

Evaluation of non-profit organisations in the Free State Province in the field of HIV/AIDS: Draft report
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Evaluation on non-profit organisations in the Free State Province in the field of HIV/AIDS.

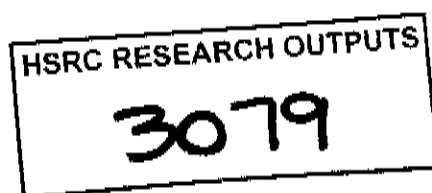
Study undertaken for the Free State Youth Commission

by the

**Human Sciences Research Council (D&G)
Centre for Development Support
Free State Youth Commission**

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EXECUTIVE SUMMARY

This report forms part of a five-year plan designed by the Centre for Development Support (CDS) of the University of the Free State on behalf of the Free State Youth Commission (FSYC). As part of a cluster of research projects on governmental youth programmes and actions, the project aims to inform government departments on how best to integrate youth related issues into their structures and programmes.

In terms of Section 27 of the Constitution (1996) access to welfare services is an inalienable right that every community is entitled to, except for certain type of services and during circumstances where government does not have adequate resources to provide the required services. This places a huge responsibility on government to find mechanisms and ways that would enable citizens to access services. The magnitude and complexity of government services alone, compels government departments to find and form partners with other service providers in order to complement government efforts. Therefore, the involvement of non-profit organisations (NPOs) in the provision of certain government services is crucial. In many cases NGOs are better placed to reach out communities, which may not be easily accessible to government structures.

The overall aim of this study was to evaluate the role of non-profit organisations in the Free State in the field of HIV/AIDS with specific emphasis on the youth as beneficiaries. The report outlines the circumstances and conditions in which NPOs in the Free State Province operate and interact with two government departments, namely Department of Social Development (DoSD) and Department of Health (DoH). The report is divided into nine sections.

The report begins by setting the broad framework for the study, including the objectives and purpose of the study; the purpose of which is evaluation of non-profit organisations in the Free State Province. The research approach and methodology used for the study are discussed. In addition, methodological difficulties encountered in the course of the study are outlined.

The section dealing with literature review sets the context for the study. The literature review begins with the modern impact of the epidemic across continents and regions and then focuses on sub-Saharan Africa. The section concludes by outlining the involvement and role of the NPOs in the fight against the HIV/AIDS epidemic.

The section on the structure and role of government departments involved with NPOs in the fight against HIV/AIDS presents an overview of the sub-directorates responsible for NPO coordination, funding and monitoring of organisations. The Free State province is divided into five municipal districts. Accordingly, the delivery of services from government departments, including DoH and DoSD are cascaded in terms of this municipal demarcation.

The most important component of the report is the section detailing all nine case studies sampled for the study. The case studies outline the services provided by these organisations, their human and financial capacity. Seven of the case study organisations are in the Mangaung (Bloemfontein) municipal jurisdiction and two in the Kopanong local municipality jurisdiction (Southern Free State).

The last sections of the report present the research findings drawn from the case studies. These findings present the challenges faced by many non-profit organisations in their quest for extending services to communities often marginalised by lack of government delivery. Based on the findings of all case studies recommendations for both government departments and organisations are made. Finally, a conclusion presenting an overall assessment of the study is made. In the conclusion, the study reveals that NGOs/CBOs are playing an important role in the extending services to communities where government does not reach such people due to lack of capacity. However, this sector is constrained by a number of challenges, key of which is the lack of adequate funding and capacity constraints.

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GLOSSARY OF TERMS

ABC	Abstinence, Be faithful or Condomise
AIDS	Acquired Immune Deficiency Syndrome
ARV	Anti-Retroviral
ART	Anti-Retroviral Therapy
ATICC	AIDS Training, Information and Counselling Centre
CB	Community-based organisation
CDS	Centre for Development Support
DoSD	Department of Social Development
DoH	Department of Health
FBOs	Faith-Based Organisations
FSYC	Free State Youth Commission
HBC	Home-Based Care
HIV	Human Immunodeficiency Virus
HSRC	Human Sciences Research Council
IEC	Information, Education and Communication
MUCPP	Mangaung University Community Partnership Programme
MTEF	Medium Term Expenditure Framework
MRC	Medical Research Council
NAPWA	National Association of People Living with AIDS
NGO	Non-governmental organisation
NPO	Non-profit organisation
UNAIDS	Joint United Nations Programme for HIV/AIDS
PLWHA	People living with HIV/AIDS
TB	Tuberculosis
STD	Sexually Transmitted Diseases
STI	Sexually Transmitted Infections
VCCT	Voluntary, Confidential, Counselling and Testing
WHO	World Health Organisation

1. INTRODUCTION

Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS) represents one of the greatest challenges facing South Africa today; it is estimated that at least five million people in the country are infected with the virus. Some statistics have put the number of people infected as high as 7 million people. Although, statistics differ and in some cases controversial about the extent of the epidemic in the country, all indicators show that the HIV/AIDS infection rate is increasing and Sub-Saharan Africa is at the centre of the epidemic. While statistics differ about the extent of the problem. It is clear that everyone in the country remains affected. The impact of the epidemic is not only limited to those who are infected but affects everyone in the country.

Already the epidemic has had a devastating demographic impact in South Africa. The social and economic impact of the HIV/AIDS pandemic on South Africa on various fronts cannot be underestimated, which is one reason why the epidemic is a policy problem. The loss of such a high number of people has a debilitating impact on the economy of the country, let alone government resources and service delivery capacity. Nowhere in the world is the impact of HIV/AIDS starting to be felt like in South Africa where the epidemic is beginning to exert a direct influence on every sector of society and the economy.

The Global Health Sector Strategy for HIV/AIDS (2003-2007) states that by the end of 2002 estimates of HIV/AIDS infected people worldwide stood at 42 million people. Sub-Saharan Africa has the most number of people infected, estimated at over 28 million. This has reduced the life expectancy of many Africans. However, more alarming is the number of HIV infections affecting the youth. A number of reports are fast coming in painting a gloomy picture for the youth of sub-Saharan Africa if proper precautions are not taken. In response to the impact of the epidemic a number of civic organisations are playing a crucial role especially in rural areas where government services do not always reach communities. However, the effectiveness (or lack thereof) of these organisations is impeded by lack of adequate funding. It is of utmost importance that both the government and civil society are equal partners in the fight against HIV/AIDS.

This report evaluates the role of non-profit organisations in the Free State Province. The non-governmental sector in this report refers to non-governmental organisations, community-based organisations and faith-based organisations. While debates about the correct terminology for organisations of this type are noted, NPO in the report refers to all non-governmental organisations (NGOs), community-based organisations (CBOs) and faith based-organisations (FBOs).

2. PURPOSE AND OBJECTIVES OF THE STUDY

The major purpose of South African Health Research, as reflected in the Health Research Policy of South Africa, 2001, is to provide an enabling framework for the conduct of research that improves human health and well being in South Africa. According to this policy document, it is envisaged as an integral part of long-term health development aimed at improving the health and quality of life of all South Africans and reduces inequalities within the system. The Health Sector Strategic Framework (1999-2004) asserts the need for an effective and efficient health information system is

vital for planning and managing health service delivery. Whilst some progress has been made in the last five years, progress must be accelerated during the next five years." It is imperative that health districts, municipalities, provinces, the private sector and the national department work together to build such an information system. In addition, various other government departments such as Home Affairs, Public Services and Administration and State Expenditure impact on the health system and we must ensure that the systems of these departments are integrated with that of the health system.¹

Against this backdrop the overall aim of the study is to evaluate the role of the non-profit organisations in the field of HIV/AIDS in the Free State Province. Some of the gaps for research identified in the Free State Youth Environmental Youth Scan are the question of reproductive health, including unwanted pregnancies and subsequent decisions to have a pregnancy terminated. Further implications include the spread of STIs and HIV/AIDS amongst the youth. Over the past few years there have been some concerted campaigns aimed at government for its perceived or real failure to come up with a comprehensive programme to effectively curb the scourge of HIV/AIDS. Now that government has outlined a comprehensive strategy for rolling out Anti-Retrovirals (ARVs), the focus has changed to other key sectors such as service provision for people in need, in particular home-based care (HBC).

3. RESEARCH APPROACH AND METHODOLOGY

The research undertaken for this report was done by three agencies, namely the Human Sciences Research Council (Bloemfontein office), the Centre for Development Support (University of the Free State), and the Free State Youth Commission. The research method consisted of two components. Firstly, information was gathered through face-to-face focus group interviews with key stakeholders (see Appendix A) from government and NPOs. For the primary interviews, only structured interviews were employed. In addition, on-site interviews with NPOs employees, caregivers and patients were conducted. Secondly, literature overview and documentary study was undertaken. Secondary research also included a desk-top based review of government policy documents and previous research on HIV/AIDS internationally and locally.

For the purposes of sampling, the team used a list of government-funded organisations provided by the Free State Provincial Department of Health (DoH) and Department of Social Development (DoSD). From these lists, organisations were contacted telephonically to determine if they have indeed received funding from government departments and their field of operation. From this procedure, a shortlist of 10 organisations was derived. These were then divided into three groups roughly representing the larger, medium-size and small organisations. Two structured questionnaires were used. One was developed for government officials and the other for NPOs. In the case of NPOs an additional structured questionnaire was developed for beneficiaries. Several problems were encountered in the course of the research. The most important include:

- One CBO withdrew its participation in the study after it became clear to the research team that it misrepresented its role and functions. In addition, the CBO demanded some form of compensation for taking part in the study.

¹ See Health Sector Strategic Framework, 1999-2004

- The lists of government-funded organisations provided by government departments were not up-to-date and required further investigation. In some cases, organisations listed on the lists provided by government departments had not been funded in the current financial year or had never been funded by either government department.
- Identified stakeholders were not always cooperative and in many instances failed to provide the necessary documentation such as financial records and statements. Some of the claims made by both government and non-governmental officials could not be verified. As such, the factual basis for the study might be compromised.
- Different types and levels of NPOs officials' staff presented themselves for the interviews with the result that the knowledge base of those officials differed. In the case of CBOs information provided was often contradictory and not enough. In some cases, information provided in interviews was incomplete and contradictory with the result that extensive telephonic follow-ups had to be made. These follow-ups were not always successful, since many key stakeholders are extremely busy.
- Although permission for the study was sought and granted by heads of departments, officials responsible for implementation of government policy were not cooperative and did not show up for arranged interviews. In fact, it was explained that these departments are understaffed and a number of studies that have been undertaken in the past which have not benefited their departments. In some instances, key officials were either on leave or attending courses.
- Many HBC patients were not aware of the service standard that they are entitled and could not provide valuable insight about the quality (or lack thereof) of health care provided by HBC organisations. As a result it was difficult and sometimes impossible to evaluate the quality of services provided by organisations.

4. LITERATURE REVIEW

This section outlines the global overview of HIV/AIDS – with particular emphasis on the impact of the epidemic in sub-Saharan Africa. In sub-Saharan Africa the spotlight is on the impact of HIV/AIDS on the youth in South Africa where a number of surveys that assessed the sexual behaviour of teenagers are discussed. While surveys and statistics are unlikely to provide the full and accurate picture of the extent of the HIV/AIDS epidemic, they do however provide useful estimates. In addition, both surveys and statistics can be helpful in tracking the progress of the epidemic in a specific group of people or community. In the section, the history, involvement and role of the non-profit-sector in the field of HIV/AIDS in South Africa is discussed.

4.1 Defining HIV/AIDS

AIDS is the acronym for Acquired Immune Deficiency Syndrome. The first diagnosed cases of AIDS were made in the United States of America (USA) among homosexual men. In many parts of the world the mode of HIV transmission is largely unprotected vaginal or anal intercourse and

possibly oral sexual contact under certain conditions. However, patterns in the mode of transmission tend to differ from one country to the next. For example, in certain parts of Europe such as Italy, Spain and Georgia intravenous drug (drug injection and sharing needles) use, fuels the epidemic. Another less prevalent mode of transmission is blood transfusion from HIV infected donors. Although all blood donated is screened for HIV, there are a number of cases where contaminated blood was used for transfusion. Also, many children acquire the virus through mother-to-child transmission, either through pregnancy, childbirth or breastfeeding. The risk of becoming infected with HIV during unprotected vaginal intercourse is two to four times higher for women than it is for men.²

4.1.1 Global overview of HIV/AIDS

In 2003 the total toll of people who had died worldwide as a direct result of HIV/AIDS was estimated at around 22 million. In the same year the global number of AIDS deaths was an estimated 3 million lives, with a further 5 million new HIV infections - bringing to 40 million the estimated number of women, men and children living with the virus worldwide.³

The estimates for Eastern Europe and Central Asia indicate that in 2003 the total known cases of people infected with HIV was at 1.5 million with about 30 000 people having died of AIDS in the previous year. The spread of the epidemic in this region is associated with risky behaviour especially amongst young males and this includes mainly injecting drug use and unsafe sex.⁴ According to Peter Piot (Executive Director of UNAIDS the United Nations Aids group) HIV/AIDS is spreading faster in Eastern Europe and Central Asia than anywhere else in the world, with a 50-fold increase in new cases during the past 10 years. Piot points out that there has been slow and steady increase in new infections in every country in Eastern Europe and Central Asia. Piot is of the opinion that due to the focus in Africa over the last few years, this has resulted in Eastern Europe "slipping through the cracks". In both Eastern Europe and Central Asia it is estimated that 80% of those infected with HIV are aged 30 or below - a result largely of widespread sharing of needles by intravenous drug users. Although the numbers may not be as big as in some parts of the world, the scale and speed of the growth in these regions clearly makes this a crisis and if the problem is not taken seriously the situation will get out of control.⁵

In Russia and the Ukraine the infection rate is estimated at around one percent of the population. In the UK, newly diagnosed cases of the HIV increased by 20% between 2002 and 2003. Almost a third of the 49,500 people currently living with HIV in the UK are still unaware they are infected. This increase has been seen amongst women, heterosexual men and gay men. Sweden with a population of 9 million people has an estimated 3200 people living with HIV/AIDS. While this number might be small the Swedish Red Cross warns that more young people do not seem to realise how serious this illness is. As a result there has been a sharp increase in the number of sexually transmitted diseases.⁶

² Van Dyk, A. 2001. HIV/AIDS Care and Counseling: A multidisciplinary approach: Second Edition. Pearson Education South Africa. Cape Town, P4-29.

³ See The PANOS institute. 2003. Missing the message? 20 years of learning from HIV/AIDS. P5 and AIDS Epidemic

⁴ UNAIDS. 2003. AIDS Epidemic update, December 2003

⁵ <http://www.iol.co.za/html/news/aids/index.php?caption>. 23 February 2004.

⁶ <http://www.iol.co.za/html/news/aids/index.php?caption>. 16 February 2004.

In India, government statistics estimate that up to 4 million adults have HIV/AIDS. According to the Indian government study, about 100 000 infants are born with HIV out of 27 million pregnancies in the country each year. But government does not add these children or older ones who may have contracted the disease in brothels or through drug use to the official totals. In fact, children are rarely tested in India. Therefore, the figure could be much higher. This view is supported by a United States government report in 2002 that predicted that the number of Indians (in India) with Aids, including children and adults, could jump to 25 million people by 2010 – a projection which the Indian government rejects.⁷

Estimates from the UNAIDS and WHO indicate that approximately 790 000- 1.2 million adults and children in North America were living with HIV/AIDS by the end of 2003. Statistics in the USA where the black (African-American) population make up only 12% of the entire US population indicate that black women are more at risk of contracting HIV than other racial groups. The US government studies found that in 2001 about 67% (an increase of 9% in the last four years) of black women living with HIV had contacted the virus through heterosexual sex and were 23% more likely to be infected with the AIDS virus than white women. Also, black women accounted for 71.8% of new HIV cases in 29 states. According to Cynthia Davis, an Assistant Professor at Charles R. Drew University, most women don't even know they're at risk and find out only when their spouse dies or when they deliver a sick baby. The situation is also compounded by an apparent scarcity of potential black male partners, particularly among the middle classes. This often contributes to black men having a higher turnover of relationships. Also, a Los Angeles survey in the same year found that 20% of HIV-positive black men have had sex with women in the past six months compared with 9% of HIV positive white men and 4% of infected Latino men. Beverly Guy-Sheftall, a Professor of women's studies at Spelman College in Atlanta argues that the disparities in HIV/AIDS are dramatic, but reflect other racial disparities in health that are most likely related to poverty and access to affordable health care.⁸ In Los Angeles, which is the second biggest city in the US, health officials posted the first increase in diagnosed AIDS cases in more than a decade. According to the Los Angeles County Department Health Services a 0.05% rise in AIDS patients was registered in 2002⁹.

China has estimated that 800 000 people are infected with HIV/AIDS. Health experts warn that the number could rise to 10 million people if the government fails to take the epidemic more seriously.¹⁰

In Asia and the Pacific the UNAIDS/WHO statistics revealed that over 1 million people were infected with HIV and that the total number of people living with HIV/AIDS was at 7.4 million in the year 2003, with a further 500 000 people having died of AIDS. Available evidence suggests the intravenous drug use is on the rise as well as low levels of condom use among sex workers.

In Latin America nearly two million people are infected. Latin America and the Caribbean is the region that has the highest number of deaths associated with HIV/AIDS after Sub-Saharan Africa and Asia. In Latin America and the Caribbean region more than 2 million people are now living

⁷<http://www.iol.co.za/html/news/aids/index.php?caption>, 01 December 2003.

⁸ Mail & Guardian, April 8-12 2004, Aids: Black women in the US at higher risk.

⁹ <http://www.iol.co.za/html/news/aids/index.php?caption>, 18 February 2004.

¹⁰ <http://www.iol.co.za/html/news/aids/index.php?caption>, 16 February 2004.

with HIV and at least 100 000 people have died of AIDS in the year 2003. The modes of transmission in this region coexist, but the ones that can be ranked as the most prevalent are early sexual debut, unprotected sex with multiple partners and the use of drug injecting equipment.¹¹

4.1. Sub Saharan overview of HIV/AIDS

Sub-Saharan Africa is the worst affected region with the highest number of people living with HIV. Statistics indicate that between 25 and 28 million people could be living with the virus. Last year (2003) estimates indicate that as many as 3 million new infections could have occurred in the region. The worst affected countries are South Africa, Botswana, Lesotho, Zimbabwe and Swaziland.¹² South Africa has the highest number of people living with the virus; estimated at around 4,7 million people. The HIV/AIDS epidemic continues to be a burden in the region and is now the leading cause of death in many Sub-Saharan Africa countries. Young people aged 15 to 24 years are at the epicentre of the epidemic. Therefore, HIV surveillance in this population group is crucial. It is expected that the total number of people infected with HIV will plateau in about 2005, as the number of new infections has slowed down and the people who are infected are dying. The MRC states that the deaths from AIDS has been increasing from the late 1990s, and without interventions such as implementation of (Anti-retroviral therapy) ART to reduce mortality, are expected to peak in 2010 at about 800 000 deaths.¹³

In South Africa the first two cases of AIDS were identified among homosexual white men in 1982. For the first eight years, the epidemic was primarily located among white homosexual men, but overtime, the number of cases rose and the disease began to spread among other groups. Since then the homosexual epidemic has been completely overshadowed by the heterosexual epidemic.¹⁴

In 1990 South Africa had an HIV prevalence of less than 1 percent among antenatal clinic attendees and now has reached levels of over 25 percent. Antenatal surveys have largely been used by the WHO to estimate HIV prevalence and in tracking the progression of the HIV/AIDS epidemic in the country. More than twenty years into the epidemic, South Africa is now the country with the highest number of HIV-infected people in the world.¹⁵ The antenatal survey of 2002 indicates that 26.5% of pregnant women were HIV positive. In 2002 KwaZulu-Natal recorded the highest HIV prevalence rate among antenatal clinic attendees at 36.5%. Gauteng also recorded a significantly high rate at 31.6%, followed by Free State (28.8%), Mpumalanga (28.6%), North West (26.2%) and the Eastern Cape (23.6). The other three provinces recorded a prevalence rate of less than 20%, Limpopo (15.6%), Northern Cape (15.1%) and the Western Cape (12.4%).¹⁶

4.1.2.1 Impact of HIV/AIDS on the youth in South Africa

Africa has the world's youngest population and estimates indicate that Sub-Saharan Africa is home to 70 percent of young people living with HIV/AIDS and 90 percent of AIDS orphans in the world.

¹¹ UNAIDS. 2003. AIDS Epidemic update, December 2003

¹² Weekly epidemiological record, 5 December 2003, 78th year. No 40, 2003, 78, 417-424. <http://www.who.int/wer>

¹³ <http://www.mrc.ac.za/bod/faqids.htm>

¹⁴ History and origin of HIV. Retrieved June 14, 2004, from the AidsInsite. <http://www.aidsinsite.co.za>

¹⁵ History and origin of HIV. Retrieved June 14, 2004, from the AidsInsite. <http://www.aidsinsite.co.za>

¹⁶ Antenatal survey, 2002. Department of Health.

Literature studies indicate vulnerability to HIV/AIDS is compounded by gender and age, making young people, particularly young women more likely to contract the virus than others. The age distribution of HIV infection in Africa is skewed towards younger females, with infection rates among teenage girls five times higher than teenage boys in some countries.¹⁷

The Reproductive Health Research Unit of the University of the Witwatersrand study conducted a study in 2003 on HIV and sexual behaviour among young South Africans, with specific reference to the 15-24 year olds. The study has reflected high levels of sexual activism amongst the youth, especially amongst males. The study notes that the HIV epidemic remains a major concern amongst youth but the epidemic may be stabilizing in this age group. The survey found that among 15-24 year-old South Africans the HIV prevalence was 10.2%; prevalence was significantly higher among women (15.5%) than among men (4.8%) as well as the 20-24 year old age group (16.5%) compared to the 15-19 year old age group (2.5%). HIV disproportionately affects young women. Among the 10% of South African youth who are HIV positive, 77% are women. This means that nearly 1 in 4 women aged 20-24 are HIV positive compared to 1 in 14 men of the same age. The highest HIV prevalence was found in KwaZulu-Natal Province (14.1%) and the lowest in Limpopo Province (4.8%). In terms of geographic area, youth living in urban informal areas had the highest HIV prevalence (17.4%). However, more alarming is that 15% of young people are not being reached by any HIV programmes. These are young people who are often at greatest risk, like teens living on farms.¹⁸

On average, 67% of young people aged 15-24 years are reported to having had sexual intercourse. What is also significant about the findings is the fact that 6% of the interviewed youth reported having been forced to have sexual intercourse, that is 10% of females and 2% among males. Among the sexually experienced youth, 52% reported using a condom at last sexual encounter. Levels of condom use was almost identical among sexually experienced men and women aged 15-19 years, but 20-24 year old females were less likely to report condom use during the last sexual encounter, in comparison to sexually experienced men (44% vs 57%) in the same age group. Overall, among youth who reported having had sex in the past 12 months, females were significantly less likely than males to report always using a condom with their most recent partners (28% vs 39% respectively). The issue of access to condoms was not a problem at all. It would seem access to condom use plays an important role; 87% of all youth felt that they were able to access condoms when they needed them. This clearly demonstrates that access to condoms does not guarantee condom use.¹⁹

The 2002 Human Sciences Research Council/Nelson Mandela study in collaboration with the Medical Research Council and Centre for Aids Development, Research and Evaluation (CADRE) sampled more than 9000 South Africans in 2002 from all walks of life, 11% of respondents were HIV positive and 15, 2 % were between 15-49 years old. The study found that behavioural patterns for 15 to 24-year-olds were changing and that the youth had less sexual partners and higher levels of abstinence. The (HSRC) study that showed that condom use has improved amongst the youth. According to Dr Olive Shisana, Executive Director at the HSRC, condom use amongst sexually

¹⁷ Multisectoral responses to HIV/AIDS: A compendium of promising practices from Africa. USAID-PVO steering committee on Multisectoral approaches to HIV/AIDS, April 2003. P33.

¹⁸ HIV and sexual behaviour among young South Africans, 2004.

¹⁹ HIV and sexual behaviour among young South Africans, 2004.

active youths aged 15 to 24 years old is high; with 57,1% of males and 46,1 percent of females having used a condom at last sexual intercourse.

The results also showed that South Africans have modified their sexual behaviour in the face of the HIV/AIDS epidemic. This is similar to trends in Uganda, where the country managed to reverse the steep upward curve of the epidemic by encouraging people to be faithful or to abstain. When asked about their risk for HIV infection, 36% stated that they were at no risk at all; 35% of all youth indicated that they were at small risk; 12% indicated a moderate risk and 14% stated that they were at high risk for HIV infection. Significantly, more females than males reported having been tested for HIV (25% vs 15%). Among all youth, 60% indicated that they would like to be tested for HIV. From the findings of the study, the vast majority of young people agreed that safe sex is a shared responsibility between partners and that it is not okay to force someone to have sex. In addition, they also agreed that having many partners is not acceptable and it also not desirable to engage in transactional sex.²⁰

Another study worth noting is the 1st South African National Youth Risk Behaviour Survey in 2002, which comprised of learners in Grade 8, 9 10 and 11 in public across all nine provinces. The study showed that that heightened sexual awareness is part of adolescence development, but it is often characterised by experimentation which has the potential of placing adolescence at risk of unprotected sexual activity, unplanned pregnancy and sexually transmitted infections including HIV. In South Africa, literature on studies of sexual behaviour of African students reflect that for a sample of 14 and 15 year-olds, between 10 percent and 24 percent of girls and 18 percent and 63 percent of boys had sexual intercourse. In addition, the study shows that gender was found to be a predictor of condom use, with more males than females reporting having used condoms. Also, past sexual behaviour was found to be a predictor of intention to have sex; for example, once learners have had sex they are much more likely to have sex again. Data on South African women attending antenatal clinics indicate that women in the 20s represent the group with the highest number of individuals with HIV infection. Furthermore, by the age of 19 years at least 1 in 3 of all teenagers have been pregnant or had a child. Also, 11 percent of termination of pregnancies was by women under 18 years old.²¹ While many young people are aware of the importance of using condoms, many studies indicate that condom use is socially acceptable, but the increasing statistics reveal that it might not be popular. The survey looked at amongst other things, the percentage of learners who ever had sex; the age of initiation of sex; the number of sexual partners learner have had; use of alcohol or drugs before sex and the methods of contraception mostly used by learners.²²

The national prevalence for learners who reported ever having had penetrative sex (vaginal or anal) was 41.1 percent with more male learners than female learners reporting ever having had sex. Significantly, fewer White (25.9%) learners reported ever having had sex compared to Black learners (43.6%) and more learners reported having sex in grade 11 (54.2%) than in grade 8 (32.6%) and grade 9 (40.9%). In each of the age groups more males reported ever having sex than females. North West Province (35.2%) had the lowest prevalence of learners who reported ever having had sex, while Gauteng and the Free State both with 47% had the highest provincial prevalence. In terms of the age of sex initiation, the national prevalence of learners who reported having had sex before

²⁰ HSRC/Nelson Mandela study. 2002.

²¹ Umthente Uhlaba Usamila The 1st South African National Youth Risk Behaviour Survey in 2002. Chapter 6, P51.

²² Umthente Uhlaba Usamila The 1st South African National Youth Risk Behaviour Survey in 2002. Chapter 6, P53.

The age of 14 years was 14.4%. Once again, more males (25.4%) than females (5.6%) reported having had their first sexual experience at less than 14 years of age. More Black (15.6%) and Coloured (12%) learners reported having sex before the age of 14 years compared to only (6.4%) of Whites. Sexual initiation at less than 14 years of age varied in provinces, from lowest in North West Province (9.9%) to highest in Gauteng (19.1%). Of the learners who reported ever having sex in their lifetime, 54% reported having had two or more sexual partners. More males (66.4%) than female (38.1%) learners reported having had two or more sexual partners in their lifetime. Grade 11 learners (61.6%) reported having had more sexual partners than grade 8 learners (52.4%). Learners in the Western Cape (48.1%) had the lowest prevalence of having had two or more sexual partners in their lifetime, and learners in Gauteng had the highest (61.3%).²³

The national prevalence of learners who reported having used alcohol or drugs before sex was 13.8%. More male (17.9%) than female learners (8.7%) reported using alcohol or drugs before sex. Fewer Black (12.1%) than White (25.7%) and Coloured learners (23.6%) who had ever had sex reported having used alcohol or drugs before sex. KwaZulu-Natal learners (15.2%) who have had sex reported the highest prevalence of having used alcohol or drugs before sex, and those in Limpopo (10.7%) reported the lowest.²⁴

The use of condoms as a contraceptive method was significantly higher in Gauteng (58.6%), Free State (54%) and the North West Province (55%) compared to the national prevalence (44.8). The Eastern Cape (30.6%) followed KwaZulu-Natal (32.3) had the lowest provincial prevalence of learners who used condoms as a method of contraception. "No method" was used to prevent pregnancy (28.1%) was the second most common answer when learners who have had sex were asked which method of contraception they mostly used. More Black learners (29.6%) and Coloured learners (25.3%) reported not using condoms as compared to White learners and Indian learners (8.6%). Encouragingly, the percentage of learners who used "no method" of contraception also decreased with an increase in age from 14 to 18 years. More 14-year-old learners (44.6%) did not use any method of contraception when compared to 15-year-old (26.2%), 16-year-olds (25.6%), 17-year-old (23.4%), 18-year-old (33.4%) and the 19-year-old (25.1%) learners.²⁵

Significantly, more learners in KwaZulu-Natal (47.1%) did not use any method of contraception compared to the national prevalence, and the Northern Cape (20.9%) had the lowest provincial prevalence. Regarding consistent use of condoms, learners who have had sex, the national prevalence for consistent condom use was 28.8%. More White learners (49.8%) and Coloured learners (39.5%) reported using condoms consistently as compared to 26.9 for Black learners. Consistent condom use increased with grade. Consistent condom use was lowest in KwaZulu-Natal and highest in the North West Province (38.8%). Regarding learners who received a treatment for sexually transmitted infection (STI), the national prevalence of ever having a STI was 7.4%. Fewer White learners (1.2%) and Coloured learners (3.2%) who have had sex reported having an STI compared to Black learners (7.7%) who have had sex. The findings of the study revealed that the overall infection rate in the country is 11.4%, lower than the previously estimated at 19%. This means that about 4,5 million South Africans were living with HIV/AIDS. The highest prevalence rate was among Africans, the Coloured prevalence rate was found to be 6,1 %, 6,2 among Whites

²³ Umthente Uhlaba Usamila The 1st South African National Youth Risk Behaviour Survey in 2002. Chapter 6, P53.

²⁴ Umthente Uhlaba Usamila The 1st South African National Youth Risk Behaviour Survey in 2002. Chapter 6, P54.

²⁵ Umthente Uhlaba Usamila The 1st South African National Youth Risk Behaviour Survey in 2002. Chapter 6, P54.

and 1,6% among Indians. Contrary to popular belief that Kwazulu-Natal is the leading province in terms of HIV prevalence rate; it was found that the HIV prevalence rate was highest in the Free State – 14,9% followed closely by Gauteng with 14,7% and Mpumalanga with 14,1%.²⁶

This view is supported by a study undertaken by University of Cape Town academics (Fiona Ross and Susan Levine). Most students at tertiary institutions continue to have unprotected sex despite being aware of HIV/AIDS and its dangers.²⁷ The UCT study, based on interviews with 480 students between 19 and 30 found many had unprotected sex despite being aware of HIV/AIDS transmission. The survey revealed that students imagine that they are immune to HIV infection and continue to practise unsafe sex²⁸. Reasons given to the researchers for this behaviour included: having gone too far without thinking, did not have condoms handy, being drunk, being in a long-term relationship and assuming it would be alright, among others. Furthermore, students also complained about HIV information fatigue. However, there were other students who revealed a shocking level of ignorance. Some said that HIV/AIDS was punishment for being promiscuous or having sex outside marriage. Another student suggested that white people introduced HIV/AIDS as a measure of population control. More positively, condom use was cited as socially acceptable.²⁹

4.2 Defining non-profit organisations

The term non-profit organisation (NPO) embraces a variety of organisations and forms. It is made up of a number of organisations ranging from small and informal to big and organised organisations. The Non-Profit Act (1997) defines the term “non-profit” organisation as collective of people who come together for a common purpose and agree to formalise a programme to fulfil this purpose. They conduct their activities towards this purpose and should there be excess income after expenditure (profit) this excess is made available to the benefit of the purpose. Non-profit organisations are known by other generic titles such as non-governmental organisation (NGO), community based organisation (CBO) civil society organisation (CSO), public benefit organisation (PBO), trust of foundation, charity and religious body or institution (also referred to as Faith Based Organisations - FBOs).³⁰

Membership in these organisations is voluntary, but it may have salaried employees. Community based organisations (CBOs) are relatively small and less formally organised than the traditional NGOs. Traditional NGOs are better organised, have a range of expertise at their disposal, and are better financed and much more professional in every aspect of their operation than CBOs. The mission and objectives of NGOs is clear and concise. On the other hand, the mission and objectives of CBOs are sometimes ambiguous and do not always match the capability and finances of the organisation. However, CBOs are more locally orientated and can respond to community needs and problems much faster than NGOs. CBOs rely quite heavily on volunteers whereas NGOs can sometimes have salaried employees depending on their access to resources and finances. FBOs

²⁶ Umthente Uhlaba Usamila The 1st South African National Youth Risk Behaviour Survey in 2002. Chapter 6, P53-56.

²⁷ <http://www.iol.co.za/html/news/aids/index.php?caption> 11 January 2004.

²⁸ <http://www.iol.co.za/html/news/aids/index.php?caption> 11 January 2004.

²⁹ <http://www.iol.co.za/html/news/aids/index.php?caption> 11 January 2004.

³⁰ The Non-Profit Act (Act 71 of 1997).

FBOs attempt to influence decision-making and behaviour as a means of preventing the youth engaging in premarital sex. Many FBOs believe this is the best method for fighting HIV/AIDS. It is important to note that all CBOs are NGOs but not vice versa. CBOs have special features that are only confined to their form and character, such as being geographically specific and being driven directly by local needs and participation. It is therefore important for NGOs to recognise that they are not homogeneous, because each has a different background, perspective, structures, programmes and approaches to development. This diversity should be regarded as a strength that binds the unity of the NGO sector in the quest to become the fourth pillar³¹ in South Africa, the paramount aim being to meet the needs of the poor and taking part in a people-centred democracy.³² The South African National NGO Coalition has made strides in this regard by defining 5 strategic objectives to help build the NGO sector as strong pillar of civil society that shapes and informs policy formulation in South Africa. These objectives revolve around making sure of the effective functioning of organisations by encouraging consolidation and teamwork and reducing competition amongst organisations. Other objectives are ensuring that there is legislation that ensures sustainability of NGOs in place, capacity building in the NGO sector considering the changing role of NGOs and the vulnerability of donor funding. This includes skills development, and fundraising skills, as well as sound financial management mechanisms.³³

4.2.1 Involvement of the non-governmental sector in HIV/AIDS

The involvement of the non-governmental sector in South Africa began in 1985 when the apartheid government repatriated Malawian mine workers who were suspected of being infected with HIV. Thereafter, debates around the AIDS policy were started. In 1991 the Congress of South African Trade Unions (COSATU) held a conference at NASREC to deliberate deeper on the AIDS issue, it was then that the Congress' first principled approach to HIV and AIDS was adopted.³⁴ Although the apartheid government had an HIV/AIDS policy, this policy lacked leadership, initiative and credibility.³⁵ The challenge of HIV/AIDS facing South Africa became a struggle fought by labour unions, civil society movements, NGOs and CBOs. However, the task of these organisations was made even more difficult in an era where there was no coherent national AIDS plan and government funding.

Since the late 1990s with the scourge of HIV/AIDS, the number of NGOs/CBOs have grown at a phenomenal rate with many of them operating informally. What has become clear over the last few years is that government cannot deliver to all communities. Non-profit organisations have an important role to play especially at grass roots level. However, they face numerous problems, the key of which is the lack of adequate funding. It would seem no NGO/CBO can claim to have adequate resources. In fact, the numerous challenges faced by NGOs/CBOs are too big for the resources at the disposal of these organisations. Lack of government capacity in key departments such as DoSD and DoH has underlined the importance of NGOs/CBOs in serving the marginalised communities especially in rural communities. Voluntary community and non-governmental responses to HIV/AIDS are diverse, ranging from self-help groups that respond to a particular need

³¹ Traditionally the three pillars in South Africa have been government, organized labour and the business sector.

³² Kumi Naidoo, Rethinking the location of the NGO sector in South Africa, in Bulletin, May/June 1997 vol 6

³³ *ibid*

³⁴ Edwin Cameron, The principles of our progress in AIDS Bulletin, May/June 1997 vol 6.

³⁵ Edwin Cameron, The principles of our progress in AIDS Bulletin, May/June 1997 vol 6.

within their locality (community). The magnitude of the need for HIV/AIDS related services alone compels all government departments, including the DoH and DoSD, to find and form partners with other service providers in order to complement government efforts.

4.2.1 Role of the non-governmental sector in HIV/AIDS

The emergence of non-governmental organisations (NGO) working with people living with HIV/AIDS signified an attempt to eradicate the failings of the government department's ability to address the HIV/AIDS epidemic. Furthermore, the inadequacy of the apartheid government to respond to the epidemic spelled out serious implications for the future of the country. The non-governmental organisations focused mainly on the marginalised and disadvantaged groups in South African society by developing programmes that address the particular needs of their target groups and drawing the links between ill health and discriminatory legislation. In this way, the NGO sector began to address some of the pertinent issues associated with the epidemic in the context of the Third world.³⁶ The struggle was multifaceted in nature; there was the struggle of educating people about HIV/AIDS, prevention of the spread of HIV, combating ignorance, eradicating stigma and discrimination. The environment in which the struggle was conducted was often unsupportive and hostile, at the same time the HIV/AIDS epidemic was progressing from dream and nightmare to being a "plague" that is a felt reality.

The National AIDS Congress of South Africa (NACOSA) is an initiative that was created in 1992 to bring government and the private sector to formulate a national AIDS Plan. The national AIDS plan bears the mark of the work, energy and vision of the NGO sector. The national AIDS plan was fully launched in 1994, but the implementation thereof by government is still making slow paced progress.³⁷ In this regard some NGO struggled to integrate HIV/AIDS programmes into their development programmes. Results from a study commissioned by SAIH/INTERFUND in 1995, which was set out to investigate the capacity and feasibility of AIDS integration in the NGO project revealed that the NGO sector had limited response to AIDS and there had been little consideration to how AIDS would impact on the organisation or target communities.³⁸ In addition to that some communities in which NGOs were operating, AIDS was not necessarily perceived to be a priority, thus AIDS integration would imply imposing AIDS issues onto the community and that would in turn be contrary to how NGOs tended to operate. The state awareness of AIDS was superficial and insufficient to integrate AIDS into organisational debates and activities. Most organisations were facing funding crises due to changing political paradigms and priorities, with many NGOs thus under constant threat of closure, with some becoming reluctant to take up new issues.³⁹

5. GOVERNMENT DEPARTMENTS

³⁶ Nikki Schaay, The history and development of NGO-based HIV/AIDS work in South Africa, in AIDS Bulletin, May/June 1997 vol 6

³⁷ Barry Smith, AIDS hits everyone: HIV/AIDS and the NGOs in AIDS Bulletin, May/June 1997 vol 6

³⁸ Nikki Schaay, The history and development of NGO-based HIV/AIDS work in South Africa, in AIDS Bulletin, May/June 1997 vol 6.

³⁹ Nikki Schaay, The history and development of NGO-based HIV/AIDS work in South Africa, in AIDS Bulletin, May/June 1997 vol 6.

This section presents a brief overview of the two government departments, namely Department of Social Development (DoSD) and Department of Health (DoH). The focus is on the sub-directorates responsible for coordination, funding and monitoring of non-profit organisations. The 2000 local government demarcation process resulted in the entire Free State being divided into five municipal districts. All government departments (including the DoH and DoSD) have also divided their regional offices accordingly in the provision for better and more efficient service delivery.

5.1 Department of Social Development⁴⁰

The main priority of the department is to render service to the poor, while ensuring the development, care and protection of vulnerable groups in the society. This is achieved through programmes that focus on the alleviation of poverty and addressing the needs of special groups such as children, youth, older persons, persons with disabilities, women, victims of abuse and violence, persons affected by substance and persons affected and infected by HIV/AIDS.

The provision of services in the department is guided by the strategic plan for HIV/AIDS and the National Integrated Strategy for Youth and Children affected and infected with HIV/AIDS. Both these documents place a priority on children infected and affected with HIV/AIDS, women infected and affected with HIV and AIDS, Youth especially out of school, Rural and vulnerable communities, e.g. Farming and rural, Communities in routes of truckers where there's commercial sex workers and Communities with high migratory patterns.

The Unit responsible for NPOs coordination, funding and monitoring was established in 2000. The unit divides NPOs into two categories, Annexure A and Annexure B organisations. Well-developed, established and better-resourced organisations are classified as Annexure A. All under-developed organisations with small budgets and little capacity are classified as Annexure B. The latter category is mainly made up of CBOs and over the last couple of years the focus of the Unit has been on the development of these organisations. Many Annexure B organisations lack sound managerial and financial skills.

5.1.1 Conditions and procedure for funding NPOs

Before funding can be allocated to organisations there are set conditions that needs to be met. Only organisations that are registered in terms of the Non-profit Organisations Act of 1997 are eligible for funding and may apply. In addition, organisations or consortiums (cluster of organisations) have to apply on the prescribed service plan format for a specific financial year that is available at one of the five district offices of the department. It is expected that all organisations should adequately reflect the demography of the target groups for the service in the Free State Province. Services

⁴⁰ See Free State Department of Social Development 2004/05, specifications for the implementation of programmes and the provision of services for HIV/AIDS in the Free State.

Free State Department of Social Development, position paper on services for 2004/2005.

Free State Province Department of Social Development, Policy on Financial Awards to the Non-Profit Organisations in the Social Development Sector: Draft report.

should target at least 80% of the previously disadvantaged communities as a target group. It is important that all services rendered by organisations enhance and promote the policies of the department and safeguard the constitutional rights of beneficiaries.

A service plan in the prescribed format must be submitted before or on the deadline at the district office of the DoSD. The business plans of organisation are received by deputy-district managers who then make recommendations and pass the plans to the Acting Executive Manager. Thereafter the department at district and provincial level will assess the submitted service plan. The approval of the service plan for funding is subject to the extent and level which the organisation is able to deliver services required. The services should be delivered in effective and efficient manner that is in line with the service specifications and the availability of government funds. The key in determining funding is geographic re-distribution of services, addressing the urban/rural divide and ensuring that services are extended to historically disadvantaged communities. Once an application has been approved the department will enter in a formal contractual agreement with the successful organisation or consortium to formalise the agreement for funding.

5.1.2 Funding guidelines to NPOs

The department has a strict policy that stipulates that no funding is allocated without training been provided. This is a three week long training covering the basics regarding administration and management of an organisation. Since the mandatory implementation of this policy, less cases of mismanagement by organisations have been reported. The budget of a successful organisation is broken down into 12 months and allocated accordingly. The organisations are not allowed to have savings accounts; only cheque accounts are to be used. Auxiliary workers closely monitor all organisations through monthly financial statements. In cases of financial mismanagement and where fraud is suspected or alleged, the responsible official may recommend the suspension of payments in consultation with the sub-directorate and the district officer, pending an investigation. The NPO concerned shall be informed in writing of suspension of funds until further notice. The department shall inform the service provider regarding procedures to be followed with regard to departmental interventions including financial inspections or any other mechanisms deemed necessary by the department.

The financial monitoring focuses on whether the service provider utilises the allocated financial award in accordance with the agreement with the department. The service provider is expected to submit monthly financial statements to the department indicating all the expenses and income before the 15th of each previous month. The service provider is also expected to submit annually, before 31 august a copy of its audited financial statements of certified financial statements to the department. The department provides training in financial management to all new service providers in terms of the requirements by the department and general financial accounting mechanisms.

The department expects a detailed quarterly or bi-annual progress report from the service provider that receive a financial award. The manager of the Directorate Developmental Social Services prescribes the format of the progress report. The department provides the service provider with the format of the progress report as well as the due dates of the reports at the start of the funding cycle. Then the comments and inputs on the progress reports are communicated to the service provider within six weeks after receipt of the report.

The department carries monthly monitoring to funded NPOs. The onsite monitoring entails the assessment of the service provided and the status of the organisation's finances. A 14-day notice is given prior to onsite monitoring. Depending on the nature and complexity of the onsite monitoring, the district officer or both the district officer and relevant sub-directorate of the provincial office carry out the task. Objectives for monitoring include assessing the quality of services rendered by NPOs for which funding has been allocated. Monitoring is also for ensuring that the target groups served are receiving effective and efficient services.

5.2 Department of Health⁴¹

The vision of the DoH is the provision of comprehensive health care service to the Free State community. The priorities of the department are determined in line with the Medium Term Expenditure Framework (MTEF) of 2004 to 2007. The MTEF is based on the strategic direction provided by the National Department of Health Strategic Plan for 2003/2004 to 2005/2006 as well as the Free State Development Plan for 2002 to 2005.

The Department of Health (DoH) has a provincial unit responsible for funding, monitoring and support of all NPOs in the five districts of the Free State Province. The unit offers funding to organisations that are rendering HIV/AIDS work that cannot be covered by the formal institutions of the DoH. However, due to the limited budget of the department, funding is only allocated to small-scale NPOs, the National DoH funds large-scale organisations. In the Free State Province District Managers and Community Liaison Officers are responsible for monitoring of all NPOs.

Since the beginning of 2002 no individual NPOs have been funded. Funding is only made available to consortiums. The unit encourages consortiums to have a minimum of 5 member organisations affiliated to the consortium. The Unit prefers consortium funding to individual organisation funding as this reduces duplication of services and keeps in check community organisations that have no experience or track record. The money granted to the consortium is paid out as a lump sum by the department. Although, the money granted is shared amongst member organisations to the consortium, funding granted does not necessarily mean it is to be shared equally amongst the member consortiums.

5.2.1 Criteria for funding and capacity building

For a consortium to be considered for funding its programmes must be in line with the focus areas of the department e.g. Information, Education Communication (IEC) campaigns. Assessment of qualification for funding is based on looking at the submitted business plan of the organisation. It is required of the organisation to submit a budget breakdown of their proposed programmes. Approval of proposal for funding does not guarantee the exact amount requested being granted by the department. The unit has the overall deciding power on which consortium is to receive funding and funds allocated are to be shared by organisation in the consortium.

⁴¹ See Free State Department of Health Strategic Plan 2004/2005 to 2006/2007.

The Unit has been involved in a two-year capacity building project involving Human Resource and Financial management companies that are part of a consortium of consultants contracted by the unit. The organisations are offered mentoring and tutoring services to organisations in, Managerial skills training, Project Management, Financial management, Human resource skills training and Policy skills training. This project is aimed at building the capacity of the organisations, and to enhance the relationship between the organisations and the DoH, issues such as drafting the constitution are also tackled in this project. Each organisation receives three sessions from the experts in the consortium in an area that needs improvement according to the organisation's needs. Sessions can be up to a day long. Thus far (2004) the department offered a two-year training programme to 175 organisations in the province training through this Price Waterhouse led consortium. Feedback from organisations regarding this training has been very positive. The unit also engages in referring organisations to other relevant government departments according to the proposal of the organisation. The organisation must submit quarterly reports written in the format provided by the department.

The department has capacity constraints but the main challenges are to empower communities at local level and to monitor the services of organizations in those communities. There is a perception that capacity of these organisations can never be enough considering the high turnover of cases and the high number of new people joining organisations. In most cases well-established NGOs do not only depend on government funding and according to the DoH these big organizations are expected to mentor small organisations. Hence the department is fostering partnerships between well-established organisations and small organisations.

6. CASE STUDIES

This section details nine case studies that preceded the drafting of this document. All case studies outline the objectives, finances and the capacity of these organisations.

6.1 Free State Christian Church Leaders Forum

Free State Christian Church Leaders is a faith-based organisation that was established in 2001 following a request by the former Premier of the Free State Province, Ms Winkie Direko to Christian organisations in the Free State. The then Premier requested Christian organisations to assist in restoring the moral values of the nation. The forum is a joint HIV/AIDS venture between a number of Christian organisations in the Free State province. The forum represents the Dutch Reformed, Pentecostal, Charismatic, African Independent and Roman Catholic Churches in the Free State. The mission of the Joint Venture is to attain an integrated response to the HIV/AIDS epidemic and to build a caring and responsible community through moral renewal actions based on Biblical principles in the Free State.

As a Christian forum, the organisation contribute towards restoring family values, assisting with youth and leadership development programmes, showing compassion to those infected and affected with HIV/AIDS and building centres for those infected and affected by HIV/AIDS. In addition, the forum assist with identifying people who qualify for social grants but do not know how to access these grants. The forum also serves on the Provincial Aids Council and Moral regeneration

movement. The forum operates from a modest building with 16 offices that has been donated by a local businessperson. The forum has 4 offices in the Free State province, Bloemfontein, Botshabelo, Welkom and Thaba-Nchu. There are plans to expand to Qwa-Qwa, Kroonstad, Bethlehem and Harare in the next few years.

Objectives of the forum

The objectives of the forum is providing a platform for mutual interaction, sharing of perspectives and resources between the Free State Government and the Christian community in the Free State in order to develop a coordinated and united action against HIV/AIDS and poverty. The forum is continually developing sustainable process for effective service delivery to fight and cope with HIV/AIDS and poverty. The forum is also mobilising resources from both the government and non-governmental sectors to provide for the basic needs of the poor and those affected and infected by HIV/AIDS. In addition, the forum provides support and advice to local communities on how to increase their respective capacities to fight and cope with HIV/AIDS. The primary message is abstinence and faithfulness to one partner.

Financing the forum

In the 2003/2004 financial year, all four offices in the Free State received a total of R276 000, R96 000 from the provincial DOSD, R100 000 from the national DoSD, R80 000 from the provincial DoH and R100 000 from various churches. The forum is aware that funding from government departments is not enough and has approached several private companies and international donors in the United States of America for donations. The total amount of funding they received from government funding is only R276 000 while the project budget is over a R1 million. Although funding is a challenge for the forum, a wide range of expertise and equipment are available within the forum. As a result, the forum can easily respond to opportunities for more funding.

Capacity of the forum

The forum has six full-time salaried staff members, the project manager, four area facilitators, and a financial administrator. All these six individuals have attended a compulsory course jointly offered by the DoH and Price Waterhouse Coopers in 2003. The course focused on Human Resources Management, Project Management and Administration. Since then, ongoing capacity building courses have been arranged to ensure that core staff is developing their human potential according to the growth of the organisation. However, more training is needed in the financial and information technology departments.

In all four regions there are 125 active volunteers who are providing Home-Based Care (HBC) to 458 patients. The forum provides HIV/AIDS, HBC, counselling and administration training to the volunteers who are provided with a T-shirt and a nametag for identification on successful completion of the course. The forum also provide drug and alcohol abuse courses to the volunteers; in 2004 nine out of 18 volunteers passed the course and were issued with certificates on the excursion day. The forum has already trained 196 volunteers for HIV/AIDS, 235 for HBC, 66 for counselling and 16 for administration. All volunteers receive a monthly stipend of R200. The forum

at tends as many national conferences on HIV/AIDS as possible to learn more about the disease and enlighten the volunteers about the new developments on the disease.

Training and support from the government departments

The forum has not received any training from the government departments; a facilitator within the organisation trains all volunteers and caregivers. The organisation attends as much HIV/AIDS conferences and workshops as possible to learn more about development in the HIV/AIDS field. The drugs and alcohol abuse course offered by the forum to its volunteers is accredited by the DoH and the DoSD.

Monitoring of funds and accountability

Ongoing evaluation and monitoring to improve effectiveness and service delivery is ranked as one of the main priorities of the forum. The following system is in place to ensure effective financial accountability to donors and other key stakeholders. The financial administrator is responsible for the finances of the organisation. In addition independent accountants are appointed to audit the books of the forum. The financial year of the organisation terminates on the 31st of March every year, the books are handed over to the auditing firm, and then the audited financial report is submitted to the DoH. The forum holds an excursion day on an annual basis for all the AIDS desk offices to report on their progress. All the volunteers, facilitators from different offices and the two governmental departments officials are invited to the function.

Care and support for the family

The forum visits and gives hope to the affected families by preaching the word of God. The forum has a prayer network for family members of all those infected and affected by the HIV/AIDS epidemic where they pray with the infected and the affected families in the community. In addition, the forum offers free counselling to the families of infected patients. Two Pastors facilitate these prayers networks on behalf of the forum. The families are provided with information on how to care for AIDS patient. Diapers are also provided to bedridden patients who cannot control their bowel system. The forum would like for their carers to visit the patients on a daily basis, but the carers live far from the patients homes and cannot afford daily transport fee as the stipends they receive from the organisation is not enough.

Programmes focusing on youth

The Department of Education (DoE) has a programme on abstinence where they teach the children in school about abstinence, this programme is called No Apology. These programmes are based on Biblical principles, abstinence before marriage and youth development. The Forum collaborates with the DoE on this programme. In addition, the forum offers youth development and abstinence, awareness course, youth camps and workshops.

Programmes focusing on boosting the immune system

The forum has developed food parcel distribution for people infected with HIV/AIDS. 160 families receive food parcels on a monthly basis, including the nutrition supplement e-pap. This supplement is nutritious and boosts the immune system. The forum also encourages its patients to use African solution that is believed to have properties for strengthening the immune system.

General knowledge about HIV/AIDS

The forum believes that it is aware of the developments on HIV/AIDS. The organisation attends as many national conferences on HIV/AIDS as possible to learn more about the disease and enlighten the volunteers about the latest developments on the disease. The organisation also attends every workshop that the DoH and DoSD conducts on HIV/AIDS.

Links with the formal health care

The forum works hand-in-hand with National Hospital, a public hospital in Bloemfontein. They also enlist the services of one of the doctors in the hospital who is part of the forum. The doctor refers all hospital patients who have no support system and requires HBC to the forum. The organisation has partnership with Red Cross and World Vision with whom information is shared.

Achievements of the organisation

The forum organisation is financially sustainable and can survive without funding from the two governmental departments. The forum uses Biblical, holistic and integrated approach to empower infected and affected communities by linking the disease with prayer. Its focus groups are children, youth, aged and affected families. The organisation offers patients with food parcels, painkillers, care, support and counselling to needy households and terminally ill patients. In addition, plans are underway to establish food gardens units on individual sites and communal gardens to improve and prolong quality of life to those infected and affected.

People (volunteers/members) living with HIV/AIDS

The forum has one carer who is openly living with HIV. The organisation has been very supportive and offers a monthly stipend, food parcels, counselling and information about living positively with HIV/AIDS.

Reasons for HIV/AIDS infection in the community

The forum is of the opinion that the lack of moral principle in the society is part of the reason for the high rate of HIV/AIDS in the community; most people in the community are unfaithful to their partners. Poverty is also a contributing factor to the scourge, people sell their bodies for money so that they can eat or buy something to eat. The forum believes it is important to educate the youth about abstinence and married couples to be faithful to their partners. The forum strongly recommends that the youth should be taught to control their sexual urges.

Services the organisation offered to patients

The forum assists patients to apply for disability grants and child support grant from the government; it assists with documentation needed when applying for governmental grants. The forum has been instrumental in persuading the Department of Home Affairs to operate on Saturdays. The forum is negotiating with the Red Cross to sponsor them with mattresses and blankets, which they intend to give to patients during 2004 winter. The forum would like to accommodate patients who are bed ridden and those who are chased away by their family members and those who the hospitals cannot accommodate in the caravan.

6.2 Kerklike Maatskaplike Diens

The Kerklike Maatskaplike Diens (KMD) is a faith based social service organisation of the Dutch Reformed Church. For years the Dutch Reformed Church has been involved in doing charity work for the poor in the community, in 1903 the wife of a minister, Mrs Charlotte Theron came up with a concept of opening a children's home for orphans and neglected children in Bethlehem called the Charlotte Theron children's home. The first body to take care of social service work was formed in 1953 and the name was changed to Kerklike Maatskaplike Diens (KMD) in 1988. At present there are 12 KMD offices in the Free State. The provincial office is in Bloemfontein. Other offices in the Free State are in Reddersburg, Botshabelo, Senekal, Reitz, Viljoenskroon, Virginia, Heilbron, Fauresmith, Welkom, Kroonstad, Odendaalsrus KMD is a fully registered social services providing organisation. The goal and programmes of KMD Free State has expanded to include:

- Prevention programmes pertaining to: HIV/AIDS, Sexual abuse and Alcohol and Drugs
- Life Skills programme
- Poverty alleviation programmes
- Sanctuary for street children and life skills for them
- Programmes with respect to crèches- their inception and development
- Programmes with respect to persons suffering from AIDS

Services provided by the organisation

An estimated 6500 people in the Free State annually receive assistance in the form of food, clothing and blankets from KMD. Also, 567 children per year receive statutory intervention and about 117 of maltreated children receive protection. In 2003 the organisation handled 88 cases of rape/molestation across the Province. Shelter is also offered to 165 children in Bloemfontein centre. The organisation estimates that 20 000 children per year are reached in the whole of Free State in terms of spreading information about HIV/AIDS and child molestation messages reach about 30 000 people in terms of community work and development. Currently there are about 150 cases per social worker.

KMD offers home-based care via auxiliary social workers as well as volunteers. For boosting the immune system food supplements are offered to patients, this includes a supplement similar to e-pap, as well as giving health talks to patients. Furthermore, patients are encouraged to plant vegetable gardens in their back yards. Most of KMD's HIV prevention programmes are targeted at the youth and children. The HIV programmes for children are carried out mainly in crèches and primary schools. These programmes mainly use puppet shows to teach children about HIV and abuse. Through the puppet shows children are informed about the facts about HIV and how they can protect themselves, and who to talk to should they require more information.

For young people the message is carried mainly through drama performances highlighting the facts about HIV/AIDS. The prevention message from KMD Free State is mainly abstinence and being faithful to one partner. However, the organisation is aware that not all young people heed the message of abstinence. Therefore, information about condom use is also provided. KMD wants to promote a high moral standard in society by making people aware of the many different alternatives that are available to them instead of choosing self-destructive behaviour like engaging in alcohol and risky sexual behaviour as ways and means of getting by in life. This, the organisation does by instilling a sense of self-worth in the communities in which it renders services to. The organisation targets the youth and children in schools, in Bloemfontein there is a programme for street children. As part of social work services teenage pregnancy, rape and abuse, as well as alcohol and drug abuse interventions are the services provided by KMD personnel.

Finances of the organisation

Each of the 12 offices in the Free State applies for funding individually from the DoSD because most of them are in different districts as per the demarcation of the Free State district councils. The main sources of income for all the services are from the DoH and the Dutch Reformed Church congregation. KMD receives a small but substantial amount of funding from private donors in addition to the two main sources of funding. Each of the 12 KMD offices drafts its own business plan based on the needs of the communities that they serve. For the 2002/04 financial year, the Bloemfontein office had an income of R1 million. R743 695 was received from the DoSD and R256 000 from donations. The rest of the money was sourced through fundraising campaigns.

A very significant amount of the organisations expenditure goes towards paying salaries and wages. The organisation spends R842 276 on salaries and wages to social workers and office personnel. KMD acknowledges that it cannot rely on funding from DoSD alone, thus it has made applications of funding to the National Lotto organisation. KMD has taken Eskom Bloemfontein on-board as a donor for the street children programme.

Capacity of the organisation

KMD Free State employs 30 qualified Social Workers, 13 Auxiliary workers and 337 volunteer workers. In the Bloemfontein office there are 7 Social Workers and 1 Auxiliary worker. KMD receives training from the department of Social development in counselling and trainings on implementation of new laws, procedures and bills such as the Child Care Act. The training offered by the department has proved to be useful such that KMD uses the training material for their auxiliary social workers as well.

Support from government departments

Each of the 12 KMD offices writes a progress report to the DoSD on a quarterly basis. From the training organised by the DoSD KMD personnel attending the trainings always writes evaluation reports and areas where the department can improve are always highlighted and this is mainly dependent of the training given. In general KMD is satisfied with the support received from the DoSD. However there is that discrepancy in terms of funds especially funds allocated for salaries of

Social workers. The KMD social workers get salaries that are less than the salaries received by social workers for the department of Social development yet they all do the same job, and have the same accredited qualifications. However KMD has managed to retain most of its Social Workers and this is attributed to the kind of support and passion amongst KMD personnel. A research done by the Social Work Profession's board recommended that all social workers in South Africa should get the same standard salary taking into account that all social workers do the same kind of job, however this has thus far been just a recommendation because the board cannot enforce salary packages across all organisations that have social work personnel.

Monitoring of funds and services and accountability

KMD personnel operate on the supervisor system where each social worker, auxiliary worker and volunteer worker reports to a supervisor. Each office writes progress reports to the provincial office in Bloemfontein, on a quarterly basis however sometimes due to heavy workloads the reporting is done bi annually.

General knowledge about HIV/AIDS

Through working with qualified social workers KMD has access to latest developments in HIV/AIDS through academic journals and publication, but also through courses provided by the Department of Social Development.

Links with formal health care system

KMD has a good working relationship with clinics in the KMD designated areas of operation, in almost all those clinics there is KMD service point for ease of access for people needing social work services. This has made social work access easier for KMD patients to the health sector.

Networking and partnerships

The Bloemfontein KMD office has good networking relations with other CBOs such as Heidedal Youth Centre and Afro DIY Home Based Care. KMD also works with HIV/AIDS orphans shelters such as Lebone and Oeratile Atra Care Centre. These networks involve giving management support and mentoring to these organisations. For instance, KMD Bloemfontein helps Heidedal Youth Centre with their drafting of their constitution and the administration of an organisation.

Achievements of the organisation

KMD Free State regards as one of its achievements the fact that it manages to handle a load of casework despite the shortage of staff. For KMD Free State rendering services in rural areas where the often the organisation is the only one offering services is more rewarding because the organisation can see the difference it makes. Also in rural areas there is a strong sense of community thus it is easier for people to know about services rendered by KMD as well as referring others to KMD service points.

People (volunteers/members) living openly with HIV/AIDS

The organisation has no member living openly with HIV/AIDS. However, the organisation believes that it can offer the necessary support should one of its employees come out with his/her HIV positive status.

Reasons for HIV/AIDS infection in the community

KMD is well accepted in the communities that it serves. In the Bloemfontein office the designated areas in which KMD office operates there is acceptance from the communities there is even request from Bainsvlei for KMD to extend its services, however because of lack of staff KMD services cannot be extended as yet. The organisation believes that the HIV infections are mostly prevalent amongst the youth. The main reason for the high rate of infection is attributed individual sexual behaviour. For example, young people are seemingly engaging in risky sexual behaviour without putting too much thought to the consequences. The organisation believes that the only way to curb the rate of infection amongst the youth is if people can start living responsible lifestyle and making the right choices such as focusing more on education and other life skills programmes to ensure a brighter future rather than one sexual issues.

6.3 Leadership Achievement Management Project (LAMP)

The Leadership Achievement Management Project (LAMP) is a non-governmental organisation that offers capacity building to other NGOs and CBOs especially those in the townships and rural areas. LAMP also offers capacity training on a consultancy and tender basis to some government departments. In addition, the organisation offers courses on Early Childhood Development (ECD) to institutions of elementary education.

LAMP categorises its programmes into two; the first programme focuses on Youth Development, which entails providing capacity skills pertaining to the running, and sustainability of an organisation. The focus here is on youth organisations that work with HIV/AIDS related issues in their communities. The second programme is on ECD whereby training is given to educators in learning institutions for children below the age of primary school level. This training pertains to implementation of best practice model for running a business in relation to the service provided. LAMP was registered as a non-profit organisation (NPO) in 2001 but has been in service long before that.

Objectives of the organisation

The goal of the organisation is to develop youth organisations in rural areas. Development in this regard refers to the creation of jobs and raising awareness of sexual issues including HIV/AIDS, among the youth. The organisation offers programmes and training on encouraging youth creativity, project management, training on the basics of a business, HIV/AIDS and training on abuse. Other HIV programmes rendered by the organisation are training on basic facts of HIV/AIDS, Master trainer, which is a training course where people are trained to be trainers on HIV/AIDS issues such as home-based care, counselling and support on HIV/AIDS. The other training course is HIV/AIDS in the workplace, whereby guidelines are given to companies on how to formulate their HIV/AIDS policies. Most on the programmes offered by LAMP are tailored according to the needs assessment

done by the organisation in the communities that they serve. The role of the organisation in ECD programme involves giving training to educators on project management and how to sustain their crèches. There is also training on fundraising and how to market the organisation. LAMP also offers board training to their beneficiary organisations, where the roles, functions and importance of a board are outlined. This type of training is referred to as board training, is only given to members of the executive committee of the organisation concerned. The organisation has a programme called food banking whereby proposals are sent to private organisation for funding. As a result of this programme, Spoomet offers regular donations of e-pap to the organisation, which are in turn donated to other needy organisations in the township, especially those on the training database.

Finances of the organisation

The main source of funding for the organisation's programmes is from the Free State Provincial DoH and DoSD. In addition, the organisation often gets contracted to offer capacity building trainings by other institutions such as the organisation for Albinism South Africa. In the 2003/2004 financial year LAMP received one million rand from the two departments for training on ECD and capacity building to youth organisations. Given its important role in the province, the organisation believes that funding from government departments is not enough as this hampers the aim of the organisation to provide training to organisations right across the Free State province.

Currently, the organisation is confined to offer training to organisations in three of the five districts in the province, namely Xhariep, Lejweleputswa, and Thabo Mofutsanyane Districts. Since the organisation is aware that funding from government is not enough it embarks on fundraising campaigns as well as tendering their services to other organisations. The organisation indicated that the core business of LAMP is training and main expenses are training related, therefore, it would be difficult for the organisation to survive without funding, because the funds from other income generating ventures are not enough. The organisation provides business plans based on guidelines and objective set by government departments, however these are integrated with inputs from LAMP staff members as well as feedback from needs assessments in communities.

Capacity of the organisation

LAMP has a total of 11 employees, 10 of which are young people. The financial manager has received training from the DoH on how to manage the organisation's books and report back to the department. In addition to this training, the financial manager is studying financial management at tertiary level. An internal auditor and auditors from government departments audit the organisation's books.

Support from government departments

There is a good working relationship with the two government departments that LAMP is receiving funding from, LAMP is happy with the support provided by the two departments. LAMP sends monthly progress reports to DoH and DoSD, so far there has not been any complaints from the two departments and more organisation are being referred to LAMP by these government departments for training. This, the organisation believes is an indication of the confidence that both departments have in LAMP.

General knowledge about HIV/AIDS

Through the relationship with the DoH, LAMP gets HIV/AIDS related information regarding the developments in the HIV/AIDS. The organisation also attends HIV/AIDS conferences to keep abreast of all the latest developments. This is in addition to reading accredited HIV/AIDS related publications.

Achievements of the organisation

Through their HIV/AIDS related work about 250 people were reached and over 35 organisations have been trained and mentored. Offering training to the National organisation of Albinism is one of the achievements of LAMP. Getting rejection of proposals by the department is perceived to be the biggest challenge for LAMP because all proposals are drafted based on the identified needs during service delivery sessions of LAMP with communities. Rejections of proposals by government departments imply that the services provided by LAMP do not efficiently meet the requirements of the communities. However, according to their assessment of LAMP in the communities- there is still more that needs to be done and this depends on the funding available. There is great support from the communities in which LAMP is offering training to and the youth in the community are co-operative towards the programmes offered by LAMP.

6.4 Mangaung Tshwaraganang Youth against HIV/AIDS

Mangaung Tshwaraganang Youth against HIV/AIDS was established by Mr Teboho Finger, after testing HIV positive in 2001. The organisation is based in Batho location (just outside Bloemfontein). The area is characterised by a high degree of unemployment and low economic development. The organisation sadly lost its founder through the illness. The organisation does not have any staff or volunteer member who lives openly with the disease, some have tested two three years ago and some are unaware of their status. The organisation lost many of their patients since its inception, the greater impact is the emotional toll these deaths exact on the staff member and the organisation itself, damaging the morale and hurting productivity. The caregivers after losing patients, they show signs of burnout and are usually stressed, as a result they fail to visit other patients. The worst thing is that the staff members and volunteers do not get any kind of counselling. Counselling is important for the staff members because they get attached to the patients and when the patient dies they get traumatised, they need counselling so that they can go on with their jobs.

Objectives and targets of the organisation

The objectives of the organisation include creating awareness in schools, providing door-to-door information in the community, providing care and support to people living with HIV/AIDS. Providing home-based care to people living with HIV/AIDS, providing life-skills education to school, building sound relationships between the organisation and various churches on HIV/AIDS related matters. Furthermore, the organisation creates support groups for people living with HIV/AIDS.

Financing the organisation

The organisation received R154 000 for the financial year 2002/2003 from the DoSD. The organisation has ten permanent staff members and each caregiver receives a stipend of R500 a month. They approached several private companies for funding with no luck. At the moment the organisation is operating without any funding, it has recently applied for funding for the 2004/5 financial year. The organisation falls under a consortium called Alliance Against HIV/AIDS which is funded by the DoH. The consortium received a sum of R80 000 from the DoH. The consortium has a number of programmes, the puppet show where they promote HIV/AIDS education to crèches, condom distribution where they promote awareness and teach the youth and the general public how to use condoms and they also promote HIV/AIDS in schools. The organisation does not benefit financially from the consortium. The finance is very little from the consortium and only a few people benefit from the consortium. The organisation is not happy to be funded as a consortium because they feel that some individuals benefit more than their organisation. They would prefer to be funded individually.

The main expenses of the organisation are monthly rental of their office, telephone, transport and stipends. The monthly rental is R500, which they pay out of their own pockets, each member donates R25 from their monthly stipend to pay for rent and telephone bill. The rent has not been paid in the last couple of months.

Capacity of the organisation

The organisation operates from an office in the Mangaung Resource Centre. All the staff members are based in the main office, field-work (Home Based Care), coordinating educational and youth awareness programmes. In addition, the organisation usually has six freelance volunteers of which only three are paid according to the work they performed. These freelance volunteers are usually called in by the Department of Education to train some of the organisation and the department pays the organisation for the work the volunteers performed for them. The department usually pays R250 to the organisation then the organisation pays the volunteers a R100. Most of the staff have matriculated, but have no jobs and instead help the organisation with its awareness campaign and home based care. The area of concern in the organisation that needs to be addressed is HIV/AIDS counselling to the patients. At the moment the only support that they are offering to people living with HIV/AIDS is moral support. The organisation would like to have HIV/AIDS counselling training. They would like to offer counselling as one of their programmes.

The executive committee members draft all business plans for the organisation. The organisation is confident that all their business and service plans meet the standard determined by the government departments, otherwise they would not have received funding from the DoSD for the previous financial year. However, the organisation acknowledges that this is an area of concern that would require attention in the immediate future.

The organisation has enough capacity for now as they do not have enough resources, but their employees need managerial skills. The organisation would like to be trained in the following fields: financial management, project management, and HIV/AIDS counselling skills by the government departments. The organisation has approached a private company for project management training; the company would not train them for free. The organisation tries to attend as many workshops and

conferences as possible so that they can gain some experiences that these workshops offer. The organisation received 59 days training from the department of social development in home-based care. The department of health provided the department with one day financial management training; although the organisation feel that it was not enough because they are battling to manage their finances. They have an unqualified treasurer who was trained by the department of health who is battling with the finances of the organisation. They do not have budget to hire an independent firm to do their finances. The department of social development audits its books once a year.

Support from the government departments

The organisation appreciates the support they are getting from the government departments, but the funding is not enough. The government department are doing the best they can. The level of support is not enough but at least their doors are always open to the organisation from both departments.

Monitoring of funds and accountability

The organisation does not have monitoring systems in place. The department of social development audits its books once a year only because it is funded by the organisation.

Care and support by the family

The only support the organisation provides to the patients and their family is moral support. The organisation would like to help with counselling the family and patients, but they do not have any training in that department. The organisation would also like to form support groups for patients and the affected families.

General knowledge

The organisation has limited information on HIV/AIDS. It is not fully aware of all HIV/AIDS developments. It does not have formal access to information about the disease. The organisation has a poor coordination with both the governmental departments. The organisation relies for information from the media.

Links with formal health care

The organisation has formal link with Batho clinic and Tshepong crisis centre. The beneficiaries are referred to the organisation by the Batho clinic, Tshepong crisis centre, neighbours and relatives of the patients. The organisation does not only target people living with HIV/AIDS, they take care of sick people who cannot take care of themselves and those who suffer from cancer.

Networking

The organization is affiliated to a consortium called Alliance Against HIV/AIDS. They are not happy to be funded through a consortium because they believe that certain individuals gain from the consortium more than the organizations. The consortium is funded by the department of Health. The

organization has a formal network with the Bloemfontein Hospice; they refer some of their patients who are bedridden to the Hospice.

Achievements of the organisation

The organisation adopted Marang Primary School so that they can help the learners to apply for social grant from the government for learners who need the grant. Because of the work they are doing with Marang they managed to get an interview in March 2004 from the Nelson Mandela fund through the help of the Department of Education. They are on the database of the department of Education also because of Marang Primary School and for promoting HIV/AIDS education in schools. The organisation is fully supported by the community and the police. The organisation would like to form partnership with the local police. When the organisation is doing the door-to-door campaign the doors of the community are always open to the organisation. The community goes to the organisation when they need information on HIV/AIDS.

People (volunteers/members openly living with HIV/AIDS)

The organisation does not have members living openly with the disease. The only person who was openly living with HIV/AIDS was the founder. The members do not know their status.

Reasons of HIV/AIDS in the community

The organisation thinks that poverty and alcohol abuse plays a major role in the spread of HIV/AIDS. They think that the general public and the youth need to change their social behaviour and churches should preach HIV/AIDS education to their congregation. Also parents need to start discussing sexual education with their children as charity begins at home. According to the organisation the schools and parents should have a relationship where children can be comfortable to talk about sex at school (with teachers) and at home a (with parents).

The area of concern in the organisation that needs to be addressed is HIV/AIDS counselling to the patients. At the moment the only support that they are offering to people living with HIV/AIDS is morale support. The organisation would like to have HIV/AIDS counselling training. They would like to offer counselling as one of their programmes.

6.5 Rephiditswe Community-Based Organisation

The organisation was established in January 1999 and was registered as CBO in 2001. The organisation operates from Botshabelo Township. Since its inception in 1999 the organisation has been actively involved in all HIV/AIDS awareness campaigns in Botshabelo and surrounding rural areas. In addition, the organisation has been involved in networking with other CBOs at district and provincial level. The organisation is part of Botshabelo HIV/AIDS consortium. This consortium is made up of 16 HIV/AIDS CBOs all based in Botshabelo.

Services provided by the organisation

The main developmental goal of the organisation is capacity building for other CBOs. One of the main emphases in all capacity building programmes is the promotion of gender equality in the fight against HIV/AIDS. Other services include, health talks and peer education, condom distribution and demonstration, capacity-building workshops for other community based organisations, project and financial management for sustainable development, HBC, pre and post HIV counselling and HIV/AIDS awareness campaigns.

Financing the organization

In 2003 two government departments, DoSD and DoH, funded the organisation. On both occasions funding was allocated through the consortium. The consortium was allocated R50 000 by DoH. From this amount, Rephidisitswe was allocated R600, which was not enough to cover all their operational costs. In addition, the organisation is contracted on a regular basis by the DoH to render a number of services on its behalf. The amount of funding from DoSD that is used for payment of caregivers was not disclosed, however the organisation believes it is not enough to cover all their expenses. The DoSD also donated a public phone container to the organisation as part of job creation project. This container has been used as a public phone business. This includes condom distribution and HIV/AIDS awareness programmes.

Due to lack of adequate government funding, the organisation approached a number of private and parastatals. In 2001 the organisation was allocated an amount of R40 000 by the Development Bank of South Africa. This funding was used to establish an Internet café in Botshabelo Township. The success of the Internet and public phone businesses' generates a regular income for the organisation that is used to supplement government funding. The organisation is also sponsored by a local Pharmacy and Supermarket with free food when it hosts awareness campaigns in the local community. In 2003 Mangaung municipality funded the organisation with R10 000, which has been used to expand the telephone and Internet businesses'.

Capacity

The organisation has 11 full-time staff members who are responsible for the day-to-day management of the telephone and Internet business. 30 caregivers who are between the ages 18 and 35 are responsible for HBC. Due to limited funding from government departments caregivers have to divide funding allocated equally. This often results in caregivers being allocated a stipend of R500 that is less than the standard rate for all caregivers. This has resulted in a number of caregivers leaving the organisation. The need in the community is much greater than the capacity of the organisation and would like to have more caregivers though, they are losing caregivers because the organisation cannot afford monthly stipends for them, and so they lose staff because of financial constraints.

Support from governmental departments

All caregivers in the organisation were provided with 59 days home-based care training by DoSD. Although the organisation believes it needs more support from government departments in terms of support it realises that government departments are understaffed and cannot respond to all the needs of different organisations. However, efforts should be made to improve the communication with all

NPOs. Also, monitoring of services could help improve the effectiveness of these organisations. The negative thing about the two departments is that the officials the organisation work with are not professional and are sometimes not well informed about HIV/AIDS especially those from the DOSD. On a number of occasions government officials criticised the proposals and service plans of the organisation without offering advice on how they can be improved.

Monitoring of funds and accountability

The management meet of the organisation meets on a monthly basis to review the activities and programmes rendered by the organisation. The management also meet to evaluate progress and backlogs of the organisation on a quarterly basis. Where possible and if complaints have been raised, management visit patients to evaluate the services offered by caregivers. To maintain quality control the organisation has forms that the patients sign after the visitation by the caregivers.

Care and support by the family

The organisation offer counselling to affected families. It is planning on have support groups for affected and infected families in the community.

General knowledge about HIV/AIDS

The organisation believes it is well informed about HIV/AIDS. The Internet café has been used to download the latest information and developments in the field of HIV/AIDS. The organisation also frequents the government departments' websites for the latest information.

Links with formal health care system and the community

The organisation works closely with hospice, Botshabelo clinic and hospital. The hospital and clinic refer patients who require HBC to the organisation. In addition, the organisation provides pre-post test HIV counselling on behalf of the clinic. Community members also contact the organisation when they have questions about HIV/AIDS.

Networking

Through its affiliation with Botshabelo HIV/AIDS consortium, the organisation has established a number of valuable links with other CBOs. This affords the organisation the opportunity to share and learn from other organisations. Furthermore, there are links with development organisations to explore different measures that can be used to make the organisation more financially viable.

Achievements

The establishment of an Internet café and public phone businesses' are listed as the achievement of the organisation. Also, over the last few years the community in particular the number of youth who seek information and condoms from the organisation has been steadily improving. Sometimes the organisation cannot keep up with the demand for condoms by the youth. The organisation also believes that their HIV/AIDS campaign has assisted in fighting the stigma and discrimination

associated with HIV/AIDS. Pre and post HIV/AIDS counselling at Botshabelo clinic also affords the organisation the opportunity to make a significant contribution to community development.

People (volunteers/members living with HIV/AIDS)

The organisation has 6 staff members who are openly living with HIV. This has contributed in demonstrating to the community that one can still live a positive and normal life even when infected with HIV.

Reasons for HIV/AIDS infection in the community

The organisation believes that poverty, ignorance and unemployment are the main contributing factors to the scourge of HIV/AIDS in the community. Lack of recreation facilities in Botshabelo Township is also cited a contributing factor in young people experimenting at a young age in sex.

6.6 Lerato Care Group

Lerato Care Group is a community-based organisation offering services in the areas of Rocklands, Phelindaba, Bloemanda and Sejake. The organisation was established in 2001 as response to the call by the State President, Mr Thabo Mbeki that people should volunteer their services in the communities that they live in. The main focus of the organisation is to address the deficiency of health care services in the fight against HIV/AIDS and other related diseases such as STIs and TB. The services offered by the organisation are not only confined to HIV positive people, because they do not want to single people based on their HIV status. The organisation operates from the homes of the chairperson and co-ordinator in Rocklands Township. The organisation links with patients via referrals from people in the community. The organisation also gets invited to the local councillor's ward meetings to give a talk about the kind of services that it offers. In addition the organisation also employs door-to-door marketing strategies.

Lerato Care Group is a member organisation affiliated to the Ngenani Emxholweni consortium. The consortium has 6 member organisations and was established in 2002 following encouragement to do so by the DoH. The consortium was officially launched on 05 March 2004. The consortium committee has 12 members, two people from each organisation. From Lerato Care Group two people serving on the consortium committee are, one as the Consortium chairperson and the other as the consortium Fundraiser.

Service provided by the organisation

The main service provided by the organisation is HBC. This service is provided to patients on a daily basis, volunteer carers come in at the Chairperson's house to sign in a logbook before going to see patients. All carers keep fieldwork notes on the progress of their patients. Once every week the co-ordinator goes into the field with the cares to get feedback on the services provided by the cares from patients and their families. The nature of the HBC is that carers would come in the patients' home in the morning for about 20 minutes to check if the patient has been washed and fed and thereafter supervise with the administering of medication to patients.

Lerato has since expanded their HBC services to include paid HBC for patients who need 24-hour attention or whole day care. This move came about as a result of being approached by attorneys of patients who were already in the care of Lerato. The attorneys offered that if the organisation put their clients/patients on 24-hour care, they would pay an amount, which the organisation was reluctant to disclose. On average the organisation takes care of 64 patients at a time with the ratio of care to patients is 1:3 however there are other carers who feel emotionally strong enough to care for more than 3 patients. For the paid home-based care service there are 4 carers for the 24-hour patient i.e. 1 during the day and 2 at night, and for the day care patient only one carer. Other service that the organisation has been doing is to help families that are struggling with funeral arrangement. This is done by approaching the local business community for donations of food as well as arranging with local ward councillor to authorise donation lists. They always strive to ensure that all deceased get a dignified funeral.

Lerato work closely with teachers in schools as the first points of identifying who qualify to receive government grants, but are not getting them. Currently the organisation has three schools in the area of Rocklands, namely Kgabane School, Karabelo School, and Mothusi School. The organisation works with these three schools only mainly because these are the ones closest to the base from which the organisation operates. Other services include HIV/AIDS awareness campaigns in schools.

To help in boosting the immune system of patients, the organisation relies on supplements such as e-pap from MUCPP clinic. For other people whose immune system is compromised by lack of nutrition, the organisation organise food parcels from the DoSD for these patients, especially those whose grant applications are still pending. Furthermore patients and their families are encouraged to plant vegetable gardens.

Finances of the organisation

The organisation does not receive any funding from government departments or the private sector. The only money from a government department was the funding granted to the consortium for the year 2003/2004. R40 000 was granted by the DoH to Ngenani Emxholweni consortium. The money was mainly used for marketing the consortium as well as Information and Education Communication (IEC) and awareness of HIV/AIDS in the community. The organisation does not have a drafted annual budget because they don't have a fixed income to budget from. The paid home-based care is the only income-generating project, together with other small-scaled fundraising initiatives. The organisation survives by using money from the members' own pockets to cover some of the organisation's expenses; this is sometimes a problem since most members of the organisation are unemployed.

Several private sector companies have been approached with proposals for funding, but so far they have not been able to secure any funding. Some of the reasons given by the companies were that they did not offer funding for the programmes that the organisations were offering, others said the organisation should apply in the following year. The organisation also approached the DoH and DoSD. From the government department the response has been that the funds for that year had already been exhausted. However the members were quick to point out that they can't complain much about the DoH because at least the department granted funding via the consortium even if it is just a small amount that was granted to the consortium. The organisation had problems with the

DoSD because there was a tendency for the department to invite organisations to submit proposals, yet no funding is ever granted and reasons that are given are that the due date for application for funding had gone by or that funds had been exhausted.

The organisation acknowledges that survival of the organisation without funding is very difficult, however they maintain that the organisation can continue to survive like it is already doing now. It is perceived that nowadays, most funders nowadays prefer to grant funding to consortiums instead of individual organisation. It would be wise for an organisation to seek funding through a consortium, even though the implications would be such that through funding via a consortium, little funds would be coming to the individual organisation, because all the affiliated organisations have to share the whole granted fund. For now, Lerato organisation is content with funding through the consortium because the needs of the organisation are being included in the business plan of the consortium, furthermore there is sharing of information and networking via the consortium.

Capacity of the organisation

The organisation has 17 non-stipendiary volunteer members, 13 of which are young people, with 8 people serving in the executive committee. The organisation received donations in the form of training from the Department of Labour and St. John's Ambulance. St John's Ambulance offered training in home-based care. The training consisted of 5 days training on basic home-based care and 2 weeks practical training at the military hospital. From the department of Labour the training was on home-based care, project management, bookkeeping and financial control. The members also received counselling training, but it was not from an accredited body.

Initially when the organisation was established, many people joined the organisation with the hope that there would be financial gains for them. When realising that this is a voluntary organisation many people left the organisation. The problem is that these people had received training, which is a loss of skill on the part of the organisation. Members of the organisations acknowledge that there are always ongoing discoveries in the research on HIV/AIDS and they feel they need to keep abreast of latest findings in the fight against HIV/AIDS, this should include getting information in the form of books and pamphlets from the DoE and being invited to seminars and conferences where issues on HIV/AIDS are going to be deliberated. Furthermore, one of the skills that the members of the organisation need is counselling services for the members. Currently members give counselling to their patients and they also give counselling to one another, this is not expert counselling it is mainly offering empathetic support to patients as well as to fellow members of the organisation when the need arises.

The organisation has a financial manager, and the executive committee does the auditing of their books, since they can't afford an external auditor. Furthermore the chairperson together with the coordinator drafts the business plan of the organisation, the draft is then presented to the executive committee to be approved. The drafting of the Business plan is based on the objectives set by the organisations, in the pursuit to meet the needs of the community.

The biggest challenge for the organisation is access to adequate finances to keep the organisation running. The organisation also struggle with material to administer home-based care with, things like dressing gauzes and gloves. At first they used to get them from MUCPP clinic, but those were

not enough because the clinic staff had to reserve those material for their own HB carers. The members of Lerato often opt to be resourceful and use plastic bags for handling HIV infected patients, the carers always makes sure that plastic bags with no colouring are used. In the case of gauzes the members use tissue papers to wipe wounds. Recently the DoH donated a box of dressing kits to the organisation, in there were gauzes, gloves and tweezers. However there is no surety if this kind of donation is going to be sustained. This donation came about as a result of the organisation writing a letter of complaint to the former Premier, Ms Winkie Direko on highlighting the plight of the organisation in ensuring hygienic apparatus for handling patients in particular HIV positive patients.

Support of government departments

The organisation appreciates the fact that the DoH granted funding to the consortium especially given the fact that it was the first time that the consortium was invited to submit a proposal. However the organisation is not happy as to the amount granted considering that it was restricted to certain activities and also that there are 6 organisations in the consortium.

The organisation seemed to be having negative sentiments toward the department of Social development. Firstly they were dissatisfied by the fact that the department kept on inviting them to submit proposal, which is in a form of a template that has to be filled in, yet no funding is ever granted. The department keeps on promising to grant funding. Furthermore the department of Social development gave support to other organisations that are offering the same services as Lerato organisation. Support in terms of stipends and regular visits by department officials. From the consortium only two organisations get that kind of support, and the members of Lerato organisation think that this kind of treatment by government officials can create tension and competition amongst organisations affiliated to the same consortium.

Since the establishment of the Lerato organisation, the organisation has been submitting reports on the home-based care services that they do to the DoSD, but since 2003 they have stopped to do so because of lack of support from the department. The organisation expects the DoSD to give support in terms of stipends for carers doing home-based care as well as providing food parcels to be distributed to the needy and poor. Currently, the organisation distributes food parcels that are organised through the office of the ward councillor. In general Lerato organisation members feel that government departments have not done enough to offer support to capacitate their organisation.

Monitoring of funds and services and accountability

The organisation monitors the funds allocated to the consortium via the members of the organisation who serve on the consortium committee. In the consortium committee, the treasurer has to report on a monthly basis, furthermore for any spending by the consortium there are requisition forms that have to be completed before the money can be issued. Furthermore the consortium has to write quarterly report on the financial activities of the consortium and present them to the affiliated member organisations.

Care and support to the family

Family support is one of the services offered by the organisations especially to families of patients who do not have enough knowledge about HIV/AIDS and the care of the infected. The organisations give health talks to these families, to ensure infection control and hygienic conditions are maintained for the family's sake and the sake of the patient.

Programmes provided by the organisation

There is a Life skills programme in schools is mainly targeting the youth, however due to some of the attitude of young people toward the organisation it is difficult to assess if the message reaches out effectively. Young people seem to be having a negative attitude toward the services provided by the organisation. Young people feel that they would never care for sick people especially those infected with HIV.

General knowledge about HIV/AIDS

The organisation acknowledges that there are always developments in the field of HIV/AIDS, thus they would want to expand their horizons in the knowledge about HIV/AIDS. Currently Lerato has been getting information regarding HIV/AIDS through their working relations with organisations such as Planned Parenthood Association of South Africa (PPASA) and Befrienders (organisation offering grief and moral support to HIV infected and affected people).

Links with formal health care system

The organisation has formal link with MUCPP clinic in Mangaung, and is also well known in other clinics in the Rocklands area, because they get referrals from those clinics as well as fetching medication for some of their TB patients.

Networking

The organisation was able to form partnership networks with other NGO that have proved to be successful; this includes LAMP, Befrienders, and PPASA. From LAMP they get a lot of information in terms of published journals, they also got training on how to write their own organisational publications. From Befrienders they get invited to motivational seminars on how to give empathetic support to people infected and affected by HIV. From PPASA they get condoms and information pamphlets and posters.

Achievements of the organisation

Among the achievements of the organisation, registering as an NPO is one of the celebrated achievements as well as registering with Thembalizwe trauma counselling. Registering with Thembalizwe is an achievement because members of the organisation can now be able to get counselling training from accredited organisation, in addition patients who require expert-counselling services can be referred. Having established networks with other established organisation such as LAMP, PPASA and Befrienders is also regarded as an achievement for the organisation because this helps in capacitating the organisation as well as ensuring sustainability of the organisation. The organisation is well accepted in the community, however young people seem

to be having a negative attitude toward the services provided by the organisation. There are some families who have not accepted the HIV positive status of their family members, because of the perception in the community that if a member of Lerato organisation goes to care for a person in a house that person must be having AIDS. This highlights that there is still a lot of stigma around the acceptance of HIV in the community. The members interviewed did not know of any other member of the organisation who is HIV positive and openly living with their status.

Reasons for HIV/AIDS infection in the community

Perception of the members of the organisation on the population of society that is mostly infected with HIV is that mostly young people are carriers of the HI virus. The reason associated with this high rate of infection is ignorance amongst the youth, young people seems to be ignoring the consequences of their reckless behaviour purposely. Members of Lerato, expressed that the youth have enough information about HIV/AIDS, and that condoms are distributed everywhere, yet many young people still engage in unprotected sex others have multiple partners. The one thing that Lerato organisation members feel needs to be done is to keep the youth busy in recreation activities, however that cannot be the only foolproof way because it is not known what young people might get into when they leave recreation facilities.

6.7 National Association of People living with AIDS

National Association of People Living with AIDS (NAPWA) is a non-governmental organisation that deals with HIV/ AIDS related social issues pertaining to both infected and affected citizens. NAPWA was established at national level in 1994 and the main focus of the organisation falls broadly under advocacy, which involves Human rights issues, Labour issues, Care and support as well as dealing with stigma attached to HIV and AIDS in society. NAPWA Free State office was established in 1998. The organisation operates from the old Mangaung municipality building in Batho location. NAPWA carries most of its job through volunteers who are members/beneficiaries of NAPWA.

NAPWA has 12 branches in the Free State, namely, Bultfontein, Winburg, Virginia, Henneman, Zamdela, Botshabelo, Thaba-Nchu, Mangaung, Welkom, Zastron, Ondendaalsrus and Ventersburg 40 members. NAPWA sees HIV/Aids as socio-economic issue more than a health issue; hence it has lobbied for grants for people who are HIV positive, especially those from poor financial background. Assessment for qualifying for a grant involves, NAPWA members doing a physical inspection and then a recommendation letter written to the DoSD. People who qualify include those who are HIV positive and unemployed from poor backgrounds.

Services provided by the organisation

NAPWA's Free State programmes are in line with National programmes, these includes community mobilisation encouraging more people to disclose their HIV status. Performance indicators include how many branches launched and how many support groups have been formed.

In terms of advocacy most of the programmes are overlapping because sometimes when doing destigmatisation, there are instances were advocacy issues are dealt with, for instance financial

exclusions, in relation to financial institutions such as banks and insurance companies. Desigmatisation, this is done through members of NAPWA who are open about their status. Putting the human face to the epidemic, which involves mobilising communities to acknowledge the existence of the epidemic by showing people who are openly living with the HIV.

NAPWA is of the opinion that visibility during other times of the year like during Easter, not only in December and on AIDS day is important in the fight against HIV/AIDS. NAPWA is in a process of introducing a Gender programme, whereby people will be made aware of situations that women are made to be vulnerable to infections. NAPWA also take special notice of men as having a role in spreading the virus, for men the focus is on attitude and behaviour change.

Care and support for both infected and affected beneficiaries is provided in addition to Life Skills Education and Counselling. The opinion of Free State is that NAPWA members should not be doing home-based care, because already there are many organisations doing home-based care. Furthermore, for an HIV positive person to care for a terminally ill patient might result in the carer reflecting deeper on their HIV status and start thinking of the time when they get to that stage. Members of NAPWA Free State are always discouraged to do home-based because it is perceived that it is going to be traumatic for them, due to the fact that they are going to be over involved emotionally and that in turn will be detrimental to their already compromised health. At the time of the interview preparations were being made for the NAPWA national congress, and there were speculations that a different decision regarding this matter might be taken at the congress.

Finances of the organisation

At national level, the DoH funds NAPWA, and the funds are redirected by NAPWA's national office to all provincial offices. In the Free State Province NAPWA receives funding from the DoSD. This came about as a result of the expansion of the services rendered by NAPWA to the communities. NAPWA was seen serving a role of linking beneficiaries to service providers. The service providers were mainly those organisations that received funding from DoSD. DoSD contacted NAPWA offices to monitor the funded organisations whether services are being delivered where they are due. As result in 2002, NAPWA submitted a proposal to the DoSD seeking funding to capacitate their expanding role of dealing with CBO's and beneficiaries at community level. With regard to the service for the department of Social development there has not been implementation as per the agreement with NAPWA, because there was mismanagement of funds on the part of board members of NAPWA. The members of the board have since been expelled and there are plans to recover lost funds.

Currently NAPWA Free State should be doing all the programmes of NAPWA as according to the mandate from NAPWA national office, because the National DoH has granted funds for NAPWA programmes. However, NAPWA Free State has been advised to spend the money sparingly because the national congress was being planned. Funding for NAPWA Free State is mainly received from the AIDS Foundation. The programme for which funding is received from Free State DoSD has not yet started due to technical problems experienced by NAPWA. NAPWA is not content with the funding coming to Free State Province, thus the province takes initiatives to fundraise by means of events such as beauty pageants. Main expenses include capacity building in the Provincial office as well as in branches. NAPWA received R 234 000 from the DoSD, R106 702 from the Aids

Foundation, it has been communicated verbally that NAPWA Free State has been allocated ± R422 000 by the NAPWA national office from the budget of the funding received from the National DoH.

Capacity of the organisation

NAPWA Free State has 3 fulltime staff members including an administrator, a co-ordinator and community outreach person. There is one fulltime stipendiary volunteer who comes in the office everyday. There are 12 branches in the Free State and most of NAPWA members are young people. Bultfontein 50 members, Winburg 26 members, Virginia 28 members, Henneman 36 members, Zandela 29 members, Botshabelo 49 members, Thaba-Nchu 39 members, Mangaung 52 members, Welkom 71 members, Zastron 35 members, Ondendaalsrus 26 members, Ventersburg 40 members. They also consult external auditors. NAPWA has no financial manager, the co-ordinator and the administrator do all the auditing of books. In terms of drafting the business plan, it depends on the programme for which funding is applied for. For instance the programme for the AIDS foundation, the drafting of the cost and activities of the programme is upon the office team to do.

Support from government departments

The organisation believes that government departments are not fully supportive of the organisation. The general perception is that government officials even at local level are not as supportive as expected to be. NAPWA is accountable to NAPWA national office and the national office accounts to the National Department of health through reports to the NAPWA national office, however from this year 2004, NAPWA Free State will submit reports to the Free State DoH.

Monitoring of funds and services and accountability

Monitoring is done in terms of attendance registers, progress reports on the activities done, and evaluation reports. In the case of those doing awareness campaigns in schools the school principal needs to signing on a report, and in clinics those doing counselling need to write reports indicating how many people have been counselled and how many have tested positive or negative. Furthermore, branches are expected to write monthly reports to the provincial office, and that is often a problem because, some branches do not have the resources, such as faxes or computers. However that problem is going to be addressed soon because many branches are going to get offices from their local municipalities. The organisation is sceptical of this move by local municipalities, because this might be a move to lobby for votes for the coming 2004 general elections.

Care and support to the family

The main service provided by NAPWA is counselling to both infected and affected people, currently there are plans to form support groups for patients and families affected by HIV/AIDS. This is seen as strategy that would decrease the stigma and help families to deal better with the status of their family members.

Programmes provided by the organisation

NAPWA acknowledges that HIV prevalence is high among the youth; hence most of the awareness campaigns taken by NAPWA are directed mainly at the youth in schools and tertiary institutions. NAPWA has included as part of their coming events to raise awareness and increase the sense of responsibility among males in the fight against AIDS. NAPWA intends to bring issues of same-sex couples in their awareness campaigns as well as support programmes because currently there are little or no programmes in the Free State that are targeted at gays and lesbians yet gays and lesbians are also greatly affected by HIV/AIDS. It is difficult to quantify the number of people reached during awareness campaigns; the only foolproof way of checking number of people reached by NAPWA programmes is the database of NAPWA branches in the Free State.

General Knowledge about HIV/AIDS

All the people interviewed at NAPWA Free State seemed to have a sizeable knowledge about HIV/AIDS issues and they seemed expressive and eloquent in expressing their views. NAPWA members are always reading relevant material on HIV/AIDS this includes conference publications, medical journals and academic books. Through the network with the Department of Health NAPWA is in a better position to get relevant published material on the developments of HIV/AIDS.

Links with formal health care system

From 2001 until 2003 NAPWA had lay-counsellors in various clinics in Bloemfontein, however early this year 2004 the lay counsellors had to be laid off because the funds, which had been paying their stipends, have been exhausted. Thus many of the links with formal health care systems have been terminated; there are however some counsellors who still offer their services voluntarily at clinics such as National Hospital and Mangaung University of the Free State Community Partnership Project (MUCPP) clinic. Currently NAPWA is making plans to get stipends for their counsellors from the Department of Health.

Networking

There is partnership with all organisations that approach NAPWA in discussing or debating on the HIV/AIDS issue. Since mid 2004 NAPWA has been part of a consortium together with Hospic, AIDS Training, Information and Counselling Centre (ATICC) and MUCPP, QwaQwa HIV/AIDS consortium. This is an independent consortium, which is more like a business venture and that is going to help with raising funds. NAPWA is also part of two other consortiums, which are under the department of Education. In Bloemfontein NAPWA has a relation with Mangaung caregiver's association, Ngenani Emxholweni consortium, and Lesedi la Sechaba. There is linking of services, in terms of programmes that these other organisations have that NAPWA does not offer. In addition, some organisations refer people to NAPWA for counselling.

Achievements of the organisation

NAPWA is 10 years old and has achieved a lot in terms of helping HIV positive, and it keeps on doing that. Furthermore NAPWA continues to destigmatise HIV/AIDS, because the rate of stigma and discriminations against HIV positive people has reduced. Though a memorandum of Understanding has been signed with the department of Social development, there is underlying dissatisfaction on

the part of NAPWA. It was expressed that dealing with Government department is difficult because they set the terms of agreement, which becomes an unequal partnership. Furthermore the department of social development funds consortiums of CBO's, but they are not closely monitored. Furthermore it has been established that some of the consortiums funded by the department have nepotistic undertones in their establishments. The department of Social development grants funding to organisations registered as PLWA (People Living with AIDS), which end not delivering effectively to the community.

People (volunteers/members) living openly with HIV/AIDS

Almost all NAPWA members are openly living with HIV/AIDS, many expressed this based move as being influenced by the support received from NAPWA as well as accepting one's status. The support provided by the organisation is credited as one of the key reason why members have been encouraged to come out and declare their HIV positive status.

6.8 Aganang HIV/AIDS prevention and Home Based Care

Aganang HIV/AIDS prevention and Home Based Care was established in January 2000 at Jagersfontein by a group of local volunteers. It was officially registered as an NPO on 19 November 2002. One of the main considerations in the establishment of the organisation was the realisation that the local community had many people who were ill and frail and there were no organisations that could provide HBC to those people. Although HBC is mainly provided to HIV/AIDS infected patients, the organisation does not confine its services to HIV/AIDS patients only. Over the last few years the organisation has broadened its goals to also include orphaned and vulnerable children and other people who need help are also helped by the organisation. In addition, Aganang also helps by ensuring that needy people are aware of food parcels offered by various government departments and making sure that children and people who are impoverished are made aware of government grants. The organisation operates from a house in Itumeleng Township in Jagersfontein.

Aganang is a member of the Lekomo consortium. Lekomo HIV/AIDS Consortium is an umbrella body of clusters of NGOs and other community structures that render service to HIV/AIDS infected and affected people in the 17 towns of the district of Xhariep. The consortium is an initiative by the DoSD and the DoH to ensure that all towns are represented and guard against duplication of services. The consortium has four focus areas namely: home based care, information, education and communication (IEC) on HIV/AIDS, distribution of food parcels, and foster care identification. Each cluster is supposed to render service in all four areas of focus. The four clusters have one specific area of focus, which is delivered across the seventeen towns. To date, only the Department of Social Development funds the consortium.

Services rendered by the organisation

The organisation strives to provide care for the ill, aged, and orphaned and vulnerable children. It also facilitates education and training opportunity for life skill education. Aganang strives to promote the rights of people living and affected with HIV/AIDS through life skill education, emotional and social care of the patients. The biggest challenge for the organisation is providing services to farm dwellers as most farms are far apart. Carers have to hire a taxi to take them to these

farms and this is quite expensive, the only alternative is hiking for transport. This is in itself a problem since there are not too many cars that go to the farms. The organisation offers special courses to the local community and engages in community awareness projects on STIs and HIV/AIDS. In addition, Aganang helps in poverty alleviation projects.

The organisation maintains that there is a direct link between poverty and HIV/AIDS in Jagersfontein. In order to address the high infection rate in the community there needs to be measures that can be introduced to address poverty. Thus informing the community about various grants available and the need to get birth certificates for children whose parents are unemployed is crucial. The organisation has no programmes specifically targeting same sex couples and has not considered this as part of their programme

Finances of the organisation

The organisation was established in 2000, but only received funding of R91 800 for the 2002/2003 financial year from the DoSD after submitting a business proposal of R157 140. Between, 2000 and 2002 the organisation relied on fundraising initiatives, donations and the goodwill of volunteers. However, these initiatives were not sustainable as the community of Jagersfontein is impoverished and mostly unemployed. It only became eligible for government funding after registering as an NPO in 2002.

In an effort to help to ease the financial burden of transportation to outlying farms the organisation has approached Spoornet, DoL and the local mining company, De Beers for assistance. They have also approached the local business community, including supermarket owners, taverns and bottle store owners. However, the organisation has not had any successful responses.

Sometimes people who are in dire need of financial assistance and food, approach the organisation for help and this creates added pressure on the organisation's financial position. While, people are made aware of available government assistance, sometimes it takes longer for government to respond and the organisation feels compelled to act in the meantime. On a number of occasions volunteers help the community with money from their own pocket.

The organisation was happy with the initial funding from DoSD but soon realised that it was not enough to meet all their financial requirements. Consequently, the DoH was approached for funding to supplement the initial funding received from DoSD, but nothing has come through.

The DoSD stipulates that R150 should be spent on stationary (files, pens and writing material) every month, but the organisation feels that their stationary requirements far exceed R150 per month. Initially all home-based carers used to get surgical gloves from the DoSD but the supply has since been terminated. As a result, the organisation has to purchase their own supply of surgical gloves this is difficult since there is not enough funds. Carers have resorted to the use of plastic shopping bags as a substitute. The beneficiaries complain about the use of plastics since it is not hygienic and scratches them. DoSD has been made aware of the situation, yet nothing has been done.

Main expenses of the organisation

The main expenses of the organisation are for payment of R500 per month stipends for each of the 14 volunteers members. Operational expenses, including telephones and electricity are covered. The organisation acknowledges that surviving without government funding will be difficult.

Capacity and Training

The organisation has a total of 14 volunteers, six of whom are under the age group of 30. Ideally the organisation would prefer to have 18 caregivers because over the past couple of years, the need for the services offered by the organisation has increased. All home-based carers have received the 59-day home-based care training offered by DoSD. DoSD had arranged a First-Aid training for the organisation with the local ambulance service in Jagersfontein. There is no administrator and financial manager, but would like to receive training on such key aspects. When required to submit a service or business plan, the organisation relies on the help of a teacher at a local school. The organisation would like to offer counselling to their patients and to improve the standard of their services by providing Hospice services. However, the fact that the organisation does not receive feedback from the department makes it difficult to determine if their service plans are acceptable.

According to the MOU between DoSD and Aganang the ratio of carer to patients is supposed to be 1:3. However, the needs in the community are much greater and often result in some caregivers attending to more than three patients.

Support from the governmental departments

No reasons given if funds are not allocated. Ensuring that where people lack food they are helped. The organisation is very happy about the relations with Social Development happy about their relations, especially about local social worker.

Monitoring of funds and accountability

Apart from the monthly financial reports submitted to the DoSD, there are no mechanisms to ensure there is no mismanagement of funds. Aganang signed a memorandum of agreement with the DoSD that clearly outline what the organisation is expected to do. A social worker from the local DoSD office also helps the organisation to keep to the stipulated guidelines.

Care and support for the family

The organisation gives information on how to handle and live with an HIV/AIDS infected person to the family, the nutritional value of eating a balanced diet is also explained. Emotional support is offered to the families of people who have disclosed their HIV positive status. Part of the challenge is to ensure that people living with HIV/AIDS inform their families about the disease so as to ensure that everyone in the family takes proper precautions. The organisation respect the wishes of all those who do not want to disclose their HIV positive status. People are encouraged to accept HIV/AIDS as another illness and being infected with the virus is nothing to be ashamed of.

General knowledge about HIV/AIDS

The organisation believes it has enough information on how to take the necessary precautions not to contract HIV/AIDS when providing services to patients. However, the organisation is lacking in keeping abreast of all the latest developments in the HIV/AIDS field.

Link with formal health care and networks

The organisation has established a relationship with the local Jagersfontein clinic, whereby they can arrange for immediate attention to patients needing emergency care. Even the health professionals working at the clinic refer some patients to the organisation for HBC services. The organisation is the only one of its nature in the Jagersfontein area. As a result there are no formal networks with other organisations.

Achievements of the organisation

There is a close and good working relationship between Aganang and the local office of DoSD in Jagersfontein. Aganang has taken the role of linking and informing community members of the relevant services provided by DoSD. The organisation is proud to have been able to provide quality HBC to many patients since its inception. Through Aganang HIV/AIDS awareness campaigns, the level of HIV/AIDS knowledge in the community has improved.

Reasons for HIV/AIDS infection in the community

Child grants have been attributed to the rise in teenage pregnancies and the increase of HIV infection amongst the youth. Alcohol and drug abuse especially Dagga seems to be major factors in the behaviour patterns of sexually active people. Aganang advocates the integration of condoms as part of people's sexual activities. Some people tend to associate HIV/AIDS with Aganang caregivers, especially young people. However, this is a misconception since Aganang does not only provide care to HIV/AIDS patients.

The organisation believes that educating people about the epidemic will help in the acceptance of people living with HIV/AIDS. It emphasises that it's not only people with loose moral values who contract the disease. The other ways that one can contract the disease for instance children and women being raped and open wounds. The organisation has no counsellors, caregivers do not get counselling when their patients die. Stigma and confidentiality are still problems for the organisation, however every one of their HIV/AIDS infected patients is encouraged to inform at least one family member.

The caregivers find that disclosing of HIV status is generally low in the community. However, more encouraging is that there are young people who have tested HIV positive and have disclosed their status. This is seen as an indication to the community that one can still live a productive life despite testing HIV positive. The adults population of Jagersfontein seem to be discreet about their HIV/AIDS status.

Volunteers/member openly living with HIV/AIDS

The organisation has one member who is living openly with HIV/AIDS. Only one member is aware of his/her status. Others are not aware of their status. It would seem they are afraid of knowing their status. They have seen how people who have tested HIV/AIDS react and are treated by the community. Although members are encouraged only one has gone for the test.

Stigma and confidentiality

Within the community stigma and discrimination is a problem; this is largely due to ignorance and the fear of death that prevails in the community. There is still a prevailing conception to associate HIV/AIDS with promiscuity.

6.9 Sakhisizwe HIV/AIDS organisation

Sakhisizwe HIV/AIDS organisation was established in 1998 after a group of local women in Koffiefontein realised the need to provide HBC and general information about HIV/AIDS to the local community. The ladies identified that there were a lot of people who did not know much about HIV/AIDS, some of which were at risk of contracting sexually transmitted infections as a result of many sexual partners and not using condoms. The organisation provides services in Ditlakeng township and surrounding farms, and operates from a rented backroom in the township. The organisation registered as an NPO in 2002.

Services rendered by the organisation

The organisation offers Home-Based Care (HBC) as their core service. The organisation's primary objectives are to ensure that basic needs of the children and families affected and infected by HIV/AIDS are met by providing food, shelter, education, alternative care, counselling and support. Sakhisizwe strives to promote acceptance of HIV/AIDS illnesses and for infected people to disclosure in a non-discriminatory environment. The youngest patient under the care of the organisation is a 13-year-old girl who was infected after being raped by a neighbour.

The secondary objectives include improving HIV/AIDS awareness in the communities; encouraging healthy lifestyles and to ensuring self-sustenance of the infected and affected through vegetable gardens. In addition, the organisation encourages people to take part in Voluntary Confidential, Counselling and Testing (VCCT), Community Home-Based Care (CHBC) and general health care. The need to use of condoms and to know one's HIV status is the main message of the organisation. Members of the organisation help with arrangement for identity documents (ID) and birth certificates for people who qualify for government grants.

The organisation sometimes embarks on door-to-door campaigns informing people about the different grants and assistance available from government departments including DoSD. The organisations try to involve the youth in their programmes by throwing street bashes where they give away condoms and pamphlets. There are no specific programmes for gays and lesbians; all the programmes are open to everyone in the community.

Finances of the organisation

Since its inception in 1998 the organisation has been surviving mainly on donations and contributions from volunteers. The organisation had also embarked on fund raising initiatives, including approaching a number of prominent local business people who all rejected the organisation's requests for funding. The fact that the organisation deals with HIV/AIDS related issues makes it difficult to access funding from the local business community. The business sector in Koffiefontein perceives HIV/AIDS as something that only affects certain racial groups and people on a certain socio-economic level. In 2002 the organisation submitted a proposal for funding to the DoSD and an amount of R92 000 was granted for the 2003/2004 financial year.

The main expenses of the organisation are monthly stipends of R500 for eight members, transport for visiting surrounding farm areas, and awareness campaigns.

Capacity and training

Initially the organisation had eight members, subsequently one member withdrew. The organisation also received five days financial management training from De Beers (local mine). Which they say it was much better than the one offered by DoSD. All the members drafted the organisation's business plan and DoSD professionally drafted it. They are happy with the quality of their business plan. The organisation received 59 days Home Based Care from the DoSD, three days foster care training and one day financial management. The organisation thinks that the HBC training was excellent and the one-day training was not enough. The organisation would like the government departments to provide them with counselling courses.

Monitoring of funds and services and accountability

The organisation keeps a file for every patient and all the carers and patient (or patient's family) have to sign the form as proof that the patient was visited. The organisation does not have a system in place for monitoring of funds because DoSD approves all expenditure incurred by the organisation.

Care and support to the family

The only support the organisation provides to the families affected is disseminating HIV/AIDS information. Members of the organisation emphasise that HIV/AIDS is not something to be ashamed of and HIV/AIDS infected people are encouraged to come out about their status. There are however, people who still insist on keeping their HIV positive status a secret.

General knowledge about HIV/AIDS

The organisation acknowledges that their knowledge of HIV/AIDS is limited to HBC principles. The organisation is regularly invited to the DoSD workshops that are often a valuable source of information on HIV/AIDS and the latest developments.

Achievements of the organisation

The organisation has been instrumental in reducing the level of discrimination toward people living with HIV/AIDS in the community. Discrimination is no longer such a persistent problem. However, young people seem to be still at the receiving end and being stigmatised. This has led to a number of people being afraid to disclose their HIV status.

People (volunteers/members) living openly with HIV/AIDS

The organisation has one member who is openly living with HIV/AIDS. Other members do not know their HIV status.

Reasons for HIV/AIDS infection in the community

The organisation sees poverty as the main contributing factor to the spread of HIV/AIDS in the community. Sexual exploitation of young people and minors is rampant, thus increasing the number of vulnerable children and young people at risk. Some of the contributing factors are rape, parents encouraging child prostitution with mine workers. This means that any man who has money can have any girl he desires. Also, the number of child headed households has increased over the last few years, thus leaving many girls vulnerable. In some cases, social workers take too long to respond to some of the problems identified, thus further putting the children at risk. The service offered by DoSD is not consistent.

6.10 Interfacing of services

An overwhelming number of beneficiaries did not have responses for the questions posed by the researchers. The main aim of interviewing beneficiaries was to assess the quality of care they receive from NPOs and how it makes a difference to their lives. In five of the case studies sampled, three patients from each case study were interviewed. In all the interviews the recurrent themes were satisfaction with the services provided by caregivers and a. In all cases the patients were unemployed and from poor backgrounds. The patients had a strong association with the caregiver rather than the organisation. The problem of lack of government delivery was apparent in the Southern Free State where most interviewees indicated the frustration of applying for social grants from government departments. According to the beneficiaries the visitation of the carers is consistent and makes a meaningful difference in their lives. Many patients expressed their gratitude for the support they receive from organisations. However, when probed further none of the respondents could give meaningful responses. The organisation assists with washing and making sure that patients take their medication. However, all of them did not link the services they received from their carers with Lerato as an organisation. When asked if they know about the government's plan to distribute ARV's, all of them seemed to support the move, but none of them knew what ARV's are and what the whole roll-out plan was all about. They appreciate morale support and the advice they receive from the organisation.

7. RESEARCH FINDINGS

Having examined the detailed case-studies, attention now turns to an integration of the key findings from the cases, with a view towards the identification of common themes – both positive and

negative. It should be noted that this study does not represent a comprehensive evaluation of NPOs in the Free State province, rather a small number of organisations in the field of HIV/AIDS in the province.

Objectives of non-profit organisations (NPOs)

The objectives of all the organisations are well articulated in their constitution and service plans. However, in the case of CBOs, it is clear that these objectives are not developed in line with their financial capability. Furthermore, it is often difficult to differentiate between the actual services being provided by CBOs and the service that the organisations would like to provide. All CBOs who were probed admitted that it would be difficult if not impossible to deliver services outlined in their constitution and service plans.

Funding

The recurrent theme throughout all the case studies has been the apparent lack of adequate resources, in particular funding. All organisations including those that are relatively better financed, identified lack of adequate finances as one of the greatest stumbling block for the provision of services. In the case of CBOs the lack of finances was closely linked with lack of capacity. Often organisations with limited capacity would request large amounts of funding from government departments on the assumption that at least a fifth of the funding requested would be granted. This is more apparent in the case of CBOs.

FBOs and NGOs are relatively well funded and have the advantage of consulting private accounting firms for the auditing of financial statements. This can be attributed to the long-standing history and credibility of these organisations. A number of CBOs have approached the private sector for funding but many of these organisations have not received a positive response. While NGOs and FBOs knew well in advance if they would be funded in the next financial year, CBOs had no idea if funding for the following year would be granted.

Sustainability

From the South African National guideline on Home based care, by the DoH. HBC care is viewed as an integral part of community based care where the consumer can access services nearest to home in a level of comfort and quality health care to ensure a dignified death. HBC is a form of community care, which encourages participation by people who are able to respond to the needs of their communities. In general HBC aims to rekindle the traditional form of community life and fosters a culture of responsibility amongst communities.

The success of community care is dependant on the investment of resources, skills, time and energy by government, private institutions, and communities. It is clear that without government funding most organisations would struggle to provide services, let alone pay for recurrent expenditure. This will be more apparent in NGOs than CBOs and FBOs since they have professional staff members who have to be paid regularly. There is a noticeable disparity of basic administration tools such as computers, fax machines and cable line telephones. Both NGOs and FBOs run their operations more

professionally than CBOs. It is relatively easy for large organisations to call on the requisite expert necessary for writing acceptable business proposals and service plans.

The business and service plans of CBOs is at times contradictory and improbable. There exist a climate of uncertainty over funding with most organisations under constant threat of closure. However, there is a desire to assist in most problems facing the community. Hence many organisations are constantly taking up new challenges and issues that often impacts negatively on the organisations' finances.

Service provision by NPOs

Despite the lack of adequate resources, the quality of services, including Home-Based Care (HBC) provided by all organisations is appreciated and the standard acceptable to most patients. Although CBOs lack the management and leadership capacity to run their organisations with the same professional principles displayed by NGOs and FBOs, their commitment, passion and dedication to the provision of services to beneficiaries far surpasses those of NGOs. In the case of CBOs there is passion and commitment displayed that cannot be identified in well-established organisations. CBOs do not keep office hours and can be called when required by patients. Many CBOs carers reside in the same localities as their patients and the relationship extends beyond that of a patient and carer, an emotional bond is created. As a result, CBOs can forge strong working links with the local community. In relation to FBOs and NGOs, CBOs are better placed to provide services or respond to patients than NGOs and FBOs. However, the most worrying aspect of the research was the fact that many carers in CBOs do not receive counselling

Relationship with government departments

There are poor communication and coordination between government departments and NPOs – all of which translate into less than optimal services. Based on the information gathered from the organisations interviewed, the relationship between government and NPOs seems to be multi-faceted, complex and sometimes problematic. The relationship between government department and the non-governmental sector is not complementary; the relationship seems to be skewed in favour of NGOs and FBOs. This is surprising, given that both government departments are aware that the scale and magnitude of the HIV/AIDS epidemic is much bigger and more complex than the capacity of government.

The level of cooperation between the NPOs and provincial officials is often determined by individual personalities, quality of leadership and knowledge of government departments. For NGOs and FBOs it is relatively easy to get information from government officials. In some cases, key government officials and politicians are invited as guest speakers to NGO and FBO annual functions. These puts both FBOs and NGOs in a better position to gain valuable insight that helps in their application for funding. In fact, one large organisation claimed to have been allocated funds without signing a memorandum of agreement with the relevant government department. NPO in the Free State province lacks an established forum to champion their cause. Lack of funding has made most fragmented and only look the benefits that they can derive from these associations. As such there is the danger of cooptation or domination by government departments. Although consortiums

