FROM QUESTIONNAIRES

The discussion now moves from focus groups to questionnaires.

The researcher developed questionnaires that were divided into two sections. Section A, required para-legals to respond to questions based on situational statements that were aimed at assessing para-legals' knowledge, understanding and perceptions on HIV/AIDS and human rights approaches. It also assessed para-legals level of understanding and willingness to deal with HIV/AIDS and human rights-based advocacy and lobbying role that they can play to address problems faced by people living with HIV/AIDS and/or their families.

Questions from situational statements that pertained to diverse issues of HIV/AIDS attempted to address issues of stigma and discrimination faced by people living with HIV/AIDS and/or their families. The questions also attempted to explore para-legals' perceptions and attitudes towards dealing with cases related to HIV/AIDS, human rights and the law at community level.

Section B, addressed questions of para-legals' lobbying and advocacy role and levels of knowledge and gaps for managing HIV/AIDS in a local community. The aim was to provide para-legals with an opportunity to identify their learning needs on HIV/AIDS issues based on human rights and legal approaches. This section also provided an opportunity for para-legals to identify their weaknesses and strengths in dealing with HIV/AIDS issues. Issues of their concern and recommendations were also included to ensure that the study determined what para-legals perceived as their learning needs for managing HIV/AIDS.

The questionnaires were aimed at collecting data from para-legals already in practice in rural-based paralegal office and/or resource centres. The researcher's assumption was practicing para-legals would be more knowledgeable on HIV/AIDS, human rights and the law related issues

compared to those studying towards the Diploma in Paralegal Studies. The researcher preferred to include the situational statements and questions that were asked and consolidated responses received from para-legals. Some of the responses that were received were common and had to be written verbatim (as para-legals stated them).

4.2.1 Section A: Para-legals' Understanding of Stigma and Discrimination and the Legal Implications.

The situational statements were developed to further explore the results of the literature review and focus groups. The aim was to assess para-legals' understanding of the issues of stigma, discrimination, human rights and the law and how these related to people living with HIV/AIDS and/or their families.

Situational statements also highlighted typical cases that para-legals might have to address in their practice with particular reference to advocating for rights of people living HIV/AIDS and/or their families. Situational statements referred to typical scenarios of discrimination against people living with HIV/AIDS and/or their families.

Situational Statement 1

'Many communities argue that virginity testing is a way of protecting the youth against HIV. Thus, at routine intervals, all the young girls (and occasionally boys) are publicly tested whether or not they are virgins'.

The purpose of this situational statement was to highlight the traditional dynamics of HIV/AIDS prevention among boys and girls that have a bearing on human rights issues.

Q1. What is the nature of discrimination experienced by young boys and girls in this situational statement?

- Forty percent (40%) of respondents (para-legals) stated that the young boys and girls were discriminated against regarding their right to security and deprived of their right to privacy because everybody got to know about their virginity status.

- Fifty percent (50%) of respondents stated that the young boys were discriminated on the basis of their age (section 9 of the Constitution) that they are young. Also that their permission or consent was not required from them before the test was conducted, but their parents, who are adults, agreed that they could go for a test.
- Sexual harassment, discrimination emotionally and spiritually.
- Those who believe the myth that sleeping with a virgin cures AIDS will subject them to rape.

The responses from para-legals clearly indicated their level of understanding of discrimination that was practiced against young boys and girls. The vulnerability of children living with HIV/AIDS confirmed the arguments in section 2.7.4 of this document. It is stated that the ill-treatment that children living with HIV/AIDS get from people will have negative consequences.

Q2. What human rights do you think were violated through this practice of virginity testing?

The purpose of this question was to probe para-legals' thinking on traditional practices that might contribute to the spread of HIV/AIDS and/or subject people living HIV/AIDS and/or their families to discrimination.

Responses received were as follows:

- Ninety percent (90%) of respondents listed the right to privacy (Section 14 in the Constitution of the Republic of South Africa).
- Fifty percent (50%) of respondents listed the right to human dignity.
- Thirty percent (30%) listed the right to equality.

Other para-legals listed the following rights:

- Right to security since they might be subjected to victimization and abused by HIV positive people who believe the myth that sleeping with a virgin cures HIV/AIDS.
- Right to self-actualization.

- Religion, belief and opinion.
- Right to equality (section 9 of the constitution)
- Freedom and security (section 12 of the constitution)

It was quite remarkable to note that 90% of the respondents felt that virginity testing was an invasion of the right to privacy. Considering that most para-legals responding to the questionnaire were from rural communities, different views were expected. However, there was general disagreement with the practice of virginity testing among all para-legals.

All para-legals stated that virginity testing was a violation of human rights. Their responses confirmed findings of Leclerc-Madlala (2001:541) cited in section 2.10, stating that in KwaZulu-Natal the dominant narratives of blame for the HIV/AIDS epidemic among the Zulu-speaking people are framed within the discourse of female sexuality. They are the ones who are subjected to virginity testing, ultimately getting exposed to those who believe the myth that sleeping with a virgin cures AIDS, who then, in turn, rape those virgins without the hope of getting cured from HIV/AIDS.

The responses confirmed arguments by Gupta (2000:4), concerning societal vulnerability that women face a double burden in a sense that “they are infected and they are women”. This is based on the fact that the practice does not apply to men.

The different views showed high knowledge in terms of para-legals’ understanding of the rights that were violated through the practice of virginity testing.

It was also remarkable to note the contrast from student para-legals in focus groups that mentioned the practise *ukusoma* as one of the means of protection against infection. This showed that there knowledge gaps between the two groups.

Situational Statement 2

‘There was a woman working at the travel agency... who reported her HIV status to the powers-that-be and the next thing she knew, she was called in and told that she was a shoddy worker and she must please leave.’

Q1. What is the nature of discrimination that was experienced by the women mentioned in the situational statement that follows?

The purpose of this situational statement was to highlight the nature of discrimination experienced by women as vulnerable group to HIV/AIDS.

Para-legals' responses received were:

- Twenty percent (20%) of respondents felt that the discrimination was on the basis of gender and health status.
- Forty percent (40%) of respondents listed discrimination based on Unfair Labour Practice.
- She ought to have informed her about the reason for dismissal. She should have been given a notice.

The low percentage of para-legals that raised legal issues indicated an inadequate level of understanding of the linkages of HIV/AIDS, Human Rights and the Law as highlighted in section 2.8. Though fewer para-legals listed gender and health status as a basis of discrimination, those issues are important for understanding contributing factors to the spread of HIV/AIDS. These are the areas that para-legals can be helpful with at local community level should they be trained to deal with similar cases.

Practicing para-legals were assumed to be knowledgeable about unfair labour practices and indeed most of the responses identified this practice. Student para-legals had also identified a need to be trained on labour laws related to HIV/AIDS. This shows that there is need to develop a programme that would incorporate an HIV/AIDS and labour law module into the curriculum.

Q2. What human rights were compromised or violated?

- Seventy percent (70%) of respondents listed the right to equality.
- Forty percent (40%) listed Unfair Labour Practice that related to Labour Relations (Section 23).
- Right to human dignity and respect.

- Right to Fair Administrative Justice. Everyone whose right has been violated through administrative action has the right to be given notice in writing.

The high percentage of those para-legals who identified the right to equality, suggested that discrimination of people living with HIV/AIDS could not be adequately addressed unless issues of gender inequality received utmost priority. This confirms findings in arguments by Gupta (1998), Walsh (2001) Mann and Tarantua (1996) that gender roles and relationships powerfully influence the course and impact of the HIV/AIDS epidemic. Student para-legals also identified gender issues as a priority in addressing HIV/AIDS problems.

Situational Statement 3

‘An elderly woman who was caring for 18 orphans in Mpolweni, was interviewed by the KwaZulu Natal Witness. The community threatened to beat her up and accused her of trying to drive away job creation and community development from the area by speaking about HIV’. They said other people would see Mpolweni as place full of “AIDS”.

The purpose of this situational statement was to find out whether para-legals understood issues of discrimination suffered by PLWA and/or their families. Particularly, the women and children as vulnerable groups to HIV/AIDS- related discrimination.

Q1. What do you think is the nature of discrimination that was experienced by this elderly woman?

- Seventy percent (70%) of respondents listed discrimination based on age and gender.
- Forty percent (40%) listed discrimination based on gender.
- Twenty percent (20%) listed discrimination on the basis of providing care to orphaned children in the community who could not care for themselves.
- Stigmatization by the community.
- Discrimination against the right to community participation is violated.
- Discrimination against freedom of speech and also securing the indigent children.

The number of para-legals who identified gender and age showed that para-legals had an understanding of the nature of discrimination. The issues of identifying women and children was

significant given the percentage of those who indicated age and gender as a basis of discrimination. It also confirmed the facts covered in section 2.9 of this document on issues of gender and sexuality as contributing factors to the spread of HIV/AIDS.

Q2. What human rights were compromised?

- Seventy percent (70%) listed the right to freedom of expression.
- Forty percent (40%) listed right to gender equality.

Others also listed:

- Right to social security of children.
- Right to equality of orphans to be treated like all other people.
- Right to freedom and security.
- Right to community participation.
- Freedom of press and media.
- Freedom to impart or receive information or ideas.

The number of respondents who listed the right to freedom of expression indicated that there is still much work to be done in the conscientising of people to respect human rights. The above list also showed that there were many issues that emerged in one incident and attempts to address it might employ a number of intervention strategies. Para-legals role in such instances would therefore be essential.

Q3. If you were to receive a complaint from a client on a matter of this nature, what action would you take to address the problem?

- The paralegal would advise that they have rights entailed in the Bill of Rights in the Constitution of the Republic of South Africa. Advice would include information that will educate them about forms of discrimination that are prohibited in terms of the Constitution. The paralegal would advise them of institutions that enforce these rights.
- Fifty percent (50%) of the Para-legals' responded that their intervention would be to try to educate the community because that will prevent this from happening again.

- The paralegal would use the rules of natural justice between the client and the community to resolve the matter. If the matter is not resolved it is then when it should be litigated to the Magistrate's Court and the court would investigate the matter. The community involved will then pay the damages incurred by the client including the damages for emotional suffering as a result of unfair discrimination.
- The paralegal will advise them that they have rights, which are protected by the Bill of Rights in our Constitution. They would educate them that they were discriminated against on the grounds of age. They are elderly people; they have the right to participate in community security. They have done a good thing. If the right is violated then they have a right to enforce those rights. They would be given knowledge of the bodies that are meant to enforce the rights. Having the right means that any person has a duty to respect other people's rights.
- The paralegal would advise the client to take the matter further to court on the basis of violating freedom of expression. They could also report to the Department of Welfare.
- The paralegal would organize a workshop on HIV/AIDS to educate the community about HIV/AIDS because the community would have to accept that HIV/AIDS is there and they have to face that.
- The paralegal would educate the community on how to protect itself against this virus and how to care for those who are now affected/infected by this disease.
- It appeared from statements that the people of Mpolweni have no knowledge of the notion of freedom of speech, nor of the disease. The paralegal thus indicated that a workshop would be organized which would deal with both issues, that is, of the freedom of speech and that of the disease itself. The para-legals indicated that they would make sure that people be made aware that everybody is at risk of infection by HIV/AIDS, therefore people should be comfortable to talk about it.

Para-legals' responses indicated variation on the intervention strategies with some preferring to educate and some preferring to refer the matter for litigation. Para-legals' scope for dealing with

HIV/AIDS seemed to be unlimited. Should they be empowered with necessary skills, they could indeed make a meaningful contribution towards managing HIV/AIDS.

Remote areas will remain unsupported within the legal system due to lack of programmes to promote acceptance and support for HIV-infected people. Para-legals could play an important role to protect the HIV-infected and/or their families against discrimination. The intervention strategies that para-legals would use are an indicator of the educational enforcement of rights responses. Intervention strategies that para-legals would employ point to the same areas that were identified by student para-legals. This is an indication that an integrated HIV/AIDS programme is necessary to improve para-legals' skills to deal with HIV/AIDS and human rights related issues.

Situational Statement 4

'I was employed by a company that requested me to take an HIV test. I went for the test and found out I was HIV positive.'

The purpose of this situational statement was to assess para-legals' understanding of the problem of stigma of stigma, discrimination and violation of the rights of employees by employers on the basis of HIV status.

Q1. Do companies have the right to ask any of their employees to go for an HIV test?

Para-legals' responses to the above question were as follows:

- Seventy percent (70%) of respondents disagreed with the action of employers to ask their employees to go for an HIV test citing that it was against the law.
- Every person has a right to go for an HIV test on his or her own will and not to be asked by someone else.
- Thirty percent (30%) of respondents stated that HIV test is a voluntary action, though a certain company may do so but it should consider the Employment Equity Act (Act 55 of 1998) and the Code of Good Practice on key aspects of HIV/AIDS and Employment.

Para-legals' responses indicated an understanding of the illegality of forced HIV status test by employers on their employees. Reference to the Code of Good Practice needed to be checked for verification to ensure future programme development based on facts. The percentage of those who mentioned the Employment Equity Act left ambiguity on whether the action of forced test may be legal. Therefore, this area would need to be highlighted in the programme design in the labour law module.

Q2. If you were to advise this employee as your client, what advice would you give?

The purpose of this question was to probe whether or not para-legals would be able to handle HIV/AIDS- related matters in their practice as advocates for human rights.

Advice would include telling the employee of his/her right to privacy. The employee would be informed that he or she could only go for an HIV test on his or her own consent. Also, that if he/she has consented to test there must be counseling provided before and after the test.

A person would be informed that his/her HIV status is confidential and the employee has no legal obligation to tell his employer about his/her HIV status. This person can take legal action against this employer because according to the Employment Equity Act an employee has a right not to be tested for HIV unless the employer has applied from the Labour Court for authorization.

The clients will be asked whether he or she is willing to go for an HIV test. If the client is unwilling the matter is to be litigated at Constitutional Court level.

The fundamental issue is that a person has a right to privacy. He/she must have been tested with his own consent and the medical practitioner should keep his/her HIV-status strictly confidential. He/she must consent himself/herself to be tested, and even if he/she had consented himself/herself to be tested, there must be counseling before and after the test.

Clients would be advised to take the matter to court on the basis that no one should be discriminated against because of his or her disability.

A client would be advised not to disclose her HIV status because the companies have no right to force the employee to go for HIV test. If it thus happened and he/she had been asked to leave the job, they would assist him/her by referring the matter to the CCMA.

Finally, the client could be advised to report the matter to the Human Rights Commission because the action is contrary to the constitution.

The advice that para-legals came up with indicated that their clear understanding on how to deal with HIV/AIDS-related matters differs. Some of them would be capable of handling HIV/AIDS related matters while some would not. This calls for para-legals' need to be trained to develop a common understanding of how to deal with such matters coherently.

Situational Statement 5

'On World AIDS Day, 1 December 1998, Gugu Dlamini publicly disclosed her HIV-status at an openness and acceptance rally - a community event aimed at 'breaking the silence about HIV'. However, Gugu Dlamini did not receive acceptance or support from her community and in fact immediately after the rally she was threatened by a youth who promised that he would return to assault her later. On the 12 December 1998, Gugu Dlamini was severely assaulted by a gang of youths outside a shebeen where she had been drinking. She was taken to hospital where she later died of her injuries. She left behind a partner and a 13-year old child.'

Q1. What was the nature of discrimination experienced by Gugu Dlamini and/or her family?

The aim of this question was to highlight the stigma and discrimination attached to HIV/AIDS and the difficulties experienced by people whose status are known and/or their families.

Para-legals responses were as follows:

- Discrimination on the grounds of personal belief that disclosure would encourage others to know that they can live positively.
- Discrimination on the grounds that she was a woman.

- Discrimination on the basis of her HIV status.
- Gugu's freedom of expression was violated and that was an implication of people failing to accept others are infected and affected.
- Grounds of personal belief as a person.
- By revealing her status she thought she would encourage those who are infected to realise that there is life though a person is HIV positive.
- Discrimination against protection and respect.
- Discrimination on the basis of freedom of expression with an intention of warning others who practice unsafe sex.
- Discrimination based on disability.
- Discrimination on the grounds of HIV status.
- Gugu experienced the discrimination of being treated differently from other people, they had discriminated against her because of the disability that she had. They have also abused her by beating her and taking her right of life.

Para-legals knowledge of human rights was enormous. They showed a clear understanding of HIV/AIDS and human rights-related issues that they could handle in their practice at local community level. The issues identified by para-legals related to issues of sexuality and gender, beliefs, opinions and status etc. This showed how complex the problem of stigma and discrimination is. Identifying the nature of discrimination is an indication of understanding of human rights, however, this does not imply that they know how to handle similar cases. There is still a need to train them as a group so that they can be at the same minimum level to deal with such HIV/AIDS and human rights-related issues.

Q2. If you were to run a workshop in your community what would you highlight about human rights violations experienced by Gugu Dlamini and/or her family?

The aim of this question was to assess para-legals reception of playing an advocacy role for the rights people affected and/or infected by HIV/AIDS and/or their families.

The workshop would highlight that every person has rights. Also that rights are limited in an open and democratic system. This means that having a right does not mean to harm others on the basis of their opinions. The workshop would raise awareness on the legal case of delict if someone has suffered harm from another.

Participants would also be informed about state institutions protecting human rights e.g. Commission for Gender Equality, Human Rights Commission and Public Protector, etc. The workshop will emphasize destigmatisation of HIV and AIDS and try to educate the community about the rights of people living with HIV/AIDS.

The workshop would highlight that people who are HIV positive have equal rights like other living subjects. Discrimination was just an unfair discrimination. Also, that people do not have the right to their own beliefs, perceptions and discourses if these infringe on others. The workshop will highlight that every person has rights. Those rights are limited in an open and democratic society. Having the right does not mean to harm other people on the basis of opinions. One can open a case of delict if harmed by another person. Every person has a right to human dignity and respect. If any person has violated another person's rights, that right can be enforced. Also we are all equal before the eyes of the law. No one is better than the other. They should be informed about bodies like the Commission for Gender Equality, Human Rights Commission etc.

The workshop would stress that perpetrators need to be prosecuted in this regard and it would encourage others to come forward and give advice to those who have not been infected.

The paralegal would highlight a right to life because although a person is HIV positive, no one has the right to assault him/her.

Section 9 of the Constitution states that no person may unfairly discriminate directly or indirectly against anyone on one or more grounds of disability

The paralegal would workshop the community on how human rights are important and how human rights affect people with HIV/AIDS.

The paralegal would also highlight that people with HIV/AIDS have the same rights as people without disability.

The para-legals responses indicated that they have a clear understanding of dealing with human rights issues in general. They also demonstrated willingness to handle HIV/AIDS, human rights and legal issues. Their responses also reflect a positive attitude towards playing an advocacy role

for the rights of people living with HIV/AIDS and/or their families. The challenge though is whether they could deal with actual issues in real life situation or not. This is based on the notion that “it is easier said than done”. It might be easy for para-legals to analyse situational statements but applying knowledge in a real situation might be difficult if that is done without prior training.

Situational Statement 6

‘Thabang faced a lot of complications. After his father died, I told his teacher that I was HIV positive. All teachers at the school said, “Do not touch that child, his mother has AIDS.’

Q1. What was the nature of discrimination experienced by Thabang and/or his family?

The purpose of this question based on the situational statement was to assess para-legals views on discrimination experienced by women and children in particular.

- The discrimination was on the basis of freedom of expression and privacy to their status of being HIV positive.
- Section 29 of the Bill of Right in the constitution gives everyone a right to education and schools cannot educate a person or a child on the basis of HIV status. Thabang and his family are discriminated against.
- Marginalisation and isolation from other children; being teased and gossiped about. Moreover, left being presumed to be positive also and not receiving care like all other children.
- They are discriminated against in their health status, dignity and respect as human beings.
- Thabang was made to live an exclusive life wdespite the fact that he had done nothing.
- He was discriminated against because he was not enjoying his right of freedom of association.
- Discrimination based on age and disability.

- He was not treated equally like other children at school.
- Thabang was instead abused of being protecteding.

Para-legals' responses indicate a fair understanding of the nature of discrimination that was faced by Thabang and/or his family. The responses also confirmed findings in sections 2.7.4 and 2.7.5 on the impact of HIV/AIDS on children and on education respectively. The behaviour of the teacher showed that discrimination has no boundary. Even teachers that are expected by society to uphold ethical values, due to the kind of work that they do to mould children for better citizenship also engage in discriminatory practices. Para-legals would play an important role in running local workshops, including at schools, to raise awareness about such discrimination.

Q2. If Thabang's family were to bring this matter to your attention for advise, what action would you take as a paralegal?

- They would be advised on their right to privacy. The teachers had violated their right.
- They would be advised that teachers did not have a right to disclose their HIV status. Also, they would be advised that they do not deserve to be discriminated against and have a rights including: human dignity, freedom of expression etc.
- The limitation of rights will be highlighted.
- The teacher did not abide by the principles of confidentiality, so Thabang and his mother could sue him so that others will learn a lesson.

There is a right to freedom of expression but that does not mean teachers have a right to say whatever they like to Thabang. The right to human dignity and pride as a person is violated. No one is allowed to harm someone verbally. That is why there is a limitation clause to the all the rights.

In South Africa there is nothing above the law. Therefore it is preferable to take the matter to court in order to cease the wrongful happening of something that violates one's freedom of association.

One paralegal stated that he would conduct a workshop with the teachers and school children, educating them about the ways of getting an HIV disease. He stated that he would tell them that you can play and hug a person with HIV and you would not get the virus because the virus is living in the blood.

Another paralegal would organize a workshop that would include all levels of people in the community. In that workshop the paralegal would highlight that HIV/AIDS can be decreased through policies that ensure that discrimination against people living with HIV/AIDS is unacceptable, through addressing the stigma associated with the disease and doing away with the widespread denial of the problem.

The advice that para-legals indicated that they would give reflected different strategies they would engage as means of remedy to the problem that might have developed. The varying responses showed lack of coherency in dealing with the problem. Their knowledge gap indicated a need for training to deal with similar matters. It indicated that there is need for developing theoretical understanding that needs to be balanced with practice.

Situational Statement 7

‘I tried to inform one of my colleagues of my status. After a couple of months, it spread all over the company and I decided to leave.’

Q1. Do you think this employee faced any form of discrimination? If so, what kind?

The purpose of this question was to expose para-legals to problems raised by HIV on employees.

Eighty percent (80%) of respondents agreed that the concerned employee was discriminated against.

The following responses supported the arguments of what was the basis of discrimination:

- The employee faced discrimination against her right to freedom of expression.

- Although it is not clear, this employee might be discriminated against in future if everyone knows his status.
- The employee faced discrimination on the basis of opinion being violated.
- The friend that disclosed such gossip should suffer the consequences because the co-workers should have not know that she had such disease, as a result she left employment whereas she should have continued until medically boarded from work. Yet she suffered loss of income that friend did not respect the right to privacy.
- Discrimination against the right to human dignity
- Discrimination against a right to privacy
- They have deprived him a right to privacy and confidentiality. He would not have decided to leave work if she was not perceived the victim of wrong behavior.

The para-legals' responses significantly indicated that there was general agreement on an act of discrimination. The rights that were violated as listed above also indicated the para-legals high level of understanding of stigma and discrimination that was faced by an employee as highlighted in section 2.8.2 in chapter two.

Situational Statement 8

'There were 2 children at the Children's Home who were HIV positive but the staff was not treating them correctly, it was not like the other kids. They used to swear at them and sometimes they did not even wash their clothes.'

The purpose of this situational statement was to highlight the nature of discrimination faced by vulnerable children.

Q1. What is the nature of discrimination that was faced by the 2 children and/or their families?

Para-legals responses to the question were as follows:

- Sixty percent (60%) of respondents listed discrimination on the basis of unequal treatment.

Others listed the following:

- Discrimination on the basis of neglect, physical and verbal abuse.
- The usage of violent and abusive language by the staff at the children's home is not allowed in terms of the constitution.
- They are discriminated against because they are not treated equally like other kids. The fact that stigma and discrimination is manifested in various forms such as attitudes, perceptions and behaviour, these children were faced with direct nature of discrimination.
- The staff is using violent abusive language to the children and this is not allowed in our constitution. They also abuse them by always talking of their HIV status, which is a confidential matter. They do not even respect these children and are mistreating them.

Freedom of association is violated in this instance because the children are not allowed to associate with other children and are thus not equally treated.

Discrimination based on age and disability that they were not given proper care that every sick person should to receive.

Para-legals responses reflected an understanding of vulnerability faced by HIV positive children in the society and other public institutions. The vulnerability of children as highlighted in section 2.5 of chapter two was confirmed by the responses received from para-legals.

Q2. What human rights were compromised or violated?

- Sixty percent (60%) of respondents listed the right to equality.
- Thirty percent (30%) listed children's rights (Section 28): Right to family care or parent care or to alternative care when removed from family environment.

The following rights were also listed by para-legals (respondents):

- Human dignity
- Health care and social security.
- The right to equality
- Right to privacy
- Human Dignity and respect
- Right to be washed as a child
- Right to be cared by someone else.

The para-legals' responses indicated a fair understanding of human rights-related issues.

Situational Statement 9

'So it hit the newspapers... Someone spray-painted "fags" on the side of the house, and bricks were thrown at our windows. Somebody poisoned our dogs.'

Q1. What is the nature of discrimination that was faced by the "fags"/homosexuals?

The purpose of this question was to highlight the nature of stigma and discrimination faced by homosexuals.

- Thirty percent (30%) listed discrimination based on sexual orientation on the basis that everyone has a right to choose a partner he or she prefers regardless of gender.
- Homosexuals are also natural beings they have all rights like others, under our South African constitution, they also need to be fairly and equally treated. Everyone has a right to freedom of choice.

- Discriminated on the grounds of unhealthy environment, everyone have a right to a healthy and clean environment.

Para-legals responses highlighted that they do have a sufficient understanding of sexuality and rights to sexual preference as provided by the constitution.

Situational Statement 10

‘One child of 16 months was taken to hospital as she had systematic thrush; the nurses told the mother there was nothing they could do for her as she was an “AIDS baby”. The mother and child were sent home without treatment and the baby subsequently died.’

Q1. What is the nature of discrimination that was faced by this mother and her child?

The purpose of this situational statement was to assess para-legals understanding of the vulnerability of women and children to HIV/AIDS and the behaviour of hospital authorities.

- The nature of discrimination is that they were not treated equally as other people because of their HIV status.
- They were supposed to be treated like everyone else.
- Deprivation to get treatment.
- The mother of the child is denied her right to equality. Whether you are sick or in any situation, a person must be allowed access to health care.

Para-legals responses indicate that they did not adequately understand women and children’s rights to deal with similar problems in real life situation. It also provided para-legals an opportunity to learn about unfair practices of health officials towards people living with HIV/AIDS. It highlighted the problems of stigma and discrimination as highlighted in section 2.8.2 of chapter two. Para-legals can play a pivotal role in advocating for the rights of access to health care as provided by the constitution. This related to the provisions of the constitution highlighted in section 2.8.2.2 in chapter 2.

Q2. What human rights were violated by the hospital authorities?

The purpose of this question was to assess para-legals level of understanding of human rights particularly in relation to treatment and access to health care.

- Sixty percent (60%) of respondents listed the right to equality.
- Fifty percent (50%) of respondents listed the right of access to health care.

Other rights listed included:

- Section 27 of the Bill of Right in the constitution that gives everyone a right to access health care services, no one may be refused emergency medical treatment, so their were rights were violated.
- Right of access to health care that is confidential, affordable, of good quality, accessible to all and given with respect.
- The health workers are not allowed to discriminate just because of illness. We are all equal irrespective of our illnesses or health.
- Freedom of expression

Para-legals' responses indicated that almost half of them had an understanding of women and children's rights. This is based on the percentages of their responses. Though both the rights to equality and access to health care were listed in their responses, those who responded were fewer than the number that would indicate a high level of understanding. Knowledge gaps were identified in this area.

Q3. What advice would you have given if this matter was presented to your office?

- Fifty percent (50%) of respondents stated that the advice they would have given would be to educate the health care workers about human rights.
- Thirty percent (30%) of respondents stated that they would refer the matter to litigation.

The other actual responses were as follows:

- Advice would be given stating that everyone has a right to access health care. Also that health-care workers can be sued for preventing access to health care.
- This family must sue the Ministry of Health for the attitude of these nurses that caused the death of this child.
- The matter is to be open-ended to all on how to handle care for people who are HIV positive.
- I would advice them that the right to enjoy health care depends if services are available. If the nurses refuses to treat the child because of her HIV status than I would assist them to refer this case to the Human Right Commission
- Would take the matter to hospital Superintendent and also open a case with the police.

The differing views on what action para-legals would take, indicate the need for training to ensure that para-legals are clear about what actions should be taken on different HIV/AIDS and human rights-related cases that would come to their attention. The intervention strategies that para-legals suggested pointed in the right direction, however, there is a need for training to ensure a correct course of action. The responses also showed the complications of addressing HIV/AIDS matters. An example with this case is that some para-legals would use an educational approach, some would take up a criminal case with the police while others will refer the matter to the Human Rights Commission. The correct channel should have been the Public Protector since the matter involves public servants.

Summary of section on assessing paralegals' understanding of stigma and discrimination experienced by people living with HIV/AIDS and/or their families

The situational statements provided an assessment of para-legals' understanding of stigma and discrimination based on HIV/AIDS status. Issues that came out clear were that: women and children are the most vulnerable groups when it comes to HIV/AIDS. The examples of discrimination were highlighted in situational statements as follows:

Situational Statement 1: **Virginity testing (young girls)**

It was quite remarkable that all para-legals' responses indicated that they were against the practice of virginity testing. They based their disagreement with the practice on the violation of rights to equality; human dignity; privacy; freedom of religion, belief and opinion and security. Others felt that the practice was based on sexual harassment.

Issues of vulnerability, personal, programmatic and societal argued by Mann and Tarantula, (1996) in section 2.9.4 of chapter two of this document, were confirmed to be true. It stated that:

Lack of access to information and behavioural factors put people at risk of getting infected with HIV/AIDS;

Programmes aimed at reducing vulnerability neglect to integrate an awareness of how gender inequality contributes to the spread of HIV/AIDS; and

Societal vulnerability referring to the broader context of women's lives, including the political, cultural, traditional, gender relations, attitudes towards sexuality, religious beliefs and poverty.

Clearly, the practice of virginity testing results in a lot of problems for those who participate in the practice. Most of those tested happen to be women. Given the misheld belief that "sleeping with a virgin cures AIDS" those that have been tested and proven to be virgins, often suffer abuse and victimization by those males who are infected.

The six factors associated with women's vulnerability highlighted in section 2.9.4.4, particularly on issues of virginity testing, confirmed how vulnerability of women contributes to the spread of HIV/AIDS.

Situational Statement 2: **A women working in travel agency**

In this situational statement it became evident that women are vulnerable to HIV/AIDS. Para-legals listed discrimination on the basis gender and health status. Section 2.6.3 in chapter two of this documents stated that STIs might go untreated due to lack or inaccessibility of services. It also stated that health was the area where the immediate and visible impact of HIV/AIDS lay.

It also emerged in the assessment of student para-legals knowledge about STIs and HIV that *information and educational communications plays an important role in reducing the spread of HIV and STIs.*

The learning from this women's situation confirmed the forms of stigma and discrimination and the complexity of dealing with HIV/AIDS issues. Two particular issues raised to back up this argument are findings in section 2.8.2.1 and 2.8.2.2 respectively. Section 2.8.2.1 highlighted that individuals do not want to be tested for HIV or to disclose their status because of fear that their partners would reject them and that they might be subjected to discrimination and be blamed for infecting others.

Section 2.8.2.2 highlighted that there are insufficient public education campaigns, particularly *education targeting the vulnerable, including young people, women and marginalized groups.* Furthermore, that insufficient community organizations and support, including lack of social and legal infrastructure to protect people from HIV-related discrimination contributes to the spread of HIV/AIDS.

The discrimination experienced by the women at the travel agency revealed that HIV/AIDS policies should be developed in all work places to avoid situations such as those experienced by the women mentioned in this situational statements. Para-legals as one resource at a local level provide legal services that could contribute towards prevention of the spread and decrease cases of stigma and discrimination of people living with HIV/AIDS and/or their families. Alternatively, para-legals could refer people living HIV/AIDS to other service providers for social care and support.

Referring back to findings from focus groups, student para-legals raised the learning needs regarding labour laws in relation to HIV/AIDS. This typical scenario confirms the important role that para-legals could play in advocating for the rights of people living with HIV/AIDS within the community, in workplaces, educational and health institutions.

When a person loses a job because of the negative connotation or impression of HIV, it becomes a human rights and legal issue. The intervention strategy should therefore address both legal and human rights. It would call for promotion and protection of human rights.

Raising awareness about the illegality of unfair labour practice by discrimination on the basis of health status would help those who might encounter similar problems in the future. In that sense people would be able to defend their rights against abusers. A culture of human rights would thus be promoted. Taking legal action against engaging in unfair labour practice would contribute towards protection of human rights against abuse.

Situational Statement 3: An elderly women caring for orphans

The nature of stigma and discrimination highlighted by para-legals indicated the right to freedom of expression and right to equality were the most popular rights violated by members of the community. Findings of NACTT highlighted in section 2.7.4 in chapter two of this document were confirmed in stating orphans are the most tragic and long term legacy of HIV/AIDS epidemic. In the case of this situational statement it was clear that taking care of children living with HIV/AIDS had a stigma for some members of the community.

Considering the possible consequences, it becomes imperative to note that an entire generation of AIDS orphans will impact greatly on most spheres of life (i.e. welfare, public spending, crime and poverty). Should orphans not be taken care of, they might become street children and add an additional burden to the government and society. Para-legals could play a pivotal role in advocating for children's rights at a local community level.

Para-legals indicated there is a need for training around HIV/AIDS-related discrimination. The difficulty with such matters is that it is difficult to prove that an incident of discrimination happened. Providing support to the sufferers of discrimination and stigmatizations calls for integrated intervention strategies.

Situational Statement 4: An employee requested to go for an HIV test

Para-legals responses indicated there was stigma and discrimination highlighted in this situational statement. Most of them disagreed with employers forcing employees to go for an HIV test. The course of action that they would have taken on this matter differed indicating a need for training to ensure that there was coherence on how similar matters would be handled in all para-legal offices and/or resources centres. Para-legals showed some knowledge of sources for referral

purposes, however, there is still a need to develop common understanding of issues, particularly, on stigma and discrimination which are difficult matters to handle.

Situational Statement 5: Gugu Dlamini, a young woman stoned to death

This situational statement highlighted the vulnerability of people who disclose their HIV status. It raised concerns and questions on whether voluntary disclosure should be promoted or not. Para-legals raised the issue of delict for bodily harm. This is one of the subjects taught in the diploma course in paralegal studies. The training material would need to be reviewed to ensure that HIV/AIDS related matters are covered.

Situational Statement 6: Thabang, a young boy discriminated by schoolteachers after HIV status disclosure by his mother

Section 2.7.4 of chapter two of this document revealed that children orphaned by AIDS were more likely to be pulled out of school. The discrimination against pupils by teachers would exacerbate the situation as it might lead children to dropout of school. Para-legals could play an important role in educating school governing bodies (SGBs) to ensure that human rights education forms part of the schools curriculum.

Situational Statement 7: Discrimination at the workplace by fellow employees after HIV status disclosure becoming unbearable and resulting resignation from employment.

This situational statement brought similar issues as those highlighted in situational statement two. The consequences of disclosure confirmed findings in the review of written materials that HIV/AIDS will have an impact on socially reproductive labour.

Some examples highlighted the social and economic impact of HIV/AIDS in instances of loss of income as a result of HIV status. These were discussed in section 2.7 in chapter two and also confirmed by para-legals' responses on typical cases that might be brought to their office ad/or resource centre.

Situational Statement 8: Two children in the children's home discriminated against by staff.

The vulnerability of children was also highlighted through this situational statement. Para-legals indicated a fair understanding of discrimination experienced by vulnerable children. Violation of the right to equal treatment indicated that discrimination results in further problems. Listing of section 28 of the Constitution of the Republic of South (1996) showed para-legals understanding of legal and human rights matters in general. The section referred to relates to children's rights. Children's rights could form part of the para-legal programme of advocating for the rights of people living with HIV/AIDS and/or their families.

Situational Statement 9: Discrimination Against of Homosexuals "fags".

Para-legals had an understanding of rights to sexuality, however, the role of sexual practices in fueling the HIV AIDS was not addressed. The learning programme of gender and children's rights would have to highlight findings of Gupta (2000) and Walsh (2001) on the "Ps" of sexuality. These relate to practices, partners pleasure/pressure/pain, protection and power. These have been explained in detail in chapter two section 2.9.3 of this document. The issue that came out clearly was that power is fundamental to both sexuality and gender.

The understanding of an individuals sexual behaviour, male or female, necessitates the importance of understanding that gender and sexuality are constructed by an interplay of social, culture and economic forces that determines distribution of power. Socially and culturally in Africa, homosexuality is not accepted as a normal sexual practice as it connotes abnormality in sexual relations. These factors might have aroused anger to the people who victimized the homosexuals mentioned in this situational statement.

Situational Statements 10: Sixteen month old child refused treatment by hospital authorities.

Unfair treatment of women and children also highlighted the vulnerability of children living with HIV/AIDS as discussed in section 2.7.4 in chapter two, HIV/AIDS as human rights issue in section 2.8, particularly, issues associated with women's vulnerability within the society and stigma and discrimination experienced by people living HIV/AIDS and/or their families.

The responses also confirmed that denial, stigma and discrimination will continue to exist unless factors at individual and community level are addressed as highlighted in chapter of this document, sections 2.8.2.1 and 2.8.2.2 respectively.

Some examples highlighted the social and economic impact of HIV/AIDS in instances of loss of income as a result of HIV status. This was discussed in section 2.7 in chapter two and also confirmed by para-legals' responses. Unfair treatment of women and children also highlighted the vulnerability of children living with HIV/AIDS as discussed in section 2.7.4 in chapter two, HIV/AIDS as human rights issue in section 2.8, particularly, issues associated with women's vulnerability within the society and stigma and discrimination experienced by people living HIV/AIDS and/or their families.

4.2.2 SECTION B: PARA-LEGALS' ADVOCACY AND LOBBYING ROLE

Q1. What contribution do you think para-legals can make towards prevention of the spread of HIV/AIDS?

Some responses included:

- Para-legals should be trained to conduct community workshops concerning HIV/AIDS. Also, para-legals should be trained to give counseling to those who are HIV/AIDS victims.
- Para-legals can contribute by conducting workshops concerning HIV/AIDS and also place emphasis on the rights of people living with HIV and AIDS.
- Para-legals can conduct workshops based on how to prevent the spread of HIV/AIDS.
- Para-legals should be trained to conduct community workshops concerning HIV/AIDS.
- Para-legals should be supplied with materials to do the workshops, samples to make things more understandable.

- Para-legals can work with the youth to educate them together with health workers and other appointed NGOs to form coalitions and also to expand as to how to challenge the violated rights as to where to take the matter further.
- Para-legals must be given a chance to conduct a workshop on the issues of HIV/AIDS they must be trained and given more information on HIV/AIDS.

It should be noted that para-legals indicated that their contributions towards prevention would be both educational and casework orientated. Para-legals indicated they would need training as outlined above on four main areas of focus:

1. Training on how to conduct workshops on general issues pertaining to HIV/AIDS.
2. Training on conducting workshops on HIV/AIDS spread and prevention.
3. Training on conducting awareness campaigns and counseling.
4. Training on how to form coalitions and networks at a local community level.

The same areas of learning were identified by student para-legals participating in focus groups. The only difference was that practicing para-legals were more knowledgeable on human rights advocacy work. This means that a training programme that would be designed should cater for para-legals who are at different level in terms of knowledge of issues.

Q2. What contribution do you think para-legals can make in their respective communities towards care, support and treatment for people affected and/or infected by HIV/AIDS?

Responses from para-legals were as follows:

- Para-legals can work hand in hand with the community to educate them how to handle issues of HIV/AIDS.
- They must work with other stakeholders and ensure that these people are taken care of, supported and treated fairly.

- They can be strategic implementers of HIV/AIDS projects.
- Para-legals can be a link for other resources nearer to the community resource centres where they can arrange accommodation for these affected people.
- Para-legals can communicate with the relevant institution dealing with HIV/AIDS, which will assist those who are affected/infected by HIV/AIDS.
- Para-legals can play important role by running workshop and getting help from other institution like health improvement and to make awareness on the issue.

Para-legals identified four areas that can assist them to contribute towards care, support and treatment. These are: networking with other stakeholders and role-players, conducting workshops and providing advice and counseling to individuals who would need help.

The role care and support interventions can play are quite important in fight against HIV/AIDS. The three fold benefits of care and support as highlighted by Girma and Schietinger (1998 & 2000:1) in section 2.8.2.2 in chapter two are an indication that integrating HIV/AIDS care and support are an essential strategy due to the fact that care and support enhances prevention, while prevention enhances care and support. This shows a two-way effect that sustains a cycle of benefits.

It also confirmed findings of a study conducted by Davies, Schneider et al. (1997: 21)) which revealed that the fight against HIV/AIDS is best fought in a collaborative manner. It stated that the fight would only be effective if all sectors combine their efforts and resources. Due to the fact that para-legals work in under-resourced areas a collaborative effort at a local level will be beneficial. With the changing governance structures in South Africa, it will mean that the networks will have to forge support of local authorities in the municipalities and traditional authorities.

Q3. What are your concerns as a paralegal on your role to advocate for human right of people living with HIV/AIDS and/or their families?

- Para-legals can provide counseling because they are closer to the community. They can also educate the community and the youth about HIV/AIDS. This is currently not happening.
- Para-legals also do not have enough knowledge on HIV/AIDS.
- Para-legals should be provided an ability of human rights, holistic care to the dying and enable the affected to assume their place in society.
- Can offer training to nurses and other health care workers about human rights focusing on affected people.
- My concern is that people who are living with HIV/AIDS must not be discriminated; they must enjoy rights like others because it might happen that we all have this virus. We don't know until we go for a test.
- Para-legals were not given more information on how to deal the issue of HIV/AIDS which leads to difficulty in providing the exact help that a person requires because we have to refer them to other institutions.

The concerns raised by para-legals highlighted the need for training in order for them to be effective in running holistic programmes.

Para-legals indicated that they have limitations in terms of knowledge on HIV/AIDS issues. The last paragraph on para-legals responses sums it all.

Limitation: This question might have appeared ambiguous to some of para-legals. Some concerns that para-legals raised related to people living with HIV/AIDS and not on the Para-legals' role as expected in response.

Q4. What Recommendations Can Para-legals Make to Address Their Concerns?

- The involvement of para-legals can strengthen the community resource centres that para-legals are able to give information to the community rather than always referring them to health care workers.
- Para-legals need relevant training in effective publicity campaigns.
- Training of para-legals to ensure that the infected and affected are not marginalized.
- Para-legals should be provided with training to train caregivers.
- Para-legals can contribute in improving social services.
- Para-legals' advocacy role, will strengthen the Community Resource Centres if that paralegal is able to provide such information to the community and not always referring them to health workers.
- Various workshops need to take place in all hospitals and clinics throughout the country.
- Para-legals must also be educated on how to provide help to HIV positive people and their families.

Q5. Do you know of any government policy or legislation that is aimed at dealing with issues of HIV/AIDS? If so, kindly name the policy or statute.

The purpose of this question was to assess para-legals level of knowledge about laws and policies on HIV/AIDS that the government has legislated on. These would be of great assistance to handle matters related to them.

- Equality Clause and Section 14 of the constitution that provides a right to equality.
- At workplace it is Employment Equity Act and Labour Relations Act.
- National AIDS Policy.

- Television programmes such as *Asikhulume* (Lets talk).

This question did not receive a lot of responses. It indicated that para-legals had general knowledge on HIV/AIDS and human rights issues but limited in knowledge of the laws and policies that are aimed at dealing with HIV/AIDS issues. This is a key area that will have to be looked at on new programme design. Para-legals advocating for the rights of people living with HIV/AIDS should have legal knowledge so as to be able to take a rightful course of action should cases be brought to their attention for assistance and while educating communities through workshops.

Q6. What further learning needs can you identify to help paralegal practitioners to be effective in managing HIV/AIDS?

- Para-legals have the ability to keep confidential information; they must be trained in counseling about HIV/AIDS.
- More training courses on HIV and AIDS and on the rights of people living with HIV/AIDS.
- Research skills.
- Intensive training on counseling and how to deal with HIV/AIDS infringed rights.
- Para-legals need a special training in this issue because it also includes human rights and to be informed about anything that can affect people with HIV/AIDS to provide help and information to people who are in need.

4.3 CONCLUSION ON FOCUS GROUPS AND QUESTIONNAIRES

This chapter has provided findings of the study on what para-legals identified as their learning needs for managing HIV/AIDS in their respective communities where they are and/or will be practicing as para-legals. In particular, learning needs identified by para-legals include training on providing counselling to people living with HIV/AIDS and /or their

families, conducting awareness-raising workshops to prevent further spread and motivation towards care, support and treatment of people living with HIV/AIDS and/or their families. Para-legals also identified a need for training on establishing local networks of stakeholders and role-players to ensure concerted effort to address HIV/AIDS issues.

Para-legals' concerns on playing an advocacy role raised important issues that para-legals felt would be difficult to deal with. These related to issues of stigma and discrimination for example:

- Unfair treatment of people living with HIV/AIDS by health workers;
- Conducting workshops in cases where people would not participate due to fear of suspicion by other members of the community that they might be infected HIV;
- Dealing with cultural and related matters of HIV/AIDS such as forced virginity testing. Others relating to the traditional norms of suppressing the truth about abuse of women and children by relatives as a shade for keeping family ties and thus comprising their rights.

Dealing with matters of retaliation as a result of suspected witchcraft that could not be scientifically proven.

The factors raised on stigma and discrimination also came out in Literature Reviews that confirmed that care and support activities are critical to the continued efforts of communities, donors and governments to promote sustainable development.

The four areas identified by para-legals as possibilities of their intervention in managing HIV/AIDS covered learning areas that included: awareness campaigns, counseling, conducting workshops and establishing local networks:

4.3.1 Creative awareness campaigns are an important component of prevention. Prevention programmes would provide information that is relevant, accessible in terms of language and literacy levels in the para-legals respective local communities. Awareness raising activities could include exhibitions on HIV/AIDS and STIs, campaigns linked to Human

Rights Days (i.e. Human Rights Day – March 21; Children’s Day; Youth Day – June 16; Women’s Day – August 9 and World AIDS Day- December 1). Educational programmes should go beyond providing information through campaigns but aim to provide people with skills that could help them to adopt behaviours that will protect them from HIV/AIDS and STIs. It should be noted that education is a two way process of sharing information and understanding beliefs, attitudes and feelings.

Other campaigns may involve lobbying government to respond positively towards its obligation to meaningful realization of human rights. In particular, this refers to provision of access to health care including treatment to minimize AIDS-related deaths and social assistance for those who cannot support themselves and/or their families.

4.3.2 Counseling. Practicing para-legals provide counseling to individual members of the community on general legal matters. HIV/AIDS counseling involves a lot of effort. Lessons from workshops I have attended are that counseling is mostly effective when conducted by a peer. This means that para-legals can establish networks with organizations or support groups of people living with HIV/AIDS who could visit local communities to address workshops and meet individuals who needs psychosocial counseling. This area of focus will need further exploration since there are a lot of issues to be considered prior to implementation.

4.3.3 Local Community Educational Workshops will form part of advocacy strategies at a local community level. Para-legals will find out community learning needs and thereafter design learning events to address issues that have been identified by the community. Other learning events will be a para-legals own initiative to highlight important issues on HIV/AIDS, Human rights and the law. This confirms Caffarella, (1994: 69) in stating that designing educational programmes is both re-active and proactive. The CLRDC curriculum review will also be helpful in designing learning events on updated curriculum for para-legals that they in turn will go out to the community and impart new knowledge that they would have gained. Workshops will serve as an educational tool to help community members avoid problems before happening or respond positively to them as they arise.

4.3.4 Networks at a local community level will play an important role in this regard. Networking can be defined as “a process by which two or more organizations and/or individuals collaborate to achieve common goals” (Waring, 1997 & 2000: 2). According to Waring, networks are characterised by the following:

- A group of organizations/individuals coming together to pursue joint goals or common interests;
- Provide venues for social action through exchange and mutual learning;
- Sustenance through some form of communication;
- Commitment to a jointly developed structure and shared responsibilities; and
- Based on member-ownership and commitment to shared objectives and means of action.

In short, network activities may involve the following:

- Generate, share information and analysis;

Provide a platform for information sharing. This is important for purposes of exchange of information and to analyze it to achieve common goals and objectives.

- Advocacy: is defined as: “a political process designed to influence policy decisions at national and international levels. It is a citizens initiative aimed at changing popular interests, needs or desires into definable policies, practices even rights.” (Women, Law & Development International and Human Rights Watch Women’s Rights Project, 1998)

Networks often co-ordinate advocacy action on matters of mutual concern to members. Networks have been quite successful at influencing decision-makers both within and without the network.

- Skills and capacity building: Members benefit from general sharing information and experience. Networks provide formal skills building opportunities for members when they organize workshops and seminars or produce educational tools such as manuals, guidebooks or resource guides.

- Building solidarity: Networks are mindful of the need to build a sense of solidarity among its members so that they are better able to achieve their goals and objectives. Networks also help to assure members that their work is important, particularly when the social and political environment is not hospitable to work in the area of HIV/AIDS.

4.3.5 Conclusion

The issues raised in this study validate the instruments used for data collection. The findings revealed that para-legals in both focus groups and those who responded to questionnaires concurred with Girma and Schietinger, (1998 & 2000:1) on the need for an integrated prevention care and support programme. They suggested that HIV/AIDS issues should be looked at in the context of sustainable development.

The authors argued that care and support activities are broad in nature and are critical to the continued efforts of communities, governments and donors to promote sustainable development. Also, the benefits of care and support are three fold:

- Firstly, care and support mitigate the effects of HIV pandemic on individuals, families, communities and nations, thereby promoting their prospects for sustainable development.
- Secondly, care and support interventions help prevent further HIV/AIDS transmission by enhancing the effectiveness of prevention efforts.
- Thirdly, care and support are rights because they promote access to basic health and welfare consistent with the Universal Declaration of Human Rights, and they are therefore ends in themselves. Para-legals contributions towards managing HIV/AIDS means that they need to be knowledgeable about prevention, treatment, care and support of people living with HIV/AIDS and/or their families.

The learning needs suggested by para-legals that include counseling, intensive training on HIV/AIDS, human right and the law and establishing local networks validates the usefulness of tools used to gather information on learning needs assessment. All the tools including literature

reviews, focus groups and questionnaires yielded results that pointed to the same direction. It came out clearly that para-legals could not manage HIV/AIDS effectively without proper training.

4.3.6 Summary of findings on learning needs to advocate for the rights of people living HIV/AIDS and/or their families.

Para-legals' understanding of HIV/AIDS-related stigma and discrimination was clearly demonstrated to be theoretically sound but difficult to implement. Paralegals recommended a need for intensive training on HIV/AIDS, Human Rights and the Law. The aim would be to empower para-legals' to reach high levels of awareness about HIV/AIDS-related discrimination and the stigma attached to it as a legal and human rights issue.

Paralegals' levels of knowledge, attitudes and perceptions of para-legals towards HIV/AIDS transmission, spread and prevention proved to be basic. The learning programme design that would emerge out of this study had to cover different aspects of HIV/AIDS issues ranging from infection, transmission, spread, treatment, care support and prevention of HIV/AIDS. Prior to designing a learning programme, the researcher had to assess how much the para-legals knew and understood about the HIV disease and its transmission, spread, prevention and risk factors.

The levels of knowledge and understanding of HIV/AIDS helped the researcher to assess whether or not para-legals were adequately trained to effectively perform the lobbying and advocacy role that could then be able to play at community or grassroots level.

Para-legals' contribution towards managing HIV/AIDS in rural areas was explored and proven possible. Para-legals raised areas of learning that would equip them to play the role of advocating for the rights of people living with HIV/AIDS.

Paralegals perceived learning needs to effectively contribute towards managing HIV/AIDS in their respective local communities would be training on counseling; how to conduct local workshops on specific issues related to HIV/AIDS, human rights and the law; how to organize campaigns to raise awareness and lobbying and advocacy skills for or against policies that have a bearing on people living with HIV/AIDS and or their families; and how to establish local

networks of stakeholders to address issues in a coordinated manner thereby sharing resources, information and knowledge.

Chapter 5

Summary, Recommendations and Conclusion

5. SUMMARY

This chapter provides a summary of findings from the study on assessing learning needs of KwaZulu-Natal para-legals for managing HIV/AIDS.

As indicated in chapter three of this document, data was collected by means of three methods, focus groups, questionnaires and literature review. Findings on what are the learning needs of KwaZulu Natal para-legals to advocate for the rights of people living with HIV/AIDS and/or their families are summarized as follows:

5.1 PARA-LEGALS UNDERSTANDING OF HIV/AIDS-RELATED STIGMA AND DISCRIMINATION.

Para-legals practicing in rural-based advice offices and/or resource centres showed basic understanding of HIV/AIDS-related stigma. This can be supported through the responses to questions covered in the questionnaire.

Para-legals showed a good understanding of human rights issues in general. The limitations that came out openly were handling HIV/AIDS-related human rights and legal matters. It was clear that there was no common understanding on responding to real issues, hence para-legals participating in focus groups and those responding to questions recommended as intensive training programme on HIV/AIDS.

Student para-legals participating in the CLRDC Diploma in Paralegal Studies had a general understanding of what would be an ideal paralegal for managing HIV/AIDS. Though this question was not posed to practicing para-legals, the responses to HIV/AIDS and human rights-related issues showed a high level of their understanding of issues.

Student para-legals' perception of an ideal paralegal for managing HIV/AIDS; their responses of being someone who will not discriminate against people on the basis of their HIV positive status, showed that student para-legals have an understanding of an ideal person to perform the role of managing HIV/AIDS in a local community.

Student para-legals identified sources of access to information on HIV/AIDS and STIs. They also indicated that they trusted the reliability of the information due to the sources that it came from.

Important points covered in chapter two of this document were confirmed when reconciled with data collected through focus groups and questionnaires. Para-legals in both groups had a general understanding of stigma and discrimination faced by people living with HIV/AIDS and/or their families.

The major problem that came out clearly was the unfair treatment of people living with HIV/AIDS and/or their families by various sectors (i.e. education, health, employment etc.) in the community whereas the Constitution enshrines equal treatment for all human-beings. The responses reflected that the right to equality was to a large extent violated in most respects, resulting in other rights being violated as well.

5.2 PARA-LEGALS BASIC KNOWLEDGE OF HIV TRANSMISSION, SPREAD, PREVENTION OF HIV/AIDS AND RISK FACTORS.

- Para-legals had basic knowledge of how and where to get access to basic information on HIV/STIs. The responses received from focus group sessions confirmed this in section 4.1.2 of this document whereby they responded to various questions on sources of information on HIV/AIDS and STIs, the reliability of those sources.
- Para-legals had general awareness about HIV/AIDS but seemed to have limitations in practice or action. The responses to all questions on session 4.1.3 in chapter four of this document reflect that the level awareness is high but not sufficient for them to impart to the community at large.
- Para-legals showed basic knowledge about HIV/STIs spread. This is reflected on section 4.1.2 in chapter four of this document. The only limitation from focus groups was that

mother-to-child transmission was not mentioned. It was surprising to discover that though most of paralegals participating in focus groups were females they did not think of the risk of transmission of HIV/AIDS from mother-to-child.

- Para-legals had an understanding of how to protect themselves against infection. They also had a clear understanding of risk factors.

5.3 SUMMARY OF DISCUSSION ON HIV/AIDS PROTECTION AND RISK FACTORS

The responses provided a general understanding of protection issues against HIV infection and STIs. Para-legals identified protection mechanisms from getting infected with HIV/AIDS and STIs. Para-legals also showed an understanding of the risk factors of practicing unsafe sex. Other areas of concern were condom usage initiation that had an impact the level trust between spouses and/or partners. The most important issue identified was the risk that might result in infection should one partner be unfaithful while pretending to be well behaved in front of the other spouse or partner.

The issues of gender and sexuality also came to the fore as it became evident that the spread of HIV/AIDS and STIs lies with the attitudes, perceptions and behaviour of spouses and/or sexual partners. Unless issues of gender inequality and sexuality are adequately addressed the spread of HIV/AIDS and STIs could never be prevented.

Para-legals had knowledge of protection issues, however, it was surprising to learn of the high risk of getting infected even though you may be conscious of risk factors. This is reflected on section 4.1.3 in chapter four of this document.

5.4 PARA-LEGALS CONTRIBUTION TOWARDS PREVENTION

Para-legals' responses in both focus groups and questionnaires identified four areas of focus that they can contribute towards HIV/AIDS prevention. The areas overlap with responses on paralegals contribution towards treatment, care and support of people living HIV/AIDS and/or their families. These areas of focus were:

- Providing Counseling to those infected and/or their families. This area would be recommended for further research as it involves a lot of work. It is not clear yet whether para-legals could provide counseling themselves or they may refer clients to other support organizations for people living with HIV/AIDS and/or their families.

- Conducting awareness-raising workshops at local community level;

Local workshops would be aimed at raising awareness about HIV/AIDS and the problems that the disease entails socially, economically and politically;

- Organizing campaigns;

Campaigns would focus on specific issues that would be prioritized from time to time; and

- In addition, both practicing and student para-legals raised the importance of working in coalitions/networks to expand knowledge in dealing with HIV/AIDS.

5.5 PARA-LEGALS' CONTRIBUTION TOWARDS CARE AND SUPPORT FOR THOSE AFFECTED BY HIV/AIDS AND/OR THEIR FAMILIES.

Para-legals participating in focus groups came up with the following areas where they can contribute:

- Para-legals identified counseling and home visits as two areas they can contribute towards care and support.

Psychosocial care is one major component of dealing with the scourge of HIV/AIDS. This area would need further research given the fact that home-based care workers are trained to perform this role. Other studies have revealed that psychosocial counseling works better if conducted by a peer who is also HIV positive. Inviting people living with HIV/AIDS especially activists to attend local workshops and encourage peers to live positively. It is also an important area for para-legals to have incorporated into their

training as peer support for prevention and care will have to be provided for people living with HIV/AIDS when they visit their offices for assistance.

Psychosocial counseling creates an opportunity for people living with HIV/AIDS to receive mutual support from a peer. Para-legals are better positioned to identify support groups of other people living with HIV/AIDS who can visit the office to counsel those affected and infected about positive living life-styles. This is based on the fact that para-legals are ethically bound by the code of their practice to keep confidential information. Confidentiality results in a sense of trust to clients when they visit a paralegal office. Inviting an activist will create an opportunity of mutual support from para-legals as they will be able to work with support groups of people living with HIV/AIDS

- Para-legals identified their role towards advocating for social grants for those affected by HIV/AIDS and/or their families.
- Para-legals also identified a number of areas that they could cover in terms of advocacy work aimed at eliminating discrimination against people living with HIV/AIDS and/or their families. They listed the following:
 - Conducting community workshops as means of awareness raising and conscientisation about stigma and discrimination.
 - Casework whereby para-legals can address matters (i.e. discriminatory practices) brought to their offices and/or resource centres by those affected by HIV/AIDS and/or their families. For example, disability grant for those who are too sick to support themselves due to HIV/AIDS; Child Support Grant for those minor children whose parent(s) or guardian(s) has no source of income; Care Dependency Grant of children under the age of 18 who cannot support themselves due to illness or disability; and Foster Care Grants for those children who have been placed under foster care by an Order of Court.
- HIV/AIDS monitoring. Para-legals felt that they could keep statistical reports on stigma and discrimination-related matters brought to the attention of the paralegal office and/or resource center. The information would be helpful in measuring the impact of managing HIV/AIDS in a local community.

- Campaigns to raise awareness of employees about their right to refuse forced HIV test by employers.

In addition to the common points raised by all para-legals, those already in practice came up with the following points:

- Working hand in hand with the community, by organizing and conducting workshops.
- Working towards establishment of coalitions or networks within a local community to deal with issues of care and support.
- Para-legals could serve as resources brokers at a local community level.

5.6 PARA-LEGALS' CONCERNS ON ADVOCACY ROLE

In both focus groups and questionnaires the following issues were raised:

- Para-legals concerns were lack of adequate knowledge to deal with issues of stigma and discrimination particularly involving doctors, insurance companies, employers and government officials.
- Para-legals also raised concerns about traditional norms that might hinder their role of advocating for the rights of people living with HIV/AIDS and/or their families. These related to situations such as relatives refusing to report cases of abuse suffered within family circles. Others relating to issues of witchcraft and traditional beliefs.
- Para-legals were not trained to run holistic HIV/AIDS programmes.
- Para-legals have limitations in terms of information to provide the exact help or advice expected by community members from them.
- Para-legals identified the discrepancy of reader-friendly materials that respond to rural settings.

5.7 LEARNING NEEDS OF PARA-LEGALs FOR MANAGING HIV/AIDS.

Para-legals identified the following areas as learning needs:

- Intensive training on all aspects of HIV/AIDS. This includes training on HIV/AIDS and Human Rights of people living with HIV/AIDS and/or their families.
- Training on counseling.
- Training on Labour Laws that relate to HIV/AIDS.
- Forming local networks and coalitions.
- Conducting HIV/AIDS workshop in local communities.

On assessing the CLRDC's course content for Diploma in Para-legal Studies (refer to subjects outline in Appendix 5), the following subjects were identified as part of areas where gaps still exist in terms of HIV/AIDS incorporation:

- Constitutional Law
- Criminal Law
- General Principles of Delict
- Gender and Children Rights
- Human Rights
- Labour Law
- Occupational Injuries and Disease
- Role of para-legals and Code of Conduct
- Social Welfare
- Social Components
- Unemployment Insurance Law
- Law of Contracts
- Law of Succession

These will have to be taken into consideration when a new learning programme is designed by CLRDC as a result of this study. The learning programme for para-legals would integrate HIV/AIDS once contents of the training materials on the above-mentioned subjects have been revised. The new materials will be used for para-legals participating in the Diploma Course in

Para-legal Studies and the practicing para-legals that would participate in the Continued Legal Education sessions.

5.8 CHALLENGES AND RECOMMENDATIONS

It is clear that the challenges posed by HIV/AIDS require both a global and a local response. There is a need for integrated intervention strategies. Some of the issues to grapple with may include looking at questions such as:

How could HIV/AIDS networks, as a need identified by para-legals, be sustained given the dwindling financial support from foreign donors and the South African government's current stance on provision of funds for HIV/AIDS initiatives by NGOs?

There is still a need to develop the will among all stakeholders at a local community level, knowledge, values and skills required to prevent the spread of AIDS. This will never be sustainable without the concerted efforts of government, local communities, non-governmental organizations, research institutions and faith-based institutions. It calls for a full range of inter-related or integrated approaches. These may include spreading information of sexual abstinence, mutual fidelity, condom use and safe practices in relation to blood and needles. Also, further studies on how para-legals can contribute towards provision of counseling services to people living HIV/AIDS and/or their families.

KwaZulu Natal, as one of the leading provinces in South Africa in terms of HIV/AIDS prevalence, faces the major challenge of making a positive response to combat the spread of HIV/AIDS. I concur with the suggested communications framework for HIV/AIDS that is key to the success of the intervention strategies that depends on sound HIV/AIDS communication strategies as suggested by Spanier and Piot, (1999:27). The five most important domains in the context of HIV/AIDS focused on developing communication strategies for HIV/AIDS prevention, care and support which ties in with the findings in Literature Review and those that para-legals have identified as their learning needs. These are:

Government policy. The role of policy and law in supporting or hindering intervention is one challenge that must be looked at. Para-legals could play a pivotal role in empowering local communities with lobbying and advocacy strategies that would ensure that HIV/AIDS issues are

prioritised and adequately addressed by the government. The local community workshops that para-legals would conduct after receiving training could be used as a platform for development of lobbying and advocacy strategies. This will never succeed unless para-legals are kept abreast of the new and changing government legislation and policies. On-going training of para-legals on the continuously changing legal environment will ensure that para-legals provide up-to-date information to the community all the time. The CLRDC Continued Legal Education programme would serve this purpose and must ensure that HIV/AIDS form part of the training programmes all the time.

Socio-economic status. Collective individual income that may allow or prevent adequate intervention is another challenge that should be looked at. Since HIV/AIDS is closely linked to poverty, socio-economic status of individual members of the community will need to be improved. Advocating for social grants aimed at alleviating poverty is one area that para-legals would specialise in. It is recommended that the CLRDC training on social welfare would have to be reviewed to ensure that people living with HIV/AIDS and/or their families, also benefit from the paralegal services.

Culture. Positive, unique or negative characteristics that may promote or hinder prevention and care practices are a challenge that should be taken into consideration. Traditional and western practices would have to be monitored to assess the most appropriate to contribute to prevention of the spread without compromising individual rights to self-determination. This will raise awareness about risky practices such as virginity testing identified as a violation of rights and discriminatory by para-legals.

Para-legals could raise the consciousness of individuals and groups on cultural and moral rights. Therefore a training programme aimed at addressing culture among diverse groups will be necessary to put the contribution of culture to the spread of HIV/AIDS on the agenda of community education is recommended. Para-legals concerns about traditional norms that might hinder their role of advocating for the rights of people living with HIV/AIDS and/or their families would have to be considered during future programme design.

Gender Relations. The challenge of dealing with status of women in relation to men in society and community and the influence on negotiating and decision-making will make a meaningful contribution in preventing the spread of infection between men and women. Gender sensitization

workshops would be beneficial in raising awareness on how gender relation may fuel the spread of HIV/AIDS. This fits in well with the learning need of para-legals to conduct workshops and establish networks. Women's issues cannot be adequately addressed without men's involvement. Para-legals as trusted people within the community can bridge the gap between gender groups through education and counseling.

It is recommended that the CLRDC current training programme on gender and children rights would have to be reviewed to ensure that issues of HIV/AIDS are addressed for the benefit of the community that CLRDC paralegal office and/or resource centre serves. Also, further research to focus on attitudes towards sexual relations and practices would be necessary.

Spirituality. The role of spirituality and religious values in promoting or hindering the translation of prevention and care messages into positive health are also important for addressing the HIV/AIDS problem in South Africa, particularly at a local community level. Networking with religious bodies at community level would be helpful. Para-legals can be a strong force to bring the stakeholders together.

5.9 CONCLUSION

The learning needs as identified by para-legals makes it explicit that with thorough training, para-legals would be empowered to deal with complex issues including the role of spirituality to encompass hope, faith, self-transcendence, a will or desire to live, the identification of meaning, purpose and fulfillment in life, the recognition of morality, a relationship with "higher power", "higher being" or "ultimate" and the maintenance of interpersonal and intra-personal relationship. These will be useful networks for para-legals especially when it comes to counseling. Some of the matters might be referred to the stakeholder forming the network at a local community level or may be addressed regionally if broad enough to require such intervention.

Education, including education for responsible sexual practices, has been shown to be effective in helping to combat the spread of infection in some parts of Africa and elsewhere. Para-legals' advocacy role to run educational workshops at local community level would highlight the importance of understanding these issues.

Strategies for prevention and care may fail if those affected by HIV/AIDS play no part in designing or carrying them out. Peer counseling will also play an important role in terms of care for those infected or affected by HIV/AIDS. Therefore, those providing counseling will have to be trained. The CLRDC will have to ensure that those providing counseling within the community would have received adequate training. Training institutions on counseling may also be recruited by para-legals to form part of local networks.

The two additional key areas that must be considered in grappling with HIV/AIDS to be tailored in the African continent indicate that community education and training and co-operation of stakeholders at local community and regional level are important: These key areas are:

- A community-based approach, and
- A regional co-operation.

A community-based approach will be addressing the HIV/AIDS situation at a local level and considering local dynamics. The CLRDC's established infrastructure for channeling resources to rural communities would be helpful in this regard. The support of power structures enjoyed by para-legals in rural settings would make it easy to initiate HIV/AIDS programmes that would suit local culture and practices. Networks at a local level would be pivotal as a key area identified by para-legals as part of learning needs. Training on establishing local networks would be important to make this learning need a reality. Home visits as identified by para-legals as one of their contributions towards care and support would be most suitable to be reserved for home-based workers who would presumably form part of local network. Reader-friendly materials that respond to rural settings would also need to be developed when learning designs for educational workshops are implemented as a result of this study.

A regional co-operation will provide information sharing and concerted effort in finding solutions to fight the disease. Other provinces in South Africa, countries in Sub-Saharan region and will also provide a platform to learn from successes of others through networks.

Para-legals concerns about lack of adequate knowledge to deal with issues of stigma and discrimination particularly involving doctors, insurance companies, employers and government officials will need to be addressed through revision of CLRDC course materials that relate such

issues and further research may be conducted on some of these issues where solutions have not been found.

The suggested approaches to address the situation cannot succeed unless the programmatic intervention is researched in order to make informed decisions for action. Civil society can play a meaningful role as lessons from other countries indicated.

Findings from this research study could be used to develop informed intervention programmes to raise-awareness about HIV/AIDS and STIs; prevent the spread of HIV/AIDS and risk factors; advocating for the rights of people living with HIV/AIDS and/or their families thereby ensuring that they are not discriminated against; counseling and networking.

Para-legals need to be well informed about HIV/AIDS, so that they can understand clearly how the virus is transmitted and what activities and interactions are necessary. This in itself will undoubtedly not be enough to promote widespread, effective behavioural change, but is an essential part of what is needed. Greater understanding and awareness should remove irrational fears and lead to supportive attitudes towards infected people. If people living with HIV/AIDS can expect to be accepted and supported, they need no longer keep their diagnosis a close secret. Para-legals, as people trained to keep confidence can play a meaningful in this regard of 'breaking the silence'. People living with HIV/AIDS also need to feel that they are not going to be blamed for having been infected in the first place. Therefore, studies geared towards development of intervention strategies for managing HIV/AIDS within a local community are necessary, particularly in KwaZulu-Natal with high incidence of HIV/AIDS.

Para-legals are better positioned to play this role since they are based in local communities and working with local communities who trust them for being able to keep confidences. Their training towards the Diploma covered advocacy skills focusing on awareness raising. The learning programme design that will emerge out of this study will have to build on knowledge that already exists. The intervention programme will thus be "people-centred and driven". Para-legals have an advantage of enjoying support from local power structures through their paralegal committees. This puts them in a better position to play a leading role of establishing these suggested networks.

This study has provided the researcher an opportunity to identify the desired state of para-legals knowledge, skills and attitudes for managing HIV/AIDS in KwaZulu-Natal local communities.

The primary areas of focus were on expanding existing knowledge of para-legals to handle human rights-related matters and taking legal action if the need be.

Para-legals currently practicing in rural-based paralegal office and/or resource centres run educational workshops on human rights and law-related matters. These will need to include HIV/AIDS in the near future. Therefore, a training programme for para-legals on HIV/AIDS, Human Rights and the Law is necessary. The existing state of knowledge is not adequate for para-legals to be able to handle HIV/AIDS-related matters.

The training to be designed out of this study would have to consider the different levels of understanding of those para-legals studying towards the Diploma in Paralegal Studies and those already practicing in para-legal and/or resource centres.

The priority learning needs identified by para-legals implied that the training would close the gap in knowledge and skills, bearing in mind that attitudinal change towards HIV/AIDS depends on individual's beliefs, values and norms. Para-legals might share characteristics, however, they still remain individuals with unique backgrounds and needs. Therefore, a study to assess their learning needs was necessary to identify knowledge levels and gaps so as the learning design would build on their existing strengths and improves on their weaknesses. The process was interactive and the information gathered and analysed could be used to construct more knowledge in the area para-legals learning needs for managing HIV/AIDS.

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Appendix 1

Questions for Focus Group Interviews

Topic Area: Learners' Basic Knowledge towards HIV/AIDS transmission, spread, prevention and risk factors.

Session 1: Introductory Brainstorm

What are the qualities of an ideal paralegal for managing HIV/AIDS?

Session 2

In this session the discussion will revolve around issues of HIV and other Sexually Transmitted Infections (STIs) awareness and the risks of getting or transmitting these disease. For the purposes of the discussion a steady partner also means a spouse.

Instruction:

In two groups of five or six nominate a chair and scribe. Discuss the following questions and write responses in a newsprint. A written report by the scribe must be submitted to the facilitator after the group presentation.

Questions

1. How and where do you get information about HIV/STIs prevention?
2. How reliable or true do you think the information is from the sources you have mentioned?
3. Tell me what you know about STIs and HIV?
4. How would you know if a person is HIV positive?
5. How do you think you may be at risk of getting HIV/STIs?
(Here the idea will be to get the understanding of learners about transmission of the disease)
6. Do you think your steady partner may be at risk of getting HIV/STIs?
7. Other than your steady partners do any of you have casual partners?

Report Back and Plenary Discussion

Session 3 - Protection Issues and risk factors:

This session will look at how learners protect themselves from getting or transmitting HIV and other STIs. The aim will be ascertain learners' attitudes and perceptions towards HIV transmission and prevention.

1. What are you currently doing to protect yourself from HIV/STIs?
(The facilitator will try to probe for: traditional methods or western methods.)
2. Do you and your sexual partner/s use male condoms? Who initiates use? What is the reaction from you or your partner/s?
3. Who initiates condoms in a relationship?
4. How often do you use condoms?

Per week ?
Per month?
5. Which situation makes you use condoms?
6. What happens when you insist on condom use with your steady partner?
7. How easy is it for you to get free male condoms and where do you currently get them?
8. How easy is it for you to get female condoms and where do you currently get them?

Report-back and Plenary Discussion

Session 4

1. What contribution do you think para-legals can make towards prevention of the spread of HIV/AIDS?
2. What contribution do you think para-legals can make in their respective communities towards care, support and treatment of people infected and/or affected by HIV/AIDS?
3. What are your concerns as a paralegal on your role to advocates for human rights of people living with HIV/AIDS and/or their families?
4. What recommendations can you make to address those concerns?
5. What further learning needs can you identify to help paralegal practitioners to be effective in managing HIV/AIDS?

Appendix 2

Focus Groups

Sessions Outline

09h00 – 09h15	Session 1
09h15 – 09h45	Session 2
09h45 – 10h30	Feedback and Discussion
10h30 – 11h00	Tea Break
11h00 – 11h30	Session 3
11h30 – 12h00	Feedback
12h00 – 12h30	Plenary Discussion
12h30 – 12h50	Session 4
12h50 – 13h00	Summary and Closure

Appendix 3

STRICTLY CONFIDENTIAL

Questionnaire

Section A

Read the following situational statements on Human Rights and HIV/AIDS and respond to the questions that follow: Please answer all questions.

Situational Statement 1

Many communities argue that virginity testing is a way of protecting the youth against HIV. Thus at routine intervals all the young girls (and occasionally boys) are publicly tested whether or they are virgins or not.

- 1.1 What is the nature of discrimination experienced by young boys and girls in this Situational Statement?
- 1.2 What human rights do you think were violated through this practice of virginity testing?

‘There was a women working at the travel agency... who reported her HIV status to the powers-that-be and the next thing I knew, I was called in and told that I was a shoddy worker and I must please leave.’

- 1.3 What is the nature of discrimination that was experienced by the women mentioned in this Situational Statement?
- 1.4 What human rights were compromised or violated?

Situational Statement 2

An elderly woman who was caring for 18 orphans in Mpolweni, was interviewed by the Natal Witness. The community threatened to beat her up and accused her of trying to drive away job creation and community development from the area by speaking about HIV. They said other people would see Mpolweni as a place full of “AIDS”.

- 2.1 What do you think is the nature of discrimination that was experienced by this elderly women?
- 2.2 What human rights were comprised?
- 2.3 If you were to receive a complaint from a client on a matter of this nature, what action would you take to address the problem?

I was employed by a company that requested me to take an HIV test. I went for the test and found out I was HIV positive.

- 2.4 Do companies have a right to ask any of their employees to go for an HIV test?
- 2.5 If you were to advise this employee as your client, what advice would you give?

Situational Statement 3

On World AIDS Day, 1 December 1998, Gugu Dlamini publicly disclosed her HIV status at an openness and acceptance rally - a community event aimed at 'breaking the silence about HIV'. However, she did not receive acceptance or support from her community as immediately after the rally she was threatened by a youth who promised that he would return to assault her later. On the 12 December 1998, Gugu Dlamini was severely assaulted by a gang of youths outside a shebeen where she had been drinking. She was taken to hospital where she later died of her injuries. She left behind a partner and a 13-year old child.

- 3.1 What was the nature of discrimination experienced by Gugu Dlamini and/or her family?
- 3.2 If you were to run a workshop in your community what would you highlight about human rights violations experienced by Gugu Dlamini and/or her family?

'Thabang faced a lot of complications. After his father died, I told his teacher that I was HIV positive. All the teachers at the school said, "Do not touch that child, his mother has AIDS".'

- 3.3 What was the nature of discrimination experienced by Thabang and/or his family?
- 3.4 If Thabang's family were to bring this matter to your attention for advise, what action would you take as a paralegal?

Situational Statement 4

'I tried to inform one of my colleagues. After a couple of months, it spread all over the company and I decided to leave.'

- 4.1 Do you think this employee faced any form of discrimination? If so, what kind?

There were 2 children at the Children's Home who were HIV positive but the staff were not treating them correctly, it was not like the other kids. They used to swear at them and sometimes they did n't even wash their clothes.

- 4.2.1 What is the nature of discrimination that was faced by the two children and/or their families?
- 4.3 What human rights were compromised or violated?

Situational Statement 5

‘So it hit the newspapers... Someone spray-painted “fags” on the side of the house, and bricks were thrown at our windows. Somebody poisoned our dogs.’

5.1 What is the nature of discrimination that was faced by the “fags”/homosexuals?

One child of 16 months was taken to hospital as she had systematic thrush; the nurses told the mother there was nothing they could do for her as she was an “AIDS baby”. The mother and child were sent home without treatment and the baby subsequently died.

5.2 What is the nature of discrimination that was faced by this mother and her child?

5.3 What human rights were violated by the hospital authorities?

5.4 What advice would you have given if this matter was presented to your office?

Section B

6.1 What contribution do you think para-legals can make towards prevention of the spread of HIV/AIDS?

6.2 What contribution do you think para-legals can make in their respective communities towards care, support and treatment for people affected and/or infected by HIV/AIDS?

6.3 What are your concerns as a paralegal on your role to advocate for the human rights of people living with HIV/AIDS and/or their families?

6.4 What recommendations can you make to address those concerns?

6.5 Do you know of any government policy or legislation that is aimed at dealing with issues of HIV/AIDS? If so, kindly name the policy or statute.

6.6 What further learning needs can you identify to help paralegal practitioners to be effective in managing HIV/AIDS?

Note: Situational statements Adapted from: ‘A Primary Capacity Development Course for Government Planners, 2001’

Community Law and Rural Development Centre and University of Natal (Durban), Faculty of Law Diploma in Paralegal Studies

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