Managing HIV and AIDS on another level

Promotion of Voluntary Counseling and Testing and Stigma Reduction through HIV/AIDS Workplace Policies in Ugandan NGOs

Master thesis for Medical Anthropology and Sociology

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Abstract
PREFACE

From the start of my medical studies I have been interested to look beyond the borders of my own future profession. Holding the point of view that there is more to health than healthcare, I felt the need to study multisectoral approaches towards health care. I was specifically interested in healthcare in resource limited settings, so I started a course in development studies. This encouraged me to think critically about health issues and when I learned about the possibility to do a master in Medical Anthropology and Sociology I was immediately appealed by it.

However, ‘becoming an anthropologist’ was not always easy. It required a 180 degree change of mind to accept that everything I had ever learned or considered as truth was socially constructed. Furthermore, the fact that the researcher is considered a central factor in research, rather than an uninfluential presence meant a confrontation with myself and my perspectives on the subject of my research. I believe that the opposite perspectives of the medical and social world need to be brought together in order for anthropological research to be effective and, as a future doctor, I aim to contribute to building bridges between the two disciplines.

The choice for my research project was a logical one in many ways. First of all I have a profound interest in HIV/AIDS. I had already studied the virus on a microbiological level and was keen to investigate the social aspects of this disease. Second, my interest in health and health care in developing countries accounts for my excitement when the opportunity to travel to Uganda arose. Third, I believe my medical background has given me a clear preference for applied research. Therefore, I was happy to be able to participate in a research project with a clear aim to improve the situation of my respondents.

My research would not have been possible without the help of so many Ugandan people. I acknowledge Spencer Birungi, coordinator of the SAN! project in Uganda, for linking me to two of the participating NGOs: the Foundation for Urban and Rural Advancement and Health Need Uganda. These organizations allowed me to carry out my research in their workplace and they received me with open arms for which I am truly very grateful. I have made some dear friends who made sure I felt very much at home in Uganda and helped me to get through difficult times. I will never forget that! In addition I wish to thank all my respondents for sharing their ideas with me. Working with you has been a real pleasure!

There are also many people in the Netherlands who deserve credits for the completion of this thesis. My family and close friends have given me endless support during my travels and writing. Thank you for being so close to me and ready to help at any time! My special thanks goes out to Winny Koster, who has initiated my choice to study medical anthropology during her lectures on health and development. Therefore, I was very happy to have her as my supervisor. Thank you for linking me to the SAN! project in Uganda, for the feedback during my research and your comments during the writing of my thesis, which always stimulated me to bring out the best of myself.
1. INTRODUCTION

1.1 Introduction

Uganda has been a pioneer in addressing the problem of HIV/AIDS, but the disease remains a major health issue in need of a suitable response. HIV is not a static phenomenon, but it is linked to a constantly changing social context. Therefore it requires continuous development and evaluation of new prevention strategies. Since HIV typically strikes adults in their most productive years, the disease has a great impact on the workforce of a society. So what to do when HIV affects your employees? And how can organizations play a role to prevent HIV among the staff? In a country such as Uganda, which has a generalized HIV epidemic, these are important questions for non-governmental organizations (NGOs) and private companies, who are at risk of losing qualified employees. For staff on the other hand, the onset of HIV can lead to job insecurity and discrimination when clear policies and awareness of rights are lacking (Asingwire & Birungi 2006:7). Private companies, Heineken for example, began recognizing HIV and AIDS workplace policies (WPPs) as a cost-effective means to address HIV-related absence and loss of staff (Pharmaccess). Furthermore, companies consider HIV/AIDS a humanitarian issue in need of response. NGOs, on the other hand, were lagging behind in adopting WPPs, mostly due to fear to discuss the issue with their fund providers, combined with silence from the side of the donors. Therefore STOP AIDS NOW! (SAN!), a collaboration of several Dutch donor organizations for a concentrated effort against HIV/AIDS, started pilot projects in Uganda, India and Ethiopia which support the development and implementation of HIV and AIDS WPPs in local partner NGOs. An applied research component was added to document and analyze good practices and to provide regular feedback to the NGOs involved (Neema & Koster 2006). Uganda was the first country to participate in this program and when I started my fieldwork, in February 2008, it had been running for approximately two years. Therefore I could participate in the first evaluations of the WPPs. I stayed in two of the participating NGOs, the Foundation for Urban and Rural Advancement (FURA), based in Kasese, and Health Need Uganda (HNU) in Soroti, for one and a half month each to study the added value of having a WPP. Since a general evaluation was carried out by an applied research team, I decided to focus on two related topics that are part of a WPP: stigma reduction and promotion of HIV testing.

1.2 Problem statement and structure of thesis

My research questions focus on the influence of the WPP on stigma reduction and promotion of voluntary counseling and testing (VCT), with the aim of providing information that NGOs or private companies can use to improve their WPPs. It is important for a WPP to address stigma and discrimination, because they are important barriers to HIV prevention and care (Campbell et al. 2005;
Ogden & Nyblade 2005). First, by creating a division between ‘us’ and ‘them’, as will be described further in chapter 3, stigma creates a false sense of security among uninfected people, which makes them feel there is no need to protect themselves (Ogden & Nyblade 2005). Second, stigma can make people living with HIV/AIDS (PLHA) reluctant to seek care, while antiretroviral treatment reduces the viral load and thereby the risk to infect others. HIV/AIDS related stigma is also reported to affect condom usage, by making couples reluctant to discuss and use them. Furthermore, individuals may be disinclined to go for a HIV test, especially when testing services are offered in separate clinics, and PLHA fear to disclose to their sexual partners (Ibid). Stigma and discrimination are very much dependent on the social context, as will be described further in chapter 3. This social context is influenced by several factors, such as laws or media, and WPPs may also have an impact which can come to benefit both infected and uninfected employees. Therefore I wanted to explore the WPP’s possibilities to increase openness and reduce stigma and discrimination in the workplace.

My second focus is on the promotion of VCT, because knowing your HIV status can be a starting point for HIV prevention. However, the effectiveness of VCT as a prevention strategy is still debated. A meta-analysis of 27 studies, in North America (19), Africa (6) and Europe (2), found that HIV positive individuals were more likely to practice safe sex after counseling and testing but HIV negative individuals did not modify their sexual risk behavior, so VCT seemed ineffective as a primary prevention strategy (Ibid). (Weinhardt et al. 1999). In addition, the effects of VCT on secondary prevention may be limited by the high infectivity during early infection, a time when most people are not yet aware of their HIV status and when standard tests do not show a positive result yet (Cassell & Surdo 2007). On the other hand, a study on behavior change among clients of health centre-based VCT services in Kenya found a significant reduction in the number of sexual partners, a decrease in reported symptoms of sexually transmitted infections (STIs) and increased condom use among both HIV positive and HIV negative tested participants (Arthur et al. 2007). These results have been found among clients who took the initiative to use VCT, but people may have various reasons for not using these services, such as stigma, fear of receiving a HIV-positive diagnosis, lack of confidentiality, and long distances to VCT sites (Matovu & Makumbi 2007; Skinner & Mfecane 2004; Wolff et al. 2005). A study on people’s attitudes towards VCT in rural Uganda revealed that there is a lot of fear to know ones HIV status, because people perceive that knowing their status will accelerate the course of disease (Wolff et al. 2005). Other feared consequences of a HIV positive diagnosis were marital disruptions or abandonment (Ibid: 114). In rural Uganda people were also afraid that rumors would start from being seen at the counseling office (Ibid: 113). Furthermore, misconceptions about the VCT services made people doubt confidentiality and validity of the HIV tests (Ibid: 112). Non-monetary costs of using VCT facilities formed another constraint: people found it difficult to find the time to leave their home or work and waiting times were long and unpredictable (Ibid: 112). Therefore, I wanted to find out how WPPs contribute to increased utilization of VCT and how NGO staff view the effects of VCT on people’s sexual behavior.
The mutual relation between VCT usage, disclosure and stigma will also be discussed and my findings will be framed in a multilevel perspective to pay due respect to structural factors, as well as the agency of individuals to make well considered decisions. In order to clarify how influences from different levels have an impact on the workplace, I will also describe HIV prevention in society, related to stigma and VCT in particular. In addition, these descriptions will serve as a point of reference for the effects of the HIV/AIDS WPP. My research is based on the following research questions:

**Core question:**
- To what extent and how do WPPs in Ugandan NGOs contribute to HIV prevention through reduction of AIDS related stigma and discrimination, increased utilization of VCT services and disclosure of people’s HIV status, and what is the relation between stigma, VCT usage, disclosure and HIV prevention?

**Sub questions:**
- How do NGO staff feel about the introduction of the HIV/AIDS WPP and its implementation?
- How do staff perceive HIV/AIDS related stigma and discrimination in society and the workplace?
- Which factors, in society and at the workplace, help to reduce stigma and discrimination and promote disclosure?
- How is VCT promoted and access facilitated in the WPP and how does this add to the ongoing promotion of counseling and testing in the society?
- Which factors influence the utilization of HIV counseling and testing and how does the WPP contribute?
- What are the effects of VCT on HIV prevention according to NGO staff?
- What are recommendations to optimize HIV prevention in Ugandan NGOs and society at large?

My thesis is structured as follows. In the second chapter I provide background information on Uganda and its healthcare system, HIV/AIDS in Uganda and the SAN! project ‘Managing HIV and AIDS in the workplace’, based on existing literature. Chapter 3 provides a description of my study perspective and main concepts, including stigma, gender and behavioral change. In the fourth chapter I set out my methodology. The following three chapters are based on my experiences in Uganda. First I describe the context of the two organizations in terms of their environment and organizational background. A description of staff’s perception of the WPP in general is also included. In the sixth chapter I discuss the way NGO staff perceive communication and stigma related to HIV/AIDS at their workplace and in
the society. Different forms of stigma are described, including self stigma, feared stigma, enacted stigma and stigma by association. In addition I will pay attention to the risks of positive discrimination and ways to reduce stigma and discrimination. In my final empirical chapter I discuss people’s considerations related to HIV testing and their utilization of testing. Furthermore, I pay attention to the recent trend towards RCT, the way VCT is promoted in the workplace and the effects of HIV testing on people’s risk behavior and disclosure. Each empirical chapter is concluded with a short discussion of its contents. Finally, I present my conclusions and recommendations in chapter 8.
Geography

Fig. 1 (right) Uganda and its surrounding countries (www.un.org)

Fig. 2 (bottom) Map of Kasese district. The arrow indicates Kasese town, where FURA was based (Kasese District 2008)

Fig. 3 (lower bottom) Map of Soroti district. The arrow indicates Soroti town, where HNU was based. (Soroti District 2008)
2. LITERATURE REVIEW

The NGOs where I performed my research cannot be seen as isolated from the context of Uganda’s society at large. Therefore I will first provide a short overview of the demographic, political and economical situation of the country. In addition I will describe the health care system to clarify the framework in which measures against HIV/AIDS are taken. Then I will discuss the HIV/AIDS epidemic in Uganda and how the country has addressed the problem throughout history, followed by a separate paragraph on HIV counseling, testing and disclosure. Finally I will provide background information on the SAN! project ‘Managing HIV and AIDS in the workplace’.

2.1 Uganda and its healthcare system

Uganda is a land-locked country, neighbored by Kenya, Tanzania, Sudan, Democratic Republic Congo (DRC), Rwanda and Burundi (Fig.1). The country was part of British East Africa from 1890 until 1962 when the Uganda People’s Congress, under the leadership of Milton Obote, was elected to rule the country (Broere & Vermaas 2005; Kaleeba et al. 2000). After independence, the country suffered greatly from political unrest and civil war. During the 1970s and 1980s Uganda was notorious for its human rights abuses, first during the military dictatorship of Idi Amin from 1971-1979, then under Milton Obote, who returned to power (Broere & Vermaas 2005) In 1986 the National Resistance Movement took over the country and made Yoweri Museveni the new president of Uganda. He introduced political reforms, mainly through extensive decentralization, and created a new environment of media freedom. The context of this liberal environment supported Museveni’s efforts to address HIV/AIDS openly (Kaleeba et al. 2000). Since 2005, Uganda has a multi party political system, but Museveni also changed the constitution, which allowed for his third term election in 2006 (Broere & Vermaas 2005; BBC 2008). The president’s main political challenge lies in resolving the unrest in the north of Uganda, where the Lord Resistance Army (LRA) has been terrorizing the people for nearly two decades (Ibid).

Uganda currently has a population of approximately 30 million and its annual population growth rate of 3.2% is one of the highest in the world, requiring high economic growth and increased investment in social services to achieve poverty reduction and human development (UNDP 2008). The country’s main economic sector is agriculture, which contributes to 90% of its total export earnings and employs approximately 80% of the workforce (Wordofa 2004). Uganda has made substantial economic improvements over the past fifteen years. The percentage of people living on less than a dollar a day has been reduced from 56% in 1992 to 31% in 2005 (UNDP 2008). However, Uganda is still among the poorer countries in the world, ranking 154 out of 177 on the human development index (UNDP 2007).
Uganda’s health care system comprises of different services at different levels in society (Fig. 4). Starting from the lowest level, in the community, village health teams (VHTs) are active in mobilization and monitoring the utilization of services and the health status of the population (MOH 2001). As a first level of interface between the formal health sector and the communities, the approximately 750 Health Centres (HCs) II provide ambulatory services at the parish level. There are roughly 680 HCs III at the subcounty level, which provide basic preventive and curative care, laboratory services, maternity care and first referral cover (Ibid). The HC IV, or general hospital, offers second referral possibilities and has facilities to perform surgical and obstetrical emergency care such as blood transfusions or caesarean sections. These centers are based at the county or district level and there are about 215 of them. In addition to the services offered at the general hospital, there are 10 regional referral hospitals at the district level to provide specialist services such as psychiatry, radiology and higher level surgery, as well as teaching and research. Finally, the 2 national referral hospitals offer comprehensive specialist services and are involved in teaching and health research (Ibid).

Health insurance is something only few Ugandans can afford, but the government strives to make basic services accessible for all. User fees for government health units were discarded by the government in March 2001 (Yates et al. 2006). Treatment for highly communicable diseases and immunizations were already free of charge since 1997 (Ibid). Although, the decision to abolish user fees was accompanied by a scale up in government budget for the health sector, financing is still insufficient and limited access to care remains a challenge. Geographical access to healthcare facilities is limited to 49% of the households and especially rural areas are vulnerable due to dilapidated infrastructure. In addition the quality of care is compromised by a lack of supplies and qualified staff, especially in decentralized health units (Ibid).

2.2 HIV/AIDS in Uganda

Like in other countries in Sub Saharan Africa, Uganda’s HIV/AIDS epidemic is rooted in heterosexual transmission. In the early 1980s, war-torn Uganda was hit by the world’s first extensive AIDS epidemic in a general population (Kinsman 2008). In 1990, HIV prevalence reached nearly 31% among women at urban antenatal surveillance sites, although rural sites had considerably lower rates of infection (Parkhurst & Lush 2004). However, since then, Uganda became one of the ‘success
stories’ in the battle against the HIV epidemic. The government called for multiple interventions, which led to a decline in prevalence rates during the 1990s and stable prevalence rates since 2000. However, there is still a generalized epidemic in the country. Among people between the ages of 15 and 49, prevalence was estimated to be 10.1% in urban areas and 5.7% in rural areas (WHO 2008). In addition, there is reason for concern, since recent data provide evidence that previous gains in risk behavior have been eroded, which may cause an increase in new infections (UNAIDS 2008).

**Uganda’s policy on HIV/AIDS**

Since the beginning of the HIV epidemic, the Ugandan government acknowledged HIV/AIDS as a major problem and by allowing a diversified approach the Ugandan government managed to contain the epidemic. At the time of the first HIV cases in Uganda, the country was in a post-civil war situation. A centrally controlled and developed health care infrastructure was lacking, which allowed for the development of decentralized health facilities in which non-state actors were of particular importance. The government encouraged this and was keen to cooperate with the World Health Organization (WHO) and local NGOs in addressing HIV/AIDS (Parkhurst & Lush 2004; Parkhurst 2005). A wide variety of groups, including NGOs and religious organizations, thus became involved in HIV prevention and care, resulting in a system that was very diverse and adapted to local situations (Ibid).

Recognizing that HIV/AIDS has causes and consequences beyond the health sector, the Uganda AIDS Commission (UAC) was established in 1992 to coordinate a multi-sectoral approach (Uganda AIDS Commission). The overarching strategy was to provide Information Education and Communication (IEC) to promote behavioral change, for prevention was the only way to fight HIV in the early days of the epidemic (Kinsman 2008:83). Messages about transmission, abstinence and faithfulness were promoted through various channels, such as churches, schools, the mass media and drama groups (Ibid:83). However, people remained concerned about transmission through casual, non-sexual contact for many years (Kinsman 2008:84). In order to reduce stigma, messages of compassion, solidarity and hope were also propagated (Kaleeba et al. 2000). From 1991 and onwards, condom producers were allowed by the government to advertise their product, although condom promotion did not become part of the national policy as formulated by the UAC (Kinsman 2008: 96-98). This changed in 1997, when the Minister of Health recognized the contribution of the condom in declining rates of HIV infection (Ibid: 98). Recently, however, human rights watch reported a policy shift towards increasingly ‘abstinence only’ HIV/AIDS programs in Uganda (Human Rights Watch 2005). This is a worrying development, considering the fact that Uganda’s success is largely attributed to a wide diversity of approaches (Parkhurst & Lush 2004).

The provision of antiretroviral treatment (ART) in Uganda followed an international policy shift and became possible through generous funding of international donors. Following widespread advocacy campaigns to lower the prices of antiretrovirals (ARVs) and promote equitable access, in
2000 there was a policy shift from a focus on cost-effectiveness towards increasing availability of ARVs in resource limited settings (Hardon 2005). From mid 2003 funds became available from the Global Fund to fight AIDS, tuberculosis and malaria and the US President’s Emergency Plan For AIDS Relief (PEPFAR), which allowed the Ugandan government to start with the provision of free ART (Kinsman 2008: 142). Treatment was to become available in larger government health facilities, starting with the regional referral hospital followed by the general hospitals and HCs IV (Ibid: 143). In addition, ART was offered by the Joint Clinical Research Centre (JCRC) for a small fee, while various NGOs, such as The AIDS Support Organization (TASO) and Uganda Cares (Ibid 145), and the government started the provision of ART free of charge (Bass 2005; Kinsman 2008). In spite of these combined efforts, coverage of antiretroviral treatment is still limited. According to the WHO coverage in Uganda was estimated at 33% in 2007 (WHO 2008).

The national policy of Uganda on HIV/AIDS is considered as a facilitating factor in the development and implementation of WPPs in Ugandan NGOs. In the baseline study that was conducted for the SAN! project, participating NGOs expressed that the government had created a supportive policy framework to recognize HIV/AIDS as a problem and promote knowledge about the basic facts of the disease (Asingwire & Birungi 2006:30). Furthermore, increased availability of HIV/AIDS related services provide NGOs with opportunities to link their employees to an organization that provides these services (Ibid: 31).

2.3 HIV counseling, testing and disclosure

In defining HIV testing, a distinction should be made between voluntary- and routine counseling and testing (RCT). According to the WHO, counseling and testing can be defined as a confidential dialogue between a client and a care provider aimed at enabling the client to cope with stress and take personal decisions related to HIV/AIDS (WHO). Voluntary counseling and testing depends on the client’s own initiative to go for a HIV test. Routine counseling on the other hand is initiated by the service provider. It is recommended by the WHO for patients who have symptoms which could be caused by HIV/AIDS (WHO). Both forms of testing require a client’s informed consent. Routine testing can be offered by asking the client if they want to be tested (‘opt-in testing’) or by informing the client that they will be tested unless they refuse (‘opt-out testing’) (Ibid).

Possibilities for HIV testing in Uganda have improved due to the development of rapid tests and the emergence of specialized HIV testing centers. In the early days of the HIV epidemic there were few HIV counseling and testing services in Uganda, so many Ugandans resorted to donating blood to find out their status (AIDS Information Center). The national blood bank was known to offer HIV testing and supportive counseling and they experienced an increase in blood donations of over 400% from 1989 to 1995 (Ibid). Therefore, the AIDS Information Center (AIC) was established to provide confidential VCT services, starting in 1990 in Kampala. Conventional testing methods
required for the blood to be sent to a laboratory and test results were available to the client after approximately two weeks (Hutchinson et al. 2007a). Consequently, about 25% of the clients never learned their results due to failure to return to AIC or late arrival of results (Downing et al. 2007). The development of rapid tests brought a radical change by allowing clients to test and learn their results within two hours. The AIC has been using this method to provide “same-day” results from 1997 and onwards (Ibid).

In Uganda’s AIC VCT ideally includes pre- and post test counseling. During pre test counseling, the client is asked about his reasons to come and a risk assessment is made. Then the possible outcomes, positive or negative, of a HIV test are discussed and the counselor assesses the clients’ willingness to test. The actual testing of blood takes approximately 20 minutes. After testing, the results are reviewed with the client and a plan of action is made. When someone tests positive, positive living and disclosure are discussed and referrals are given for future support. When someone is negative, HIV transmission and options for prevention are discussed (AIC).

In spite of the increased VCT services, expanding testing remains a priority, because the percentage of people who know their status is still limited. In 2004, among the general population, 12.8% of women and 10.8% of men were ever tested for HIV and received results (WHO 2007). This can be due to various factors that make people reluctant to test, as I described in chapter 1, or to provider related constraints. Although VCT services were available in 51 out of 56 districts by 2004, in many areas coverage within the district was limited to a few sites (UAC 2006). In addition, AIC reported that remote providers often had difficulties with logistics. Therefore, UAC considers expanding VCT and RCT for inpatients, priority intervention areas (UAC 2007) and AIC continues to scale up VCT services and works together with the government to promote RCT.

Voluntary counseling and testing can be the first step towards disclosure of a HIV positive status, which may have positive effects on the individual and their surroundings, although people do fear negative effects such as stigmatization. Disclosure of individuals can help to break through the silence that is caused by denial, stigma and discrimination, and open up the epidemic (UNAIDS 2000). However, disclosure should not come at the expense of breaching confidentiality, or bypassing consent. Therefore, UNAIDS and WHO promote ‘beneficial disclosure’, which is voluntary disclosure that comes to the benefit of infected individuals, their partners and families, by allowing them to seek care and support. In addition it may lead to greater openness in the community when more people disclose. In Uganda, a study among HIV-positive members of TASO found that 83% of people disclosed to someone on the day they tested positive and 69% had disclosed to their most recent sexual partner (King et al. 2008). Positive outcomes of disclosure included taking risk reduction measures, creating open, honest communication, showing trust and love for ones partner, facilitating partner testing and being able to openly seek care and counseling (Ibid). Although few participants experienced negative outcomes, fears of stigma and discrimination, in particular at the workplace or from in-laws, and fears of blame and abandonment were common barriers among those who did not
Therefore, in order to increase the number of people who are willing to disclose, a conducive environment is needed (Paxton 2002). The fact that the experience of stigma at the workplace was mentioned in particular by TASO members (King et al. 2008) indicates that WPPs can be important to create an accepting environment for PLHA.

2.4 Addressing HIV and AIDS in the workplace

The International Labor Organization (ILO) started the attention for HIV/AIDS in the workplace. They recognized HIV/AIDS as a major threat to the world of work, because the disease affects the workforce and may give rise to violations of workers’ rights through stigma and discrimination (ILO 2001). Therefore they developed a code of practice, which describes key principles for a WPP. In addition, SAN! developed ‘Good Donorship Guidelines’, a document that lists a number of reasons for having a WPP (Holden 2006). First, the costs of employees falling ill can be substantial, in terms of health care expenditures or increased absenteeism for example. Furthermore, when clear policies are lacking, managers are forced to support staff on a case-to-case basis, which carries a risk of discrimination and setting standards which cannot be maintained when more staff members fall ill (Ibid). HIV/AIDS deserves special attention because in high prevalence settings, all staff are likely to be affected, it is highly stigmatized, concentrated among people of working age and having a WPP may also help staff to address HIV in the community, thereby supporting wider development (Ibid). The key principles for a WPP are based on the ILO code and include: recognizing HIV/AIDS as a workplace issue, non-discrimination, gender equality, creating a healthy work environment, social dialogue, no screening for HIV, confidentiality, continuation of employment, prevention and care and support.

The SAN! project ‘Managing HIV and AIDS in the workplace’ is a cooperation between Dutch donor organizations and local actors. Supervision is provided by the SAN! project officer in the Netherlands and the local project coordinator in Uganda (Birungi et al. 2005). In addition, Uganda has a Local Project Group (LPG), which is comprised of eight participating NGOs. Their duty is mainly to develop and periodically review the country working strategy and monitor the implementation process (Ibid). Furthermore, the country is divided into three regions, western, central and eastern, which all have their own lead organization that is responsible for local monitoring and support supervision (Koster & Neema & Koster 2007). Each of the participating NGOs has a HIV and AIDS focal point person (FPP) who spearheads the project on the organizational level.

The applied research was conducted in three phases. The first, exploratory, phase, from June to December 2006, concerned the process of developing a WPP. In the second phase, from January to June 2007, NGOs worked on implementation of the WPPs. My research was part of the final phase, from July 2007 to June 2008, during which the effects of HIV/AIDS WPPs were evaluated.
From the moment of baseline onwards, an increasing number of NGOs started developing and implementing WPPs. At baseline, only 4 out of 52 visited NGOs had a WPP, while an additional 14 were in the process of drafting one (Asingwire & Birungi 2006). In general, staff of visited organizations had high levels of knowledge about HIV/AIDS and high awareness of existing HIV/AIDS services (Ibid). Staff members of partner NGOs reported that attitudes towards PLHA were increasingly positive and cases of discrimination at the workplace were becoming rare. However, fear of stigma and discrimination was still cited as a constraint to disclosure in the workplace. Furthermore, a FPP emphasized that cases of stigma against (suspected) HIV positive members of staff were still prevalent even if it was not the policy of the company to discriminate PLHA (Ibid).

In the first, developmental, phase of the project it was clear that the need for HIV and AIDS WPPs existed. A quantitative survey among staff revealed that 70.8% had been personally affected by HIV/AIDS and 48% said that this had a negative impact on their work performance (Neema & Koster 2007). Although staff had generally good knowledge on the basic facts of HIV, almost all expressed a need for more information, especially on ART and how to fight stigma and discrimination (Ibid). About 62% stated that they had ever gone for a HIV test, which is much higher than the percentage in the general population. Young female staff members were more likely to have gone for testing, while support staff had used VCT less (Ibid). Testing for HIV was also mentioned as one of the main messages that was propagated as a prevention strategy within organizations and 72.5% indicated that they would disclose if they would test positive. The main reasons for not disclosing were fear of stigma and discrimination (Ibid).

In the second, implementation, phase, efforts started to yield results. Among the participating organizations, 24 had produced a final WPP and 23 had produced a draft WPP (Neema & Koster 2008). Furthermore, 36 organizations reported having started activities, such as awareness raising, providing condoms and information material and securing access services, such as VCT and ART (Ibid). The Agency for Cooperation and Research in Development (ACORD), for example, signed an agreement with a consultant to provide counseling and testing in the main part of the hospital, as a replacement for the separate HIV unit where staff were afraid to be seen (Hadjipateras et al. 2006). In focus group discussions with staff, other effects were also reported. Awareness among staff had increased, prevention materials had become available, there was increased uptake of VCT, reduced stigma and discrimination, more trust in confidentiality and increased productiveness of HIV-positive staff. Interestingly, staff also reported a spill-over effect of increased openness and discussion on HIV/AIDS with their family members (Ibid).

In summary, a lot of progress has been made in the development and implementation of HIV/AIDS WPPs. Promotion of VCT appeared to be a key intervention, so it will be interesting to see the results of this in FURA and HNU. Commonly cited barriers in all phases of the SAN! project were stigma and discrimination, particularly the fear of this kind of negative responses. A detailed description of stigma is provided in the next chapter.
3. THEORETICAL FRAMEWORK

In this chapter I will first introduce my study perspective, followed by a detailed description of my main concepts; stigma, gender and behavior change, and how they are relevant for HIV prevention in Uganda.

3.1 Where levels meet

My research perspective is composed of elements from critical medical anthropology and the empiricist tradition. The field of critical medical anthropology is known for its effort to describe how political and economic forces, of both global and societal scope, influence health conditions and medical institutions (Good 1994:56). This corresponds to my view of stigma, as very much related to existing power structures and inequalities. Furthermore, I will apply a multilevel perspective, which allows the subject of research to be seen as linked to higher and lower levels of social organization (van der Geest et al. 1990: 1026). This will allow me to pay due respect to linkages between national, regional, organizational and individual level. On the other hand, my perception of the individual is more in line with the empiricist tradition, which considers people as rational value maximizing beings (Good 1994: 56). This model may not be applicable in every cultural setting and it contains a risk of neglecting structural factors. However, I believe that the model may be useful in the setting of my research and it can be placed within a framework of macro, meso- and micro level structures. Within this framework, I consider people capable of weighing pros and cons of health related decisions, even when their space for decision making is limited.

3.2 Stigma

In the early days of the HIV/AIDS epidemic in Uganda, people responded with denial and heavy stigmatization of people who were believed to have the disease (Kaleeba 2000: 3). They were rejected by their family and friends, especially after it became known that HIV was sexually transmitted. To have HIV was seen as a punishment from God and a disgrace to the patient and his family (Ibid: 11). As a result AIDS victims were left alone and died deprived of care and support (Ibid: 42). Although the situation has improved considerably over the years, stigma is still a major barrier to openness about HIV/AIDS and prevention, so it is an important concept in my research.

Descriptions of stigma have evolved from a focus on interpersonal relations towards an increased emphasis on social context. Most of the work on stigma builds on Goffman’s classical definition of stigma as “an attribute that is deeply discrediting” which reduces the bearer “from a whole and usual person to a tainted and discounted one” (Goffman 1963: 3). Goffman already recognized stigma’s dependence on a social context that defines an attribute as devaluing. However,
the starting point of conceptualizing and investigating HIV/AIDS related stigma has often been the notion that stigma is an inter-individual process (Parker & Aggleton 2003). Consequently, efforts to reduce stigma aimed at increasing tolerance for PLHA through provision of knowledge and counseling to increase empathy (Ibid). However, a determining factor within a social context is the dependence of stigma on power. Link and Phelan (2001) describe how stigma arises when five interrelated components converge. Stigma starts with distinguishing and labeling human differences. Second, dominant cultural ideas link these differences to negative attributes. Third, separation between ‘us’ and ‘them’ is established. By marking PLHA, for example, as an ‘out-group’ a sense of personal invulnerability is generated among those who stigmatize (Campbell 2005), and it facilitates dehumanization of the stigmatized group (Link & Phelan 2001). Fourth, labeled individuals will suffer from status loss and discrimination, and the resulting inequality. Finally, stigma depends on access to power in social, cultural, economic and political spheres, which allow the first four processes to unfold (Ibid). Parker and Aggleton (2003) expand on this broader perception of stigma and argue that stigma feeds upon, strengthens and reproduces existing inequalities of class, race, gender and sexuality. They build on Foucault’s work, which highlights that the social production of difference is linked to established regimes of knowledge and power. Castro and Farmer propose the concept of ‘structural violence’ as an explanatory model for HIV related stigma. Structural violence determines who is at high risk of infection, who lacks access to healthcare and, ultimately, who suffers from AIDS-related stigma and discrimination (Castro & Farmer 2005: 55). For example, their research in Haiti showed that introduction of quality HIV care can lead to a rapid reduction of stigma and discrimination (Ibid). On the other hand, when structural violence limits access to healthcare, people are more likely to suffer from stigma and discrimination. It is important to consider stigma within a larger context of structural factors related to HIV/AIDS. Therefore I will apply a multilevel perspective to link my findings at the workplace to the WPP and to Uganda’s national policy on HIV/AIDS.

The concept of stigma can be subdivided into different aspects, which also incorporate discrimination. First of all there is self stigma, which results from a judgment of the individual towards him- or herself, although it can be based on societal norms (Overton & Medina 2008). It is a private shame that diminishes self-esteem, causes self-doubt regarding whether one can live independently, hold a job, earn a livelihood and find a life mate, and may cause individuals to develop an identity that dehumanizes them (Corrigan & Watson 2002 in: Overton & Medina 2008). Feared stigma is based on negative expectations and may lead to self exclusion from services and fear of disclosure (Holzemer & Uys 2004). Enacted stigma can be defined as an adverse response from others towards a stigmatized individual (Reidpath et al. 2005). For example, people may gossip about HIV infected individuals or family members may hide a HIV positive relative, thereby depriving them from care (Campbell 2005). HIV stigma can be seen as a precursor or co-factor for discrimination (Reidpath et al. 2005). Discrimination is systematic exclusion or rejection of individuals, who belong, or are perceived to belong to a particular group (Ogden & Nyblade 2005). This may result, for example, in the denial of a
job or promotion opportunities within an NGO, based on a person’s HIV status. Discrimination can also be considered as part of enacted stigma (Holzemer & Uys 2004). In addition, stigma by association may be considered as another manifestation of enacted stigma, but I will discuss it separately. It signifies that people who interact with a person who is stigmatized become “obliged to share some of the discredit of the stigmatized” (Goffman 1963: 30) and the resulting negative treatment.

After defining the concept of stigma it is important to discuss the reasons why HIV/AIDS is such a stigmatized condition. First of all, the principal causes may lie in a fear of contagion, for HIV is often incorrectly perceived as highly contagious, and the connection of PLHA with negatively valued attributes (UNAIDS 2008). For example, in their description of stigma in a South African community, Campbell et al. argue that HIV/AIDS stigma derives from an association with immoral and shameful sexuality, especially for women and young people (Ibid.; Campbell et al. 2007). Given the association between HIV and immoral behavior, stigma tends to be more on those who are expected to uphold moral traditions, women for example (Ogden & Nyblade 2005). In addition, HIV is incurable, it can be disfiguring and it is associated with a painful degrading death (Ibid). This leads to fear for the disease, which can be mitigated by marking PLHA as an out-group, as I described above, and to the perception that PLHA are useless. Building on this perspective, Reidpath et al. (2005) argue that stigma is a mechanism to protect limited resources. Expectations of reciprocity determine a person’s social value, so that people are more likely to be stigmatized when they cannot contribute to the community anymore (Ibid). Research in Uganda has shown that stigma within households increased when an infected person ceased to contribute to the household (Monico et al. 2001 in: Reidpath et al. 2005).

Bearing in mind these different views on the origins of stigma, I will now discuss different strategies for stigma reduction. It is a common assumption that IEC helps to reduce stigma (UNAIDS 2008:80) and this strategy has been systematically applied in Uganda. However, results from a household survey in South Africa show that exposure to HIV/AIDS related messages in the mass media increased people’s knowledge, but had no effect on stigma. Social networks on the other hand, as measured by whether one had discussed HIV with someone in the past two weeks, were positively associated with both higher knowledge and lower levels of stigma (Hutchinson et al. 2007b). In line with this, Campbell et al. argue for community participation to encourage critical thinking by analyzing the reasons for stigmatization (Campbell et al. 2005). WPPs might contribute to this through discussions at the workplace. On the other hand, when stigma is considered as depending on a person’s social value, intervention strategies should be based on creating circumstances that increase the capacity of the stigmatized group to contribute to society (Reidpath et al. 2005), for example through provision of ART, which makes people stay alive and productive. WPPs can form another way of increasing the social value of PLHA, by safeguarding their position on the job.
3.3 Gender

As in other Sub-Saharan African countries, women are disproportionally affected by the HIV/AIDS epidemic in comparison with men. Especially stark differences exist in HIV prevalence among young people (aged 15-24) (UNAIDS 2008). This can be explained by biological vulnerability, for women are more susceptible for sexually transmitted diseases, and gender differences. Gender is a culture specific concept that can be defined as the widely shared expectations and norms within a society about appropriate male and female behavior, characteristics and roles (Rao Gupta 2000). It determines women’s social vulnerability to HIV/AIDS as will be described in this paragraph.

In spite of a strong women’s movement and efforts to involve women in the government, gender inequality prevails in Uganda. Gender relations are traditionally based on a patrilineal system and women have a subordinate position in decision making at the household and community level. Furthermore, women’s right to co-ownership of land is not protected by law (Koenig et al. 2004; Wordefa 2004). Marriage practices also reinforce the subordinate position of women, because of the practice of brides wealth payments, which creates a sense of obligation to the male partner and his family (Koenig et al. 2004).

Gender inequalities, combined with economic vulnerability, have implications for women’s susceptibility to HIV/AIDS. A qualitative study in rural Uganda found that poor economic status is a reason for young girls to engage in sexual activities to achieve things they could otherwise not afford (Kipp et al. 2002). Exchanging gifts also tends to be an intrinsic part of many sexual relations in Uganda, irrespective of wealth (Darabi et al. 2008). A national survey in Uganda revealed that three-quarters of unmarried, sexually experienced women aged 15–19 received gifts or money from their boyfriends in exchange for sex in the past year (Ibid). The practice also occurred the other way around as was reported by three out of ten adolescent sexually active men (Ibid). Furthermore, in low- and middle income countries, early marriage, often prompted by a young woman’s need to sustain herself, represents the most common factor that increases women’s risk of contracting HIV, especially when the husband is significantly older (UNAIDS 2008).

Decisions concerning sex are considered largely a right of men, giving women limited space to negotiate condom use or timing and occurrence of sexual relations (Koenig et al. 2004). Although Uganda’s tradition of polygamous households is fading, being replaced by discourses of monogamy through HIV/AIDS information campaigns and growing evangelical movements, ethnographic research in South Eastern Uganda showed that having an extramarital relation is still a common practice among Ugandan men (Parikh 2007). According to the men, you can still be “faithful” as long as you provide your wife with the necessary economic support and maintain a respectful public reputation, by hiding your extramarital relation from the home and the family’s social networks (Ibid). This statement also indicates the reduced social acceptability of extramarital affairs and the associated
increased secrecy, which can be considered unwanted side effects of the faithfulness based information campaigns (Ibid).

The gender differences I have described are important determinants of the HIV epidemic in Ugandan society. It will be interesting to see how these differences are expressed at the workplace and how they influence HIV/AIDS related stigma and utilization of VCT.

3.4 Behavior change

Behavior change is a core concept in HIV prevention, for most of the interventions focus on changing people’s risk behavior. The basis for IEC campaigns and VCT as prevention strategies is the assumption that they will lead to risk reduction and behavior that safeguards people’s health. But how exactly are people motivated to change their behavior?

There are several models that describe the individual factors that are necessary to initiate behavioral change. The Health Belief Model, the Theory of Reasoned Action and the Social Cognitive (Learning) Theory are all products of the empiricist tradition, since they consider people as value maximizing individuals (Aggleton et al. 1994; Elder et al. 1999). The main focus of these models is thus on risk perception, outcome expectations, perceived social and community norms and self-efficacy as determinants of change (Ibid). A different model with an individualistic focus is the Transtheoretical, or Stages of Change, Model. This model describes five phases of progress in behavioral change. First, there is precontemplation (no intention to change), second there is contemplation (considering change on the long term), then preparation (ready to change and preparing to act), followed by action and finally maintenance (Ibid). It can be useful for me to keep these stages in mind when evaluating the impact of a WPP on staff’s behavior with regard to VCT usage.

Although the above mentioned models can be useful to explain individual processes of decision making, behavioral change is also largely dependent on social and community factors (Aggleton et al. 1994). Individual behavior can be restricted by the larger context. Laws and regulations may marginalize certain groups in their access to information and services, political or religious agendas may determine which kind of safe behavior is promoted and facilitated, cultural expectations or gender roles may influence people's ability to change behavior and public and private resources may be insufficient to support good quality interventions (Ibid). However, larger structures may also facilitate behavior change. The provision of free ART for example encourages people to disclose and seek care and support. Therefore, I will try to frame the impact of a WPP on people’s behavior within the larger context of society and its available services. In addition, the WPP itself can be a facilitating structure to promote behavior change and it will be interesting to see how it influences the behavior of NGO staff.
4. METHODOLOGY

4.1 Study type, location and population

This study is a qualitative evaluation study, performed in two Ugandan NGOs who participate in the SAN! project: FURA and HNU. I was linked to these NGOs by the Ugandan coordinator of the SAN! project. My aim was to evaluate the effect of WPPs on VCT usage, stigma and openness about HIV/AIDS in the workplace, while also taking into account other programs in society related to HIV/AIDS. My study population comprised mainly of NGO staff, but I also talked with key informants outside the workplace including service providers and PLHA in the community. In both organizations I talked with the entire range of employees, from volunteers to managers in order to gain insight in the effects of the WPP at different staff levels. According to their official records, FURA is an organization of approximately 25 staff, but the number of staff who were actually active during the time I was with the organization was about 17. HNU had 15 staff members, who were assisted by 20 part time employees based in the communities, called community focal point persons (cFPPs). Details of my respondents are provided in appendix 1. In chapter 5 the organizations will be described further.

4.2 Data collection methods

In spring 2008 I traveled to Uganda, to be attached to the SAN! project in Uganda for three months. In each of the organizations I stayed for six weeks, while using several data collection methods including documents review, participant observation, semi-structured interviews, informal conversations and group discussions.

Documents review

In both organizations I collected their HIV and AIDS WPP as well as their general human resource management policy. In order to gain insight in the organizational background and their activities I also collected the strategic plan of FURA, quarterly and annual reports of HNU and project proposals and budgets of both organizations. In addition, I kept track of the media and collected relevant newspaper articles on HIV/AIDS and related topics, such as sexuality.

Participant observation

Participant observation was an important research method to obtain data on the way WPPs work in practice and the activities of the organization. My presence in the office gave me the opportunity to interact with staff and to get to know them. Furthermore I attended discussions related to HIV/AIDS and registered the availability of information and protective materials, including condoms and a first
aid box, in both offices (Appendix 2). In FURA I have only been able to join staff on their fieldwork on few occasions, because there were not many projects running at the time of my visit. In HNU, by contrast, accompanying staff to the field was a frequent activity and by witnessing the interaction of staff with the clients, I gained more insight in the challenges related to HIV/AIDS in the society. Furthermore I had the opportunity to attend a VCT day that was organized by HNU in cooperation with the SAN! project. In addition I visited several service providers in the vicinity of the two NGOs to assess the available services related to HIV/AIDS.

Semi-structured interviews
In both organizations I have been able to interview most of the staff and I also performed several interviews outside the workplace. In FURA I conducted in-depth interviews with 16 out of the 17 staff who were active at that time. In HNU I did in-depth interviews with 11 of the 15 staff members. During these interviews I explored staff’s experiences with the WPP, HIV testing and stigma and discrimination (Appendix 3). With regard to the latter two subjects I enquired the situation in general, as well as personal experiences. In HNU I also carried out short interviews with 4 cFPPs, in which I quickly assessed their knowledge of the WPP, the way they benefited from it and the biggest challenges they saw in the community. Besides staff members I performed 11 short interviews with health workers in government clinics and NGOs about the services provided related to HIV/AIDS (Appendix 4). All these interviews were conducted in English. Finally, I interviewed 3 women in the community who were living with HIV/AIDS and I questioned them about their personal experiences related to HIV testing, stigma and discrimination (Appendix 5). Two of these women did not speak English, so I worked with an interpreter.

Informal conversations
Informal conversations about HIV/AIDS and related issues, with both staff and people outside the workplace, turned out to be one of my most valuable research instruments. It was often after an interview or during social activities that I had the best discussions with my respondents. Possibly because people feel more free to talk when they are ‘off record’, but I assume that my own input in the conversation also encouraged people to continue talking. These conversations were mainly about gender relations and the way HIV/AIDS and sexuality were addressed by the Ugandan government as compared to the Dutch approach, but I also discussed HIV testing and stigma informally. I always made notes afterwards and kept a record of these conversations.

Group discussions
In FURA regular morning discussions offered a platform for group discussion that was very useful to me. I was able to facilitate three discussions on the following subjects: ‘social security and donor funding’, ‘VCT versus RCT’ and ‘HIV stigma’. The number of people present during these
discussions varied from three to eight. In HNU I have not been able to organize a group discussion, mainly due to lack of time, both on my side as well as on the side of the organization.

4.3 Data processing, analysis and presentation

During my fieldwork I kept different diaries and I documented all the information I gathered as quickly as possible. First, I kept a journal of my daily activities, in which I also reflected on what I had done. In addition, my personal diary functioned as a record of some of the informal conversations I had. I also kept a journal to write down ideas about preliminary findings and the direction of my research. On my computer I kept several files to organize information from different sources. Under ‘media’ I documented newspaper articles, commercials and road signs related to HIV/AIDS. All my informal talks with people were written down as soon as possible in the file for ‘informal conversations’ and I had separate files for reports about fieldwork and visits to service providers. My interviews were recorded, but I also transcribed them as soon as possible.

For data analysis, I categorized my information on the basis of my research questions. For each theme, I extracted the information from all my sources and put it together as a starting point to describe my findings. Then I compared my findings of different sources and from the two different organizations on the same theme and analyzed the differences. My findings are presented together, but existing differences between FURA and HNU are brought to the attention.

4.4 Ethical considerations

In any research project it is important to consider what kind of information is produced, what the consequences of a research project are for daily practice and who will benefit from it. With my research, I aim to contribute to NGO’s resilience to the HIV/AIDS epidemic by providing knowledge to improve their WPP on HIV/AIDS. This provides legitimization for my research, because participation can also be beneficial for the NGOs involved. In order to make sure that the NGOs became aware of my findings, I have given a short presentation of my preliminary results at the end of my fieldwork in FURA and I discussed my findings in HNU with the focal point person for HIV/AIDS (FPP). Furthermore, I hope this report will benefit the SAN! project by contributing to their evaluation of the effects of HIV/AIDS WPPs.

It is important to treat respondents with respect and acquire informed consent. Permission to do my fieldwork in the two NGOs involved was obtained by mediation of a ‘gatekeeper’, the Ugandan coordinator of the SAN! project. At the start of my stay with both organizations I introduced myself to all of the staff and I explained that the aim of my study was to evaluate the implementation of their WPP on HIV/AIDS, in order to help their NGO and other NGOs to improve their HIV/AIDS WPP. For each interview, I asked the staff whether he or she was willing to participate and I asked separate
permission for recording, which was always granted. All the information that was shared with me should be kept confidential. Therefore the names that appear in this report are pseudonyms.

4.5 Reflection

In general my fieldwork went very well, because of the good support I received in both organizations. However there were some problems I would like to reflect on. In particular the challenges related to expectations people had from me, the influence of my presence on the functioning of the NGOs, difficulties in building rapport with my respondents, problems with language and formulating of questions and time constraints.

Especially during my fieldwork in FURA, I was confronted with a lot of expectations on the side of my respondents, for which I was not well prepared. My position as a ‘mzungu’, a white person, from the Netherlands made people assume I could be of much help to them. So I received several requests for money, or assistance to get scholarships or donor funding. I had not anticipated this, because I assumed that NGO staff were not that much in need of support that they would have to ask me for money. The first time it occurred after an interview I felt very bad. It was as if my respondent had been waiting the whole time to ask me that question. I did not fulfill the request, but I was much in doubt whether I should have. Later on I became more confident in holding the position of not giving money as I realized it would be impossible for me to sponsor all of the staff and unfair to give money only to a few. However, these events made me question the ethics of my research. My aim was to make a contribution to the SAN! project, and my host NGOs in particular, by evaluating the HIV/AIDS WPPs, but this was not what they wanted from me. Rather than the HIV/AIDS WPP, their major concern was to get funding and I had become a window of opportunity. It made me realize that before starting any research I needed to be very clear to my respondents about my goals and the way I intended to make a contribution, but also about my limitations.

Inevitably my presence in the NGOs had some influence on the way they functioned. Merely the fact that I was doing research about HIV/AIDS WPPs made staff more aware of their own WPP and also enhanced activities related to it. For example in FURA at the start of a morning discussion, someone literally said “Mischa is here, so we should talk about HIV/AIDS”. In HNU Friday afternoons were reserved for discussions on HIV/AIDS and one time I also felt that I was the one who initiated this program by asking whether it would still be organized on a certain Friday. I also noticed that condoms were put (back) in the toilet during my stay in FURA and this was explicitly brought to my attention by the FPP. This may have created a bias in my research in favor of the WPPs and needs to be taken into account when looking at my findings.

The importance of building rapport became evident as I noticed that interviews went much better when I had a personal bond with my respondents. In general I felt that I managed to create a good understanding with my respondents and they really shared a lot with me. However, as a young
person it was sometimes easier for me to interact with other young people and I had more frequent informal conversations with them, which provided me with a lot of information. Therefore it is possible that my results are slightly biased towards the perception of the young people.

During my fieldwork, I had some problems in communicating with people. First of all I was unable to interview the guards of HNU, because they could not speak English and time constraints made me unable to organize an interview with an interpreter. However, I have been able to observe their participation in activities related to the WPP and through informal conversations with others I also learned about the way they responded to the WPP.

Besides actual language problems, it was sometimes difficult for me to formulate my questions in a way that was comprehensible to my respondents. I had the advantage that most of my respondents were NGO staff and highly educated, so they were usually quick to understand my questions. But when I talked to people with a lower educational background, for example when I had an interview outside the workplace with two women living with HIV, the conversation did not go very smoothly. I believe my questions may have been too theoretical, or abstract, to make much sense to their frame of reference.

I also struggled with the way I posed my questions during interviews. At first I felt my questions should be as open as possible in order not to influence my respondents. However, this could make it difficult to be clear about what I was asking. Furthermore, I noticed that people with a less talkative nature told me much more after I stimulated the discussion by throwing in an example or telling something about the way things are in the Netherlands. So I was always trying to find a balance between encouraging people to talk, while at the same time limiting my influence.

Generally I have been able to do most of the research activities I had planned, but time constraints incidentally limited my activities. Although I experienced many times that a planned interview did not go through, the six weeks I had with each NGO usually allowed me enough time to reschedule. However with HNU, time became a constraining factor after I had been ill for one week. In addition, there were many projects running, so the staff were also busy. Therefore I was unable to interview some of the staff members and I did not manage to organize a group discussion in HNU.
Promotion of facilities for HIV/AIDS

Fig. 5 (top left) Outside St. Pauls clinic all signs, except one, refer to HIV/AIDS.

Fig. 6 (top right) Sign by the road in Soroti advertising treatment.

Fig. 7 (right) A sign by the road indicates Kilembe hospital and the counseling and testing services available.

Fig. 8 (bottom right) The separate HIV/AIDS clinic in Kilembe is clearly marked.

Fig. 9 (bottom left) Posters inside Kilembe hospital promote HIV testing.
5. BACKGROUND OF FURA AND HNU

Applying a multilevel perspective means considering the context in which the two NGOs, and their WPPs for HIV/AIDS, were operating. Therefore, I will first provide background information on Kasese and Soroti districts with regard to demographic characteristics, challenges related to HIV/AIDS and the various providers of HIV/AIDS services. When the scope is narrowed, it is also important to have a general understanding of the organizations. Hence, I will pay attention to their origin and programs, the way they deal with human resource management in general, daily routines and the organization culture. I will also describe the development of the WPP, its main contents, the way staff look at the policy in general and their views on the effects of the WPP. This chapter starts with a description of Kasese district and FURA, followed by Soroti district and HNU.

5.1 Kasese district

Demographic characteristics

Kasese district is located in the Western Region of Uganda and borders the Democratic Republic of Congo (DRC). The district covers approximately 31,200 sq km that is covered by wetlands, water and a savannah type of vegetation. The Rwenzori mountains in the northwest mark the border with the DRC, while there are flat plains in the south (Fig.2)(Kasese District 2008). Among the population of approximately 530,000 people, the main ethnic groups are the Bakonzo and Batooro, but other tribes like the Banyankole, Basongora and Bakiga are also represented in the area (Ibid). Like in most parts of Uganda, people’s main sources of livelihood are agriculture and keeping of livestock. A livelihood analysis in Kasese district by Oxfam G.B. in Uganda showed that, by 2003, 59.2% of the population were involved in agriculture, mainly for home consumption, and the majority of them does not have any other employment (FURA 2008). Accordingly, household incomes were below national average and only 12.2% were able to save money. However, there are also numerous industries in the area, including Kasese Cobalt company Ltd. (KCCL), Hima Cement and two operational mining operations in Kilembe, which have contributed to the availability of formal employment (Kasese district 2008).

HIV/AIDS in Kasese

Reliable statistics on HIV/AIDS in Kasese district are hard to find. According to the district’s local government the seroprevalence is 11.2% (Kasese District Local Government 2005). FURA mentions a seroprevalence of 12% in one of their project proposals (FURA 2008) and Bishop Masereka Christian Foundation (BMCF), an NGO working on HIV/AIDS in Kasese, reports a prevalence as high as 15.2% in 2003/2004. However, a report by UAC indicated a seroprevalence of 6.9% in the western region in the period of 2004-2005 (UAC 2006). Given the national trend of declining and stabilizing rates of infection, it is likely that the current prevalence of HIV is below the numbers presented.
The differences in statistics may be related to the various interests of stakeholders, but in any case there are several factors which allowed HIV/AIDS to firmly establish itself in Kasese. Instability played a key role, because from 1996 to 2001 the region suffered from conflict with the rebels of the Allied Democratic Forces (ADF) (Kasese District Local Government 2005). The Rwenzori mountains offered a convenient base from which attacks were carried out. The resulting large internal displacement affected the local economy by forcing farmers away from their land. Unfortunately, protection in the camps was inadequate and civilians continued to be attacked by rebels (Hovil & Werker 2005)\(^1\). The lack of social security and income generating activities provided opportunities for HIV/AIDS to spread, because these factors may force women to exchange sex for money (Internal Displacement Monitoring Centre 2007).

In the local government’s HIV/AIDS workplan several other factors are described as contributors to the HIV/AIDS epidemic. Commercial activities, such as KCCL, Hima cement and Kilembe mines, are considered to have caused an influx of polygamous men (Kasese District Local Government 2005). Furthermore, the fishing communities by the lakesides are dominated by men who are away from their families and who are said to consider drink and sex as a traditional reward for their hard work (Ibid). The district’s proximity to the DRC, and the resulting cross border trade, is also mentioned as a factor that increases the prevalence of HIV (Ibid).

**Service providers for HIV/AIDS care**

Kasese district has one district hospital and 63 health units (Kasese District 2008), supplemented by private facilities and NGOs. There are four larger clinics that provide VCT and ART. The government owned district hospital is located in Kilembe, about ten kilometres from Kasese town. Free HIV counseling and testing is offered in a separate building on the hospital’s premises and there is a separate HIV clinic for free treatment, about 200 meters up the road, which is clearly marked. In addition there are two other hospitals in the district, one in Kagando and one in Bwera, where VCT and ART are offered free of charge. However, these two centres were approximately 2 hours by car from Kasese town, so they were not as much within reach of FURA staff. St. Paul’s clinic, a private facility, is the main service provider in Kasese town. Like in Kilembe, VCT services were in a separate building. One of the counselors in St. Paul’s informed me that testing is offered for a fee of 1500 UGX (about €0,60). Antiretroviral treatment is free of charge, though a consultation fee is required. In both Kilembe and St. paul’s the VCT services were hard to miss, since there were signs indicating the services at the sites as well as in town (Fig. 5, 7 & 8).

Although VCT and ART are available in four health units in the district, FURA staff still perceived the provision of services as inadequate. Seven staff members indicated that the clinics sometimes suffer from shortages in drug supplies. Another problem is the accessibility of services.

\(^1\) For more information on the ADF conflict see Hovil & Werker 2005
Staff members told me that the mountainous areas are hard to reach and therefore lack sufficient healthcare services. This also has consequences for HIV prevention, since health units are an important provider of free condoms. In addition remote areas are seldom reached by information campaigns of NGOs and government. The smaller health units present in the rural areas usually don’t offer VCT or ART and there is a lack of qualified staff. This was illustrated when I went on a field visit to Kalibu Health Centre III, about two hours walking into the hills from Kilembe. The HC was quite big and relatively new, but due to a lack of staff most of the facilities were not operational. The HC would like to offer VCT, but two staff members told me that, although the lab equipment was present, reagents and a lab technician were not. Another problem for PLHA in Kasese district is to get a CD4 count, which is often required before ART can be started. Jackie, the FPP in FURA, explained that the nearest CD4 count machine is in Fort Portal, Kabarole district, approximately 2 hours by car from Kasese town.

Besides these health centers, which are owned by government, NGOs or private companies, there are a few NGOs in Kasese district that provide services related to HIV. One of the most important NGOs for PLHA in Uganda is TASO and there is a mini-TASO attached to Kilembe hospital. They provide ART, additional food and group counseling sessions for PLHA. These sessions are given by so called ‘expert patients’ who pass on information and give testimonies for groups. When visiting the HIV clinic I witnessed such an occasion. Approximately 35 people, 25 of them female, were surrounding a man who talked and interacted with them about other disease that may occur when you have HIV, like tuberculosis. In addition the National Community for Women Living with HIV/AIDS (NACWOLA), an organization by and for women who are HIV positive and their families, has an office in Kasese town. BMCF also assists PLHA, by providing education, counseling and assistance to get medication. Other organizations, such as Save the Children and CARE, are not focusing on HIV/AIDS as their core intervention area, but they mainstream HIV/AIDS in their programs.

5.2 Foundation for Urban and Rural Advancement

Organization background

FURA is a local, non-profit, humanitarian service and development organization that assists poor and disadvantaged communities with several programs, which are divided among the staff. The three major program areas, include ‘disaster preparedness and management’, ‘advocacy and human rights’ and ‘sustainable livelihoods’ (FURA 2006a). The organization is managed accordingly with three program officers, one for each field, who are assisted by a team of community based trainers (CBTs) and volunteers. In addition there is a program officer for research and documentation, and staff responsible for finance and administration (Fig. 10). The program officer for human rights doubled as FPP. She had been assigned this task only one month before the start of my research, after the first
FURA recognizes the effect of cross-cutting issues, like HIV/AIDS, gender and the environment, on their target groups, so these are integrated into all programs and activities (Ibid).

FURA’s office was based in Kasese town and the compound was shared with one family (Fig. 14). The office is surrounded by a small garden, which offered a popular site for staff to chat. Upon entering the office there’s a main hall where visitors are received, FCs are held and three project officers have their desks. From the main hall, a corridor leads to the back of the office, where the administrator’s small working chamber and the manager’s large office are located. There was a minimal number of chairs and one couch in the main hall, so on busy days it was common to see staff sharing a chair. The walls were covered with posters, many of them related to HIV/AIDS (Fig 15 & 16).

In spite of a continuous struggle for funds, FURA has managed to implement several projects over the years. The organization was founded in 1993 (FURA 2006a) by the current manager and a friend of his. By then, a lack of funds and staff severely limited its operational capacity. By 1998, however, some staff members had joined the organization and programs started running. In cooperation with the local government FURA responded to the ADF crisis (FURA 2006a). In the years that followed several other projects were implemented, most of them in partnership with Oxfam Novib, Save the Children and CARE, but collaboration with the local government remained important (Ibid). From 2001 onwards FURA assisted displaced people by providing trainings on HIV/AIDS and human rights (Ibid). The recent focus was on sustainable livelihoods through projects where communities were trained and supported to form Village Savings and Loans Associations (VSLA). These are autonomous groups of 15-30 participants who weekly save a small amount of money, which is kept as a fund from which group members can borrow against a predetermined interest rate (Fig. 12 & 13). When I was visiting FURA the last of these projects, in Bwera, had just been completed. Furthermore the organization assisted the local government by making an assessment in a camp for internally displaced people (IDP). This camp was the result of a conflict between Bakonzo cultivators...
and resettled Basongora Pastoralists in Kasese district. Notably, the WPP for HIV/AIDS and FURA’s role as a lead organization in the region were also considered to be a core activity of the organization. Alvin remarked: ‘the only project we now have is the SAN! project which has only one staff, the FPP’

Human resource management

FURA has an extensive Human Resource Management manual (FURA 2002), which was issued in 2002 and has not been revised since. I will describe a few key points of the document, with regard to health, job security and salaries, and relate them to my experiences in FURA.

Several provisions in case of illness of employees or their families are described. When an employee falls ill, he is entitled to continued salary for three months and half payment for an additional three months. After six months of sick leave the contract can be terminated. The document states that there are no medical facilities, but special arrangements shall be made for an employee, their spouse and four biological children. I was also informed about a HIV related support fund, derived from excess money from projects and a small part of the staff’s salary. It was used for example to support a child, who is a relative of one of the staff and lost its father. In addition, the management told me that they were in the process of getting health insurance for employees and three dependants, a facility that Oxfam Novib was going to fund.

Overall, staff informed me that the social security of employees has improved over the years. Mark told me: ‘Before everyone was on contract basis, but now at least there are some people who are there even when there is no project running, we have some fixed staff.’ Furthermore, since approximately three years, FURA encourages payment through the bank, so that staff can easily get loans. Because of the organization’s growing experience, they no longer have to depend on funds only, but they can also earn money by doing consultancy work.

In spite of these positive changes continuity of salaries is still a problem. Five out of the seven fixed staff members specifically indicated this problem. During the time of my visit there were no projects running and although these people had a contract, there was simply no money to pay them, so they received only allowances, while other staff had become volunteers. Charles explained “NGOs don’t have enough until you put up income generating activities” and Solomon added that even when there are projects running, getting enough money can be difficult. “When you write a proposal you have to mention the contribution of the organization, so an organization will say we have staff and we will contribute to the salary, for example 50%, but in practice that means the staff is cut.”

Daily Routine

In FURA office hours and a daily program were fixed, but staff did not always comply to the schedule. A day in office usually starts at 8am when the office attendant comes in to clean and prepare tea. By 8.30am all staff should be present to attend the daily morning discussions, called Foundation Courses (FCs). The FC is facilitated by one member of staff and covers a wide range of topics, including
conflict, domestic violence, HIV/AIDS and experiences from the field. These 30 minute- to one hour discussions were held approximately three times per week, depending on the time available and staff present. Turn up for the FC was usually low, at some occasions there would only be three people present, including one student and the office attendant, but on other days there could be a lively discussion with eight people. Staff also came in during the FC or later in the morning. As Roger explained, this was due to the fact that there were no projects running. In better days, staff would be in office at 8am sharp in order to go directly to the field after the FC. Lunchtime started around 1pm and the office closes until 2pm. During this time some staff go home, while others take lunch in town together. In the afternoon staff gradually drop in to continue with their work and the office closes around 5pm. During the weekend the office is also closed.

At the time of my visit the work of FURA revolved mainly around finding funds to start new projects. The senior management spent most of its time on meetings with partner organizations, attending trainings and administrative work. The project officers would write new project proposals and some of them also attended trainings, but usually they were in office only for part of the day. Solomon linked this to the fact that staff received no salary: ‘so long as there is no proper remuneration, people will always move up and down’. The other members of the staff were sometimes in office to assist the project officers with proposal writing or just to hang around, chat or read newspapers. The reason for volunteers to be around even when there is no work may be related to general job scarcity. Thomas said he would like to have a fixed contract with a NGO, but such a position is hard to get. Therefore he sticks around in FURA, hoping for a job opportunity to arise.

However, when there is fieldwork to be done, office hours and lunchtime are of little importance, as I experienced on a few occasions. In April FURA was asked to assist the local government with a needs assessment in an IDP camp in the district. Although FURA would not receive any money for their work, a project officer and the manager of FURA joined the team and spent the whole Saturday talking to people in and around the camp. “Because it is in our mandate”, the manager explained. Furthermore, when I joined Dan, one of the CBTs, on a fieldtrip to Mahango to visit a VSLA group, lunch had to be delayed to 4pm when we finally reached Kasese town. Dan explained that this is one of the challenges of fieldwork, since there are no restaurants to take lunch in the remote area where he works.

Organization culture
When reading through FURA’s documents, some key principles stand out. Their human resource manual mentions, teamwork, commitment and voluntarism as core values (FURA 2002). In FURA’s strategic plan, accountability, volunteerism and teamwork are valued as the three guiding principles (FURA 2006a) and these are also mentioned in project proposals (FURA 2008). Naturally, these are good guidelines, but how do they work out in practice?
Overall I have found the atmosphere among FURA staff in office quite encouraging to work as a team. The way people interact with each other was generally friendly and supportive and during morning discussions people did not fear to give their opinions or share experiences. It was also a common sight to see staff sharing a chair when there were many people in office and staff would often sit together behind the computer to work on a proposal.

On the other hand, there were some challenges for teamwork. First, the CBTs are based in the field and often work alone, so they are less likely to benefit from team spirit. Second, my view is that the way the organization was managed was not stimulating teamwork. The manager has the final responsibility on all of the work; his signature has to be under any official document. This may have been the reason why staff did not seem to feel responsible for tasks assigned to them and little work was done when the manager was not around. Furthermore, Alvin shared with me that it would be difficult for anybody else to run the organization, first because of the contacts the manager had made and second because no one else in the organization has the commitment to do it.

Commitment was another core value, but motivating staff was difficult because of a shortage of funds and a lack of clear guidance. Charles told me: ‘There are staff who are not committed when there is no cash’. And during an FC about motivation, the discussion mainly revolved around rewards, in terms of salary and allowances. The fact that no salaries were paid during the time of my visit thus provides an explanation for the fact that staff were often late for work, or not coming at all, and their lack of efficiency when they did attend the workplace. However, staff showed a strong sense of commitment when there was fieldwork to be done, as I described earlier under ‘daily routine’.

Introduction and implementation of the WPP
The WPP in FURA was developed as a participatory process involving both the organization and the SAN! project. Development started around the beginning of 2006 by a committee of a few staff members, mainly senior staff and the CEO, under guidance of the FPP, who was sent to FURA from Kampala by the SAN! project. Anton recalled that they felt HIV should be addressed, because of the past war and the risk that people had been a victim of forced sex. David mentioned accidents as a potential way of infecting staff when they would go on fieldwork. The manager also emphasized that there needed to be more awareness among the staff. In developing the WPP, FURA recognized that the policy should be for staff and relatives. Roger explained: ‘if someone in the family is sick, automatically it will affect me and my work’. Eventually the main themes that were addressed in the document are stigma and discrimination, confidentiality, no compulsory screening on HIV, education, communication, gender, providing a safe work environment and finally care and support, which is supposed to comprise medical insurance for staff and three dependants (FURA 2006b).

The WPP in FURA is a stand alone policy, but the organization intends to integrate it into their general human resource policy. It was presented to the other staff members by the FPP and discussed. Everyone could access a copy of the document in the office and it was put on the wall for
everyone to read. During the time of my visit, however, the WPP was no longer on the wall, but a hard copy was available in office and the document could also be accessed on the computers. However, most of the staff heard about the policy during general discussions. Susan explained:

‘She [the former FPP] never talked to me individually, but I was hearing of it as an organization and it was actually the chief [the manager] who emphasized that we should all read the WPP, so those who were interested were reading, some neglected it, but I have read it, copies are at the office’.

Some elements of the WPP had already been implemented, while other aspects required more funding. Increased communication was a commonly mentioned effect, as will be described further in chapter 6, and I experienced several discussions related to HIV/AIDS. In addition, numerous educational posters on HIV/AIDS covered the office walls and a safe work environment was realized by having a first aid kit and condoms in the toilets. Gender inequality did not appear to be a problem at the workplace, for both male and female staff were free to express their opinions during discussions. However, FURA was still awaiting additional funds to provide medical insurance, so the WPP had not yet added to the provisions for illness that are set out in the human resource manual.

With regard to the way people see the WPP, staff were not completely convinced of the benefits. It appeared that staff who had joined the organization recently had a less positive attitude towards the WPP, for two staff members who had joined recently mentioned they did not see any benefits for themselves. Overall, several staff members described that it is difficult to get everyone involved. Alvin explained: ‘Because the FPP is the only one receiving money from the project, the other staff don’t mind about it so much’. Furthermore, in eight of my interviews, staff mentioned lack of funding as a severe constraint, to an extend that some people felt that the whole policy was not yet operational. Kabale illustrated the relative importance staff attributed to the part of care and support: ‘The WPP is there but not operational, because we have no funds. We need them for a medical scheme for staff and dependents, for HIV and other diseases’.

Another interesting issue was that staff generally considered the WPP not only as a means to achieve internal mainstreaming, but also external mainstreaming, or even as a program to deliver services related to HIV, such as VCT. Since the focus of the SAN! project is more on internal mainstreaming, this view led to many recommendations for improvement. Charles said: ‘we need more resources to make the program very full fledged, so that as we do something in the workplace we can also do it in the community’. Other staff members expressed their wish to improve the WPP by looking at how it could also benefit the communities, their neighbors and relatives.
5.3 Soroti district

Demographic characteristics

Soroti is located in the mid-eastern part of Uganda. It covers an area of 2,662 sq km of which 406 sq km is water (Soroti District 2008) (Fig.3). As opposed to Kasese, Soroti is a very flat region, containing large stretches of swamp. Soroti district used to be larger, containing also the areas of Kaberamaido and Katakwi, but these two districts were recently carved out of Soroti. The population of approximately 372,000 people consists mainly of Iteso and Kumam tribes, but traditionally, other tribes have co-existed, including Baganda, Bakenyi and Bahima cattle keepers.

The majority of the population depends on agriculture for food and income. The livestock industry was once booming, but suffered from cattle rustling by the neighboring Karamojong, a lack of infrastructure for cattle markets and a high prevalence of disease among livestock (Ibid).

HIV/AIDS in Soroti

In Soroti long lasting instability and lack of income and food may have offered fertile grounds for HIV to establish itself in the area, but the situation seemed to be improving. According to a report by UAC seroprevalence in the north eastern region of Uganda is 3.5% in the period of 2004-2005 (UAC 2006). However according to William, manager of Soroti Network of AIDS Service Organizations (SONASO), the current percentage in the region is 6.8% and he expressed his concern that HIV was on the rise again. Although reliable figures may be lacking, the presence of HIV in the region was incontestable, for example when large numbers of patients came to the premises of HNU for food distribution by TASO (Fig.19). William described the long lasting conflict with the Karamojong as a contributory factor to HIV/AIDS in the region. Traditionally, cattle raiding was a semi-tolerated means of survival for Karamojong tribes (Jabs 2007). However, access to modern weapons, from the 1970’s onwards, multiplied the number of people affected and levels of destruction escalated (Ibid). This has driven people away from their land, their source of food and income, into IDP camps, of which numerous can be found, particularly in Katakwi district (Fig.17). The problem of food shortages may have been aggravated by recent floods, which made the camps difficult to reach for some time. The lack of income generating activities in IDP camps created circumstances that may have encouraged transactional sex, thereby increasing people’s risk to contract HIV/AIDS. However, safety in the region has increased and resettlement is encouraged. When I visited an IDP camp during daytime, it was rather deserted, because most people had gone to the fields where they started cultivating again.

Service providers for HIV/AIDS care
Soroti has a regional referral hospital located within the municipality, which is an important provider of HIV/AIDS related services. In this hospital, services for HIV/AIDS are not separated, like they were in the hospitals I visited in Kasese. HIV counseling and testing can be done in every department, but is mainly offered in antenatal care, the department for STI, HIV and family planning, and the outpatient clinic. In antenatal care RCT is offered to pregnant women and, according to the nurse on duty, about 35-45% bring along their partners for testing. Women are tested early in pregnancy and again after three months. When they test positive ‘Prevention of Mother to Child Transmission’ (PMTCT) services are offered in cooperation with TASO, who provides the drugs. The STI clinic mainly receives patients who have been referred by JCRC or the outpatient clinic. They offer VCT on Tuesdays, but patients come here mainly for treatment and health education. Patients who come for treatment of an STI also receive RCT. At the outpatient clinic people can be tested daily. The hospital does not provide ART, so when people test positive they are referred to TASO or Uganda Cares.

Besides the main hospital there are 21 other health facilities distributed in the sub-counties (Soroti district 2008), which offer limited services for HIV/AIDS. During my stay in Soroti I had the opportunity to visit three HCs; two of them were of grade III and one of grade II. The HC II had little to offer for PLHA besides counseling. In the HCs III septrin\(^2\) was available and testing was offered. However, at the time of my visit one HC III had run out of test kits completely, while the other had test kits available for pregnant women only. This means that many people would have to travel for long distances to be able to take a HIV test.

In Soroti international donors and NGOs played an important part in the provision of health care and HIV/AIDS related services in particular. First, donor support accounts for 90% of the total funding of Soroti’s health sector, while only 10% is contributed by the local administration (Soroti district 2008). Second there were numerous NGOs active in the field of HIV/AIDS, including HNU. There was even an organization set up for coordination of all the NGOs working on HIV/AIDS in the region called SONASO. I will not provide a complete record here of all, but I have been able to visit the main providers of HIV/AIDS services. The AIC, to begin with, has a neat office just outside the centre of town where VCT is offered for a fee of 2500 UGX (about €1). Another important player in the field is TASO. The organization is located on the main hospital’s premises, its bright new building in sharp contrast with the hospital’s slightly rundown appearance. ‘Primary testing’ is not performed, but when patients are referred, TASO tests again to confirm the results. After testing positive anyone can become a client of TASO, after which they can receive ART, treatment for opportunistic infections and counseling. All services are free of charge due to funds provided by many donors, including the United States Agency for International Development (USAID) and the centers for Prevention and Disease control (CDC). Uganda Cares also offers ART and treatment for opportunistic infections.

\(^2\) Septrin is the brand name of co-trimoxazol, an antibiotic that is recommended for usage in HIV positive patients in resource limited settings to prevent opportunistic infections.

(http://www.who.int/hiv/pub/guidelines/ctxguidelines.pdf) 27-11-2008
infection for everyone who can prove they are HIV positive, and they also have the means to do a CD4 count, all free of charge. One of their medical staff explained that patients only have to pay for transport costs. Treatment costs only come in on the rare occasions that Uganda Cares runs out of supplies, but she assured me that this hardly ever happens.

When I questioned HNU staff about the health services for HIV/AIDS they expressed some criticism. According to Alex, VCT is only offered in the hospital on specific times: ‘you cannot go any time, in Soroti [hospital] they focus on the ones who are pregnant, those who go for antenatal, so it’s a bit difficult [to come for VCT], it takes time, they refer you again to AIC’. Didas commented on the poor support mechanisms after testing.

It’s like any service, it is very poor, because there is a small team of health workers that cannot provide effective counseling, we have a poor follow up system, so you'll find that you might develop a team of desperate people among the community that are not well supported with counseling.’

The problem of staffing gaps was also mentioned in the information of the local government (Soroti district 2008). With regard to testing services in the rural areas, field-based staff of HNU said that some areas are not reached by VCT services and that the HCs often run short of test kits.

5.4 Health Need Uganda

Organization Background

HNU is a national civil society organization that evolved continuously over the years. The organization was formed in 1997 out of HealthNet International, a Dutch NGO, and it implements health development programs in Soroti, Kaberamaido and Katakwi Districts (HNU 2005). I was informed by a senior staff member that the organization evolved from hiring consultants to do most of the work, to becoming increasingly independent, dividing responsibilities among the staff. With regard to their programs, the work had changed over time from providing HIV/AIDS care to the communities directly to linking clients to existing services. Therefore, cooperation with the local government has become more important. In line with this, the organization constructed two new field offices in the neighboring districts of Kaberamaido and Katakwi. These offices have been operational for about one year and their main purpose was to be in closer proximity to the local government, while at the same time cutting transport costs of the staff. At

![Fig. 11 Organization structure of HNU (Adapted from HNU 2005)](image-url)
the time of my research there were two project officers based in Kaberamaido and one in Katakwi. The other staff members were based in Soroti, bringing the number of staff working for HNU to 15 (Fig.11). In addition the project officers are assisted by community Focal point Persons (cFPPs). These people are part time employees who are based in the community and help in mobilization and sensitization of the community and data collection.

The main office of HNU is located on a spacious compound just outside the center of Soroti town. The large mango tree in front is a popular source of refreshment among the staff and there is plenty of space to sit outside. Inside the walls are covered with posters of projects and educational material on HIV/AIDS (Fig. 20 & 21). Most of the staff in office have their own desk, and the manager, administrator and project coordinator even have a private room. The office also comprises a kitchen, an entrance room, where the secretary has her desk, and a central hall with a large table, which is used for taking tea and lunch.

Health Need Uganda has four different program areas, but their focus was mainly on HIV/AIDS. The program areas are: “HIV/AIDS, malaria and reproductive health”, “food security and nutrition”, “water and environmental health” and “Human rights promotion”. I have been able to see them working on several projects related to these areas. First of all there was an ‘Integrated HIV/AIDS program’ funded by ICCO (HNU 2007). Project officers visited PLHA groups and educated them on issues like septrin usage or condoms. Furthermore they discussed with them how they could benefit the most from the financial support offered for income generating activities. In addition, HNU was running a project on Health and Nutrition, funded by UNICEF, in Kaberamaido district. Health Need Uganda was active in training VHT members about nutrition, so they could pass on this knowledge to the community. Furthermore drama groups had been trained to perform plays about health, nutrition and the role of the VHT. Drama performances were also an important means to disseminate information in the third large project on HIV and Human Rights in Katakwi district, funded by Dan Church Aid. I witnessed an impressive show during a conference that was part of this project. The actors traveled long distances with no means of transport besides their own legs, while many of them were HIV positive. They presented the story of a widow, whose husband had died of HIV/AIDS and consequently her family in law chased her and took all her possessions. The play was very informative on where to seek assistance when a person’s rights are violated, and it attracted a large crowd of people who received it with great enthusiasm (Fig.18).

**Human resource management**

HNU is guided by an extensive Personnel and financial policy manual (HNU 2005), which is very detailed on a large number of issues. However, I will limit my description to some key points, with regard to working conditions, health and facilitation of saving, and relate them to my experiences in HNU.
Staff are expected to be committed to the work, which is regularly evaluated. New employees initially serve on probationary terms for a maximum period of four months, after which they can get a contract on project basis or as headquarter staff. The first depends on project duration and funding, while the latter is subject to annual appraisal. This was a practice that staff were facing with some uneasiness. Although people were relatively sure they would not lose their jobs, the possibility of getting a negative assessment made them nervous. The policy manual states that senior staff are expected to work beyond official working hours, which was a common practice for several staff members, including the drivers who often made very long days when there was fieldwork to be done.

Like in FURA, HNU had some provisions for illness among staff and their family, including a specific section on HIV/AIDS. Staff are entitled to sick leave with up to three months payment, followed by another three months on 50% of payment. After six months they will cease to be an employee, but are entitled to an additional three months on 50% of payment. In case of illness or death of family members staff can get compassionate leave and the organization also contributes to burial costs of staff and their immediate family members. Furthermore, the organization committed itself to assisting staff in the payment of medical bills. This used to be arranged by deducting 30,000UGX (about €12) per month from each staff’s salary to build a fund that was used to pay medical expenses. However, since this year the 30,000UGX has become part of the salary and staff now have to manage their own medical bills. Not everyone was happy with this arrangement, because, as Moses and Marianne told me, medical care can be expensive and you don’t always have cash in hand. There is also a short section on HIV/AIDS at the workplace, which states that ‘When staff declare their sero-status, the organization will assist them to be attached to a HIV/AIDS centre for assistance. Sensitization at work place will be effected.’ (HNU 2005). The FPP informed me that this part was added after formulation of the WPP for HIV/AIDS.

HNU facilitates saving in two ways. I was informed by the administrator that there is a staff saving scheme, for which every month 10% of each person’s salary is put in an account. Therefore, staff is obliged to save, but in the end they can use the money for anything they want. The manager explained to me that staff are also enrolled in Uganda’s pension fund, the National Social Security Fund (NSSF), for which the organization pays 10% and the staff themselves 5% of each person’s salary.

**Daily routine**

Daily routines are relatively fixed in HNU and staff are well catered for in the office. Officially the day starts at 8.00 am and most of the staff come in between 8.00 am and 8.30 am. Monday mornings are reserved for staff meetings if there are issues to be discussed, which I only experienced once, and Friday afternoons for discussions or videoshows about HIV/AIDS. After greeting the other staff members people immediately start working, either on writing reports or preparing to go to the field. Tea is prepared by the office attendant and is usually ready at 10.30 am. Some staff join at the table in
the central hall, while others take it at their desks. People used to go home for lunch, but since approximately one year it is provided by the organization and brought to the office around 13.30 am. For this occasion, unless they had a very heavy workload, most people were ready to leave their desks to sit at the table, or outside in the courtyard, and share stories. After lunch, work normally continued up to 5.00 or 5.30 pm.

A typical day of fieldwork usually meant making long hours. Staff would first come to office to prepare, after which they would set off with one of the drivers. Most of the time, fieldwork consisted of meeting groups of PLHA or community leaders to evaluate group activities, give advise or information and discuss. A lunch allowance was always given to staff before they went on fieldwork, but time was often a constraining factor and I experienced on several occasions that lunch was skipped completely. A day in the field often went beyond office hours and coming back between 6.00 and 7.00 pm was not unusual.

I also spent a couple of days in Kaberamaido field office and I will describe the way staff worked there. Two project officers were based in Kaberamaido. One of them always kept the office, while working on reports, so that the other could go on fieldwork. To reach the project sites, staff had to ride for up to 2 hours on a motorcycle, although some projects were more in the vicinity of the office. An important part of the work in field offices was also to keep close contact with the local government. Therefore, one of the project officers also went to the field one day with a team of government officials to show them the work of HNU.

Organization culture
What can be read clearly from the above is that staff were very committed to their jobs. They tried to use office hours efficiently and did not mind about skipping lunch or making a long day. I believe this attitude was encouraged by the fact that responsibilities were well divided among the staff. It was not the manager who had the final word on everything, but everyone had their tasks and influence within the organization. I believe this has helped to build mutual respect between management and staff.

The atmosphere in office was generally friendly, though there was some gossip. Daisy described that the good thing about HNU was that you could always leave valuable things in office. No one would take it, because the organization is not too big and people are like family. I also experienced that staff tried to make me feel at home in their organization. In my opinion, the fact that staff always take lunch together and an annual joint trip contribute to a pleasant atmosphere among staff. On the other hand I did experience some occasional gossip about other staff and Moses told me there’s a lot of talking about others going on.

Introduction and implementation of the WPP
Before the SAN! project came in the concept of a WPP was not well known and there was nothing like it in place, but several of my informants described that the concern, of what can be done about HIV for
the staff, was already there. Morine described that people already discussed about HIV/AIDS at workplace and Didas told me that the project started both because of initiative on the side of the donor and because of the local need, for the organization had experience with cases of HIV among the staff. According to Rose it was difficult for HIV positive staff to disclose within the organization before the WPP and Didas added to this that people did not see the role the organization could play to support them or their family members. One of the drivers emphasized there was a need to have a safe work environment, for example by having a first aid box in office and in the cars.

Health Need Uganda was very active in the SAN! project from the start. They were part of the LPG and after decentralization HNU became a lead organization. The motivation of HNU may have come from their experience of working with PLHA in the community. Rose explained: ‘It has helped so much that we’ve dealt with other people before. So when the policy came it just fitted’. Furthermore staff may have been motivated by their hands-on experience at the workplace.

The development of the HIV/AIDS WPP started in the beginning of 2006 and was initiated by the SAN! project, after which the FPP continued to spearhead development and implementation in cooperation with the other staff. Spencer Birungi, project coordinator in Uganda, introduced the concept of the WPP in a workshop for participating NGOs. After that, a FPP was appointed by the staff of HNU and the organization started with discussions on Friday afternoons. Marianne recalled ‘During the very first meetings we had, we were discussing the WPP, what we should include because it had to be a shared thing.’ Christine said ‘the person who developed the WPP went round, asking for ideas from everyone, so I strongly believe I was involved in the development of the WPP.’ The organization did not want the WPP to be a separate program, so after developing the document, some of the issues were also put in the general human resource manual.

All of the staff was aware of the WPP, with the exception of the cFPPs. Two staff members mentioned having their own copy and Morine told me that the FPP is very accessible. ‘She is really available with the information about the WPP, documents, books, they are really available’. However the cFPPs seemed to be much less informed about the WPP. None of the 4 cFPPs I talked to were familiar with the policy. The FPP explained to me that these people, as well as the board members, are officially not part of the WPP.

In the WPP several topics are addressed, but staff had mixed feelings about the effects. The WPP mainly focuses on non-discrimination, gender equality, creating a healthy work environment, encouraging social dialogue between management and staff, confidentiality and care and support for staff and three dependants (HNU 2006). In practice the issue of care and support is catered for by Uganda Cares, with whom HNU has a good working relationship, so staff and their relatives will be helped quicker. The fact that staff now recognize the role the organization can play to assist them was considered a main achievement of the WPP by Didas and Rose. Other major effects of the WPP mentioned by staff were the condoms and first aid kit in office, the availability of information related to HIV/AIDS, increased discussions at workplace about topics related to HIV and encouraging people
to test and to open up. I could also observe most of these effects in office, for example in the HIV/AIDS corner (Fig. 21) and during Friday afternoon discussions, as will be described further in chapter 6. However a few staff members expressed their disappointment about the WPP, because they felt that it had not created enough openness for people to really feel free about disclosing. Discussions at workplace had been limited due to time constraints and it was not always possible for staff to attend, especially for those based in the field offices. Furthermore, Moses said he had expected the health insurance to improve and Alex told me that people were generally disappointed by the lack of financial support for health care. According to the management, providing health insurance is too expensive, the costs are approximately 320,000 UGX (€128) per person per year, and donors usually don’t commit themselves to funding for longer periods of time. Funding should be secured for a period of about five years for such a program to be sustainable, but most donors commit themselves for only one to three years. Therefore the organization kept its old system.

5.5 Discussion

In both Soroti and Kasese district, conflicts that may have fuelled the HIV/AIDS epidemic in the past have been resolved and the health services available can support the HIV/AIDS WPPs. For FURA staff, health services are within reach, although they need to pay either a small fee at the clinic in Kasese town, or transport to Kilembe hospital, where TASO is based as well. In Soroti, there is an abundance of HIV service providers, due to the vast number of NGOs that work there. Free testing and ART are thus well within reach of HNU staff. However, in both areas, services in the communities are still limited, due to a lack of manpower and supplies.

While FURA struggled for funds to run projects, HNU was able to secure funds and implement programs. As an organization, FURA focuses on community development, but at the time of my research their activities were severely limited by a lack of funds. This affected their human resource management, because there was no money to pay the staff or to sustain the HIV/AIDS support fund. Furthermore, during a day in office, turn up of staff was low, especially in the morning, so that daily FCs could not always take place. This was probably related to a lack of work and salaries, but also to a lack of guidance from the management. The program areas of HNU focus on HIV/AIDS and their activities are targeted towards community participation and linking clients to existing health services. Staff members are committed to their jobs, possibly because responsibilities are well divided among the staff. In addition, HNU contributes to medical expenses and facilitates saving.

In both organizations developing the WPP had been a participatory process in cooperation with the SAN! project and both organizations had become lead organizations for their region. In HNU, experiences with PLHA in the community and at workplace may have motivated them to take on this task. What stood out in FURA was that senior staff, who had participated in the development of the WPP, seemed to have a more positive attitude towards the policy.
In FURA, as well as HNU, staff focused on the aspect of medical insurance when they talked about the WPP. Although other effects, such as condoms in office and increased discussion had been realized, staff were disappointed by the lack of financial benefits and in FURA staff even described the WPP as not operational. The focus on financial aspects also made FURA staff look at the WPP as the FPP’s business, for she was the only one who received salary. Furthermore, staff members of FURA considered the WPP, and their role as a lead organization, as a program for internal and external mainstreaming, so they wanted more funds to extend activities to the community.
FURA and its projects

Fig. 12 (top left) Meeting of VSLA in Mahango, Kasese district. The group is completely autonomous and has its own chairman and treasurer.

Fig. 13 (top right) Savings book. The amount of money saved is represented by stars, so that people who are illiterate are also able to keep track of their savings.

Fig. 14 (right) FURA’s office

Fig. 15 (bottom left) Poster against discrimination in FURA’s office.

Fig. 16 (bottom right) Staff member presenting the FC.
**HNU and its projects**

Fig. 17 (top left) Life in an IDP camp. The close proximity of the houses to each other is characteristic in the appearance of these camps.

Fig. 18 (top right) Crowd watching a play on HIV and Human Rights.

Fig. 19 (right) HIV patients on the compound of HNU, waiting for food distribution by TASO.

Fig. 20 (bottom left) Poster on HIV/AIDS in HNU’s office.

Fig. 21 (bottom right) HIV/AIDS corner in HNU’s office.
6. COMMUNICATION AND STIGMA

6.1 Communication in society and at the workplace

Before discussing stigma in paragraph 6.2, I will elaborate on HIV/AIDS related messages and how they are communicated in various settings in Ugandan society. I start with this topic for two reasons. First, as I described in chapter 3, stigma occurs in a social context that defines an attribute as devaluing (Crocker et al. 1998, in Yang et al. 2007). By describing communication about HIV/AIDS in Ugandan society and in the workplace I will provide insight into this social context. Second, I discussed in chapter 3 that talking about HIV/AIDS within social networks can reduce stigma (Hutchinson et al. 2007b). Therefore it is important to discuss communication about HIV/AIDS in order to understand the effects of the WPP on stigma reduction. I will start with a discussion of communication about HIV/AIDS in society, whereby I will distinguish between different age groups, followed by a description of communication on HIV/AIDS at workplace in FURA and HNU.

Communication in society

There is an abundance of information on HIV/AIDS in Uganda, which is disseminated through various channels. On my very first day in Kampala I faced a giant billboard showing an elderly looking man with the following message: ‘Would you let your teenage daughter be with him? Then why are you with his? Cross generational sex stops with you.’ In Soroti a sign by the road said ‘Take caution AIDS is still a problem’ (Fig. 23) and advertisements promoting ART could be spotted frequently (Fig. 6). Schools also made an effort to educate their pupils, as can be concluded from the appearance of a primary school, which had texts related to HIV/AIDS painted all over (Fig. 24 & 25). These included messages such as ‘Abstinence keeps you free from HIV/AIDS’ and warnings against going to bars and taking drugs and alcohol (Fig. 24 & 25). Children were also warned by their parents. Kabale shared with me how he talked to his children who were in primary school. ‘They are still young, but I already tell them, if you misbehave you might get it and you will die’. Furthermore the newspapers reported on the epidemic on an almost daily basis. For instance on president Museveni’s latest viewpoints: ‘Museveni criticizes condom promotion. Those were meant for prostitutes.’ (Daily Monitor 18-3-2008) (See textbox 1).

According to staff members in both NGOs, sensitization through all these different channels had made an important contribution to increased openness to talk about HIV/AIDS in society. Geoffrey, one of the project officers in HNU, shared his experience that people in the communities came to him asking for condoms. Other staff members in each organization told me that they were free to discuss topics like prevention, testing and transmission among friends. Steven, who had become a volunteer in FURA after his work as a CBT ended, said: ‘When you are chatting with someone you
just end up talking about HIV.’ I also noticed this with my neighbors, who had no problem to discuss HIV/AIDS with me and were eager to share ideas on transmission and prevention.

\[\text{Textbox 1}\]

Shaping thoughts

It was interesting to see how messages formed at a higher level returned in my conversations with staff and others. One evening I was talking with a friend about HIV prevention. He had a strong belief in the widely promoted ABC model, putting Abstinence first and second, after marriage, Being faithful. He saw condoms as a last resort, but then you would be a ‘terrible person’. Thereby clearly reflecting Museveni’s critics on this type of protection. The rationale that condoms are used mainly by those who cheat on their partner, which does not do much good for the image of the condom. David also said that people feel shy to buy condoms, because ‘even for partners who are married, people perceive you are going for another person.’ On the other hand, some people were not as concerned about Museveni’s critics and had a more liberal view. Flora said that Museveni only made such a statement because he’s a married man, but when you are not married it is a different story, because then using condoms is not as much associated with cheating. Another example of the way thoughts are shaped came from Alvin’s remark that some tribes are unable to enjoy sex when they use a condom. This statement also appeared to be a reflection of Museveni’s words, because during the XVth international AIDS conference on HIV/AIDS he stated: ‘People assume that all people have sex in the same way.. Condoms may be all right in some varieties, but in other varieties it’s quite a hindrance, and I’m sure these Africans know what I’m talking about’ (Kaiser Network 2004 in: Kinsman 2008:112)

At first sight HIV/AIDS thus seems to be a topic that can be discussed openly, but sexuality, which is closely related to the subject and a major cause of HIV/AIDS related stigma, is not talked about as easily, especially among young people. What stands out from the discussion above is that most messages contain warnings and focus on abstinence. Kabale’s warning to his children is a case in point. Misbehavior is said to cause HIV/AIDS, thereby associating HIV with immoral behavior, and the warning clearly implies that HIV infection is a death sentence. Messages spread through the media also seem to influence people’s thinking, as I discussed in textbox 1. While creating an open environment to discuss basic facts about HIV/AIDS prevention and transmission, most messages reinforce the taboo on ‘immoral’ sexuality. This is especially true for the youth. Through conversations with staff members in both organizations I learned that the law in Uganda is not at all tolerant towards sexual relations among teenagers. When you are under 18 in Uganda sex is considered as defilement, a criminal offence, but usually charges are only pressed when the girl becomes pregnant. The emphasis of any sex education for youth therefore lies on promoting abstinence. Health Need Uganda, for example, used to have a program in schools in which a contract with the youth was made stating that they would keep their virginity until marriage (Fig. 22). The law also corresponds to the strong Christian norms in the country that condemn sex before marriage. One of the young women I talked to said she felt as if she was a bad person in the eyes of the church for not having kept her virginity until marriage. Culturally sex education within the family is also a taboo topic. Even having a boyfriend is something that parents should not know about, let alone having them to sleep over. ‘They will cut your throat’ was the comment of a staff member when we talked about
such a situation. He explained to me that girls can only have a boyfriend openly when there are plans to get married. That is the time when you can ‘go for introduction’.³

Talking about HIV/AIDS at the workplace
In both FURA and HNU, staff reported increased communication about HIV/AIDS at the workplace as a core result of the WPP. In FURA, daily FCs formed a convenient platform for discussion, while HNU had reserved Friday afternoons to talk about HIV/AIDS. Topics of discussion that were most frequently mentioned among FURA staff were transmission, prevention, and stigma, while HNU staff members reportedly discussed mainly about testing, prevention and stigma. Positive comments were made about the influence of the WPP. Kabale, for example, told me: ‘Before the WPP staff feared to discuss HIV, but after the policy discussing it at workplace became free.’ Staff members of FURA reported that discussions at the workplace also had a spill over effect to their family and the community. David described: ‘When you are not hungry you will not think of eating, so when it was on radio it was as if it was some other people’s business. But now that it has come into our system, in our workplace, we have just picked it and we also have the responsibility to communicate it.’ As I described above, a trend towards increased openness about HIV/AIDS was also manifest in society at large, which probably complemented the effects of the WPP.

In both organizations I have been able to witness organized discussions about HIV/AIDS at the workplace. During my visit to FURA I was present at FCs about the following topics: ‘how would you feel after testing positive’, ‘HIV progression’, ‘domestic violence’, ‘discordant couples’, ‘VCT versus RCT’ and ‘HIV/AIDS stigma’, the latter two being organized by me. The discussion about the first topic did not run very well, possibly because of my presence for the very first time or the personal nature of the subject, but during the other discussions people were free to talk about HIV. I was pleasantly surprised by the high levels of knowledge among NGO staff when they talked about HIV progression and during the FC about domestic violence sexuality was an issue that could also be discussed. In HNU I observed one Friday afternoon video-show on basic facts of HIV testing. The material was in Ateso, the local language, so the guard was also able to participate. However, staff members found the video too simple, because most of the information was already known to them, and they did not discuss the subject further at that time.

In addition to organized discussions, staff also reported increased informal conversations about HIV/AIDS among colleagues. In HNU Morinea gave an example of how the WPP opened up the environment to joke about condoms. ‘The condoms, that box in the toilet, the rate goes and sometimes we even make fun with the FPP. When the rate does not go, she asks ‘what happens? These things have not gone, what’s wrong?’ Staff of HNU attributed the increased openness to the information and

³ This expression was commonly used throughout Uganda to indicate the moment when a boy goes to the parents of his girlfriend to introduce himself. At this time, the young couple will also present their intention to get married.
education people receive under the WPP and Didas added that the atmosphere in HNU is also encouraging for people to talk freely.

In spite of the increased openness, there were some constraints with regard to communication about HIV/AIDS among NGO staff. In FURA, the effect of FCs was limited due to the fact that many staff members were not yet in office in the morning. I also found that it could be difficult to involve everyone and get people’s attention. This may have been related to the general atmosphere of limited motivation in the organization, as I described in chapter 4, or perhaps people had already discussed about HIV very often and were therefore losing interest. Furthermore some staff members remarked that the former FPP’s character was not encouraging for open discussions, thereby further compromising the effect of the WPP. In HNU there were different constraints and lack of time was the most obvious one combined with a lack of effort when the FPP was not around. The FPP also explained that it was difficult to find suitable material for videoshows. I experienced how this problem caused the failure of one Friday discussion, because the videos turned out to contain material that was not related to HIV/AIDS. Finally, staff members felt a need to have people from outside the workplace coming in to talk about HIV more often. Marianne explained: ‘I feel we need someone from out, because now when we discuss amongst ourselves it is very informal. I like it that way, but still I would prefer that someone from outside would come and add more, because they have had many experiences in their office, they meet so many people, different cases.’ Furthermore, staff would like to see a real counselor coming to the workplace, because the FPP was not trained in counseling skills. Rose felt that this was particularly important to address stigma: ‘It should really be facilitated that trained counselors can come and talk to us, because we’ve already had enough information, the knowledge is there, but now that stigma..’

6.2 The multiple faces of stigma

What stands out from the above is that HIV/AIDS is frequently discussed in Uganda in various fora. The workplace is one of those settings where even a generally taboo topic as sexuality is becoming more open for discussion. But how are people still burdened by stigma in this increasingly open context? Before answering this question, I will first describe the meaning NGO staff attached to the word stigma. Then I will discuss the burden of various forms of stigma, including positive discrimination, and I will conclude with a paragraph on the reduction of stigma and discrimination, including a description of the contribution of the WPP.

The meaning of stigma

When I started my fieldwork, I had not formulated particular questions with regard to the meaning of the concept stigma. However, as I conducted my interviews, I soon realized the need to address this issue because the way people interpret stigma is neither self-evident nor universal. Sometimes the
meaning people attributed to the word stigma became clear in the way they spoke about it, while other times I explicitly asked my informants what the word stigma meant to them.

Most of the NGO staff in both organizations associated the concept ‘stigma’ with the inner feeling of an individual, rather than something that was enacted upon a person from outside. Within FURA, HIV/AIDS related stigma was mainly described as the feeling of being worthless or self-isolation, and some also mentioned the fear of how others will look at you. Only two felt that stigma was more about others isolating you. Solomon provided me with a definition that represented the predominant view of stigma: ‘Stigma is feeling as if you are no person, you feel like anytime you will die, there is nothing you can do on earth, you are no longer productive. So if that’s on your mind there’s nothing you can do, you can even run mad.’ Alvin focused on the aspect of isolation when he gave an example of a friend who had become HIV positive. ‘Why I say he was stigmatized, is that he never came back to associate with us, he feared that we would reject him.’ Finally, Kabale described stigma as the fear of how others will see you: ‘Stigma is not that I’m saying you have the disease, but you yourself may cause it. You will always feel that people know you are sick. People still consider that if I’m told I’m sick, how will people view me?’ This was also the predominant view among HNU staff. Marianne explained: ‘Suppose I have all the signs of AIDS, then I have that fear of people eying at me, that is what I think is stigma.’ Rose also described that people fear to become associated with prostitution and Alex felt that the fear to be laughed at was important, especially among youth. ‘[Young people feel like] if they find that I’m positive, what am I going to do, my fellow youth will laugh at me, that’s the problem, they have that stigma.’

The burden of stigma and discrimination
Examples of stigmatization and discrimination at the workplace were limited, while staff shared many experiences they had related to stigma in society. However, society, the workplace and individual experiences are interlinked and I relate descriptions of stigma in general to staff’s personal experience as much as possible. I start with a discussion of ‘self stigma’ and ‘feared stigma’, because these aspects stood out the most when NGO staff defined stigma and they seemed to cause most of the burden of stigma. Then I describe the extent to which fears with regard to stigmatization still come true. This section on ‘enacted stigma’ also includes discrimination. Then I provide a short discussion of ‘stigma by association’ and I conclude with a description of positive discrimination.

Dying of Worries
Given the fact that people saw stigma mainly as something that people enact upon themselves, it is natural that, when I asked them about the burden of HIV/AIDS stigma, they gave me several examples of ‘self stigma’. Staff members described that people can become traumatized after discovering they are HIV positive. One staff member recalled the story of a fellow student in university who attempted suicide after finding ARVs in his girlfriends’ bag. The cause of this might be that, in spite of the drugs,
HIV is still generally associated with death, as I was told by Didas. Staff members in both FURA and HNU, the young people in particular, felt that self stigma weighs more heavy on youth. The reason for this is that they still have a whole life ahead of them and fear they will be unable to find a marriage partner. Furthermore, Moses felt that young people will become more demoralized when they hear others talking in a negative way, compared to people who are more mature. Finally, PLHA may also be more inclined to feel rejected as was illustrated by the story of another staff member’s cousin: ‘At times when we would tell her we had no money she would feel very humiliated, because she thought we were not giving her the school fees because we know she has the disease.’

Fearing status loss

Although enacted stigma was said to have reduced very much, people themselves may still fear to be abandoned or associated with undesirable attributes, such as low productivity and prostitution. Flora told me ‘fear of stigma may be for the people who are sick, but the people who are not sick are not minding about it.’ However, seven staff members mentioned that people fear divorce or abandonment when they disclose to their partner. Steven, Jackie, Lydia and Morine felt women are more afraid of this than men, especially those who are not yet married but cohabiting, because, as Steven explained, ‘staying together is usually determined by the willingness of the man, given the tendency of the man dominating.’ Rose and Alvin explained that people fear to be associated with prostitution, or having multiple partners, when they are HIV positive. This is especially problematic for women as I will explain in the next paragraph. According to Alvin: ‘People used to see it as a crime, because there was a strong association with immoral behavior. That has reduced, but the association is still there, because sex is still the main mode of transmission.’ He admitted that he would also fear that people would see him in this way if he would be HIV positive. Lore felt the same with regard to disclosure at the workplace:

‘I would not share it comfortably, because one I’m not married, and then two I don’t have someone serious that people know I’m engaged to and will marry in the future. So I would have that feeling that people would say “this is what Lore has been doing, moving up and down, you see what she has got now!”’

Moses would also fear disclosing at workplace if he would have HIV, because he felt it could easily spread outside the workplace. In FURA, Alvin had the same concern and he and Anton both told me that people will look at you as if you are no longer productive. According to Alvin, ‘The moment they [your colleagues] go tell people you are sick, you will lose status, everybody will see you as a person who is just there wasting time.’

Tot Hier gewijzigd!

The consequence of the fear to be stigmatized is that people become reluctant to use services or disclose to others. Several staff members described this as a general problem and Geoffrey said that
the first time he tested he went to another town because he feared his colleagues would see him. The problem is also illustrated by Flora’s story about her village mate who postponed testing until she was about to die and taken to the clinic by others. Furthermore, Didas reported how clients complained that services for HIV are offered in an open place, while they prefer to have some privacy, especially the women, because they fear their husbands: ‘some of them have been beaten because they disclose their status’.

Pointing fingers

In both FURA and HNU, staff members agreed that enacted stigma had greatly reduced over the years, although PLHA in the communities still suffered from it. They described that PLHA were cared for nowadays and people no longer point fingers, because, as Morine explained, ‘we usually say that when you point at someone with one finger, the other fingers are pointing at you’. In the past however, stigmatization had been a big problem as was illustrated by Jackie. ‘There was some lady in my village. When her husband died, she tested and was found HIV positive, so people would call her “Aids”. They said “that one goes with many man”.’ Although there has been a great change, stigmatization still occurs, especially in rural communities, which was attributed to a lack of information. Jackie explained: ‘in most cases those who pinpoint people are those who are not learned, those who think that if you have HIV you will die the next day’. I heard first hand experiences of stigmatization when I accompanied Lore to a meeting with a group of PLHA in a rural area. We were informed that some group members had died, because they were abandoned by their family members. Lore later explained to me how people blame the patient and that HIV is still seen as a shameful disease, even within her close environment. ‘People believe that if you have HIV, you have been sleeping around.’ Jackie said this was especially stigmatizing for women, because for men it is more accepted to sleep with many women. According to FURA staff, blaming women was still a common practice in both urban and rural settings. Charles explained that this was because women’s position in general is weaker and Lydia gave an example of what happened in her hospital: ‘We had one case where a woman was found positive and the man abandoned her without paying hospital fees, without giving money to feed the infant, even though he had money.’ Furthermore, people may still insult PLHA, in rural areas as well as in town. Moses for example told me that people still say things like ‘you’re a moving coffin!’

There was a general agreement among FURA staff that stigmatization and discrimination did not occur at the workplace, although one staff member realized there was still a problem when it comes to hiring PLHA. Given the fact that there were no PLHA among the staff, statements about stigma at workplace were mainly hypothetical, but Roger illustrated the open environment with an example of a friend who often visited FURA. ‘Most people at office knew his status, but I would never hear people laughing about him, or talking about him.’ Mark, however, felt that, although it is not compulsory to share your status upon appointment, the WPP should be extended to include adequate
care before FURA could advocate for PLHA to join the organization. ‘As FURA we can fail to select those people who are infected, because we have nothing to give them. You cannot say I want to get people who are infected at the workplace and just talk to them and that is all.’

In HNU, however, staff members did provide concrete examples of stigmatization at workplace. First of all, Christine, who was living with HIV herself, recalled that before the WPP she experienced some stigma at the workplace. ‘There were some people who at some point refused to go into the field with me. And for me I was just thinking, is it because of my... Because everybody knows that I’m HIV positive. That was before, but now at least we are going into the field freely.’ This example shows that there has been a positive change at the workplace. However other staff members reported more recent incidents which may have been stigmatizing. Geoffrey told me ‘People can say things that really hurt. For example there are tasks available which everybody could do but people then say ‘this one is sick, so she cannot’, and yet that person is really healthy and capable.’ This was an incident that was also reported to me by Lore and Marianne. Furthermore Marianne had noticed people talking about another staff member, who was showing signs of sickness, but in an unsympathetic way. Rose summarized the situation at the workplace as follows; ‘Discrimination is not there, we have no fear of losing the job, or that people will treat you differently at the workplace, but we still have to fight that last bit of stigma.’

In contrast with the positive trend of diminishing stigma and discrimination, close examination of staff’s views on HIV/AIDS revealed that many of them had ideas about the disease that can contribute to self stigma or stigmatization of others. Most importantly, staff members still considered HIV as a deadly disease that makes people less productive. Seven staff members of FURA and two of HNU made remarks that indicated this association. Alvin, for example, told me that ‘before I go for masters, I may take myself for testing, so that if I would test positive I would not waste my money on that education.’ This remark should be seen in a context where resources to provide for education are limited and need to be divided within the family. Senior staff also associated HIV with reduced productivity. Roger said: ‘If there’s no WPP people would fear their jobs, because you know when someone is positive they will be less productive’ and Morine told me that being in a discordant relationship would be risking life. Furthermore, among FURA staff, HIV was associated with certain groups of people, notably the people who live at the lake shores and were said to be idle for most of their time, but also truck drivers and prostitutes. The fact that HIV is associated with immoral behavior was illustrated by the judgmental way Charles told me about two staff members who got pregnant last year without being married. ‘I felt like what kind of situation is this, freely getting pregnant and not married? I didn’t feel good about it, because I knew that there had just been some recklessness, or they could have had sex when they were drunk.’ Although this example is about pregnancy, it can easily be applied to HIV if such a case would arise. Finally, the common view that people who are positive deliberately continue spreading HIV, as will be described further in chapter 7, gives PLHA a negative image.
Birds of the same feathers

Although it was not mentioned as much as other types of stigma and discrimination, stigma by association can still be a problem for families of PLHA or other people who interact with them. Five staff members of FURA and one staff member of HNU, Alex, mentioned this issue. Jackie recalled that in the first days of the epidemic all the children, grandchildren and other people who associated with a HIV patient were said to be HIV positive. Nowadays this is no longer the case, but families may still suffer from humiliation. According to Anton this is especially true for the family of a women. People will say ‘we cannot let our children marry to someone in that family, there is prostitution’. Another problem arises when you interact with someone who is known to be positive. All the staff members with whom I discussed the issue recognized this as a problem. Jackie described ‘If you disclose that you are HIV positive and they see me talking to you, they will think I’m also HIV positive. Birds of the same feathers.’ And according to Alvin ‘Even the close friends may fear someone, because when people see you together, they will say ‘they are together, so they must have used the same person’’. When that kind of rumor goes around it will be difficult for you to find a woman to marry you.’

This kind of stigma may also be fed by the widespread advise that PLHA should focus on a partner who is also HIV positive. The Church encourages this combined with their policy of RCT, which will be discussed in chapter 7, and it was also the recommendation FURA staff came up with when they discussed about a woman who was HIV positive and about to marry.

Positive discrimination: What about malaria?
The wide range of special services for PLHA, including the WPP, carry with them a risk of building positive discrimination. Although I did not discuss this issue with many staff members, some senior staff of both organizations argued convincingly that this was a problem that should be taken into account. Roger was concerned that PLHA might lose sympathy from other staff members when they were given special benefits. ‘A challenge for the WPP is when you’re working with someone positive who takes on less workload, but at the end of the day remuneration is the same, it may not feel fair.’ This was a problem that also worried Geoffrey. Furthermore, Didas argued passionately that HIV should be seen as any other disease. First of all in the services that are provided to the communities; ‘If you go to the community, all of them are poor and then you are supporting the PLHA with the food. People will now say maybe it’s good to be positive, because then I can also come and collect food.’ At workplace he felt there are also risks attached to a separate program for employees with HIV/AIDS.

‘I think the WPP needs to be looked at in a broader sense of providing a health scheme, because it has got a high risk of building stigma again within the institutions. When you isolate a scheme you also isolate people who benefit from that. And we need to put resources there, while malaria is also a serious thing. People here have children and one of the highest costs of this is treatment for malaria.’
**Reducing stigma and discrimination**

Although stigma has not been eradicated, the problem has reduced very much over the years, in society as well as at workplace. Christine mentioned that ‘when HIV/AIDS started many people died of stigma and discrimination’, but this seemed to be no longer the case. Whenever I asked people how the position of PLHA could be further improved, they did not talk about stigma, but they mentioned extending health services and food support. The HIV patients with whom I talked also emphasized their economic difficulties, rather than stigmatization. But how has this change been brought about? In the following section I will discuss the answers NGO staff provided to this question, with specific attention for the contribution of WPPs.

In line with the government’s view and policy, there was a high level of agreement among NGO staff that the main mechanism for stigma reduction was sensitization of people by providing health education through various channels. Anton felt that people mainly fear to die soon after testing when they lack information and Marianne said: ‘The position of PLHA is improving greatly because there are so many talk shows on the radio, so many programs by influent organizations talking about stigma, discrimination, prevention.’ Within FURA, creating awareness was also considered a core achievement of the WPP, which also had a positive effect on the way staff worked with PLHA in the communities. Jackie described: ‘Stigma is not there at FURA because we are aware. The WPP contributed big time, because of sensitization by the FPP. When she went for workshops she told the staff or she gave a small training.’ Within HNU, people also acknowledged the WPP’s contribution to sensitization of staff, but the effects on stigma reduction had been limited due to a lack of time for discussions or trainings.

Seeing positive examples was another way of reducing stigma and discrimination. Alvin told me that people who give testimonies can really create awareness and Mark explained; ‘For me, I’m free because I have known PLHA who have lived for long.’ Moses also recalled how he was encouraged by seeing PLHA who were doing well.

‘I believe that even if I’m positive, I can still be strong and do work, I will not get scared and I can still live for many years. I gained that when I was in HNU, because I saw so many families that were doing badly, but HNU used to help them until they became strong, and they are still living up to now, while they were bedridden!’

Third, some staff members reported that the increased availability of ART helped to fight stigma and discrimination. Jackie explained: ‘Since the introduction of ARVs, HIV is like any other disease, it’s like malaria, most people now don’t fear because of the drugs.’ Lore added to this; ‘ARVs helped to reduce stigma, because when people start treatment early, you don’t see the signs.’ Self stigma also reduced and Rose said this was illustrated on days when TASO handed out food: ‘These people are all sick, but they don’t mind about it, don’t you see them laughing? As long as they have their food and their drugs.’ The WPP can contribute by providing health insurance, as FURA
intended, or by linking HIV positive staff to a service provider, as HNU did. However, this had not yet been put into practice, since the one staff member who was HIV positive had organized treatment for herself before the introduction of the WPP.

With regard to the WPP as a mechanism to reduce stigma and discrimination in itself, staff were very pleased with the fact that PLHA cannot be sacked from the job because of their illness. Within HNU people also felt that the way PLHA were treated at workplace had improved. Christine, whose experience of stigma at the workplace was described above, mentioned she also felt that the WPP contributed by not allowing stigma and discrimination, so that people would go to the field together without problems.

6.3 Discussion

The topic of HIV/AIDS is frequently discussed in Ugandan society as well as at the workplace. Communication about HIV through various channels, such as the radio and the newspapers, have created a facilitating environment in which HIV can also be discussed at workplace. Widespread IEC campaigns probably caused the high levels of knowledge on the basic facts of HIV among participants in the SAN! project at baseline and among my informants during the time of my research. In addition, the majority of NGO staff was highly educated and some also worked with PLHA in the communities. However, much of the information that is spread focuses on abstinence and faithfulness after marriage. Hence, people in Uganda have no problem discussing HIV in general, but sexuality is more taboo, especially among young people, who, according to law and Christian norms, are not supposed to have sex. By increasing discussions about HIV at workplace, WPPs seem to have created more openness with regard to sexuality, for people in both organizations reported they could joke about condoms and during an FC in FURA sexuality was also discussed. In addition, WPPs have brought the topic ‘closer to home’, so that staff felt that HIV/AIDS was not only other people’s business, but also their concern.

However, stigma still appeared to be a problem in society and among NGO staff. The examples people shared with me and the way they defined stigma, indicated that the main burden was caused by self- and feared stigma. The first was mainly due to the association of HIV with death and illness, while the latter was caused by the feared association with decreased productivity and immoral behavior. Within FURA, staff reported that stigmatization and discrimination did not occur at their workplace, but this discussion remained rather hypothetical, for there were no HIV positive employees in the organization. In HNU, however, people had more practical experience with HIV among staff and they shared some examples of stigma at the workplace with me. Rather than outright discrimination, stigmatization seems to occur on a level more below the surface. This can be concluded from the high levels of self- and feared stigma and from the way staff see HIV/AIDS. In spite of the reported stigma reduction and their awareness about ART staff strongly associated HIV/AIDS with death and decreased productivity. Past experiences, for example the death of family
members, may have caused this association to become firmly rooted in people’s thinking. Furthermore, the association with immoral behavior was feared, especially among young staff members. Finally, positive discrimination is a relatively new phenomenon which can prevent HIV from becoming like other diseases. By isolating HIV positive staff and services for them, WPPs also carry a risk of building stigma.

Although stigma continues to burden people, the problem seems to have reduced considerably over the years. In line with the government view and policy, NGO staff generally agreed that IEC campaigns were very important in stigma reduction. Information campaigns may have tackled stigma that was related to fear of contagion by providing basic facts. And according to NGO staff increased communication at workplace led to reduction of both self- and enacted stigma. Positive examples of people who have lived for long with HIV, the availability of ART and guarantees of non-discrimination at workplace may have increased people’s social value, thereby reducing stigma. This mechanism is described in chapter 3. However, the views of NGO staff show that knowledge about ART does not necessarily eliminate the association with death and decreased productivity. Furthermore, eradicating stigma related to the association with immoral behavior is hard in a society where discussing sexuality is difficult and Christian values condemn pre- and extramarital sex.
The focus of IEC in Uganda is on warnings and promoting abstinence

Fig. 22 (top left) T-shirt used by HNU during an education project in schools.

Fig. 23 (top right) Sign by the road in Soroti warns against HIV/AIDS

Fig. 24 & 25 (right and bottom) Educational messages related to HIV/AIDS painted on a primary school on Ssesse Islands
7. HIV COUNSELING, TESTING AND DISCLOSURE

In order to contextualize the promotion of VCT at workplace, the first paragraph of this chapter is dedicated to considerations related to HIV testing and trends in utilization of HIV counseling and testing in Ugandan society. In addition, the recent movement towards increased RCT and staff’s view on this development are discussed in the second paragraph. Then I describe the promotion of VCT at workplace and the effects of the WPP with regard to VCT. This chapter concludes with a paragraph on the effects of VCT, in terms of its effectiveness as a prevention strategy and the extent to which people disclose after testing.

7.1 Utilization of VCT

To determine which factors influence the decision to go for VCT, I explored the reasons people have in favor of- and against testing. These will be discussed in general and for staff personally, followed by a description of trends in utilization of testing. It is difficult to say anything about differences in utilization of testing between different groups among staff, given the small number of my informants. However, from discussions with staff I could draw some points of interest related to testing behavior in society, which may also be applicable to the staff. Differences in testing utilization according to gender and age groups are discussed in the second part of this paragraph.

Fearing death or facing the future?

Going for testing can be a big step and there can be numerous reasons that hold people back, such as stigma and practical concerns. The fear to become traumatized after receiving a HIV diagnosis was a frequently mentioned barrier to testing. Alvin explained: ‘People fear that if they are found positive all their future plans and developments will be destroyed, they will become occupied by death only’. This statement reveals that the fear to become traumatized signifies people’s fear that they will suffer from self stigma after receiving HIV positive test results. Marianne shared her own experience that this concern withheld her from testing for many years. ‘I’d fear that if I would turn out HIV positive, I would get scared and maybe fall sick and die sooner.’ Jackie and Marianne related the fear to become traumatized to economic aspects. They felt that receiving a HIV diagnosis is worse for those people in the communities who can’t afford drugs and have more difficulties to sustain themselves. Feared stigma was another reason that withheld people from testing, which comprised mainly the fear of divorce or abandonment. Staff also mentioned lack of awareness and inaccessibility of services as a constraint in rural areas. Furthermore, in some places a fee is required, which can discourage regular testing and can burden the already limited resources of people who are sick.

For NGO staff personally however, most of them saw no reason why they shouldn’t test, while only two said that fear withheld them from testing. Marianne’s experience was described above and
Jackie said doubts about her husband made her reluctant to test ‘I’m not so sure, unless I have a good counselor. Because for me, I may be faithful to my husband, but I don’t know what he is doing elsewhere, so of course I fear’. In addition some staff members never tested because they didn’t feel the need, or because they hadn’t given it much thought.

On the other hand, there are also reasons in favor of testing. My informants described that people in the communities are very willing to test because they know they are entitled to benefits when they test positive. Staff of HNU told me that when they went to the field, people were ‘begging’ for another VCT outreach after they had seen distribution of septrin for PLHA. Naturally, staff felt that people’s willingness to test increased when they would be more educated about the benefits of testing.

Staff’s personal reasons for testing were related to being able to plan for the future, or they were prompted by some form of RCT. As I described in chapter 6, my informants still related HIV to early death and therefore they saw testing as a means to plan for the future. Stella, for example, said: ‘When you have HIV you start planning for your children because automatically you know you have limited days’. The initiative to test was in many cases not taken by the individual, but people tested when they became involved in RCT. One way was before getting married in church, especially in the Protestant- and Pentecostal Church. Roger explained ‘I was going to marry and before you marry, you must get your status. To me it is a must, but it is now also a principle in church’. Adding to the principle of testing before marriage, some of the men said they had also tested to bring confidence in the relation. Kabale told me: ‘I have a wife, so she will feel more comfortable when I come home and tell her that I still tested negative’. Most of the women had been tested during antenatal care and some of the men had also tested when they accompanied their wives. One person told me he had been tested when he was admitted in hospital to undergo surgery.

Besides these considerations, the incentive to go for testing was usually born out of a person’s concern that they had been at risk, for example after feeling sick or when suspecting a partner. On one occasion I was able to talk with two women in the community who lived with HIV. They told me that the decision to go for a HIV test was very easy for them to make when they started having repeated episodes of illness that did not respond well to medication. Christine, who was an assistant project manager in HNU, and Erieme, who worked for NACWOLA, both told me they had taken a test after the death of their husband. When I visited AIC, I was also told that most people who go there come for ‘confirmation’ when they feel they are infected, while only a minority comes ‘just to be sure’.

But, rather than being dependent on people’s assessment of their risk alone, the decision to go for testing also seemed to depend on a person’s character and experience. Fear to be HIV positive may encourage someone to test, but it may also hold people back because they fear to receive a definite diagnosis. As I described in the previous paragraph, doubt about ones partner may cause someone to refrain from testing. However, Rose told me that she definitely wanted to test, for that very same reason of being unsure of her husband’s sexual behavior. This was also related to her experience with a young female friend who was also married and died recently of complications related to HIV/AIDS.
Furthermore, in contrast to an example of a friend of Alex who refused to test because he had been going with more than six women, Geoffrey shared with me that the first time he tested was because he had two girlfriends at that time.

**Going for VCT**

It stood out clearly that people had generally become more willing to test, which was possibly related to improved support for PLHA and upscaling of RCT. This was mentioned by most of the staff in FURA and HNU. Lore, for example told me: ‘everywhere I have gone, people are crying for it, to have that test.’ Staff related the increased uptake of testing to the increased availability of ART and other kinds of support from various organizations, mainly NGOs. Solomon also connected it to increased RCT. ‘At the moment there is no way you can avoid it. If you don’t do it now, you have to do it tomorrow, so people are now going.’ People’s openness and willingness to test was also illustrated by a conversation I had with one of my neighbors. I had only just met her and found out that she was married to a man who already had another wife. She then informed me, without specific questions from my side, that they all went for testing every three months to make sure they were still negative.

When I asked staff about gender differences, the majority felt that women are in most cases more likely and more willing to take a HIV test. Most women in Uganda get tested when they come for antenatal care, where they are offered RCT, but, as one nurse of Kilembe hospital told me: ‘if you forget mentioning testing in antenatal they are the ones who remind us.’ As I understood from NGO staff and health care providers, men are often reluctant to join their wives. Steven described that culturally men are not involved in pregnancies, and Rose said that men feel that everything in the home is a woman’s responsibility. Another reason why women might test more than men was because of their relatively powerless position. Four staff members of FURA mentioned that women go for testing because they have less influence on the sexual contacts they have, so they want to make sure they are still safe (See also textbox 2). This was illustrated by an example of Jackie: ‘I have a friend who suspected that her man was going out with her friend who was HIV positive, so she went for testing and found out, unfortunately, that she was HIV positive. She did not tell her husband, because she fears to be blamed.’

Another differentiation in utilization of HIV testing was made according to age groups. As I described before HIV related stigma is perceived to weigh heavier on the youth. And, as I learned from various discussions with staff members, the prospect of getting a HIV diagnosis is far more daunting when you are young, because at that time your life is not yet ‘stable’. Young people still want to find a partner and have children, which becomes very difficult when you are HIV positive. One thing my Ugandan friends were sure of was that a relation with someone who is HIV positive was out of the question. Alex formulated it like this: ‘if you see there’s a hole there, why do you again go and put your leg in it’. He was very determined about testing when he would get a new girlfriend and said that if she was HIV positive they could only be friends. Older staff members also told me that they
would not encourage a relation when a couple is discordant. Morine said: ‘It would be risking life really, suppose condoms are not there. And even when you use condoms, married life is very long and if you want children you will infect your partner.’ Instead, several staff members expressed that they would advocate for PLHA to find a partner who is also positive.

**Unfaithfulness: men’s business as usual?**

Through various conversations with staff members as well as people from outside the workplace, I learned a lot about people’s ideas of a relationship and the position of women within a relation. Overall the norm of having more than one wife appeared to be vanishing. Most of the people I talked to came from families where their fathers had more than one wife, but for themselves both men and women were looking for a marriage with only one person. Jackie explained that traditionally it made sense to marry more than one woman to have more manpower to cultivate the land, but nowadays land is not an issue anymore. Rather, a larger family meant more mouths to feed and school fees to pay. Following the Western example, people in Uganda now prefer to have a small manageable family with two or three children. In addition, vigorous public education campaigns in response to the HIV epidemic focused on a monogamous relationship with one partner. However, whether this development has improved women’s position in relationships is questionable. As my neighbor explained; ‘Cheating is not accepted [for men], but it can be overcome. For a woman, when she cheats, she cannot even sleep in the same house as her husband. That same day, it will lead to a divorce.’ This illustrates that double gender related standards prevail. In other conversations with women I was amazed how lightly and fatalistic they took the matter of cheating husbands. One friend told me that there’s no way you can mind about it when you are not around, as long as he continues to be nice and take good care of you when you are together. Another woman said that, since there is little you can do to avoid it, she preferred not to know about it as long as he would protect against HIV. Cheating being a standard rather than an exception also meant that women who were not prepared to accept this kind of behavior would end up being resistant to engage in a relation with a man altogether, as I saw happening with another friend. She feared that having a sexual relation would expose her to HIV and was not willing to pay that price.

**Textbox 2**

7.2 Moving towards RCT

Although RCT is promoted by the government some pregnant women and inpatients, practice appears to be running ahead of the official policy, applying RCT to a larger population an patients often have little room to ‘opt out’. As I described earlier, RCT for all inpatients is described as a priority intervention area in the government’s strategic plan (UAC 2007). I was informed by Rose that testing had become a routine for in-patients in 2006, while RCT was offered to pregnant women since 2001. When I talked to NGO staff, they described the policy in variable ways, especially with regard to RCT in antenatal care. Some staff members told me testing was compulsory for pregnant women, in order to protect the baby and the medical staff. Others said that it was possible to refuse but few people opt for that because of the good counseling people that is offered and the fact that people have become used to it. Before marriage testing can also be compulsory, depending on the church. Some churches, especially the Protestant and Pentecostal churches, require testing certificates showing both partners are negative before blessing the marriage. When both partners are tested positive, the marriage can
also go on, but when a couple is discordant, Morine informed that the Church considers the union undesirable.

Among NGO staff almost unanimously positive remarks were made about routine testing for HIV. They felt that it was important for everyone to know their status, so testing should be encouraged. Lore pointed out the benefits of testing during antenatal for the unborn child. ‘Now that we have a solution, that even when you are sick you can give birth to a normal child, why don’t we do it?’ And Morine felt that, for the case of inpatients, testing is for their own good, because the right treatment can be started immediately, which shortens their stay in hospital. Another advantage of RCT was that it made testing more accepted. David explained that increased RCT made it easier for women to bring up the subject of testing to their husbands. During a group discussion in FURA it was also pointed out that few people use VCT, because educating people about testing is not sufficiently encouraging, while much more go in RCT. Some also felt that HIV should be considered as any public health issue and Alvin challenged the status quo by saying ‘When there is a cholera outbreak you also respond without asking people whether they want a latrine first.’ The policy of testing before getting married in church was also mainly received with enthusiasm, though Alvin questioned its ability to prevent new infections, because ‘Most people start having sex before getting married, so by the time they marry, they may already be infected.’

Two senior staff members of HNU, however, had some reservations about the policy shift that is in process. Although they agreed with their fellow staff that testing people was good, they argued that it could only be done on routine basis when it was accompanied by adequate mechanisms for support. Marianne said: ‘It [RCT] should be accompanied by a lot of other things, for example support for those who test positive. Because if you test and find me positive, but then you just leave me, I don’t think that’s good. It can even quicken your death.’ And, as pointed out by Didas (in chapter 5), the follow up system at the moment is not equipped to handle many people who are positive and in need of counseling and support, so this needs to be improved.

7.3 Promoting VCT at the workplace

In accordance with findings of the SAN! applied research team at baseline, the above description shows that staff had generally positive attitudes towards HIV testing and quite a number of them had already tested at some point in their lives, but some lacked the initiative to go for a HIV test. Therefore, the SAN! Good Donorship Guidelines advocate that NGOs should encourage their employees to go for VCT by providing information and education at workplace (Holden 2006). On paper, VCT promotion is mentioned, but neither FURA’s, nor HNU’s WPP document specifies the activities that should be organized (FURA 2006b; HNU 2006). Therefore I examined staff’s experiences with VCT promotion at the workplace, the activities that had been organized and the
effects of the WPP on VCT utilization by staff. These issues will be discussed in the following paragraph, starting with FURA, followed by HNU.

From talks to practice

In FURA, staff were not very quick to mention VCT as an issue that was addressed by the WPP. Only three, out of the 15 staff members I interviewed, mentioned VCT when I posed general questions about the effects of the WPP. All of them were senior staff. Mark was among them and said VCT had been discussed during FCs, as a result of the WPP, which made him think about going for testing again. When asked explicitly whether VCT promotion was part of the WPP, Susan and Flora told me that discussions at workplace encouraged people to go and Charles mentioned the upcoming VCT day for staff and relatives. Solomon, however felt testing should be addressed more: ‘I have not seen people being really open about going for testing’.

The plan to organize a VCT family day in May 2008 made the subject of testing more alive in the organization. The initiative to organize such an event came from the SAN! project and FURA was the second lead organization to carry out this plan, following TPO in the central region. The aim of the VCT day was to organize free HIV testing in a central place where staff and their families, of all the seven NGOs involved in the SAN! project in the western region, would be encouraged to come and test. Furthermore, people in the vicinity of FURA would be able to join. Unfortunately I was unable to attend the day myself, I left one week prior to the event, but I did talk about it with a few staff members afterwards. Jackie said it had been a great success and that all the staff had tested. However, Stella told me that not the entire staff had attended and some staff members did not go for testing even though they were present. This information seemed more reliable, given the fact that the people who reportedly did not test were the same people who expressed doubts about testing in interviews with me. What I observed in the process of preparing for the VCT day, was that it was headed by the FPP and one other staff member, without others being very involved in it. Furthermore, I have not experienced any discussion or trainings about VCT in FURA during my stay there, which may provide an explanation to why some staff remained reluctant to test at the VCT day.

On the other hand, most of the staff had a positive attitude towards testing and quite a number of them had been tested for HIV. Ten out of fifteen staff members reported they had ever tested for HIV, though only four of them had done so at a time when the WPP was operational, so the impact of the WPP on this figure is limited. From the information Stella gave me, I concluded that four staff members tested again during the VCT day and three others tested for the first time.

Testing boda-boda cyclists

Within HNU, VCT was not the first topic staff mentioned, but most of them did feel encouraged to test by the WPP. The first things people told me about when I asked general questions about the effects of the WPP were usually openness and support. However, once staff started talking about VCT, most of
them, though not all, felt that the WPP was encouraging to go for testing. Geoffrey, Alex, Morine and Marianne mentioned video shows, discussions and informal conversations on the topic. Although, time constraints limited these initiatives, I have been able to observe one Friday afternoon video show about testing, which I described in chapter 6. Alex also told me how discussions at the workplace and a training by SAN! encouraged him to test and talk about HIV with friends: ‘I always encourage others, if you have a girlfriend, make sure you test yourself and be faithful to one another. And then, the second thing, I always encourage them to use condoms and have one partner.’ Ensuring support also encouraged people to test. Alex told me, for example, that the WPP also made the guards go for a test every time they felt ill, because they wanted to profit from the help you get when you are HIV positive. The support in HNU comprised linking staff to Uganda Cares for treatment, which was appreciated by staff even though individuals can also register with Uganda Cares. In addition, staff was allowed to come late if it was necessary to collect and take medication.

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Like FURA, HNU organized a VCT family day with the primary objective of offering VCT to staff and family members, but passers-by were welcome to join. With HNU I was more involved in the preparations and I also attended the VCT day. Therefore I can now give a more detailed description of the organization and practice of such an event.

During the organization some concerns about the VCT day were expressed. The event was to be held at the compound of HNU, but the organization decided to approach AIC to do counseling and testing. I accompanied the FPP to various partner organization in the region and AIC to discuss the matter. The proposal was not received without reservations. Partner organizations felt that a lot of sensitization would be needed to convince staff and it would be difficult to get everyone together, because some staff were based in the field. When I mentioned the VCT day to two HNU staff members, about two weeks prior to the event, they were not yet aware, so one of them expressed that all of the staff should be informed and consulted about the VCT day in advance to see how they wanted it. This was a gap in the preparations that may have been caused by the fact that the initiative had not come from the organizations themselves, but from the SAN! project. The other organizations I visited with the FPP felt that it would be best for AIC to come to them, rather than staff having to go to AIC. We were informed by a FPP that ‘some may even get traumatized by going there, going to AIC makes their knees tremble’. The AIC coordinator, on the other hand, was positive about the initiative and about looking at HIV as a workplace issue, but he felt that confidentiality could be realized better within their building. The manager of HNU also expressed his concern that staff might feel pressured to test, so he said that it should be made very clear that it is a personal choice. In spite of these reservations, it was decided that the day would be held by the end of June, on the premises of HNU.

The VCT day was a lively event which attracted many visitors, though most of them were not NGO staff. I returned to Soroti to attend the day after being away for two weeks. I was informed by Lore that in the previous week, the AIC coordinator had come to HNU to discuss HIV transmission and testing to prepare the staff. The program of the VCT day consisted of registration and group
sensitization, during which the AIC coordinator informed the people and made them comfortable with the idea of testing, after which people could go for individual counseling and testing. All of this was done in the garden of HNU and there were three counseling sites (Fig. 26-28). The program was made more interesting by several performances of music and drama by groups of TASO. The day was quite successful because halfway during the afternoon people were still coming in, but they had to be disappointed because all the 100 test kits had been used. On the other hand, I had some doubts whether the target group, NGO staff and their family members, had really been reached. Although most of the staff from HNU were present, they were very busy organizing, while few staff members from the other partner organizations had turned up. Furthermore, we did not register many family members, so the participants were mainly passers-by, particularly boda-boda cyclists.

During the VCT day the circumstances for counseling and testing, with regard to privacy and quality of counseling, were not ideal. Privacy was difficult to guarantee, since counselors were sitting out in the open, while others gathered around, waiting for their results. Sometimes, such a group of people would come within a distance of only 2-3 meters from the counselor and his client. Time constraints had an effect on the quality of counseling. Pre test counseling was short and consisted of a few standard questions about prior testing, last exposure and the number of sexual partners. Post test counseling was even shorter. Those who had tested negative were given their results without any further comment, as I observed by being part of that group (Fig.29). Others, of whom at least some were positive, were counseled for only a few minutes. The clients received their verdict with blank faces, possibly because the circumstances did not allow for any expression of emotions. Staff of AIC explained to me later that they also felt that counseling had been limited due to lack of time and they had only been able to give people the references of places where they could get further support.

Though the VCT day stimulated people to test, it did not pull in those who had doubts prior to the event. Marianne told me that she felt really encouraged to test by all the others who took that step. However she had already decided before that it was the right time for her to test. The lack of privacy and time constraints made me think that those who were not sure of their status would prefer not to test in such a setting. When talking to Alex and Lore, who had both tested, they confirmed that they would not have felt comfortable about testing if they had serious doubts about their serostatus. Two others, who had previously indicated to me that they were not sure about their status did not test. All the organizational activities provided a very legitimate reason for them to ‘miss out’ on testing, but I felt that the way the VCT day was organized may have discouraged them. However, both of them said they would go to AIC themselves later, so the event may have motivated them after all.

In HNU almost the entire staff had tested for HIV, part of which might be attributable to the WPP. Out of the eleven staff members I talked to, nine reported they had ever tested for HIV and six of them had done so at a time when the WPP was already in place. Therefore the WPP might have influenced them, like it did with Alex, as I described earlier, although others did not specifically
mention the WPP as an encouraging factor. During the VCT day five staff members tested again, while Marianne tested for the first time, which can be considered an achievement of the WPP.

7.4 What to do with test results?

In order to get an idea about the effectiveness of VCT as a prevention strategy I asked staff in both organizations whether people in general change their behavior after testing and how it worked for staff personally. This will be described in the first part of this paragraph. In the second part I will discuss disclosure of HIV positive test results. I will shortly describe general trends in disclosure and then focus on disclosure at workplace and the contribution of the WPP.

Personal choices and structural constraints

In both FURA and HNU staff generally agreed that people change their behavior in a positive way after testing negative. The consensus was that once people have realized they are HIV negative, they will do their best to keep it like that. Solomon formulated it as follows: ‘When people test negative, they change, because when you tested negative, why do you go again and expose yourself to that thing? Unless you are mad.’ Two staff members of FURA also described how testing had enabled them to communicate openly about testing. Kabale was encouraged by the counselor to tell his wife and sisters to go and test while Anton said that after his wife and he had both tested, they could communicate about the issue more freely. However, in the midst of all the optimistic stories, Christine recognized that behavior change, either after testing positive or negative, is not always easy. ‘People can change their behavior in a way that they will not have multiple partners, but they will still continue having unprotected sex with their own partner. That’s the only way their behavior can change.’

When people test positive, staff saw a lot more difficulties. Eight staff members, five of FURA and three of HNU, told me that once people are positive, quite a number of them will deliberately start spreading. Statements were made such as; ‘They declare war on the other sex!’ (Lore) and ‘They believe they do not want to die alone.’ (Alvin). At first I was tempted to dismiss this often heard comment as some kind of myth, but when Alex told me a more personal story about a friend, I started to doubt.

‘I have a friend, a lady, she has been infected by a teacher when she was in a certain school. She was focusing on money, and this man, this director was a bit rich, so they got together in a relationship, not knowing he was infected. But when she realized she felt cursed, she started drinking, going to the disco overnight. Most people didn’t know, but I was close to that family so one time she told me about herself, what happened. She was frustrated, so I talked to her, I consoled her, I tried to give her advice, but she kept going to discos. The next day you see her with a different person, the next day again.’
Fortunately staff also mentioned positive effects after testing positive. They described that people would start taking ARVs and some patients even started teaching others about HIV/AIDS. Among FURA staff, it was also mentioned several times that after receiving proper counseling people feel more free to open up. Naturally, the way people change after testing positive is also dependent on the person, as Alvin said; ‘Those who refuse [to change] were the ones that were always careless. Those who have always kept themselves continue to do so.’

There are also problems related to behavior change after testing positive which are structural, rather than individual, such as gender inequality, poverty and limited availability of condoms. First there are problems related to the subordinate position of women in Ugandan society. Lore gave a very clear example of the consequences of this inequality.

‘A relative of mine was tested positive, but his wife was negative. So she said, since we have children, we should continue with a condom, so that I can take care of the children after, though I’m not saying you’re going to leave now. You know what he said? He said “I have married you, I have paid dowry for you, who has bought the other? You cannot tell me to use a condom on you, why should I use a condom on you?” Like that. So some people when they get to know they are positive, they don’t want to die alone.’

Morine also commented on women’s position in general: ‘In most cases, the man is the over ruler. When he comes you just have to have him. There is no way you can avoid him having sexual intercourse with you’.

Second, poverty can limit women’s options for behavioral change. Upon visiting the home village of one of my friends, she explained to me that many girls there start sex very early in order to obtain money. Furthermore, married women sometimes had to use this strategy, without their husbands knowing, to be able to sustain their family. This practice of transactional sex can be a barrier to behavioral change if women see no other options to obtain resources that are vital to them. Furthermore, transactional sex may put women in a weak position to negotiate condom use, thereby increasing their risk to contract HIV.

Another barrier to behavior change can be the limited availability of means to protect yourself. Poor distribution of condoms can be a limiting factor in the villages, as David told me. Furthermore there may be few shops that sell condoms and people may fear that the shopkeepers will gossip. The youth may encounter even more difficulties to obtain these essential protectors, because shopkeepers can be reluctant to sell them. According to David: ‘When you ask for condoms they will say they don’t have it. They will not sell it to you because you are young.’ By the end of my stay in Uganda I also had my share of experience regarding this problem. When the VCT day in HNU was organized people could also take a box of free condoms. This offer was received with a lot of enthusiasm, especially from the many boda-boda cyclists, all of them young men, who had walked in on the event. At one point, a boy, looking like he was about 15 years old, strolled of with a box of condoms under his arm. He was spotted however by one former staff member of HNU, an elderly woman, who was just holding the microphone. She called after him, for everyone to hear; ‘Hey you, young boy! Where are
you going with those condoms?’ She and another staff member explained to me that they feared HNU would be seen as an organization that promotes sex under young people. This association was much rather avoided, since sex among people under 18 is legally considered as defilement and a punishable offence in Uganda.

**Going for airtime**

My informants generally described increased openness about ones HIV status in society because of the support people can receive, but this trend did not persist among upper class people and the youth. Lore for example described: ‘When it comes to the food element of it, the benefits, people tend to be very open. They come and say “I was tested positive, you give me food!” even when they are not positive’. Mark also related disclosure very much to expected benefits. ‘Within FURA and in the communities, it is hard to disclose to us because we have no support. In life when I benefit, that’s when I tell you!’ For people in a higher social rank, however, things appeared to be different. Roger told me that ‘People who are more educated are less open about their status in public. Like a chairman for example, for them in high jobs, high profiles, for them it’s still a shame.’ For the youth disclosure is also more difficult, because, as I discussed in chapter 6, stigma affects them more then older people.

From my conversations with NGO staff it was hard to draw conclusions with regard to gender differences when it comes to disclosure, but in my observations, women join groups for PLHA more. When I asked staff whether it was more difficult to disclose for men or for women I received mixed answers. Jackie for example said ‘In most cases the women open up and go to these organizations, but the men don’t follow them, they just keep quiet.’ In contrast, Lore argued that it is harder for the women to open up because they are likely to be blamed by their husband. However, the high turn up of women on group meetings of PLHA was clear. Therefore it appears that women are more willing to come out in public to get support, possibly because they are more in need of it then men. On the other hand disclosing to their partners at home might be more difficult since they are more likely to suffer from rejection and abandonment.

In spite of increased HIV testing, communication and stigma reduction, staff’s experiences showed that disclosing your status, or making the subject discussable, can still be very difficult. This is illustrated by the story about Rachel, a young colleague who died recently of an illness that was assumed to be HIV/AIDS. Morine explained how she had noticed that Rachel was worried and how she had tried to find angles to make the subject discussable, but before she managed to talk openly about it her colleague passed away. Morine said: ‘Unless someone is open to you, you have to find opportunities to put it in a comfortable way. We don’t need to say it is easy, as soon as you are positive. We give you time.’ David provided another example. He had a young girl in his family who was born HIV positive and she had to start taking ARVs, but no one had the courage to inform her why she had to take those medicine, not even the nurse. Staff of both organizations also felt that whether you can disclose to someone depends on the person. You can disclose to close friends, people
whom you trust that they will keep it a secret or people of whom you expect assistance. Christine described from her own experience; ‘First of all you have to get used to people, you don’t have to go and disclose to everybody, so I was watching the people and see which person. You start looking at people’s attitudes before you start disclosing everything.’

With regard to disclosure at workplace, staff members had different feelings about hypothetical disclosure. Within FURA, five people, mainly senior male staff, said to me they would have no problem to disclose at FURA. Others had more reservations, saying they could disclose to a few or not at all. Alvin, for example, said he would not disclose at FURA out of fear that people would not treat the information confidentially and feared stigma, which also made Moses and Lore of HNU uncomfortable about disclosing at workplace. Other staff members of HNU, however, said they would be open at workplace when they would be HIV positive. This organization also had the positive example of Christine who had lived positively and continued working in the organization for years. Morine described: ‘A very good example of positive coming up is one colleague of us. She’s on ARVs, she’s doing well and she even mentions to some of us that, today I’m going for airtime.’

Within FURA, staff felt that the contribution of the WPP to disclosure would be limited, but in HNU people were more positive about the WPP as a means to create openness. It should be kept in mind that FURA staff could only talk about hypothetical disclosure, for they had not yet experienced HIV among staff. Only Kabale and Roger said the WPP encourages disclosure, because it ensures that people take your illness into account when handing out tasks. Roger also added that people are all aware, they understand what it means and how to deal with PLHA. Other staff members, however, did not see the benefits of disclosing at workplace. Jackie, for example, said: ‘you feel if I disclose no one will help me, because the insurance scheme is not yet there’. Staff of HNU were generally more positive about the WPP. Morine and Rose mentioned that the WPP really created space for people to open up because they could not be sacked and most of the staff agreed that the WPP encourages disclosure because you know you are entitled to get support from the organization. For Christine, however, the policy did not change much. She had been living with HIV for 12 years and felt that she already had ‘her own WPP’, getting her drugs from Uganda Cares and being open to the people who could assist her, though she did tell me that the WPP encouraged her to open up to more people within the organization. However, Moses and Lore, who did not feel comfortable about disclosing at workplace, were not as enthusiastic about the WPP. Moses referred to Rachel, saying that if there had been more trainings, the organization may not have lost her. This tragic event also made Lore doubt the effectiveness of the WPP. ‘If people were open, there would be a way you could talk to someone when you see they have a problem, but now it’s difficult.’

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4 In Uganda airtime means calltime for the phone, but it is also an expression among PLHA to indicate they are going to get drugs.
7.5 Discussion

Although going for VCT can be a big step, staff reported a trend towards increased utilization of HIV testing, both voluntary and through RCT. Efforts to encourage VCT at the workplace should thus be seen in a context where increased support for PLHA and the availability of ART are starting to outweigh the reasons against testing, such as the fear to become traumatized or demoralized. For staff personally their main reason for testing was to be able to plan for the future and in most cases testing was done in relation to a big life-event such as a new relationship, marriage or pregnancy, and in case of the latter two staff tested through RCT. Women reportedly test more, because they receive RCT in antenatal care, but they are also more willing to learn their status because of their vulnerable position towards their husbands or boyfriends. For youth testing is more difficult, because stigma weighs heavier on them.

Staff members generally had positive attitudes towards HIV testing, though some lacked the initiative. They were very supportive of the recent trend towards increased RCT, because they felt it was important for all to know their status. But not everyone had taken the initiative to test themselves. The Stages of Change Model, which is described in chapter 3, is useful to explain this discrepancy in vision and action.

Promotion of VCT had been limited to some discussions at workplace, but the initiative of the SAN! project to organize a VCT family day boosted awareness on the subject in both organizations. However, HNU received the idea with some reservations about guaranteeing privacy and the need for prior sensitization, which turned out to be grounded objections. Participation in the preparations and sensitization of staff were limited in both organizations. Furthermore, lack of privacy and limited time for counseling may have withheld people who had doubts about going for testing. However, both VCT days have made a major contribution to bringing the topic to the attention of staff, thereby also encouraging all to know their status.

After testing positive people can change their behavior in positive and negative ways, but staff mainly expressed their concern about negative behavior change. They described that many people deliberately continue spreading HIV. Furthermore there are structural factors that limit people’s options for behavior change, such as unequal gender relations, poverty, limited availability of condoms and limited openness about sexuality among youth. Addressing these factors and proper counseling are therefore of vital importance to promote positive behavior change and prevent further infections. This is particularly important when RCT is to be further expanded. Otherwise there is a risk of creating a group of desperate people who know their status, but have no options to care for themselves and others.

Although staff described a general trend towards more openness, their personal experiences show that disclosure of a HIV positive test result can still be very difficult. As a result of increased support and availability of ART, NGO staff, especially in HNU, described increased disclosure in the
community. Especially women seemed eager to disclose in order to be able to join a group and receive support. However, these are examples of disclosure towards community workers in order to receive benefits. Staff’s personal experiences revealed more difficulties, probably resulting from feared stigma. Furthermore, whether a HIV diagnosis is shared depends on interpersonal relations.
The VCT day in HNU

Fig. 26 (top left) Registration at the VCT day of HNU.

Fig. 27 (middle) Group sensitization by a counselor of AIC at the start of the VCT day.

Fig. 28 (bottom left) Counselor talking to a patient.

Fig. 29 (bottom right) Patients gathering around a counselor to get their test results.
8. CONCLUSION

In this final chapter I provide an answer to my main research question ‘To what extent and how do WPPs in Ugandan NGOs contribute to HIV prevention through reduction of stigma and discrimination, increased utilization of VCT services and disclosure of people’s HIV status, and what is the relation between stigma, VCT usage, disclosure and HIV prevention?’ First, a multilevel perspective is applied to describe the context of the WPPs, which is helpful to determine the extent to which WPPs contribute to HIV prevention. For each level I will indicate how factors contribute to the WPP or provide constraints. Second, I describe how the WPPs contribute to stigma reduction, increased usage of VCT and disclosure. Third, the mutual relations between stigma, VCT and disclosure, and their impact on HIV prevention are explored. Then I combine the three components to provide a comprehensive answer to my main research question. Finally the recommendations that can be drawn from this study are presented.

8.1 Multilevel influences

In order to understand the way WPPs work in local Ugandan NGOs, influences at the international, national, local, organizational and individual level need to be considered. Internationally, HIV/AIDS WPPs should be seen in a context where HIV/AIDS is considered a major public health issue. This has stimulated scientific research to develop ART and rapid HIV tests, which, combined with an international lobby to make ART available in resource limited settings (Hardon 2005), increased the availability of these services in Uganda. Furthermore, international organizations, like the ILO and SAN! recognized the importance of addressing HIV/AIDS at the workplace (ILO 2001, Holden 2006), which resulted in the initiative of SAN! to support partner NGOs in Uganda to develop WPPs. Stigma and discrimination are considered core intervention areas (UNAIDS 2008) so they have become important elements of HIV/AIDS WPPs. With regard to HIV testing, there is an ongoing movement towards increased RCT, albeit with the patient’s consent (WHO). ‘Beneficial disclosure’ is promoted by UNAIDS and the WHO to help PLHA to get support and to open up the epidemic (UNAIDS 2000).

Looking from a different angle, HNU and FURA depend on international donors to sustain their organization. While HNU managed to secure funds, this meant a struggle for survival in FURA. This also had consequences for FURA’s WPP, because staff were frequently absent, due to the shortfall in projects and lack of salaries, and therefore unable to benefit from the WPP. In both FURA and HNU problems with donor funding were recognized with regard to the provision of health insurance. International donors are usually not prepared to pay for expensive health insurance and they don’t commit themselves for long enough to provide sustainable funds for healthcare of the staff. Even when the Good Donorship Guidelines are applied (Holden 2006), donors should commit to support an organization for three years, while the manager of HNU expressed that a period of five years should be
secured in order for health insurance to be sustainable. In addition, the guidelines estimate that 4% of the payroll is needed to support organizations with a WPP, which is not enough to cover for health insurance.

At the national level, there are many facilitating factors for stigma reduction, increased usage of VCT, disclosure and HIV prevention, but also some constraints. First of all, the Ugandan government has always been very active in addressing the HIV/AIDS epidemic through IEC campaigns, which advocated for the ABC approach, HIV testing and compassion for PLHA (Kinsman 2008, Kaleeba et al. 2000). Second, the government and many NGOs make an effort to provide services for HIV/AIDS throughout Uganda (Parkhurst & Lush 2004). According to NGO staff, this has facilitated HIV testing and encouraged people to disclose because then they can receive treatment and other benefits. In addition staff felt that the availability of ART has reduced stigma, because people no longer show signs of sickness and can still be productive. This is in line with the findings of Castro & Farmer (2005) in Haiti, which show that introduction of quality HIV care can lead to a rapid reduction of stigma and discrimination. Furthermore, RCT is an increasingly common practice, which has made several NGO staff members take a HIV test, especially women who are tested as a part of antenatal care, and was said to have created increased acceptance of HIV testing. However, gender inequalities are described as a persisting problem in Uganda (Koenig et al. 2004), which compromises women’s options to protect themselves (Kipp et al. 2002). Furthermore, laws that forbid sex among people under eighteen and Christian norms that condemn pre- and extramarital sex make sexuality taboo and fuel stigma. Especially young, unmarried staff expressed fear to become associated with immoral behavior if they would be HIV positive. This example illustrates the dependence of stigma on power (Link & Phelan 2001), for it shows how dominant institutions in Uganda, like the Church, determine the undesirability of behavior that is associated with HIV/AIDS.

At the local level increased services for HIV/AIDS facilitated the WPPs. In both Kasese and Soroti services for HIV testing and care were readily available. While NGO staff in Kasese had to pay either a small fee at the clinic or transport to the government hospital, Soroti had an abundance of free services for HIV/AIDS. These services can be seen as a result of international, national and local efforts and they provide good opportunities for NGOs to link their staff to existing services. This was how the WPP of HNU secured access to ART. In addition the abundance of organizations working on HIV/AIDS provides possibilities to invite external experts, as HNU did with the organization of the VCT day.

Factors at the organizational level both facilitated and impaired the WPP. First, the organizations’ activities in the community comprised working with PLHA. This was especially true for HNU, while FURA had less programs for PLHA specifically. This helped to reduce stigma and staff of HNU did not associate HIV with death and decreased productivity as much as their counterparts in FURA. In addition, both organizations already had some provisions for medical care, though FURA may have lacked the finance to materialize these when necessary. The organization
culture was another influence, which encouraged friendly interaction among staff in both organizations and although some of the stories staff shared illustrated continuous gender inequality in Uganda, this could not be observed at the workplace. However, limited motivation among FURA staff, due to limited resources, impaired the impact of the WPP, for staff were often not in office during discussions about HIV/AIDS and they did not feel involved in the WPP. Furthermore, staff may have been less interested because there were no PLHA among them and they had already received a lot of information through other channels. In HNU the amount of time available for discussion about HIV/AIDS was limited by their busy schedule. Finally, both organizations worked with staff based in the field who were less likely to benefit from the WPP.

Finally it is important to mention factors at the individual level that have their influence on the WPP. The fact that most of the NGO staff were highly educated made it possible to have discussions at workplace without requiring external expertise. In HNU some staff members were even medically trained. Furthermore, women may have been empowered by their education, thereby reducing gender inequalities at the in- and outside the workplace. Good interpersonal relations also had a positive impact on the WPP, for it encouraged disclosure and informal conversations.

8.2 How does the WPP contribute?

The WPP contributed to stigma reduction by providing clear guidelines and encouraging discussion. By making a clear statement that stigma and discrimination are not tolerated at the workplace, the WPP assured that employees could not be sacked from the job on the basis of a HIV positive status. Furthermore, the HNU staff who was living with HIV felt that these regulations made sure she was treated like any of her colleagues. Reidpath et al. (2005) argue that talking about HIV/AIDS within social networks helps to reduce stigma and Campbell et al. (2005) promote critical thinking as a way to fight stigma and discrimination. Both of these mechanisms apply to the WPP, which encourages communication at the workplace. The main reasons why HIV is such a stigmatized condition are the association with immorality and death (Ibid; Ogden & Nyblade 2005). These associations still appeared to be rooted in staff’s thinking. The fear to become associated with immorality prevailed, especially among young, unmarried staff and the views of FURA staff still revealed a strong association between HIV and death or decreased productivity. Among HNU staff this association was less commonly expressed, probably because they had seen more positive examples of PLHA in the community as well as in their own workplace. However, especially in FURA, but also in HNU, discussions created more openness about sexuality and they made people more aware that PLHA can still be productive, thereby reducing stigma. A risk of WPPs is that they increase stigma through positive discrimination. By singling out HIV/AIDS and providing separate services for infected staff, other staff members may feel as if they are bypassed, which may cause negative feelings towards HIV positive staff.
The WPP contributed to increased uptake of VCT through discussions, guaranteeing support and the organization of a VCT day. The stages of change model (Elder et al. 1999) can be useful to look at the effects of the WPP on staff’s utilization of VCT, because it acknowledges that behavior change does not happen overnight. Some staff members reported that discussions at workplace or a training by the SAN! project had made them realize the need to test themselves, so they may have moved from a stage of precontemplation to contemplation. However, not everyone was appealed by discussions at the workplace. Another often mentioned factor that encouraged HIV testing was increased support for PLHA. By guaranteeing non-discrimination and support the WPP can thus make staff more confident to test themselves. The initiative of the SAN! project to organize a VCT day boosted awareness, but it did not pull in those staff members who had prior doubts about testing. Therefore, the VCT day may have stimulated people who were already in a stage of preparation to take a HIV test, but it could not convince those who were still in precontemplation or contemplation. This was probably due to limited involvement and prior sensitization of staff, as well as lack of privacy and time for good quality counseling during the VCT day.

The WPP encourages disclosure by ensuring non-discrimination and support. Paxton (2002) described that in order for people to disclose, a conducive environment is needed. WPPs created this through guarantees of non-discrimination and increased communication at the workplace, which, according to staff, created space for people to disclose. Furthermore, empirical models of the individual describe how behavior change is encouraged by expected support (Aggleton et al. 1994; Elder et al. 1999, Good 1994: 56). This corresponds to NGO staff’s pragmatic view on disclosure, which entailed that they would disclose when they required support and expected benefits. In addition, the manager of HNU felt that staff only needed to disclose when the disease interfered with their work. Like with other health problems disclosing to others is not necessarily the first thing to do. The views of NGO staff thus correspond largely to the international discourse on disclosure. However, the promotion of beneficial disclosure, as described by UNAIDS (2000), is meant to come to the advantage of individuals and communities, while NGO staff focused on individual benefits. To ensure support, HNU linked HIV positive staff to existing services, while FURA was in the process of organizing health insurance.

8.3 Mutual relations

The final part of my research question looks at the relations between stigma, VCT, disclosure and HIV prevention. Since my answers are derived from research among NGO staff, these relations should be placed in the context of their work and life environment.

Stigma was a frequently mentioned barrier to VCT and disclosure. What withheld people from testing was the fear to become stigmatized if they would test positive and the fear to become traumatized. Feared stigma is caused by associations with death and immoral sexuality. Although
these associations were still present in the NGOs, the increasingly open environment enabled people to take condoms from the workplace, thereby facilitating HIV prevention. The fear to become traumatized can be explained as fear of self stigma, because it entails that people fear to get worried and think little of themselves. Going for a HIV test and receiving positive results may indeed cause self stigma when people are not counseled properly. The way staff members looked at HIV, as a deadly disease which will prevent you from carrying out your plans for the future, will cause heavy self stigma when these ideas are not rectified. On the other hand, proper counseling has the potential to help people overcome these fears and reduce self stigma. In relation to disclosure, stigma can be a major barrier, because staff members expressed fear of status loss through the association of HIV with immoral behavior. Furthermore, staff’s experiences with enacted stigma, for example colleagues who gossip or talk about PLHA in a negative way, discouraged disclosure.

On the other hand, once people disclose they can set a positive example of living a normal life with HIV and get support. Staff members of HNU, who had more experience with PLHA, did not associate HIV/AIDS as much with death as FURA staff. Therefore, disclosure can help to reduce other people’s self stigma and fear to become traumatized, thereby also encouraging people to take a HIV test. According to NGO staff, the risk of suffering from enacted stigma was limited. In FURA, stigma at the workplace was said to have been eradicated, but some HNU staff reported how colleagues still talked in a negative way about PLHA sometimes. On the other hand, people who had disclosed were likely to get support, and being open enabled them to use services for HIV. This contributes to HIV prevention, because treatment reduces the viral load and thereby a person’s likeliness to infect other people. Staff members in HNU described how they supported their HIV positive colleague, for example by getting drugs for her.

There are two sides to the effects of HIV testing. Knowing your status is a necessity for disclosure which can encourage HIV prevention. Furthermore, HIV testing, and counseling in particular, may encourage people to protect themselves and others, after testing negative as well as positive. However, changing behavior is not always easy. Structural factors, such as poverty, gender inequality and limited availability of condoms may limit people’s options for behavior change. This was often the case in the communities and staff also shared experiences of this within their close environment (chapter 7). In addition, staff reported that some people deliberately continue spreading HIV when they are positive because ‘they don’t want to die alone’. Proper counseling is thus very important to initiate behavior change aimed at HIV prevention, because it can make people aware of their options to care for themselves and encourage them to protect others.

8.4 Final conclusion

Amidst all the influences from different levels, the effect of the WPP is limited, but it certainly has an added value. International and national efforts to combat HIV/AIDS have preceded the SAN! project
and issues like stigma and discrimination, HIV testing and disclosure had already been addressed frequently in Uganda. In addition the work of NGO staff and their education created high levels of awareness on HIV/AIDS. WPPs have added to this by making explicit that the workplace should offer a conducive environment for PLHA as well as a platform to prevent HIV/AIDS. By increasing communication at the workplace, the WPP is one factor that encourages people to think critically about HIV/AIDS, reduce stigma, go for VCT or disclose. Furthermore activities, such as the VCT day, boosted awareness among staff and some also took the opportunity to test. The combined efforts against HIV/AIDS on several levels strengthen the WPP, because they allow for NGOs to link staff to existing services, as HNU did, which is a very sustainable way of dealing with HIV at the workplace. On the other hand, the effects of WPPs are limited by several problems at different levels. The functioning of the organization was particularly influential. Structural factors at the national level, like the deeply rooted association of HIV with immoral behavior and death, the taboo on pre- and extramarital sex and the lack of affordable health insurance in Uganda, also constrained the WPP. However, the open discussions about sexuality at the workplace illustrate how the WPP has created an environment that is slightly more progressive than society at large. Furthermore, NGO staff influence other levels by communicating their knowledge and attitudes towards HIV/AIDS in the communities where they work and in their personal circle of family and friends.

My results mainly show the mutual relations between stigma, VCT and disclosure, but it is more difficult to draw conclusions on the relation with prevention. Stigma indirectly influences HIV prevention through its effect on VCT and disclosure, while the reduced taboo on condom usage and talking about sexuality at the workplace directly influenced HIV prevention by facilitating condom use among staff. A vicious circle can be visualized upon examining the relation between stigma and disclosure. Stigma leads to fear to open up and the resulting silence on HIV/AIDS reinforces stigma. However, once people disclose, they break through this cycle by providing a positive example of living a normal life with HIV. This reduces stigma that is caused by the association with death and therefore people’s fear to go for VCT may subside. Disclosure can have a direct influence on HIV prevention by allowing PLHA to seek treatment and counseling on how they can change their behavior in a way that protects themselves and others. Naturally HIV testing is required before someone can disclose, but the direct relation between VCT and prevention is ambiguous, for VCT can initiate both positive and negative behavior change, and is probably influenced by the quality of counseling.
8.5 Recommendations

Based on the findings of this study, I want to give some recommendations to local Ugandan NGOs, the SAN! project that supports them and policymakers at national and international levels. With these recommendations I aim to contribute to the effectiveness of WPPs and other HIV/AIDS related programs.

Local NGOs

- Overcome time constraints by reducing the amount of discussions, but invest in organizing a few discussions of good quality, for example by inviting a guest speaker. On such an occasion efforts should be made to make sure all staff can attend.
- Use existing services as much as possible, because this ensures sustainable access to HIV/AIDS care. Relying on international donors, on the other hand, creates dependence that may not be sustainable. Furthermore, the abundance of HIV/AIDS service providers creates many opportunities to invite people from outside the workplace, counselors or HIV patients for example, to come and discuss HIV/AIDS.
- In order to resolve stigma at the workplace, the root causes of stigma need to be addressed. This can be done by discussing and challenging the associations people have with HIV/AIDS.
- To encourage disclosure at the workplace, the WPP should be clear about non-discrimination and the support that HIV positive staff can expect.
- When organizing a VCT day, or other events related to the WPP, involve all staff and explore their needs, in order to offer a suitable program. In addition, on a VCT day privacy and good quality of services should be guaranteed.

The SAN! project

- When supporting local NGOs in the development of a HIV/AIDS WPP consider what is feasible in a setting of limited funds and time constraints. Take care not to create false expectations, especially with regard to the amount of funding NGOs will receive, in order to prevent disappointments.
- Evaluate thoroughly what is needed. Staff attributed most value to the part of care and support, but in NGOs with a small number of staff, the number of PLHA among them is automatically limited. Therefore, I found that the need for an improvement in general human resource management, especially with regard to health insurance, was more urgent.
- Consider the ethics of a VCT day carefully before stimulating partner organizations to organize such an event. My observations during the VCT day in HNU showed that the large
number of people who tested compromised the quality of counseling and privacy was difficult
to guarantee.

Policymakers on organizational, national and international levels

- Be aware of the risk of initiating positive discrimination when targeting programs at
  HIV/AIDS specifically. A WPP for HIV/AIDS singles out this disease and neglects other
  health problems that burden staff, such as malaria. It prevents HIV/AIDS from becoming a
disease like any other, thereby possibly fuelling stigma.

- Avoid vertical programs for HIV/AIDS that result in services being located in separate clinics,
because this makes patients easily recognizable and vulnerable for stigmatization.

- Ensure enough resources and staff when increasing RCT services in order to provide adequate
  counseling and follow up after testing.

- Take into account structural constraints to behavior change, such as poverty and gender
  inequality, as a background against which the ethics of increasing RCT should be considered.
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<thead>
<tr>
<th>Abbreviation</th>
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<tr>
<td>ACORD</td>
<td>Agency for Cooperation and Research in Development</td>
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<td>AIC</td>
<td>AIDS Information Center</td>
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<td>AIDS</td>
<td>Acquired Immuno Deficiency Syndrome</td>
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<td>ADF</td>
<td>Allied Democratic Forces</td>
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<td>ART</td>
<td>Anti Retroviral Treatment</td>
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<td>ARV</td>
<td>Anti Retroviral</td>
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<td>BMCF</td>
<td>Bishop Masereka Christian Foundation</td>
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<tr>
<td>CBT</td>
<td>Community Based Trainer</td>
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<tr>
<td>CEO</td>
<td>Chief Executive Officer</td>
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<td>cFPP</td>
<td>Community Focal Point Person</td>
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<tr>
<td>CSO</td>
<td>Civil Society Organization</td>
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<td>DRC</td>
<td>Democratic Republic of Congo</td>
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<td>FC</td>
<td>Foundation Course</td>
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<td>FPP</td>
<td>HIV and AIDS Focal Point Person</td>
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<td>FURA</td>
<td>Foundation for Urban and Rural Advancement</td>
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<tr>
<td>HC</td>
<td>Health Centre</td>
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<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<td>HNU</td>
<td>Health Need Uganda</td>
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<tr>
<td>ICCO</td>
<td>Interchurch Organisation for Development Co-operation</td>
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<td>IDMC</td>
<td>Internal Displacement Monitoring Centre</td>
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<td>IDP</td>
<td>Internally Displaced People</td>
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<tr>
<td>IEC</td>
<td>Information Education and Communication</td>
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<td>ILO</td>
<td>International Labor Organization</td>
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<tr>
<td>JCRC</td>
<td>Joint Clinical Research Centre</td>
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<td>LPG</td>
<td>Local Project Group</td>
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<td>LRA</td>
<td>Lord’s Resistance Army</td>
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<td>MTCT</td>
<td>Mother To Child Transmission</td>
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<tr>
<td>NACWOLA</td>
<td>National Community for Women Living with HIV/AIDS</td>
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<tr>
<td>NGO</td>
<td>Non-Governmental Organization</td>
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<tr>
<td>NSSF</td>
<td>National Social Security Fund</td>
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<td>PEPFAR</td>
<td>The US President’s Emergency Plan For AIDS Relief</td>
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<tr>
<td>PLHA</td>
<td>People living with HIV/AIDS</td>
</tr>
<tr>
<td>PMTCT</td>
<td>Prevention of Mother To Child Transmission</td>
</tr>
<tr>
<td>KCCL</td>
<td>Kasese Cobalt Company Ltd.</td>
</tr>
<tr>
<td>RCT</td>
<td>Routine Counseling and Testing</td>
</tr>
<tr>
<td>SAN!</td>
<td>STOP AIDS NOW!</td>
</tr>
<tr>
<td>SONASO</td>
<td>Soroti Network of AIDS Service Organisations</td>
</tr>
<tr>
<td>STI</td>
<td>Sexually Transmitted Infection</td>
</tr>
<tr>
<td>TASO</td>
<td>The AIDS Support Organization</td>
</tr>
<tr>
<td>UAC</td>
<td>Uganda AIDS Commission</td>
</tr>
<tr>
<td>UGX</td>
<td>Ugandan Shilling</td>
</tr>
<tr>
<td>UNAIDS</td>
<td>United Nations Joint Programme on HIV/AIDS</td>
</tr>
<tr>
<td>UNDP</td>
<td>United Nations Development Program</td>
</tr>
<tr>
<td>UNICEF</td>
<td>United Nations Children’s Fund</td>
</tr>
<tr>
<td>VCT</td>
<td>Voluntary Counselling and Testing</td>
</tr>
<tr>
<td>VHT</td>
<td>Village Health Team</td>
</tr>
<tr>
<td>VSLA</td>
<td>Village Savings and Loans Association</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
<tr>
<td>WPP</td>
<td>HIV and AIDS Workplace Policy</td>
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The photographs in this thesis were made by me during my research.
**Appendix 1: Background respondents**

**FURA staff**

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Function</th>
<th>Duration of employment</th>
<th>Background</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kabale</td>
<td>34</td>
<td>Project officer</td>
<td>2.5 years</td>
<td>Bachelor in social sciences, did research for another NGO before joining FURA.</td>
</tr>
<tr>
<td>Alvin</td>
<td>25</td>
<td>Volunteer</td>
<td>10 months</td>
<td>Degree in development studies.</td>
</tr>
<tr>
<td>Solomon</td>
<td>38</td>
<td>Project officer</td>
<td>10 months, but also worked with FURA from 2000-2002</td>
<td>Degree in geography and sociology, postgraduate diploma in human resource management. Worked with National Forest Authority.</td>
</tr>
<tr>
<td>Isaac</td>
<td>24</td>
<td>Volunteer</td>
<td>8 months</td>
<td>Diploma in water engineering, worked on project of Mbale floods.</td>
</tr>
<tr>
<td>Susan</td>
<td>25</td>
<td>Volunteer, worked as CBT</td>
<td>5 years</td>
<td>Diploma in social works, worked on FURA project of sustainable livelihoods.</td>
</tr>
<tr>
<td>Lydia</td>
<td>45</td>
<td>On call, gives technical advise in case of a disaster</td>
<td>2 years</td>
<td>Nurse midwife, works with the community health department which has a partnership with FURA</td>
</tr>
<tr>
<td>Charles</td>
<td>38</td>
<td>CEO</td>
<td>15 years</td>
<td>Diploma in human resource management and development.</td>
</tr>
<tr>
<td>Mark</td>
<td>45</td>
<td>Administrator, human resource manager</td>
<td>8 years</td>
<td>Accountant, worked with various NGOs and the government.</td>
</tr>
<tr>
<td>Steven</td>
<td>34</td>
<td>Volunteer, worked as assistant CBT</td>
<td>1.5 years</td>
<td>Diploma in project planning and management, worked with various NGOs.</td>
</tr>
<tr>
<td>David</td>
<td>34</td>
<td>Assistant accountant</td>
<td>4 years</td>
<td>Diploma in business studies, worked with another NGO.</td>
</tr>
<tr>
<td>Stella</td>
<td>21</td>
<td>Office attendant</td>
<td>2 months</td>
<td>Finished 4th class in secondary school.</td>
</tr>
<tr>
<td>Flora</td>
<td>25</td>
<td>Volunteer, worked as CBT</td>
<td>2.5 years</td>
<td>Diploma in social work, started as an intern with FURA and came back after finishing her studies.</td>
</tr>
<tr>
<td>Anton</td>
<td>34</td>
<td>Project officer</td>
<td>4 years</td>
<td>Bachelor of arts, major in economy and geography. Worked with various NGOs.</td>
</tr>
<tr>
<td>Roger</td>
<td>34</td>
<td>Research and documentation</td>
<td>2 years</td>
<td>Diploma in development studies. Worked with the district.</td>
</tr>
</tbody>
</table>
officer development network as a researcher.

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Function</th>
<th>Duration of employment</th>
<th>Background</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jackie</td>
<td>30</td>
<td>Project officer, FPP</td>
<td>10 months</td>
<td>Degree in social sciences.</td>
</tr>
</tbody>
</table>

### HNU staff

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Function</th>
<th>Duration of employment</th>
<th>Background</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rose</td>
<td>36</td>
<td>Secretary</td>
<td>9 years</td>
<td>Used to work as a cashier in a photocopy shop.</td>
</tr>
<tr>
<td>Christine</td>
<td>50</td>
<td>Assistant project manager</td>
<td>10 years</td>
<td>Worked with the government. Started in HNU as an office messenger, but was promoted to field assistant and eventually to assistant project manager.</td>
</tr>
<tr>
<td>Moses</td>
<td>30</td>
<td>Driver</td>
<td>3 years</td>
<td>Studied mechanics, worked for the government.</td>
</tr>
<tr>
<td>Didas</td>
<td>42</td>
<td>CEO</td>
<td>11 years</td>
<td>Economist, worked as a teacher and with another NGO.</td>
</tr>
<tr>
<td>Geoffrey</td>
<td>27</td>
<td>Project officer</td>
<td>1 year</td>
<td>Doctor, worked with other NGOs.</td>
</tr>
<tr>
<td>Lore</td>
<td>29</td>
<td>Project officer</td>
<td>3 years</td>
<td>Diploma in development studies.</td>
</tr>
<tr>
<td>Morine</td>
<td>35</td>
<td>Project officer</td>
<td>9 years</td>
<td>Nurse by profession.</td>
</tr>
<tr>
<td>Marianne</td>
<td>40</td>
<td>Administrator, FPP</td>
<td>10 years</td>
<td>Business studies, worked as accounts assistant in two other organizations</td>
</tr>
<tr>
<td>Alex</td>
<td>26</td>
<td>Office attendant</td>
<td>6 years</td>
<td>Studied for his diploma in public finance and management.</td>
</tr>
</tbody>
</table>
Appendix 2: Observation checklist

- **Within the workplace**
  - Social intercourse between members of the staff
  - Type of work (specific risks for contracting HIV)
  - Availability of information about HIV/AIDS, VCT services or condoms
  - Availability of the WPP document

- **At project group meetings or workshops**
  - Social intercourse between members of staff
  - Communication about HIV/AIDS and PLHA (myths, gossip)
  - Equal representation of different types of staff
  - Equal opportunities to share opinions and be heard

- **At the VCT service**
  - Location, setting; related to existing health facilities or separate
  - Organisation; possibility to make appointments, waiting time
  - Sanitary conditions
  - Where are patients received? Privacy?
  - Impression of confidentiality
  - Impression of attitudes of health workers and quality of services
  - Availability of information about VCT or ARVs
Appendix 3: Topiclist for interviews with NGO staff

- **Introduction**
  - Introduction of myself, the aim of my research and rules of the interview: confidentiality, autonomy
  - Explain my relation with the applied research team
  - Ask permission for recording
  - Ask if there are any questions
  - Work history: how did you come to work in this NGO? What kind of work do you do? What sort of contract do you have?
  - For senior staff members: How did the organization evolve over the years?

- **WPP on HIV/AIDS**
  - Is the WPP well known? How can you get access to the WPP? Did staff read it?
  - How did the process of developing and implementing the WPP go?
  - Did you feel there was a need to have a HIV/AIDS WPP?
  - What are the main effects of the WPP? Did it change things for you personally?

- **Health care and VCT**
  - How is healthcare organized in this area?
  - How are VCT services and access to ARVs organized in this area?
  - Are people willing to use these services? Is there a difference in usage between men and women?
  - Did you ever test for HIV? Why, or why not? Accessibility? Confidentiality? Treatment of patients and quality of services?
  - Do you think that the WPP contributes to increased usage of (or willingness to use) VCT? What is needed to increase usage of VCT?
  - Do you think VCT helps to prevent HIV? How?
  - What is the effect of increased RCT? (This question was added later during my research)

- **Communication about HIV/AIDS**
  - How do people in Uganda communicate about HIV/AIDS
  - How do people communicate about HIV/AIDS at the workplace?
  - Has communication about HIV/AIDS changed since the implementation of the WPP?
    - Increased communication? Increased openness? At workplace and or in other social settings?
    - Are there (routine) meetings to discuss HIV/AIDS? What topics are discussed then? VCT, stigma, disclosure?
    - Is there a confidential adviser to talk about HIV related problems?
    - If you or a family member would fall ill or test HIV positive, would you talk about it with someone at the workplace? Why, or why not?
• **PLHA, stigma and disclosure**

  - How are PLHA treated in Uganda?
    - Do you know someone with HIV? How are they treated? Do they suffer from stigma and discrimination? How? In which environment (family, community, social services)?
    - Can PLHA be open about their serostatus?
    - Is there a difference in treatment of HIV positive men or women?
    - Do/would you feel comfortable if others knew that your friend/relative is HIV positive? How do people respond to that?
  - How are PLHA treated at the workplace?
    - Do you think PLHA would be at risk of losing their job?
    - Do you think PLHA would be at risk of suffering from stigma or discrimination at the workplace?
  - Contribution/influence of the WPP?
    - Which provisions are incorporated in the WPP to support HIV positive staff? Are there measures against stigma or discrimination? What do you think of this?
    - Did treatment of PLHA change since the implementation of the WPP?
    - How can the position of PLHA be improved? Can WPPs play a role?
  - How does VCT usage influence stigma and disclosure? Increased openness? Own experience, or friends’/relatives’ experiences?

• **Closure**

  - What challenges do you see with regard to HIV/AIDS in general?
  - Would you like to give any recommendations to improve the WPP, or the implementation of the WPP?
  - How do you feel about the interview?
  - What do you think of my idea to give a presentation to all members of the staff to give a general overview of my findings?
Appendix 4: Topic list for interviews with HIV/AIDS Service Providers

- Introduction of myself and the aim of my research.
- What kind of services do you offer?
- Are people willing to use these services?
- What is the policy with regard to RCT?
- Are people willing to take a HIV test? Why, or why not? Difference between men and women?
- Do you think VCT is effective as a prevention strategy?
- What are the main challenges you see with regard to HIV/AIDS?
- Are stigma and discrimination important problems?
Appendix 5: Topiclist for interviews with PLHA

- **Introduction**
  - Introduction of myself, the aim of my research and rules of the interview: confidentiality, autonomy
  - Ask permission for recording
  - Ask if there are any questions
  - Can you tell me something about your background?
  - How does HIV affect you?

- **Living with HIV/AIDS**
  - How does HIV affect you? What difficulties do you have?
  - How does your environment respond?

- **HIV testing and disclosure**
  - How did you decide to go for a HIV test?
  - Was it a difficult decision?
  - Do you think people are willing to test for HIV/AIDS? Difference in men and women?
  - Was it difficult for you to disclose to other people? Why, or why not?

- **Stigma and discrimination**
  - Do you think stigma and discrimination are important problems? Is there a change over time?
  - Do you have any personal experiences with regard to stigma and discrimination?
  - How can the position of PLHA be improved? Do you have any recommendations?
References

Aggleton P., K. O’Reilly, G. Slutkin & P. Davies

2007   Behavior change in clients of health centre-based voluntary HIV counselling and testing services in Kenya. *Sexually Transmitted Infections*. 83: 541-6

Asingwire N. & S. Birungi

A. Bass

BBC
2008   *Country Profile: Uganda.*
http://news.bbc.co.uk/1/hi/world/africa/country_profiles/1069166.stm

Birungi S., H.K.Nkalubo & Y.Fleming

Broere M. & P. Vermaas


Campbell C., Y. Nair, S. Maimane & J. Nicholson

Cassell M.M. & A. Surdo

Castro A. & P. Farmer

2008   *Protecting the next generation in Uganda: new evidence on adolescent sexual and reproductive health needs*. Guttmacher Institute, New York.
http://www.guttmacher.org/pubs/2008/03/05/PNG_Uganda_mono.pdf

Elder J.P., G.X. Ayala & S. Harris

Foundation for Urban and Rural Advancement

Foundation for Urban and Rural Advancement
2006a *Five year strategic plan*. Kasese.

Foundation for Urban and Rural Advancement

Foundation for Urban and Rural Advancement
2008 *Livelihoods Improvement Project*. Kasese.

Geest, van der S., J.D. Speckmann & P.H. Streefland

Goffman E.

Good, B.J.

Hadjipateras A., S. Abwola & H. Akullu
2006 Addressing stigma in implementing HIV/AIDS workplace policy. *INTRAC. PraxisNote No. 21*

Hardon A.

Health Need Uganda

Health Need Uganda

Health Need Uganda

Holden S.

Holzemer W. L. & L.R. Uys
Hovil L. & E. Werker  

Human Rights Watch  

Hutchinson A.B., B.M. Branson, A. Kim & P.G. Farnham  
2007a A meta-analysis of the effectiveness of alternative HIV counseling and testing methods to increase knowledge of HIV status. *AIDS.* 20:1597–604

Hutchinson P.L., X. Mahlalela & J. Yukich  

Internal Displacement Monitoring Centre  

International Labor Organization  

Jabs L.  


Kasese District  
2008 *Background information*  

Kasese District Local Government  

King R., D. Katuntu, J. Lifshay, L. Packel, R. Batamwita, S. Nakayiwa et al.  

Kinsman J.  
2008 *Pragmatic choices. Research, politics and AIDS control in Uganda.* Amsterdam: University of Amsterdam

Kipp W., G. Kabagambe & J. Konde-Lule  

Link B.G. & J.C. Phelan
2001 Conceptualizing stigma. Annual Review of Sociology. 27: 363-85

Matovu J.K.B. & F.E. Makumbi

Ministry of Health

Neema S. & W. Koster

Neema S. & W. Koster
2007 The views of staff regarding HIV and AIDS in the workplace in the SAN! partner organisations in Uganda. Quantitative report.

Neema S. & W. Koster
2008 Starting implementation of HIV and AIDS workplace policies by SAN! partner organizations in Uganda. Study report.

Ogden, J. & Nyblade L.

Overton S.L. & S.L. Medina
2008 The stigma of mental illness. Journal of Counseling & Development. 86(2):143-51

Parikh S.H.

Parkhurst J.O.

Parkhurst J.O. & L. Lush
Paxton S.  

Rao Gupta G.  
2000 *Gender, sexuality and HIV/AIDS: The what, the why and the how*. Speech at XIIIth International AIDS Conference. Durban, South Africa  

Reidpath D.D., K.Y. Chan, S.M. Gifford & P. Allotey  

Skinner D. & S. Mfecane  

Soroti District  
2008 *Background Information*.  

Uganda AIDS Commission  

Uganda AIDS Commission  
2007 *Accelerating HIV prevention. The road map to universal access to HIV prevention in Uganda*. Kampala

UNAIDS  
2000 *Opening up the HIV epidemic: Guidance on encouraging beneficial disclosure, ethical partner counselling, and appropriate use of HIV case reporting*. Geneva.  

UNAIDS  

UNDP  

UNDP  

Weinhardt L.S., M.P. Carey, B.T. Johnson & N.L. Bickham  
WHO

WHO

Wandofo D.

Wolff B., B. Nyanzi, G. Katongole, D. Ssesanga, A. Ruberantwari & J. Whitworth

2007 Culture and stigma: Adding moral experience to stigma theory. Social Science & Medicine. 64: 1524-35

Yates J., R. Cooper & J. Holland
ABSTRACT

To assist Ugandan non-governmental organizations (NGOs) in managing the impact of HIV/AIDS in the workplace, STOP AIDS NOW (SAN!) started a project in 2005, which provided support on the development and implementation of HIV/AIDS workplace policies (WPPs). This study is part of the evaluation of the SAN! project and addresses the following research question: To what extent and how do WPPs in Ugandan NGOs contribute to HIV prevention through reduction of AIDS related stigma and discrimination, increased utilization of voluntary counseling and testing (VCT) services and disclosure of people’s HIV status, and what is the relation between stigma, VCT usage, disclosure and HIV prevention? A multilevel perspective is applied to frame my findings in order to pay due respect to influences from the individual up to the international level. I conducted a qualitative study in two participating NGOs. My main informants were NGO staff, but I also talked with HIV/AIDS service providers and People Living with HIV/AIDS (PLHA) in the community. I conducted semi-structured interviews with these people and I also used documents analysis, participant observation, informal conversation and group discussion as research methods.

My findings show that amidst all the influences on different levels, the effect of the WPP is limited, but it certainly has an added value. On the one hand Uganda’s national efforts to provide information and create openness about the HIV epidemic, as well as staff’s educational and professional background created high levels of awareness. In addition, service providers for HIV/AIDS, often free of charge, were in the vicinity of both organizations. On the other hand, the general taboo on sexuality and the association of HIV with death appeared to be firmly rooted in Ugandan society, which constrained the WPP. The WPPs effects lied mainly in ensuring non-discrimination and support for PLHA and providing a platform for discussion, which encouraged staff to develop a more positive attitude to HIV/AIDS.

My results mainly show the mutual relations between stigma, VCT and disclosure, while it is more difficult to draw conclusions on the relation with prevention. The relation between stigma and disclosure can be seen as a vicious circle; AIDS stigma makes people fear to disclose a HIV positive status and the resulting silence reinforces stigma. However, disclosing is a way to break through this negative spiral, because then PLHA can provide positive examples, thereby reducing stigma, which also encourages VCT usage. Naturally VCT is a necessity for disclosure, but its relation to HIV prevention is not as straightforward, because awareness of a HIV positive status may cause people to change their behavior to protect themselves and other, but NGO staff reported that others deliberately continue spreading HIV/AIDS, because they don’t want to die alone.