



The AIDS Pandemic in Uganda: Social Capital and the Role of NGOs in Alleviating the Impact of HIV/AIDS

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To my wife, Juliet

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List of Acronyms

AAI	Accelerated Access Initiative
ABC	Abstain, Be careful and use Condom
ACD/VOCA	Agricultural Cooperative development International/Volunteers Overseas Cooperative Assistance
AIC	AIDS Information Centre
AIDS	Acquired Immune Deficiency Syndrome
AIM	AIDS Integrated Model District Programme
AMREF	African Medical and Research Foundation
ART	Anti-Retro-Viral Therapy
ARV	Anti-Retro-Viral
AWOLFS	AIDS, Widows, Orphans, Family Support
CAO	Chief Administrative Officer
CBOS	Community Based Organisations
CCM	Country Coordination Mechanisms
CDC	Centres for Disease Control and Partnerships (USA)
CEO	Chief Executive officer
CHAI	Community HIV/AIDS Initiatives
DACC	District AIDS Coordination Committees
DAFP	District AIDS Focal Person
DAI	Drug Access Initiative
DHE	District Health Educator
DHS	Directorate of Health Services
DDHS	District Directorate of Health Services
DSS	Director of Social Services
FIDA	Uganda Association of Women Lawyers
FPAU	Family Planning Association of Uganda
FUE	Federation of Uganda Employers
GBC	Global Business Coalition
GFFAMTB	The Global Fund to Fight AIDS, Tuberculosis and Malaria
GFPMU	Global Fund Project Management Unit
GPA	World health Organisation Global Programme on AIDS
GDP	Gross Domestic Product
GMHC	Gay Men's Health Crisis
GNP plus	Global network of people living with AIDS
HIV	Human Immunodeficiency Virus
HOD	Head of Departments
IAEN	International AIDS Economics Networks
ICASO	International Council of AIDS Service Organisations
ID	Institutional Development
IDPC	Internally Displaced People's Camps
IEC	Information Education and Communication
IGAS	Income Generating Activities
INGOs	International Non-Governmental Organisations
IPAA	International Partnership against AIDS in Africa
JCRC	Joint Clinical Research Centre

KWG	Kiswahili Women’s Group
LGDP	Local Government Development Programme
MAI	Makenke AIDS Initiative
MDLG	Mbarara District Local Government
MFI	Micro Finance Institutions
MFPED	Ministry of Finance Planning and Economic Development
MISD	Mbarara Institute for Social Development
MOH	Ministry of Health
MTCTH	Mother to Child Transmission of HIV
MUST	Mbarara University of Science and Technology
NACOSA	National AIDS Council of South Africa
NACWOLA	National community of Women Living with AIDS
NAPWA	National Association of People Living With HIV/AIDS
NGEN	National Guidance and Empowerment of People with HIV/AIDS
NGDO	Non-governmental Development Organisations
NGOs	Non-governmental Organisations
NHAP	National HIV/AIDS Partnership
NNGO	Northern Non-governmental organisations
NORAD	Norwegian Agency for Development Cooperation
NOTU	National Organisation of Trade Unions of Uganda
NSF	National Strategic Framework
OECD	Organisation for Economic Cooperation and Development
OD	Organisational Development
PACCS	Parish AIDS Coordination Committees
PEAP	Poverty Eradication Action Plan
PEPFAR	USA President’s Emergency Plan for AIDS Relief
PHA	People Having AIDS
PLI	Philly Lutaaya Initiative
PLWHA	People Living With HIV/AIDS
PMTCTH	Prevention of Mother-to-Child Transmission of HIV
POMU	Positive Men Union
PSI	Population Services International
PTA	Parents Teachers Association
PTC	Post Test Club
RATN	Regional AIDS Training Network
SACCS	Sub-county AIDS Coordination Committees
SDS	Service Delivery Surveys
SNGOs	Southern Nongovernmental Organisations
SPSS	Statistical Package for Social Scientists
STD	Sexual Transmitted Diseases
SWAP	Sector Wide Approach
TASO	The AIDS Support Organisation
TB	Tuberculosis
THETA	Traditional and Modern Herbal Practitioners Together Against HIV/AIDS
TREAT	Timetable for Regional Expansion of Antiretroviral Therapy
TV	Television
UAC	Uganda AIDS commission

UACP	Uganda AIDS Control Programme
UACS	Uganda AIDS commission Secretariat
UBS	Uganda Bureau of Statistics
UHRC	Uganda Human Rights Commission
UMA	Uganda Manufacturers Association
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNASO	Uganda National AIDS Service Organisations
UNCST	Uganda National Council of Science and Technology
UNDP	United Nations Development Programme
UNESCO	United Nations Educational, Scientific and Cultural Organisation
UNGASS	United Nations General Assembly Special Session on AIDS
UNHCO	Uganda National Health Consumer Organisation
UNICEF	United Nations Children's Education Fund
UNISD	United Nations Institute for Social Development
UPSAA	Uganda Private Sector Alliance on HIV/AIDS
USAID	United States Agency for International Development
UWESO	Uganda Women's Effort to Save Orphans
VACCS	Village AIDS Coordination Committees
VCT	Voluntary Testing and Counselling
VCTS	Voluntary Testing and Counselling Services
WHO	World Health Organisation
WLI	World Learning Inc

Summary of the Thesis

AIDS has a devastating impact on individuals and society. It is defined as Acquired Immune Deficiency Syndrome and it is a condition caused by the Human Immunodeficiency Virus (HIV). This condition occurs when people who have lived with HIV for a long time lose their immunity and become susceptible to various opportunistic infections. AIDS often results in death. At present, there is neither a vaccine against HIV nor a cure for AIDS. Apart from the numerous deaths it causes, HIV/AIDS has other related problems, including increased dependence, deepening poverty and reduced households' incomes, social discrimination, and depletion of national finances and human resources. Some of these problems have their own implications and often result in other AIDS-related problems; for example, social discrimination, especially of people infected with HIV, may result into stigmatisation, which in turn may prevent them from seeking treatment, care and support for fear of further discrimination. The purpose of this study is to explore the role of non-governmental organisations (NGOs) in alleviating HIV/AIDS-related problems in Uganda.

This study argues that the causes of the widespread of HIV are rooted in the social, economic and political conditions of different communities, such as gender relations¹, culture, poverty and policies among others. These not only perpetuate the spread of HIV, but also limit the care provided for AIDS patients, minimise the effect of prevention and control approaches, and increase the overall negative impact of HIV/AIDS (Wilson 2004). Thus, this study argues that the challenges of HIV/AIDS cannot be successfully addressed unless issues of gender relations, poverty, etc are dealt with. Thus, in addition to medical approaches, addressing the challenges of HIV/AIDS requires approaches that take into consideration the social, economic and political environment in which people live (Barnett and Whiteside 2002; O'Manique 2004; Seckinelgin 2004). Strengthening social relations and the way people live with others is one way such challenges could be addressed. Thus, this study argues that successful fight against HIV/AIDS by NGOs depends on social relations between individuals, groups and organisations.

¹ For the purpose of this study, gender will be considered as production and consumption, social and political relations between men and women.

The importance of social capital in improving people's welfare and health conditions is well documented (Szreter and Woolcock 2004)². In this thesis, social capital is considered to be the networks and associated resources. The study argues that networks are embedded with resources which can be utilised to generate benefits that would improve people's health conditions. The reason for adopting this conceptualisation is that there are many kinds of networks. However, not all networks are embedded with resources that enable cooperative behaviour and facilitation of the transfer of network benefits to individuals and groups.

The transfer of different kinds of network benefits from one person to another or from groups and individuals to the community is facilitated by formal and informal interaction between different individuals and groups. Such interaction makes it possible for a social problem such as HIV/AIDS to be addressed. For example, networks and information embedded in them, facilitate communication, social support, psychological counselling and sharing of experiences that benefit the individuals and communities affected by HIV/AIDS. It is for these particular reasons that the study argues that HIV/AIDS-related problems can be alleviated through strengthening social relations between individuals, groups, communities and organisations.

There are over 1,000 NGOs, including community based organisations (CBOs), involved in different HIV/AIDS-related activities in Uganda. This study focused on two of these: The AIDS Support Organisation (TASO) and Post Test Club/Philly Lutaaya Initiative (PTC/PLI). These NGOs are engaged in different HIV/AIDS activities in Uganda. These NGOs were purposively selected because of the uniqueness of their activities, which stress strengthening social relations between their members/clients, groups and the community (see 5.4).

The study was carried out in the district of Mbarara of Western Uganda, which in 1991 had a prevalence rate of HIV/AIDS of about 24.3%, and in 2001 had a prevalence rate of only about 10.8%. Uganda has in recent years registered marked declines in the HIV/AIDS prevalence rate. The rate declined from about 18% in 1991 to about 6.2% at the end of 2002. Compared to the general situation in Uganda, the trends in prevalence rate in Mbarara district may be

² A detailed discussion on the importance of social capital in social, economic and political development may be found in chapter 2.

representative for the country. This was the major reason³ for selecting Mbarara district as an area for this study.

A variety of qualitative and quantitative methods were employed, including interviews, focus group discussions, observations and secondary sources (chapter 3). Data were gathered on a number of variables, including types of networks and frequency of interaction among different categories of people, as well as what they talk about, who they interact with, and the extent of their involvement in NGOs activities. Data were also collected from government officials employed in the district directorate of health.

The study answers the following main research questions.

(a) What role do HIV/AIDS NGOs⁴ play in alleviating HIV/AIDS related problems in Uganda? Specifically the study examines the roles played by TASO and PTC/PLI in fighting HIV/AIDS in the Mbarara district of Western Uganda. In order to answer this question the main approaches employed by these NGOs have been examined. The thrust of the study is on examining the process by which these NGOs fight HIV/AIDS. The study argues that in order to alleviate the impact of HIV/AIDS, it is necessary that social relations at both individual and community levels be strengthened.

(b) What factors influence the performance of NGOs in alleviating the impact of HIV/AIDS in Uganda? How do NGOs feature in government programmes? Does the government play a role in facilitating social capital formation, and consequently in NGO performance in addressing HIV/AIDS' challenges?

In order to answer the above questions, the study examines the structures of NGOs, their relationships with other actors and the overall social and political environment in which they

³ See, chapter 3(3.2) for a discussion on the reasons for choosing an area for the study.

⁴ These are Non-Governmental Organisations engaged in fighting HIV/AIDS

operate. In particular, the way NGOs and the state relate⁵ to each other in fighting HIV/AIDS is analysed.

In Uganda, social relations at family⁶ and community levels have declined due to HIV/AIDS (Barnett and Whiteside 2002; Kayazze 2002; Marshall and Keough 2004). In addition, the government is under pressure to privatise the public health sector, so its direct involvement in fighting HIV/AIDS is limited to activities emphasising prevention and individualised responses (O'Manique 2004). Prior to the outbreak of AIDS in Uganda, families, neighbours and community were the providers of social, financial and psychological support, and were the safety nets during hard times, such as loss of employment (Kayazze 2002; Keough 2004; Marshall and Keough 2004; Tumwesigye 2003). Similarly, since the government infrastructure and officials were distributed in different parts of the country, this placed them in an ideal position to fight AIDS more successfully, if these facilities are well utilised. I have therefore, argued that synergy between government and HIV/AIDS NGOs is important in the generation of social capital needed for HIV/AIDS mitigation. In this context, I have explored the role of public institutions in facilitating the generation of social capital and consequently the extent to which NGOs alleviate the impact of HIV/AIDS in Uganda. In addition, I have argued that a partnership between government and civil society organisations, including NGOs, is more important in alleviating the impact of HIV/AIDS than individual actors.

In order to examine the contributions of the public sector and NGOs in facilitating the development of social capital, the study inquires how social capital is generated and maintained. The answer lies in the NGOs ability to mobilise local social networks at community and family levels. In addition, they are linked to the government, to business organisations and to international donors. These linkages facilitate the mobilisation of finances for their activities. The public sector, on the other hand, plays an important role, for example, in the provision of infrastructure and an environment that facilitates interaction, communication and correspondences between different actors. The role of political leadership, mobilisation of

⁵ See complementarity and embeddedness in chapter 2

⁶ The concept of family is voluminous and is used in many contexts. For the purpose of this thesis and in Ugandan context, a family refers to the people who are closely related to one another; husband and wife, their children and close relatives, such as brothers, sisters, uncles and aunts. The relationship may extend to immediate cousins.

funding and the creation of an enabling environment in which the Non-governmental sector can function and mobilise social capital is also examined.

c) To what extent are TASO and PTC/PLI successful in mitigating the impact of HIV/AIDS?

This study examines the extent to which social capital is meaningfully utilised in addressing the HIV/AIDS problem in Uganda. It evaluates how successful TASO and PTC/PLI are, in fighting HIV/AIDS.

I- Findings and Conclusions

The study revealed that TASO and PTC/PLI are engaged in a variety of activities aimed at addressing the HIV/AIDS-related problems. These activities help in bringing clients together and making it possible for them to interact regularly. The activities include formal meetings at the NGOs' centres and the medical clinics, in which group counselling and discussions about HIV/AIDS are used to raise the issue of HIV/AIDS. Other activities include community outreach programme, drama and music activities. All these activities were found to facilitate interaction and facilitating communication among individuals in organisations and communities, and were effective in addressing the different HIV/AIDS related problems. For example, interactions that takes place at the organisations' centres and in the community were found to be important in mitigating the problem of stigma and social exclusion. Recreational activities contributed not only to the physical fitness of organisation members, but also shaped character, fostered friendship and, above all, prevented activities that would increase their vulnerability to HIV infection (chapter 6).

11- Does Social Capital Matter?

Based on the theoretical discussions (chapter 2) and empirical findings the study argued that there are various perspectives, conceptualisations and wider application of social capital. In relation to alleviating the impact of HIV/AIDS, it was found that social capital does matter for the well being of people affected with HIV/AIDS. Findings from the study of TASO and PTC/PLI indicate that in spite of limited resources, the scale of operation of NGOs in effective prevention of HIV and mitigation of HIV/AIDS-related problems in Uganda depended on networks and social relations between individuals and groups.

Networks were important in fighting HIV-related problems in a number of ways; for example, regular face-to-face interaction between individuals and groups served as sources of knowledge⁷ regarding HIV/AIDS. In addition, regular interaction facilitated the transfer of such knowledge from one group or individual to another. Discussions and the sharing of experiences were found to be effective in mitigating stigma and social exclusion, and bridging the gap between people with HIV/AIDS (PWHA) and other members of the community. Regular interaction was also important in addressing the issues of social-culture that facilitate HIV transmission. Hierarchical relationships between individuals and government, between NGOs and other organisations (business, private and not-for-profit), and between government and international donors were revealed to be avenues for the mobilisation of funding for activities such as poverty reduction strategies, education and mobilisation for HIV/AIDS mitigation.

On a more general level, the importance of social capital is vital in restructuring the socio-economic environment in which HIV/AIDS thrives. While it is not possible to apply the concept of social capital fully to address HIV/AIDS-related problems in all environments and contexts, the relevance of the concept cannot be ignored, especially in the African context. In this thesis, I have discussed the fact that the spread of HIV/AIDS across Africa was facilitated by more or less similar conditions: a vulnerable economy characterised by poverty and cultural factors such as those which promoted stigma, gender imbalance and the associated marginalisation of women (chapter 4). These factors exist in many African countries, although in different dimensions and forms. Similarly, the policy responses throughout this region were more or less the same, since all nations chose to follow the World Health Organisation (WHO) and the World Bank's approach. The WHO HIV policy focuses on education, prevention and use of condoms, and the World Bank's approach focused on debt recovery and required the state to roll-back its support in favour of private initiatives(O'Manique 2004).

However, the rates of prevalence of HIV/AIDS varied in these countries, indicating that there are different explanations other than these policies. For example, the study found that the infection rates are high in South Africa, Botswana and Zimbabwe compared to Uganda (see 4.4.1). At the

⁷ It is defined as the “the fact or condition of knowing something with familiarity gained through experience or association”(Encyclopaedia Britannica/Merriam-Webster Dictionary on line

end of 2001, for example, in Zimbabwe, 33% of the adult population was HIV/AIDS infected compared to 5% in Uganda (UNAIDS 2002). The alternative explanation was identified as social capital. For example, it was found that in Uganda there was more open communication about HIV/AIDS than in other countries. It was also found that there was a more positive state-society relation in Uganda than in South Africa. Thus, Effective prevention of HIV in Uganda was found to depend on a combination of preventive measures and increased interaction among different people, and between civil society organisations and government (chapters 6 and 7). Interaction was the avenue for communication, and acquisition of HIV/AIDS-related knowledge and the sharing of experiences between individuals and groups. Networks were found to be channels through which information was processed, discussions were held and experiences about HIV/AIDS were shared by members. In addition to facilitating the sharing of knowledge and experiences by people infected with HIV, networks were found to reduce the cost of conveying messages about HIV/AIDS and transferring HIV/AIDS-based knowledge from individual to individual and to communities. Networks were found to be sources of social, psychological and economic support for people with HIV/AIDS (chapter 8).

When compared to the approach of religious or Faith Based Organisations (FBOs), particularly religious fundamentalists⁸, the network approach of TASO and PTC/PLI was found to have a greater impact on stigma and social discrimination. Religious fundamentalists tended to focus on individuals and morality rather than on issues such as poverty, discrimination and gender, which are important for the spread of HIV/AIDS in Africa in general and Uganda in particular (Barnett and Whiteside 2002; O'Manique 2004). The focus of FBOs emphasises the individual, which heightens blame, social exclusion and stigma instead of mitigating them (see discussion in 7. 4.1).

<http://search.eb.com/dictionary?va=knowledge&query=knowledge>

⁸ Religious fundamentalism in this case was taken to refer to those religious groups with a strong moral tone in their religious teachings. For example, they were identified with strong criticism of people who contract HIV/AIDS regarding them as immoral and deserving punishment from God. This was different from other mainstream religious teachings as in the Anglican sect which although not in approval of contracting HIV/AIDS, but they talk about it with little criminalising the victims.

A comparison between Uganda and South Africa (7.8 – 7.8.2) revealed that one of the reasons why South African AIDS policy has failed to achieve the desired results is the gap that exists between government and non-governmental organisations. In Uganda, it was found that political leaders, led by the president, were important in legitimising action and streamlining the flow of HIV/AIDS-related knowledge from government and other actors to the communities. Government involvement in coordinating the various actors involved in HIV/AIDS activities streamlined the work, thereby avoiding duplication and conflicting objectives and programmes. Moreover, the government initiative to incorporate research and treatment in its programmes and negotiations for reduced drug prices, created trust in the political leaders in fighting HIV/AIDS. In South Africa, the situation was different; there was lack of political will with a president opposed to scientific findings about the relationship between HIV and AIDS and willingness of government to provide antiretroviral drugs (ARV) to reduce the suffering of AIDS patients. All these factors provided an enabling environment for the success of interventions in HIV/AIDS in Uganda compared to South Africa.

The discussion in this thesis also revealed that the government of Uganda has been instrumental in forging partnerships between government, donors, and NGOs. The involvement of civil society organisations including HIV/AIDS NGOs, religious and faith based organisations, in the HIV/AIDS policy-making process in Uganda was found to foster legitimacy and more effective state-society relations. This involvement was not evident in South Africa, and as a result there was more conflict and collision between civil society organisations and government. The study revealed that the conflict between civil society organisations and government in South Africa hampered the development of a relationship of trust between these two sectors, as well as the flow of information that is necessary for minimising the impact of HIV/AIDS. Thus, the conclusion is that, despite having fewer resources than South Africa, Uganda has managed to be more effective in preventing the spread of HIV/AIDS because of the existence of networks between individuals, groups and government.

The study findings confirmed that TASO and PTC/PLI have been successful in addressing the problems of stigmatisation and social exclusion, as well as those related to the increasing number of orphans (chapter 8). The two organisations were found to be successful in providing better

social and health care services to their clients and their families. The extension of services to rotating outreach centres in different community, family and home establishments had proved to be an important contribution in the health delivery system⁹. It was evident that this approach not only enhanced the skills of people in their homes, but also minimised the expenses that would be incurred by patients who travelled long distances to reach to the nearest health units.

On the basis of the discussions in the thesis and examples as those discussed above, I therefore, concluded that the activation of social capital is more effective in mitigating the impact of HIV/AIDS than focusing on individuals (chapter 9). In general the study concluded that, despite their limitations, TASO and PTC/PLI have been successful in tackling the various challenges of HIV/AIDS.

The Need for Synergy as a Model for Addressing the Impact of HIV/AIDS

Synergy implies mutual and reciprocal relationships between government and civil society. This may take the form of either complementarity or embeddedness. Complementarity refers to mutually supportive relationships between public and private actors exemplified in the creation of an enabling environment (Evans 1996; 1996a), while embeddedness refers to the nature and extent of ties connecting citizens and public officials. Such relationships facilitate cooperation and communication between citizens and state officials, and between citizens.

This study found that the impact of HIV/AIDS is widespread; for example, in causing death, increasing the number of orphans, and encouraging social discrimination and stigmatisation. In view of the magnitude of the HIV/AIDS problem, the study concluded that in order to alleviate the impact of HIV/AIDS successfully, synergy is required between government and various other actors, particularly NGOs. This is because of the comparative advantages possessed by these actors.

The study found that both the NGOs and the government recognised that they can play a role in fighting HIV/AIDS and therefore the need to work together in a collaborative manner. Through

⁹ It is of recent that the government is planning to have home-based HIV/AIDS care services (see <http://www.newvision.co.ug/D/8/13/533674/AIDS>)

synergy, it is possible to facilitate personal, intercommunity and other social relations. These social relations are important for fighting HIV/AIDS. The study revealed that TASO and PTC/PLI have done better than the government because they select a small region and are better able to streamline their programmes to achieve their goals. They operate on a small scale and are selective with regard to the types of activities they engage in. Moreover, they facilitate the development of trusting relationships between their members/clients, on the one hand, and between members/clients and officials of the organisations, on the other. They also provide gateways for the flow of HIV/AIDS related knowledge from the organisation to the community through engagement into activities that facilitate community participation.

The study also found that the government operates on a wider scale and has an already established physical infrastructure, as well as personnel in different health centres across the country. If utilised, this would facilitate provision of large-scale health services. In addition, the government designs policies and coordinates different actors involved in HIV/AIDS related activities. It also establishes an enabling environment for the functioning of NGOs. Moreover, through its international connections, the government mobilises funding which it uses to support the NGOs and other actors engaged in various HIV/AIDS activities. Apart from these advantages, the government is in position to design and implement nationwide poverty reduction programmes. These programmes can have a positive impact on the spread of HIV and minimising the effect of AIDS.

On the basis of the above findings, the study concluded that because of the comparative advantages of both NGOs and Government, synergy between government and NGOs facilitated effective intervention in HIV/AIDS by NGOs. As mentioned it was found for example that NGOs select a small area to work with and they work effectively while the government works with a large area and eventually fails to successfully implement their programmes. Further more, it was found that NGOs are good at mobilising the people; for example, it was found that the use of people infected with HIV/AIDS instead in the delivery of HIV/AIDS messages was more effective since people get the true picture of HIV/AIDS from the stories of people who are the real victims. It was however, found that the government has some comparative advantages over NGOs in for example its ability to negotiate for financial resources from international donors, it

obviously has more capacity than NGOs and therefore, the government may be in a position to implement programmes more effectively if the resources it has are well maintained and utilised.

The study found that there were three types of networks which characterise NGO operations: bonding, bridging and linking networks. Each of these networks was revealed to have different benefits for individuals, groups and communities affected by HIV/AIDS (see 6.1.1 – 6.1.3). It was concluded, therefore, that no network should be considered as more important than others; rather, networks should be viewed as interdependent when fighting HIV/AIDS (see 9.2.3).

III- The Structure of the Thesis

The thesis is divided into three parts. Part one, which consists of chapters 1, 2, 3 and 4, discusses the HIV/AIDS problem and the conceptualisation of social capital in relation to a social problem – HIV/AIDS. The objective is to develop a model and a methodology for the analysis of a specific social problem in a particular context such as HIV/AIDS in Uganda. Part two, chapters 5, 6, 7, and 8 considers the process of generating social capital and its effective utilisation by HIV/AIDS to address HIV/AIDS challenges. Actors involved in this process and their relationships to one another are discussed. Part three is composed of chapter 9 and examines the extent to which TASO and PTC/PLI are successful in fighting HIV/AIDS by making conclusions from the study.

Introducing the Different Chapters

Chapter one introduces the study and provides a general overview. The focus is on the salient issues relating to the increasing impact of HIV/AIDS. The chapter discusses the purpose and the scope of the study. In addition, in this chapter a contextualisation of NGOs response is made.

Chapter two presents the general theoretical discussions about social capital: its formation, its meaning and different perspectives on it. The chapter explores different sources of social capital: families, communities, organisations and the state. In addition, it considers the arguments for social capital measurements that can be used in a specific context and when addressing a specific problem -HIV/AIDS. Based on these discussions, an analytical model is developed, which recognises the role of the state institutions and NGOs in generating social capital - the synergy model.

In chapter three, different methodological tools for conducting the study are discussed, as well as the methods used to collect, analyse and present data. This is an empirical study done in Uganda based on two cases involved in fighting HIV/AIDS in Uganda. Because of the vulnerability of people affected with HIV/AIDS, in this chapter ethical issues that must be taken into considerations when doing research on vulnerable groups are also discussed.

Chapter four discusses various impacts of HIV/AIDS. The chapter premises that an understanding of these impacts will further our knowledge of the dynamics of HIV/AIDS and contextualises the NGO response. In this chapter, the historical development of HIV/AIDS policy responses in Uganda is also discussed.

Chapter five outlines the evolution of HIV/AIDS NGOs in Uganda. In this context, it explores the different explanations of the emergence of HIV/AIDS organisations as a distinct group of NGOs. The formation of such organisations was intended to fill the gaps left by a non-responsive state at a time when society was discriminating against its own people. Having presented the enormous number of HIV/AIDS NGOs in Uganda, the choice of the two cases under investigation is discussed.

Chapter six presents the empirical findings regarding the process and approaches employed by NGOs in building social capital in Uganda. By focusing on the two selected HIV/AIDS organisations in this chapter, it is possible to trace this process and how it can be utilised to fight the HIV/AIDS problem.

Chapter seven continues the discussion of the process of building social capital. An argument is developed regarding the role of the state institutions in social capital construction in a developing country. I argue that it is the role of the state to provide a favourable environment for the participation of the organisations working with HIV/AIDS. This chapter demonstrates that the relationship between state and other actors particularly the HIV/AIDS NGOs contributed significantly to the revival of the social capital which had declined at community and family levels due to HIV/AIDS.

Chapter eight discusses the extent to which TASO and PTC/PLI have alleviated the problem of HIV/AIDS. Data is presented to illustrate how social capital is utilised to achieve these aims.

Chapter 9 provides a synthesis of the various findings and conclusions drawn from the study. Some of these findings and conclusions have been mentioned above.

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Roberts Kabeba Muriisa
(Bergen, December, 2006)

PART 1

UNDERSTANDING SOCIAL CAPITAL

And

**IT'S RELEVANCE IN ALLEVIATING THE IMPACT OF
HIV/AIDS**

CHAPTER 1

Socio-economic and Political Dynamics of HIV/AIDS and the Need for Social Capital to Alleviate the Impact of HIV/AIDS in Uganda

1.0 Introduction

More than two decades after the identification of Human Immunodeficiency Virus (HIV), a virus that causes Acquired Immune Deficiency Syndrome (AIDS), there is neither a vaccine for HIV nor a cure for AIDS¹⁰. HIV/AIDS causes numerous problems for individuals and communities. The purpose of this study is to explore the role of non-governmental organisations (NGOs) in addressing HIV/AIDS-related problems in Uganda. The study argues that the extent to which these problems are alleviated depends on the extent to which social relations between individuals, groups and communities, are emphasised by intervening institutions¹¹, and in this case NGOs.

AIDS refers not to a particular disease, but to a condition affecting individuals who are living with HIV. This condition is characterised by weakened human immunity, which renders the individual susceptible to attacks by various diseases such as fevers, diarrhoea and tuberculosis, to mention but a few. The virus is contracted through sexual contact with an infected person, through infected blood transfusions and through contact with infected blood that is transferred by sharp objects such as needles shared by drug users, or razors used during circumcision and other traditional ritual practices. Children can be infected by HIV from their mothers at birth and through breast feeding.

Ultimately, HIV infection generally leads to death, although people can live with it for a period of between 5-10 years before showing signs of AIDS. The time span depends on whether the person has periodic health checkups, eats well, abstains from sex, stops smoking and drinking alcohol. These habits are known to accelerate the loss of immunity, to deplete the body and to eventually cause death. Uganda has featured as one of the world's successful countries in reducing HIV prevalence and incidence¹². Uganda's HIV prevalence declined from around 30% in the 1990s to 5% in the year 2000. The Uganda's *Ministry of Health*

¹⁰ Treatment, however, is offered for multiple diseases which a person with HIV/AIDS may get due to a weak immune system.

¹¹ See for example, 1.3, 2.2 and 2.3, for discussions on the importance of social capital

¹² According to Parkhurst (2002), the incidence of HIV is the number of new infections, while the prevalence is the total number of HIV infections in a country or region or group .

HIV/AIDS Surveillance Report 2003, reports that HIV/AIDS in Uganda declined from around 18%, for the whole country and about 30%, for worst hit areas in early 1990s, to about 6.2% at the end of 2002 (MoH 2003: 9)¹³. More recent studies however, have shown that HIV infection rates have risen to around 6.5% (Allen 2005), attributing the rise to relaxed use of condoms. In spite of the increase, UNAIDS (2006) points out that the prevalence rate has stabilised.

In spite of the above success, HIV/AIDS has had a devastating impact which has required immediate action. UNAIDS (2002b), reports that at the end of 2001, there were about 1 million people living with HIV/AIDS in Uganda. *The HIV/AIDS Epidemic: Prevalence and Impact Report* (UAC 2003) states that, up to the end of 2001, about 940,000 HIV/AIDS-related deaths had occurred in Uganda. Apart from death, HIV/AIDS increases the burden of dependence due to the increasing number of orphans and of people with HIV/AIDS needing care and support. The ill-health caused by HIV infection, causes people to put less effort into their work, and AIDS patients may totally withdraw from productive employment. For the government, HIV/AIDS exerts enormous pressure on its budget, causes a loss of human resource and is a threat to national security. Socially, AIDS divides society through stigmatisation, discrimination and denial. For people with HIV/AIDS, the stigma often results into lack of care, support and access to medical treatment and other services (Barnett and Whiteside 2002; Kayazze 2002; Marshall and Keough 2004). All these problems need to be addressed.

As earlier mentioned, Uganda is one of the successful countries in fighting HIV/AIDS. This success is attributed to the contribution of many actors including the government HIV/AIDS policy. There are various actors involved in the battle against HIV/AIDS, including non-governmental organisations (NGOs), business organisations and government. This study is concerned with the roles plaid by NGOs in fighting HIV/AIDS.

The number of NGOs involved in HIV/AIDS-related activities in Uganda is over 1000. Some reports have estimated that the actual figure may be about 2500 NGOs (Garbus and Marseille 2003), which indicates the extent to which non-governmental organisations are engaged in

¹³ UNAIDS, *2006 Report on the Global AIDS Epidemic*, shows that by 2005, the prevalence had reached 6.7%. The report notes that the prevalence rate continues to decline among pregnant women in Kampala, but it remains stable for the whole country even in the rural areas (Pp 20).

this battle. I can rightly assert that there has been an explosion of NGOs working with HIV/AIDS in Uganda (see chapter 5 for the various organisations working with HIV/AIDS in Uganda).

Counted among these NGOs are various indigenous¹⁴ NGOs, including a growing number of Community Based Organisations (CBOs) that register from time to time to work with HIV/AIDS, Faith Based Organisations/Religious Organisations (FBOs/ROs) and international NGOs such as Action Aid. The present study focuses on NGOs which were established within the Ugandan context to specifically address numerous HIV/AIDS-related problems. These NGOs, which I have termed HIV/AIDS NGOs, are engaged in various HIV/AIDS-related activities. In particular, the study focuses on NGOs whose activities contribute to building social relations among different groups and individuals, such as clients, their families and communities. The reason for this focus on social relations is the recognition of the contribution these make to improving people's health (Hyypa and Maki 2003; Lomas 1998; Putnam 2000; Szreter and Woolcock 2004). In addition, for Africans in general and Ugandans in particular, social relations at individual, family and community levels are important as safety nets and sources of social support in times of crisis (Kayazze 2002; Keough 2004; Marshall and Keough 2004; Tumwesigye 2003). Since a cure for AIDS and a vaccine for HIV are not forthcoming, social relations are essential in meeting the aforementioned challenges.

However, the study recognises that, as a result of HIV/AIDS, social relations at all levels have diminished or are diminishing, as indicated by the amount of social support provided to the needy, such as AIDS orphans¹⁵ and people with HIV/AIDS (Barnett and Whiteside 2002; Marshall and Keough 2004). The study suggests, therefore, that for effective mitigation of HIV/AIDS challenges, social relations need to be revived, regenerated and reconstructed; and that this reconstruction is possible if synergy between NGOs and Government is emphasised (see 1.3 and 2.4 for discussions on generation of social capital).

This study specifically examines the way the impact of HIV/AIDS in Uganda is dealt with by two indigenous NGOs: a) The AIDS Support Organisation (TASO), and b) Post Test

¹⁴ These are organisations whose establishment has been precipitated by the conditions in the countries of their operation and origin. They may operate at community, district, regional or national level.

¹⁵ Orphans whose parents died due to HIV/AIDS.

Club/Phily Lutaaya Initiative (PTC/PLI). TASO provides care and support to people with HIV/AIDS, and to their close relatives and beneficiaries such as orphans. PTC/PLI, on the other hand, provides care and support to people who have gone through the HIV testing process, irrespective of test results (HIV positive or negative), and who register with the organisation as members. These organisations are engaged in many activities that mitigate HIV/AIDS¹⁶, but as mentioned, their selection was based on the fact that they focused on strengthening social relations among their members/clients, groups and the community. The activities of these NGOs facilitated regular interaction both within and outside the organisations, and the modes of interaction were both formal and informal.

The study argues that networks and associated resources constitute social capital, which can be utilised to alleviate the impact of HIV/AIDS (see 1.3 and more discussion on social capital in chapter 2). The study will attempt to answer the following research questions:

- (a) What roles do HIV/AIDS NGOs play in alleviating the impact of HIV/AIDS in Uganda?*
- (b) What factors influence the performance of NGOs in alleviating the impact of HIV/AIDS in Uganda? How do NGOs feature in government programmes? Does the government play a role in facilitating social capital formation, and consequently in NGO performance in addressing HIV/AIDS' challenges?*
- (c) To what extent are TASO and PTC/PLI successful in alleviating the impact of HIV/AIDS?*

(a) What role do HIV/AIDS NGOs play in alleviating the impact of HIV/AIDS in Uganda?

To address this question, the study specifically examines the roles played by TASO and PTC/PLI in fighting HIV/AIDS in Uganda. The main approaches employed by these NGOs to fight HIV/AIDS are examined. The thrust of the study is on examining the process by which these NGOs fight HIV/AIDS. The study argues that in order to alleviate the impact of HIV/AIDS, it is necessary that social relations at both individual and community levels be strengthened.

- (b) What factors influence the performance of NGOs in alleviating the impacts of HIV/AIDS in Uganda? How do NGOs feature in government programmes? Does the government play*

¹⁶ In chapter 5 the establishment of these NGOs is discussed and their activities.

a role in facilitating social capital formation, and consequently in NGO performance in addressing HIV/AIDS' challenges?

In order to address these questions, the study examines the structures of the NGOs, their relations with other actors and the overall social and political environments in which they operate. Here, I hypothesise that, for successful HIV/AIDS intervention to take place, social capital needs to be built or strengthened where it has weakened as is the case of family and community levels. I argue that synergy between NGOs and government facilitates the strengthening of social capital at the micro level, and that this social capital is necessary to meet the challenges posed by HIV/AIDS.

In order to examine the contributions of government and NGOs in facilitating the development/strengthening of social networks, the study asks: how is social capital generated and maintained? It argues that it is the government's roles to provide certain basics, such as the provision of infrastructure, the maintenance of political leadership, the mobilisation of funding and the creation of an enabling environment for participation, interaction and collaboration. The NGOs, on the other hand, mobilise local social networks at the community and family levels.

c) To what extent are TASO and PTC/PLI successful in alleviating the impacts of HIV/AIDS in Uganda?

The study evaluates how NGOs deal with HIV/AIDS-related problems and the extent to which these problems are alleviated. The study examines the extent to which social capital is meaningfully utilised by these organisations in the battle against HIV/AIDS in Uganda.

This study was carried out in the Mbarara District¹⁷ of Western Uganda, which in 1991 had an HIV/AIDS prevalence rate of about 24.3%. By 2001 the prevalence rate had declined to about 10.8%. This is keeping with the marked decline in the HIV/AIDS prevalence rate that was registered in Uganda; the HIV prevalence rate declined from about 18% in 1991 to about 6.2% at the end of 2002 (MoH 2003: 9). The study focuses on records of HIV infection in the period before and up to the end of 2003, since this was the period for which data existed at the

¹⁷ Mbarara district is located in South-Western Uganda. It has a population of about 1,093,388 (4.5% of national population), and a population growth rate of about 2.9% (National population Census 2002); see 3.2 for reasons why it was selected for this study.

time I collected my data (January to August 2004). However, this does not mean that the literature on NGOs and HIV/AIDS, which has emerged after this period is not included.

A variety of qualitative and quantitative methods were employed, including interviews, focus group discussions, observations and secondary sources. In addition, data were gathered on a number of variables, including types of networks and frequency of interaction among different categories of people, as well as what they talk about, who they interact with, and the extent of their involvement in NGOs activities. Data were also collected from government officials employed in the district directorate of health.

1.1. HIV/AIDS and Different Responses

Recent studies trace the first cases of HIV/AIDS-related deaths as far back as 1959, to mysterious deaths among Congolese tribesmen¹⁸. The term AIDS was first introduced in 1982¹⁹. In Uganda the first HIV cases were identified in 1982 along the shores of Lake Victoria²⁰. It was not until 1985, however, that cases in Uganda were linked to HIV cases which had been found in the US in 1981 and the linkage between HIV and AIDS was established (Putzel 2004). HIV cases began to appear and be identified in many parts of the world. In some countries, for example, in Europe and Asia, new cases appeared only occasionally; in other countries, especially in Sub-Saharan Africa, the rate at which new cases of HIV appeared was alarming.

Since the 1980s, HIV/AIDS has posed a new challenge to development, not only in Africa but also in other parts of the developing world. In 2002 alone, about 3 million people in the whole world died due to HIV/AIDS-related causes. As the global figures indicate, many others may continue to die until effective medical and other interventions are introduced. At the end of 2002, 60 million people throughout the world had been infected by HIV/AIDS since its detection.

Nevertheless, it is in Africa that HIV/AIDS is increasing more rapidly than anywhere else in the world. According to UNAIDS and WHO (2003: 2), "...there have been steady increases in the number of people living with HIV/AIDS as well as the number of deaths. The number

¹⁸ <http://www.aegis.com/news/sfe/1998/se980201.html>

¹⁹ <http://www.aegis.com/topics/timeline/> 11/07/06

²⁰ See chapter 4 for a history of HIV/AIDS in Uganda.

of people living with HIV/AIDS continues to increase in several regions, most markedly in Sub-Saharan Africa”.

Because of HIV/AIDS long history in Africa, African countries have suffered the most. In Botswana, Lesotho, Namibia, and Swaziland, the epidemic has reached extremely high levels with no signs of levelling off (UNAIDS and WHO 2003: 9). In 9 African countries at the end of 2001, at least 15% of the adult population was infected with HIV/AIDS²¹. HIV/AIDS is the fourth biggest global killer and is the leading cause of death in Sub-Saharan Africa (UNAIDS 2002a; World Bank 2000a).

In Uganda, over 1 million people are HIV/AIDS infected, and from its identification in 1982 until 2001, over 900,000 had died of it (see 4.4.1). In spite of these dramatic figures, in Uganda, there has been a remarkable decline in HIV/AIDS prevalence and incidence as mentioned earlier.

1.1.1 HIV/AIDS Causes, Impacts and Responses

By the 1990s, HIV/AIDS was registered as the first global epidemic since the influenza epidemic of 1918 - 1919 (Barnett and Whiteside 2002: 27). As the global HIV/AIDS figures presented in the preceding discussion indicated, almost no part of the world is now untouched by the impacts of HIV/AIDS.

The causes of HIV/AIDS spread and its impacts are rooted in the social, economic and cultural structures of everyday life. The social origins of HIV/AIDS include gender imbalance, which is rooted in property relations, as well as in social cultures that recognise male dominance in decision making and resource control. Such cultures make women dependent on men for survival; and such dependence leaves women unable to negotiate for safer sex and the use of available HIV preventive measures (Batard and Ouma 2005), and may force them to resort to commercial sex as a way of earning a living and even to take the risk of getting infected with HIV although they know the dangers of infection (Barnett and Whiteside 2002; O'Manique 2004). These factors cannot be simply isolated from each other, since they work hand in hand to facilitate the spread of HIV.

²¹ The highest figure of about 38.8% was listed in Botswana.

In many parts of Uganda, women are considered man's property (Leistikow 2003). Until recently, therefore, women could not own property and generally depended on men for survival and support. Poverty affects women most, but the state provides only limited welfare services. This situation was worsened by the neoliberal structural adjustment policies and market mechanisms that prevailed in the 1980s. In that period, the active involvement of the state in providing welfare benefits, such as health benefits and education, was reduced. A market based approach to welfare provision is still emphasised and supported by international donors. Since about 50% of Uganda's expenditure is foreign financed (O'Manique 2004) - with more than three quarters of public expenditure on health being foreign funded (Van de Walle 2001), Uganda finds it hard to resist the neoliberal demand for the state to roll-back. State withdrawal from providing welfare has meant that people have to fend for themselves for survival and poverty is on the increase, especially among women. HIV finds a safe-haven in such an environment.

HIV/AIDS Policy in Uganda

HIV/AIDS policy in Uganda can be traced back to epidemiological studies which located the roots of the problem of HIV in the behavioural patterns of groups of people. The initial patterns of HIV distribution pointed to heterosexuality as the main source of the disease and the cause of its spread. When HIV was identified in Uganda in 1982, it was initially associated with witchcraft by the community members (Putzel 2004). However, a pattern began to emerge based on the increasing death rate for widows, widowers and those who inherited widows after the death of their male partner, which indicated that another explanation was required. It became clear that the cultural practice of widow inheritance contributed significantly to the spread of HIV. Later, Barnett and Whiteside (2002) associates the spread of HIV/AIDS in Rakai with commercial sex.

In war-torn areas such as northern Uganda, the spread of HIV/AIDS has been associated with the disruption of people's social lives and with the practice of having unprotected sex with multiple sex-partners. The prevalence of unprotected sex in Internally Displaced People's Camps (IDPC) and the frequency of rape cases in war zones, also explain the rapid spread of HIV in these areas (Hankins et al. 2002).

The focus on heterosexuality as the cause of the spread of HIV in Uganda has meant that behavioural change has become the prime target of HIV/AIDS programmes. The initial response to HIV targeted “high risk groups” such as sex workers and truck drivers, and the initial focus of HIV/AIDS policy was on the prevention of the spread of HIV among these groups through distribution of condoms and education for behavioural change. When HIV/AIDS became associated with cultural practices such as widow inheritance and circumcision, education for behavioural change was extended to cover these groups. Prevention has remained the predominant policy approach in addressing the problem of HIV spread in Uganda (see chapter 4).

This emphasis on prevention as the main HIV/AIDS policy focus also has its roots in the neoliberal economic policy of the 1980s. The main component in neoliberalism is privatisation with a view of freeing the government the burden of heavy expenditure. This called for a reduction in government spending and more reliance on the private sector (O'Manique 2004; World Bank 1991). Thus, HIV prevention and education for behavioural change was viewed as a means through which government expenditure could be minimised.

Thus, the initial response to HIV/AIDS focused on the immediate cause of the spread of the disease. These focused on prevention rather than on the social, economic and political environments that facilitated the spread. This focus was further emphasised after the introduction of structural adjustment programmes (SAPS) in the 1980s, since these required that the state minimise its expenditure and encourage the growth of the private sector. The aim of the restructuring process was to reduce the government debt (Muriisa 2005), as well as to increase state efficiency and productivity. In the era of HIV/AIDS, the government was being called upon to create an efficient private sector that would be able to handle the epidemic without imposing more “burden” on the government.

Another component of the neoliberal policy was the public-private partnership in financing HIV/AIDS activities, with the emphasis that the public sector finances prevention and the private sector finances treatment and care. In the 1990s when the World Bank became interested in HIV/AIDS, the concern was about the affordability of treatment. Its immediate concern was that the status of HIV/AIDS should not be special compared to other diseases (Dumoulin et al. 2003: 223). Even when the Bank recognised the need for Antiretroviral

Drugs (ARV)²², it required that the government should emphasise prevention and reduction of transmission, and leave the provision of drugs to be financed by private insurance schemes and companies (ibid.).

Therefore, an efficient private sector was deemed essential for the successful fight against HIV/AIDS; it was meant to “empower” households and women, so as to enable them to protect themselves against HIV/AIDS and to cope with its multiple impacts. Private sector involvement in managing HIV/AIDS became the major policy focus, including different stakeholders drawn from the business sector, NGOs, CBOs and FBOs. This policy focus emphasised the need for increased knowledge and information about the disease among the general population. Communities were to be trained in managing HIV/AIDS, for example in handling the sick, and after training they were to find their own sources of financial, material and spiritual support (O'Manique 1996: 157-158).

Within the above framework, Ugandan government interventions were channelled mainly through the Ministry of Health. HIV was made an integral part of the whole health programmes. However, the government HIV/AIDS policy focus does not include the basic social and economic factors facilitating HIV spread and limiting the mitigation of the impacts of AIDS. The Uganda Sexual Transmitted Diseases/AIDS (STD/AIDS) Control Programme (ACP), which was established in 1986, had epidemiology, research and prevention of sexual transmitted diseases, including HIV/AIDS, as its initial target. Although the programme was the first of its kind in Sub-Saharan Africa²³, its aim was to create awareness and increase education for behavioural change. Later the target was extended to cover HIV prevention among health workers.

The multisectoral strategy for HIV prevention, which included all sectors of the economy (through the respective ministries) also stressed the role of private financing in HIV/AIDS treatment and care. This has led to a reduction of public funding to the health sector. Medical expenses are to be met by private individuals. In government hospitals, private wings were established where those who are able to pay can obtain exclusive services. This approach disregarded the poverty levels of the general population and the extent to which local

²² These are treatments that have been developed to minimise the multiplication of the HIV. They facilitate the restoration of the immune system and can thus help people infected with HIV to live longer if other factors such as diet and avoidance of health risks such as smoking and alcohol are controlled.

communities were able to mobilise their own funding for medicine and general medical care for the sick. The vast majority of HIV/AIDS victims are excluded from benefiting out of these services since they cannot pay for them. As the spread of HIV/AIDS intensifies, the burden of care and medication continues to fall on private individuals (O'Manique 2004). The NGOs have stepped into this gap and provide a large portion of HIV/AIDS-related medical care and support services. The government continues to play a major role in providing education for behavioural change and supervising the NGOs' activities, while at the same time reducing its own expenditure on curative measures as a whole.

The government has disregarded the fact that education may not produce desired results if such issues as gender inequality, poverty and the social environment are not addressed. Kayazze (2002) notes that increasing knowledge is not enough to control the spread of HIV/AIDS. As mentioned, the causes of the spread of HIV are rooted in the social, political and economic structures of society. If not addressed, these issues may make it hard to control the spread of HIV and to deal with its impacts successfully. Recent studies have indicated that behavioural change cannot be achieved in a context where gender imbalance, poverty and other social ills are responsible for the creation of a disadvantaged class, which is more susceptible to disease. Hence, these social ills need to be addressed in order to bring any behavioural change (Barnett and Whiteside 2002; O'Manique 2004; White 2002).

Apart from looking at the social and economic causes of HIV/AIDS that are rooted in the environments in which people live, other studies have considered the impact of HIV/AIDS on control and mitigation efforts. White (2002: 5-6) argues that HIV/AIDS impoverishes, or increases impoverishment, in a way that increases people's vulnerability. For example, HIV/AIDS orphans who are lacking basic resources migrate from rural areas to urban centres where they are exposed to HIV infection. Similarly, stigmatisation associated with HIV/AIDS prevents people from seeking medical services, as well as practicing preventive methods. According to White (2002), therefore, the failure of mitigation approaches is related to the failure of governments and international donor communities to directly address the social and economic impact of HIV/AIDS.

²³ <http://www.state.gov/documents/organization/61631.pdf> 04/08/06

All in all, greater focus should be put on the social, economic and political environment in which people live. It is this local environment that stimulates the spread of HIV and worsens the situation of those with HIV/AIDS.

Community Responses

It is widely acknowledged that the African social support system based on family and kin relations has traditionally been the means of survival in times of hardship (Kayazze 2002; Marshall and Keough 2004; Tumwesigye 2003). In many African countries, there is limited government supported welfare system. As a result, families take care of the sick and they act as safety-nets when unemployment strikes. The relatives take care of orphans and they provide credit and other financing. Put simply, families and relatives are sources of economic and social support in many African countries. However, the increasing number of orphans and HIV/AIDS infected cannot be supported by the existing resources which families and communities have. As a result, the support available from these sources has declined (Barnett and Whiteside 2002; Marshall and Keough 2004; Orla 2004).

Thus, the increasing impact of HIV/AIDS has affected access to the support originally provided by the community and the family support systems. In addition, the increasing stigma, in the form of either individual responses or community exclusionary pressure, has minimised the individual HIV/AIDS victim's access to such social support. There is an increasing barrier between the HIV/AIDS victims and the community due to this stigma. In some cases people with HIV/AIDS have faced harassment from their relatives and community due to their HIV/AIDS status. For example, they were not allowed to share the family utensils or to shake hands with others (Muyinda et al. 1997).

The impact of HIV/AIDS, for instance in causing the decline of social and psychological support and the rise in the number of orphans needing support, led to the emergence of NGOs to fill this gap. Initially, these organisations were simply informal gatherings of people with HIV/AIDS. Later, organised groups emerged and their work took a more formal approach. The AIDS Support Organisation (TASO), which was established in 1987, was the first NGO in Uganda to address the problem of HIV/AIDS. Other organisations have been established since then and there are now more than 1,000 NGOs working with HIV/AIDS in Uganda.

This increased involvement of NGOs partly explains the focus of this study on the NGOs' roles.

1.2 Why are NGOs Important for this Study?

There is evidence that the number of NGOs working with HIV/AIDS activities in Uganda is increasing. A study by Barr, Fafchamps and Owens (2005) involving about 300 NGOs randomly selected from Kampala and 14 rural districts of Uganda, found that about two-thirds of the surveyed NGOs were reported to be involved in HIV/AIDS awareness and prevention. These findings are supported by other reports (see 5.3.1), all of which indicate the extent to which NGOs are working with HIV/AIDS in Uganda.

The importance of NGOs to this study is based on the advantages they have over other organisations involved in the development process. The comparative advantage of NGOs in promoting development is well documented (Clark 1991; Dicklitch 1998; Hulme and Edwards 1997; Jamil 1998; Riddell and Robinson 1995; Robinson 1997; Tvedt 1998; Viswanath 1991). These studies stress the role of NGOs as agents of change. Official donor funding is channelled through NGOs (Robinson 1997), usually in the form of grants and official loans, thereby promoting increased NGOs involvement in the delivery of public services.

NGOs are viewed as emerging advocates for self-reliance (Aubrey 1997) and as the best mechanism through which society can be democratised (Hulme and Edwards 1997; Tvedt 1998). NGOs have been found to be channels through which participation can be developed and, according to Barr, Fafchamps and Owens (2005), NGOs are catalysts for social capital development. They facilitate interaction between different actors and promote the development of trust relationships (Putnam 2000).

As mentioned, there are various agencies and NGOs involved in different activities that address the problem of HIV/AIDS in Uganda. These agencies and NGOs also employ different approaches to address HIV/AIDS problem; for example, some NGOs target individuals through counselling, while others are engaged in preventive approaches such as social marketing, which involves condom distribution, for instance. Still others have a more diversified approach that not only focuses on the individual but also on the overall social-economic environment in which the individual lives. These organisations and agencies have

focused, for example, on the families of person(s) with HIV/AIDS infection, on communities affected by HIV/AIDS and on interpersonal relationship within these families and communities.

The focus of this study is on NGOs whose activities involve the creation of avenues for interaction that link the people they serve on a regular basis. As previously stressed, networks and interaction provide a variety of benefits to the interacting individuals, which are important for the alleviation of HIV/AIDS related problems. I have argued, for example, that networks provide individuals with social support, and that communication and sharing of knowledge and experiences among people with HIV/AIDS may minimise stigmatisation and the further spread of HIV.

Apart from the contribution made by NGOs to social, political and economic development, this study's interest in these organisations arises from their importance in generating social capital (Barr, Fafchamps, and Owens 2005; Putnam 2000).

1.3 Why is Social Capital Important for this Study?

The concept of social capital has recently gained prominence in social research. Although there is no clear agreement on whether social relations can be conceived as social capital independent of the resources in them, there is no disagreement that networks and the resources imbedded in them are important for people's wellbeing. According to Coleman (1988), social capital is conceived as resources such as the internalised norms of obligation, loyalty, honesty and dependability embedded in social relations. According to Putnam (2000) social capital refers to networks and the norms of reciprocity and trustworthiness that arise from them. Woolcock(1998) on the other hand, conceives social capital as networks and makes a distinction between bonding, bridging and linking networks as different forms of social capital, based on the structure, nature of the resources and the outcomes of such networks. For the purposes of this study, social capital is conceptualised as social networks and the associated resources which allow people to work together. Social capital however is not only beneficial to interacting individuals and groups, but also the whole community and people as a group, or to individual members although they may not be part of the organised group²⁴.

In my discussion, I borrow from Woolcock's idea of network types to demonstrate the extent to which people can be benefited by activities of organisations engaged in HIV/AIDS activities. This is because, as Woolcock demonstrates, there are different resources inherent in each particular network.

Studies have shown that people's health depends not only on the medical treatment they receive from medical professionals, but also on their social relations. The way people live with others, the number of friends they have, and their interaction in the neighbourhoods contribute to their health conditions (Barnett and Whiteside 2002; Lomas 1998; Putnam 2000; Szreter and Woolcock 2004; 2002; Veenstra 2001). Lomas (1998: 1182) argues that "individuals (and their ill-health) cannot be understood solely by looking inside their bodies and brains; one must also look inside their communities, their networks, their work place, their families and even the trajectories of their life".

In the case of HIV/AIDS, studies have shown that social communication channels, for example open discussions among family members, have contributed greatly to behavioural change which in turn has led to a decline in the HIV/AIDS prevalence rate (Barnett and Whiteside 2002; Low-Beer and Stoneburner 2004a; 2004b; 2004c). These studies identified two related factors explaining Uganda's success in reducing HIV/AIDS prevalence: (a) communication about AIDS through personal networks, and (b) personal knowledge of people with AIDS. Barnett and Whiteside (2002: 320) argue that the main communication channel was discussions involving friends and family members. About 90% of Ugandans were participating in such discussions, compared to less than 35% of South Africans. They argue that access to the right information about HIV/AIDS is crucial for successful prevention. However, the above studies do not show how such communication was made possible compared to other countries.

Other studies have also acknowledged the importance of social capital, although without direct reference to the concept or exploration of how it may be generated and used in working with HIV/AIDS. For example, Jönsson (1995: 461-465) points out that, while AIDS as a medical problem entails searching for the causative agents of the disease, the social impacts and causes of HIV/AIDS require a social approach. President Museveni of Uganda argues

²⁴ A more elaborate discussion of the conception of social capital is to be found in chapter 2.

Uganda succeeded in reducing the prevalence rate of HIV because of social immunisation, since there was very low condom use per capita²⁵. The questions to ask however are; how did the social immunisation take place? What factors made “social immunisation” successful? These and other questions are answered by looking at the process employed by NGOs (TASO and PTC/PLI) to fight HIV/AIDS in Uganda.

In addition to the benefits of social capital in terms of improved health, it is also important because of the social aspect of HIV/AIDS. The discussion introduced earlier in 1.1.1²⁶ indicates that the social relations which characterise different communities, areas and countries have implications for the spread and impacts of HIV/AIDS. Consequently, in order to reduce the impacts of HIV/AIDS, it is necessary to focus on social relations.

Until recently, it was not recognised that the problem of HIV/AIDS extends beyond the medical profession and health concerns of treatment and research. It is now widely accepted that the causes and spread of the disease are rooted in the social, economic and political environments of different countries (Barnett and Whiteside 2002; O'Manique 2004; Seckinelgin 2004). The social environment includes the way people live, their social integration in their communities, the amount of social support they receive from their family members and their social relations with others, and is important in determining the impact HIV/AIDS may have on individuals. The economic environment includes the income levels of people and general levels of poverty, which affect not only their ability to access health services, but also their means of survival; for example, women may resort to means of survival which expose them to HIV infection. The political environment includes the general political situation of the country, and may affect the spread and impacts of HIV/AIDS; for example, in war torn areas, HIV spreads more rapidly than in politically stable areas (see chapter 4). It also involves political and policy responses to fighting HIV/AIDS.

The above recognition of non-medical factors has furthered our understanding of why the spread and impacts of HIV/AIDS differ in magnitude between nations (Allen and Heald 2004; Barnett and Whiteside 2002; Low-Beer and Stoneburner 2004a; 2004b; Putzel 2004). In many African countries, it has been established that socio-economic factors determine their vulnerability to the spread of HIV, particularly the social structures of gender and culture, the economic factors such as levels of poverty and income distribution, and the health policies

²⁵ <http://www.newvision.co.ug/D/8/13/394820/pfizer>

and political situations (see chapter 4). Thus, Seckinelgin (2004) points out that without a clear understanding of the context of HIV/AIDS, mitigation approaches cannot be effective. It is for this reason that this study considers social relations to be important in mitigating HIV/AIDS.

It is important to bear in mind, therefore, that the impacts of HIV/AIDS such as, stress, increased mortality, increased spread, social discrimination and stigma, can be reduced through building networks for HIV/AIDS intervention on both micro and macro levels, and on individual and organisational levels. However, it has to be emphasised that this study is predominantly concerned with social networks at the micro level. Such networks facilitate participation in HIV/AIDS-related programmes, and increased participation in HIV/AIDS programmes, especially those that target social and economic structures of society, will mean that they have a greater impact. For example, participation in NGOs' programmes may promote access to new forms of knowledge, to financial assistance and to forums in which people with HIV/AIDS can share their knowledge and experience. In the wider community, social networks linking communities and people with HIV/AIDS make it possible to transfer HIV/AIDS-related knowledge, especially regarding the mechanisms of HIV transmission. HIV transmission myths such as (a) "one can get HIV by touching a person who has the virus", and (b) "one can get HIV by eating, drinking or sharing utensils with someone who has the virus" are demystified (Muyinda et al. 1997).

1.3.1 The role of NGOs in Generating Social Capital

NGOs may be seen as "catalysts of social capital" (Barr, Fafchamps, and Owens 2005). Lewis and Wallace (2000) cite Bebbington (1999) and argue that NGOs are regarded as important actors in studies that recognise the facilitating role of social capital in addressing problems related to livelihoods and to the linking of policy responses at local, national and regional levels. Other scholars have considered civil society organisations such as NGOs to be forums where trustworthiness and the norms of reciprocity can be nurtured. Thus, NGOs are seen as channels of participation and increased interaction (Putnam 2000). Hall (1999) observes that investment in the voluntary sector (including the establishment of NGOs) – by facilitating its formation directly through funding or by entering into an active partnership in the delivery of services, for example by contracting out service delivery or by integrating them in the service delivery system – facilitates the growth of social capital.

²⁶ A detailed discussion is provided in chapter 4 (4.1 and 4.2).

To contextualise the functioning of NGOs in generating social capital, they can be seen to operate on three levels: Micro, Meso and Macro. The micro-level operations are evident in the NGOs' relationships with communities, individuals and families on the local level. On the meso-level, NGOs are linked with different organisations and local government agencies that provide different forms of support. On the macro level, financial, technical and personnel resources can be mobilised through the NGOs' connections with governments and international donor communities.

1.3.2 Government/State Institutions and Social Capital Generation

Proponents favouring a leading role for institutions in development argue that institutions are important because they can act as motivational and constraining forces for certain activities in society. They reduce uncertainty and support collective action; they structure social interaction in particular ways (Night 1992: 3); they condition economic development and facilitate exchange by providing a basis for appropriate behaviour (March and Olsen 1989: 23; North 1990: 48). In fact, Grootaert and Bastelaer (2001) have argued that institutions create an enabling environment, in which individuals and communities participate. It has to be emphasised that participation and membership in civil society organisations and the voluntary sector may show the levels of social capital (Blomkvist 2001; Wollebæk 2000; Wollebæk and Selle 2003).

There is increasing evidence to show that civil society does not operate in a vacuum, but rather depends on the functioning of government and its institutions. In this respect, it is important to consider how the state facilitates the development of social capital. This can be done by examining how state institutions such as political leadership affect network formation and practice. For example, voluntary participation and association may be limited where the state threatens or stifles such initiatives. In countries where freedom of association is suppressed, people are not allowed to participate and freely associate with one another (Selle 1999).

According to Krishna (2002; 1999), there are other factors apart from grass roots organisations and local networks that facilitate collective action; these include the presence of local agents such as vigilant young administrators who can contact and influence decisions at

the higher level in government. Maloney, Smith and Stoker (2000: 216) argue that, “public authorities are deeply implicated in the shape and activities of voluntary associations, whether it is in terms of the institutions they create or the resources they provide to encourage participation”.

Thus, in his main criticism of Putnam’s approach, Selle (1999: 146) points out that spontaneous local processes cannot be understood separately from the contribution of public policies. He argues that the work of the voluntary sector is facilitated by government action. Szreter (2002) and Rothstein and Stolle (2001) claim that there is less generalised trust in countries that fail to invest in an impartial legal system; and that this lack of generalised trust spills over to the entire society, generating low trust relations.

1.3.3 Synergy Between NGOs and Government

There is increasing evidence that government activity reinforces the formation of social capital. Studies have shown that governments cannot act alone in initiating change, and have recently turned to the voluntary sector for help (Hall 1999); hence, they are supporting civil society organisations. There is increasing literature pointing out that the autonomy of NGOs from government may not have a great impact on economic development, especially in developing countries (Bishwapriya 1997). Reviewing evidence by scholars such as, Ostrom (1990; 1996) and Lam (1996; 1998), Evans (1996a) concludes that synergy between government and civil society facilitates development of norms of cooperation, and that this is important in promoting development. The evidence demonstrates that there is a need for state and civil society to mutually reinforce each other in order to achieve development goals.

Uganda’s success in fighting HIV/AIDS is largely attributed to its effective implementation of a multisectoral strategy (Barnett and Whiteside 2002). This is a strategy which focuses not only on involving multiple sectors in fighting HIV/AIDS, but also on how different actors cooperate with the government. There is a need, therefore, to examine the relationship between government and these actors, and in particular the nature of relationship between the government and the non-governmental sector, and how this relationship influences NGOs work in fighting HIV/AIDS. Thus synergy in this regard is seen as one of the factors that contributes to the extent to which NGOs successfully fight HIV/AIDS.

1.4 Conclusion

The purpose of the chapter was to highlight the main concerns of the study and to provide background material related to the research problem. The long history of NGOs in development and community work means that the international donor community views them favourably and is prepared to support their involvement in HIV/AIDS. With regard to this wider involvement of NGOs in HIV/AIDS, it was emphasised that the study's goal is to explore their contribution to the battle against HIV/AIDS through the building of social capital.

The issues raised in this chapter have indicated that HIV/AIDS is a global problem requiring not only medical attention, but also attention to the socio-economic and political environments that facilitate the spread of HIV. It is stressed that the root causes of the spread of HIV/AIDS do not lie in the perceived epidemiological patterns of disease, such as high-risk groups, but rather in the environment that shapes these patterns. Thus, the chapter concludes that, unless the environment is included, the impact of HIV and its continued spread may not be adequately addressed.

The relationship between social factors and HIV/AIDS has led to the conclusion that it is important to focus on the social aspects of the disease. In this respect, this chapter has argued that NGOs successful performance is dependant on the extent to which they address the social, economic and political environment. The study argues that, in order to alleviate the impacts of HIV/AIDS, particular attention should be paid to the spread of the disease by developing appropriate mechanisms within civil society to deal with it. Social capital is identified as one of the social approaches to mitigate the impacts of HIV/AIDS. The next chapter considers the theoretical discussion surrounding this issue and the model of analysis for the study.

CHAPTER 2

Theoretical Background and Discussion

2.0. Introduction:

The purpose of this chapter is to discuss the theory of social capital and its relevance to this study. The focus, therefore, will be on obtaining a deeper understanding of the concept and its relevance for alleviating the impacts of HIV/AIDS in Uganda. It is generally agreed that social capital enables people to access certain benefits which might have been inaccessible without it. This study, in accordance with this assertion, examines how NGOs are able to alleviate the impact of HIV/AIDS through strengthening social relations; and consequently, how networks and resources embedded in them may benefit individuals, groups and communities affected by HIV/AIDS.

The previous chapter has outlined the problem of HIV/AIDS in Uganda and the need for NGOs to address this problem through the development of social mechanisms. In this discussion, it was suggested that the building of social capital was a precondition for the success of approaches addressing the problem of HIV/AIDS in Uganda. In the present chapter, the theoretical basis for further discussion is laid in a discussion of issues relating to the meaning and application of social capital. In addition, these theoretical discussions are related to the research problem of the present study.

The chapter proceeds as follows: first, the meaning of social capital is established before proceeding to discuss the historical development of the concept, why it has gained prominence in current development and policy debates, why it is important in the context of development, and how it can be measured. Second, the theoretical discussion is applied to the context of HIV/AIDS in Uganda, and then to the development of the analytical model that guided the discussions in this study. This model focuses on the relationship between NGOs and state institutions in generating, mobilising and reviving social capital in Uganda, and the extent to which the utilisation of social capital by NGOs results into the alleviation of the impacts of HIV/AIDS.

2.1 What is Social Capital?

Although the conceptualisation of social capital has evolved over time, its recent application grew out of the work of Bourdieu and James Coleman, who focused on the nature of

resources that accrue to individuals by virtue of their social ties. According to Coleman (1988: 98), “social capital is defined by its function. It is not a single entity but a variety of different entities, but with two elements in common: they all consist of some aspects of social structures, and they facilitate certain actions of actors...” Bourdieu too, views social capital as resources which are accessed through relationships between individuals, and defines social capital as “the sum of resources, actual or virtual, that accrue to an individual or group by virtue of possessing a durable network of more or less institutionalised relationships of mutual acquaintance and recognition” (cited in Field, J. 2003: 15).

The systematic conceptualisation especially in political science began with the seminal work of Putnam – *Making Democracy Work: Civic Traditions in Modern Italy*, who first defined social capital as those “features of social organisation, such as trust, norms, and networks, that can improve the efficiency of society by facilitating coordinated actions” (Putnam 1993: 167). He later reformulated this definition, arguing that social capital refers to “connections among individuals – social networks and the norms of reciprocity and trustworthiness that arise from them”(Putnam 2000: 19). According to Putnam (2001: 42) social capital includes all those social aspects, including unrecognised traditions such as greetings, nodding to each other on the street or in the supermarket. Putnam’s conceptualisation of social capital has received a lot of criticisms from scholars who have argued that the outcomes of social capital should be separated from social capital when one is defining it²⁷.

It should be emphasised however, that the definitions and the debate about social capital has generated a lot of controversy and the conflict is often over the content of social capital and out comes – as to which one should be considered as “capital”, but not what social capital is capable of doing. Thus, Woolcock (2001: 27) argues that “social capital refers to the norms and networks that facilitate collective action”. However, Lin (2001b: 3) considers social capital as “assets in networks” and Portes observes that:

Whereas economic capital is in people’s bank accounts and human capital is inside their heads, social capital inheres in the structure of their relationships. To possess social capital, a person must be related to others, and it is those others, not himself, who are the actual source of his or her advantage. (Portes 1998: 7)

²⁷ See for example, Woolcock (1998).

The above is emphasized by Portes and Landolt (2000: 533-534), who define social capital as the “ability to obtain resources through social networks or other social structures”, and further by Adler and Kwon (2000: 93) who define social capital as “a resource for individual and collective actors created by the configuration and content of the networks of their more or less durable social relations.”

Given the above discussions, it has to be emphasised that in spite of the diversity in definitions of social capital, there is a consensus that social capital is about relations, and that these relations are of beneficial value to associating people.

Based on the above discussions, a working definition has been formulated for this study. For this study social capital is defined as, “networks and associated resources, which are meaningful for individuals, groups and communities in dealing with the HIV/AIDS-related problems which they are facing”.

This takes into consideration not only the meaning of social capital, but also the constituent components of networks. Thus, the definition includes the premise that, networks are embedded with resources which benefit individuals or society. The definition is analytically strong since it links the concept to the empirical phenomenon in question (see for example Goertz (2006)²⁸).

The Historical Development of the Concept of Social Capital

Various scholars in different disciplines have been responsible for developing and refining the notion of social capital. It was not until the 1980s that this concept was applied on a large scale by academics, both within and across disciplines, although the roots go further back in time.

The concept of social capital was implied in many studies in the early 19th and 20th centuries, although not directly addressed. Woolcock (1998) for example, traces it back to 19th century sociologists such as Marx and Durkheim. Likewise, Trigilia (2001) observes that the idea of social capital was implied in Max Weber’s essay, *The Protestant Sects and the Spirit of Capitalism* (1906). Citing Weber, she notes that, in order for a new community member to

²⁸ Goertz points out that the central attributes that a definition refers too are those that are relevant for hypotheses, explanations and causal mechanisms.

initiate an economic activity in the United States at that time, he/she would first need the acceptance of the community. This acceptance would be based on his/her perceived moral credibility, which implied joining a religious sect such as the Baptist church. Thus, sect membership granted access to credit; only then would newcomers be allowed to open bank accounts, let alone be able to attract customers. By joining a sect the newcomer would win the trust, acceptance and confidence of would-be customers and creditors. Thus, the concept was not new although the title, social capital, was.

According to Putnam (2000: 19), the term social capital has been evolving ever since its first usage in 1916 by L. J. Hanifan, the supervisor of schools in West Virginia. Hanifan employed the concept to stress the importance of community involvement in the activities of schools for successful school performance. Putnam then traces the development of the concept in the 1980s to the works of Bourdieu and Coleman. Bourdieu uses the concept to explain how individuals can access economic resources through social networks, while Coleman uses it to explain the scholastic performance of children whose parents helped them with extra reading outside school. To add to this list of early usage, Nahapiet and Ghoshal (1998) trace the term in Jane Jacobs seminal work, *The Death and Life of Great American Cities* (1965). Jacobs discusses the importance of relationships in generating personal trust and facilitating cooperation and collective action.

More recently, Field (2003) has traced the concept from the works of Durkheim in the 1930s, to its appearance in the works of Bourdieu and Coleman, and later in Putnam's. He claims that, since Bourdieu, the development of the concept of social capital has been tremendous, as evident in the growing number of academic publications on this subject. Citing Harper, Field (2003: 3-4) points out that the number of academic articles that have social capital as a key word grew from about 20 prior to 1981, to 109 between 1991 and 1995, and to 1,003 between 1996 and March 1999. Not only has the number of publications increased, but also the diversity. According to Portes (1998; 2000), the term social capital has moved from its original discipline (sociology) to other disciplines, and on into everyday vocabulary.

The concept was also undergoing various refinements. For example, Granovetter (1973; 1983) takes up the question of types of relationship, making a distinction between "strong" and "weak" ties. Strong ties refer to relationships between members of the same community, family and/or kin, while weak ties refer to relationship that cut across social, political and

economic divides. According to Granovetter, individuals with multiple “weak” ties are in a position to access the latest information about the job market (Granovetter 1983).

In spite of its long history, the concept of social capital came into systematic usage only in the 1980s, with the works of Coleman, in particular, and the later refinements by Putnam. In political science, it became popular with the publication of Putnam’s (1993) seminal book, *Making Democracy Work: Civic Traditions in Modern Italy*, in which the concept is employed to explain issues of local governance in Italy. Putnam (2000) has since explained the great number of benefits to be accrued from social capital, ranging from governance, education and health to neighbourhood safety. At the same time, other scholars have employed the concept to explain issues of public health (Kawachi, Kennedy, and Glass 1999; Kemenade 2002a; 2002b; Szreter and Woolcock 2004; Veenstra 2001); and some have implied its importance in dealing with social and health problems such as HIV/AIDS (Barnett and Whiteside, (2002)), although not directly discussing social capital.

Another important refinement in the late 1990s was Gittel and Vidal’s (1998) effort to relate bonding and bridging to Granovetter’s distinction between “weak” and “strong” ties. Woolcock (1998; 2001) then developed bonding and bridging distinction further and added a third type of network which he called linking. According to Woolcock, therefore, there are three types of networks²⁹: a) bonding, b) bridging, and c) linking. This distinction has been used by institutions such as the World Bank (2000a) as a basis on which to develop a systematic model for the analysis of economic development and underdevelopment across and within nations.

The growing popularity and acknowledgement of the importance of social capital in explaining the social, political and economic problems facing various countries is influencing public policy in these countries³⁰. Given the growing interest and expanding applicability of the concept, it is important to question why it is so widely applied, both by academics and policy makers. That is the topic of the next section.

2.2 General Views about the Importance of Social Capital for Development

As mentioned above, the growing interest in social capital is largely the result of its usefulness in explaining various socio-economic and political problems, and in offering a way

²⁹ See 2.3 for a detailed discussion about these types of networks.

to address these. The importance of social capital is recognised at all levels, from governance to improved quality of life and general development. The following examples illustrate the importance of social capital for a range of issues.

In the economic sector, social capital is increasingly recognised as an important resource for economic advancement. It is considered to be necessary if countries and communities and individuals, are to prosper and develop (Fukuyama 1995; Krishna 2002; Woolcock 1998; 2001; World Bank 2000a).

In the political sector, social capital is considered a tool for creating democratic and responsive governments. Social capital in the form of civic engagement and trust-based relationships, leads to democratic governance (Putnam 1993; 2000). Putnam (2000) argues that participation in voluntary associations and formal meetings facilitates acquisition of deliberative skills and democratic values. Through such meetings and associations, deliberations on major political issues take place. Moreover, cohesive social groups have the power to hold government agencies accountable to the public. When people organise themselves into groups, it is more likely that they will be heard and that their demands will be met (Fukuyama 2004: 40-41).

In addition, social relations generate some benefits. When people regularly interact, especially if they share multiple affiliations to organisations, honesty and trustworthiness come to characterise their mutual relations (Wollebæk 2000: 30). Regular interaction inculcates certain qualities in the interacting individuals; for example, habits of tolerance and respect for others, the ability to manage conflict and a willingness to forgive (Putnam 2000). Confidence in dealing with others leads to generalised trust, reciprocity and cooperation, which in turn can be utilised for mutual benefit (Tillie 2004).

Applying these ideas to communities, social capital provides a basis for solving the common problems which they face. For example, farmers in various parts of the world have organised themselves into groups responsible for such activities as maintaining irrigation systems, administering common grazing grounds and watering points, or solving joint problems such as when negotiating high prices for their produce.

In a study, Kilpatrick and Falk (2003) note that there is a positive correlation between, on the one hand, the members and formal and informal infrastructure (relations and networks) of

³⁰ http://policyresearch.gc.ca/page.asp?pagenm=rp_sc_index, http://www.isuma.net/v02n01/index_e.shtml

communities, and on the other hand, the quality of outcomes achieved by these communities. They argue that, when people interact regularly, they know one another and consider each other to be credible members for ongoing interaction. Moreover, through regular interaction individuals come to identify with each other; they develop a sense of belonging and commitment to work towards the common good (Kilpatrick and Falk 2000; 2003).

In addition, trust-based relationships facilitate the flow of resources between various actors, provide access to information and facilitate knowledge transfer. This is because transaction costs decline as interaction increases. A study of agricultural traders in Madagascar concluded that the traders with better connections had better information on prices and on the reliability of clients. As a result, they enjoyed larger sales and gross margins on their transactions (Fafchamps and Minten 1999; Grootaert and Van Bastelaer 2001).

Another field in which this concept is useful is immigration. In many parts of the world, social relations have constituted an important source of financial support for immigrants. In overseas Chinese communities, networks based on extended family or on close-knit ethnic communities ensure lower transaction costs, speedy information transfer and innovation (Trigilia 2001). Portes and Sensenbrenner (1993) describe a range of benefits that social capital offers various immigrant groups. In addition to other benefits such as access to credit, they describe how immigrant solidarity enables groups to confront the racial prejudice of the natives, as in the case of Nicaraguan immigrants in Miami.

Yet another role of social capital is in reducing crime rate, according to Putnam (2000). He argues that, where there is enough connectedness, safe neighbourhoods develop since everyone watches their neighbours' house.

With regard to education, Coleman (1988) claims that parental involvement with their children is an important factor in their children's intellectual development. Based on Coleman's arguments, Putnam (2000) investigates the causal relationship between social capital and children's academic performance. He finds out that the social relations within a child's family, school, peer group and community affects a child's opportunities, behaviour and development. For example, when parents are more involved with their children, children may watch less television and their performance in schools is likely to be better. Moreover, in societies that are rich in social capital, teachers are in touch with parents, feel loyal to schools,

seek innovative approaches to learning and have a deep sense of responsibility to their students' development, which in turn will improve their students' performance.

In public health, the concept of social capital was introduced by Richard Wilkinson (1996) in his book, *Unhealthy Societies*. Since then, scholars have argued that this concept is useful in explaining people's health and well-being (Hyypya and Maki 2003; Putnam 2000; 2001; Szreter and Woolcock 2004; Veenstra 2001). They argue that people are able to deal with life-threatening crises if they have social relationships for support, and that this may even extend an individual's life span. In a sweeping statement, Putnam asserts that "controlling for your blood chemistry, age, gender, whether or not you jog and for all other risk factors, your chances of dying over the course of next year are cut in half by joining one group, and cut to a quarter by joining two" (Putnam 2001: 50).

This link between social capital and improved health is also addressed by Campbell (2000: 182). Campbell criticises government's neglect of social capital in their efforts to improve people's health; he claims that governments emphasise improvements to the health care infrastructure, for example hospitals, but overlook the social capital infrastructure. He cites Lomas, thus;

On the one hand, millions of dollars are committed to alleviate ill health through individual intervention. Meanwhile we ignore what our everyday experience tells us, i.e. the way we organise our society, the extent to which we encourage interaction among the citizenry and the degree to which we trust and associate with each other in caring committees, is probably the most important determinant of our health. (Lomas 1998)

Health care systems have offered medical support that has somewhat improved peoples' health. However, social relations and networks which are not considered by the health care systems may also be important for people's health. Lin (2001a) argues that social relations strengthen identity and recognition, which assures individuals of their worth as individuals and as members of social groups sharing similar interests. This reassurance is important in improving the mental health of such individuals. It is in these areas that social relations make an important contribution to health.

Szreter and Woolcock (2004) argue that individualistic policy approaches have failed to improve people's health. The increasing emphasis on neoliberal policies³¹, and the recognition of the fact that medical interventions and media campaigns have failed to rectify social ills influencing the spread of HIV/AIDS, have led to a re-examination of the impact of social environment on people's health with regard to HIV/AIDS³².

2.2.1 The Negative Consequences of Social Capital

The above discussion has focused on the positive side of social capital. However, social capital may have another side – “the down side of social capital” (Portes and Landolt 1996); the “dark side of social capital” (Putnam 2000). Strong ties may create social problems such as crime, and may limit access to economic resources and new ideas (Adler and Kwon 2000; Granovetter 1973; 1983; Portes and Landolt 1996; Portes and Sensenbrenner 1993). In addition, Portes and Landolt (1996: 19) claim that “the same strong ties that help members of a group often enable it to exclude outsiders.” As a result, such relationships may limit the flow of information and economic resources from outsiders (Narayan 1999a) or may exclude third parties from accessing economic resources embedded in the social network (Portes and Landolt 2000). This lack of access to economic resources may result in increased poverty, as Narayan's (1999a) study of poverty vis-à-vis ethnic networks illustrates. Furthermore, strong ties may impose pressure on the individual members of a society to meet their social obligation by providing for members of their community or family. This, in turn, may limit economic progress (Portes and Landolt 1996).

In terms of access to information, individuals in bonding networks, have limited relations with people outside the group, and they continue to access the same information over and over again, rather than accessing the diverse sources of new information outside the group (Burt 2000; Granovetter 1973; Woolcock 2001). Without access to information, Loury (1977) argues, residents of inner-city ghettos find themselves trapped in low-wage employment. Similarly, Adler and Kwon (2000) argue that strong ties may over embed individual members in a group and limit their access to new ideas.

³¹ Colleen O'Manique's discussion of the impact of neoliberal policies on HIV/AIDS policies has revealed that neoliberal policies fuel the deepening impact of HIV/AIDS (see chapter 4).

³² In Chapter 4, I discuss the relationship between the social, economic and political environments and the spread of HIV.

According to Woolcock and Narayan (2000), networks based on religion, ethnicity, class and gender may promote sectarian tendencies and may encourage individuals to pursue narrow-minded goals. In the case of Rwanda, they argue that, in spite of the existence of a large number of cooperatives and farmers' organisations, the civil war that took place in 1994 could not be prevented. They cite a study by the World Bank, which found that in 1989 there were about 3,000 registered cooperatives and farmers groups and an estimated 30,000 informal groups in Rwanda. The genocide that took place in Rwanda in 1994 may partly be explained by the exclusive social capital that heightened hatred between ethnic groups of Hutu and Tutsi. The argument, therefore, is that social capital based on ethnic relations may result into ethnic violence and bloodshed.

Similarly, a community characterised by densely connected trusting groups may be faced with insecurity and violence; the drug dealers, street gangsters, mafias and recent global insecurity all rely upon social capital as the foundation for their organisational structure. Lately, crimes committed by terrorist groups have become common throughout the world: the Oklahoma City bombings in 1995; the planes that crashed into the twin towers of the World Trade Centre (popularly known as the 9/11 terrorist attack); and the more recent July 2005, bombings in Britain, are the work of networks of terrorists. Given the above general view about the importance and the negative consequences of social capital, it is important that particular attention be given to different types of social networks with a critical view of the range of benefits that each type may offer. The understanding of the different types of networks will provide a basis of analysis of how social capital may help individuals groups and organisations interested in addressing social phenomenon.

2.3 Types of Networks and Their Relative Importance

Since Granovetter (1973) identified the importance of "strong" and "weak" ties for individuals' access to employment, there has been a marked development and use of the concept of networks in the analysis of various social and economic problems. The distinction between bonding and bridging social capital has recently become fundamental to the analysis of the implication of various social networks in different contexts. This distinction is used in the analysis of the causes of poverty and other social and economic conditions. This categorisation has been developed still further by Woolcock (1998; 2001), who distinguishes between three types of networks – bonding, bridging and linking networks – and analyses how each relates to poverty. Later, Szreter and Woolcock (2004) applied a similar analysis to

public health. My study will borrow from this analysis and examine how this categorisation of networks can be applied to the organisations involved in activities addressing HIV/AIDS-related problems in Uganda. I will discuss the distinctions between the three types of networks and contextualise them in the present study.

2.3.1 Bonding Networks

Bonding networks refer to relations between people who view themselves as sharing similar characteristics (Szreter and Woolcock 2004; Woolcock 1998). They include networks of family and kin, and of close friends and neighbours (Woolcock 2001). One of the characteristics of bonding networks is particularised or “thick” trust (Williams 1988). Trust among associating members is based on knowledge of the other, resulting from routine contact or what Seligman (1997) calls “face-work”.

Bonding networks may be exclusionary to people who are outside the network while limiting the freedom of those inside the network (see 2.2.1). They however, offer a range of benefits to members of the network; for example they are sources of psychological and emotional support (see 2.3.4). Thus, scholars such as Barry and Scot (1990) have argued that bonding networks of family, friends and relatives are sources of support services to the members and Lin (2001a), argues that people who face a similar problem may benefit more by associating with each other than with people unlike them.

2.3.2 Bridging Networks

These are networks that include distant friends, associates and colleagues (Granovetter 1973; 1983; Woolcock 1998; 2001). Granovetter (1973) defines bridging networks as weak ties, and according to Williams (1988), such ties are based on “thin” trust or what Uslaner (1999; 2002) calls generalised trust. The relationship between associating members is based on limited knowledge of the other, therefore, ties between them are not very deep (Uslaner 2003). There is limited attachment to the group values, therefore members find it easier to integrate with others unlike themselves³³. This element of integration makes it possible for bridging networks to act as linkages to external resources. They provide avenues for

³³ One of the disadvantages of social capital – the down side of social capital is that it binds an individual to the group values, which may be a basis for excluding others outside the group.

accessing better information and opportunities beyond those provided by the group to which an individual belongs (Burt 2000; 2001; Lin 2001b).

2.3.3 Linking Networks

Linking networks are a special kind of bridging networks, and they describe vertical relationships between various individuals, groups and organisations (Putnam 2000; Szreter 2002; Woolcock 1998; 2001). They describe relationships that exist between people with few resources and those possessing more resources; for example, the relationship between people in a community and those in authority or government (Szreter and Woolcock 2004: 655). According to Woolcock (2001), poverty is largely a function of powerlessness and exclusion. He asserts that the task of policy makers, therefore, is to create avenues that can facilitate access to the institutions that can provide funding, for example, banks and insurance companies. He thus, proposes a third type of network – linking, that provides an avenue for the access to these resources. Examples of linking social networks include the relationship between individuals and the people occupying positions in government, such as legislators, between local organisations, between government and larger NGOs, and between international donors and the business community.

Like bridging social networks, linking networks are characterised by trust based on properly functioning state institutions. For example, the more people expect that state institutions will respond to their needs, the more they may trust others. This is also true for the facilitation of inter-organisational cooperation.

2.3.4 What Types of Network Matter for Individual or Social Wellbeing?

Having defined and discussed the different types of networks and how they are constituted, it should be noted that these networks are contextual and may not be mutually exclusive. The question addressed in this section is whether bonding or bridging, or linking is more important, as well as why it is important. The following discussion will explore the relative importance of such networks as they have been employed by various scholars, and will later contextualise the discussion in the study.

Social relations involving family members and kin have been considered to be sources of social and psychological support for the less fortunate members of society. Barry and Scot

(1990) argue that networks involving family members would produce a great deal of services for the members, while those linked to neighbourhood would result into limited services. Bonding relationships also function as sources of financial capital for immigrants in foreign countries who cannot access the formal credit system due to lack of collateral (Portes and Sensebrenner 1993; Trigilia 2001).

There are, however, studies which have considered bonding networks to be a disadvantage to communities (see 2.2.1 for negative consequences of social capital). Narayan (1999) for example, argues that such networks limit economic advancement and perpetuate poverty. These studies consider bridging networks to be more important than bonding networks. Bridging networks may generate broader reciprocity and identities, and may provide links that enable members to access external resources and current information. They provide avenues for accessing better information and opportunities beyond those provided by the group to which the individual belongs.

The above discussion indicates that each type of network has some advantages and disadvantages. Because social networks have advantages and disadvantages, individuals will tend to associate with others from whom they can benefit. Lin (2001a: 21) points out that social capital has three elements: a) the number of persons within one's social network who are prepared to offer help when called upon, b) "the strength of the relationships indicating readiness to help", and c) the resources possessed by persons in the network. These three elements determine whether individuals decide to associate or not and with whom to associate.

Lin (2001b: 14) argues that a person facing personal stresses, for example due to a divorce, may benefit from access to and interaction with others who have experienced similar stress and understand its psychological effects, rather than interacting with someone who is happily married. She argues that social capital is more than mere social relations and networks: it evokes the quality, the resources embedded and accessed through the networks. She concludes that, "without anchoring the concept of social networks and embedded resources, chances are that social capital would fade away as an intellectual enterprise for the ever-broadening and confounding definitions and almost utopian expectations of its practical application"(Lin 2001b: 23).

It is also important to stress that, in spite of the distinction made between various types of networks, these networks are only analytical constructs. The distinction may be hard to maintain in any empirical work (Szreter 2002)³⁴. Moreover, the three categories are not mutually exclusive and depend on context. They work hand in hand and produce different benefits which an individual may enjoy. For a fuller analysis of their impact, it is important to examine how these network types function together for the betterment of society or of individual lives. The table below summarises the distinctions between the three types of networks, and reveals how each network type may be an advantage or disadvantage to the individual or community³⁵.

Table 2. 1 Difference between Bonding, Bridging and Linking Networks

Network Type	Structure	Function	Implication
Bonding	-Composed of people with the same ethnic background, belonging to the same community and family members, religious sects, or membership to the same club.	-Main source of social support -Indicators of solidarity and social cohesion	-Source of social and psychological support. -Facilitates collective problem solving. -May influence policy and hold governments accountable because of their ability to mobilise solidarity (Fukuyama 2004). -May exclude outsiders. Members are less tolerant of non-members
Bridging	-Horizontal. -Composed of people who have different social backgrounds but comparable economic and social resources.	-Facilitates information flow among various groups and between individuals. -Facilitates access to resources outside the network or group.	-facilitates acquisition of new information -members are tolerant -Inclusive
Linking	-Vertical. -Composed of people with different social backgrounds and resources.	-Facilitates access to power and economic resources. -Relationships between state institutions, donors, business organisations etc, are a source of financial and technical resources.	-Facilitates access to better resources outside the community (see (2001:13) -May have greater influence, and gain faster responses to issues that affect people (2000a: 186-187)

2.4 How is Social Capital Generated?

Various scholars have explored the factors that may lead to the generation of social capital. Hooghe and Stolle (2003) for example puts together works of scholars from different fields and environments who propose the way social capital is generated. Putnam (2000) reviews what he believes to be the reasons behind the decline of social capital in America and proposes the ways through which the revival of social capital can be achieved in that environment. Although these scholars do not agree on the causal order of factors relating to

³⁴Associating members usually have different characteristics, even if they are members of the same family and kin group. They may differ with regard to age, education, etc. Making a distinction between bonding and bridging social capital on the basis of one aspect of these membership characteristics, ignores other defining characteristics which may influence interaction.

generation of social capital, they at least agree that the generation of social capital depends on the performance of state institutions and the local social environment – families and neighbourhoods. From the literature concerning the generation of social capital, I can make the following deduction; that the generation of social capital depends on three basic factors:

a) The functioning of state institutions and local government. The basic argument is that properly functioning state institutions, for instance law enforcement and welfare institutions, will lead to increased generalised trust (Rothstein and Stolle 2001). When state institutions respond to people's needs, people feel they can trust them, and consequently, people come to trust their fellow citizens (Szreter 2002). One such study was carried out by Rothstein and Kumlin (2003), who argue that, in spite of strong institutions created in the former Soviet countries, there was low generalised trust compared to the welfare states of Scandinavia. The reason is that, in the former Soviet Union, people had little trust that the state would respond to their needs, consequently they had less generalised trust. Similarly, Rothstein and Stolle (2001) argue that in communities where institutional responses to people's welfare needs, are limited, people tend to have less trust in their fellow citizens.

b) The vibrancy of civic associations and family and community networks. The argument is that participation in such associations as bowling clubs, religious groups and volunteer organisations, as well as willingness to contribute to charity organisations, as important factors for the formation of social capital. These milieus are considered channels through which participation can be nurtured and in which trustworthiness and norms of reciprocity may develop. Scholars such as Putnam (1993; 1995; 2000; 2001) and Krishna (2002) are proponents of this approach.

c) The synergy between government and local and civic associations: I argue that the government and civic associations may work together to facilitate growth, revival and generation of social capital. I argue that the development of social capital can be affected by the complementary roles of society (associations and groups at community level and various networks within the community) and by the roles of state (Woolcock and Narayan 2000). I take this argument as the basis of analysis in the present study.

³⁵ A similar table contextualising the types of networks in this study is presented in chapter 6 (table 6.8).

2.4.1 Synergy as a Model for Understanding Social Capital Generation

Evans (1996a) conceptualises synergy as mutually reinforcing relationships between government and groups of engaged citizens. Putnam (1993a) argues that synergy implies that civic engagement strengthens state institutions, and that effective state institutions create an environment in which civic engagement is likely to thrive. According to Putnam(1993a: 42), "Social capital is not a substitute for effective public policy but rather a prerequisite for it and, in part, a consequence of it...Wise policy can encourage social capital formation, and social capital itself enhances the effectiveness of government action".

As mentioned, the synergy perspective argues that the generation of social capital depends on the complementary roles of society and the state (Woolcock and Narayan 2000). The explanation of how such relationships are manifested and facilitated is the task of researchers and theorists.

The synergy approach has recently been applied to development. This perspective maintains that both state and society can contribute more to development if they work together, than each can contribute, working in isolation. In his book, *State-Society Synergy: Government and Social Capital in Development*³⁶, Peter Evans (1996) has assembled the research findings of experienced scholars in the field, who have examined how synergy functions. The evidence from the works of Ostrom (1996) shows the complementary roles of state and society in the production of goods or services. The study of irrigation systems in Taiwan by Lam (1996; 1998) reveals that state-society interaction is essential to generate trust, without which equitable water distribution and management of irrigation channels, would not have been achieved. These studies show that the government, as well as the society, has a role to play in facilitating coordinated action. It is on this basis that synergy is advocated for in the present study.

According to Evans (1996a) synergy may take the form of either embeddedness or complementarity. He argues that under a complementary relationship the activities of government complement the activities of civil society organisations. There is clear division of labour between the two realms. Each may act with relative autonomy in pursuing goals where there is mutual understanding.

³⁶ In this volume, he explores the contributions of empirical studies done by different authors in different environments with varying contexts and conditions which facilitate synergy.

Alternatively, with embeddedness, the government provides not only inputs and a favourable environment that facilitates the development of social capital, but also incorporates members of civil society in the government team involved in the delivery of goods and services³⁷. The involvement of the civil society often depends on the social relations within the community it self. Such involvement of citizens encourages the development of trust-based relationships not only between within civil society but also, between state and society. He argues that “social capital inheres, not just in civil society, but in an enduring set of relationships that spans the public-private divide (Evans 1996a: 1122).

In spite of the distinction between “complementarity” and “embeddedness” the line between them cannot be simply drawn in empirical discussions. The two are mutually supportive of each other. The distinction only helps to understand how state-society relations affect development initiatives.

However, it has to be emphasised that with respect to my study, complementarity is more suitable than embeddedness. This is because there are limited institutional structures at the macro level to facilitate sustained and vigorous state-society relations. But there is evidence that with respect to HIV/AIDS government has created an environment which facilitates involvement, interactions and coordinated actions of different stake holders especially at the micro level. Thus, complementarity is exemplified in the states role in providing an environment such as the multisectoral approach, which allows participation of different actors such as business communities, religious organisations and other civil society organisations, and also, protection of the rights of people with HIV/AIDS, political leadership, mobilization of funding for HIV/AIDS activities and partnerships in providing HIV/AIDS services (see chapter 7).

Similarly, complementarity is exemplified by the functions of civil society and other organisations outside the government sphere, such as business organisations and families, in the provision of welfare and support services to the needy especially with limited public welfare system. This is well documented to exist or to have existed before the advent of HIV/AIDS in Uganda. For example, social relations at the family and community levels are important sources of social support for the needy in African countries, and Uganda in particular (Kayazze 2002; Tumwesigye 2003). Although HIV/AIDS often led to the

³⁷ See Lam (1996)

withdrawal of the social support from community members (Barnett and Whiteside 2002; Marshall and Keough 2004), this support can be revived through rebuilding relations at these levels. This study argues that the revival of social capital on these levels may only take place when civil society organisations with the support of the host government are involved together in a mutually supportive manner. Thus the long involvement of HIV/AIDS organisations such as TASO in providing support and care services gives them credence to strengthen social relations between individuals, groups and communities. Similarly, as mentioned in chapter 1, NGOs do not work in a vacuum. They are influenced by government activities and institutions. Therefore, generating social capital depends on the activities of government. In order to understand the extent to which NGOs reduce the impact of HIV/AIDS, therefore, it is necessary to observe the contribution of government and state institutions to their functioning (see chapter 7).

On the basis of the above discussion, the present study therefore, argues that, in order to alleviate the impacts of HIV/AIDS, it is necessary for the NGOs and government to have mutually reinforcing relationships. As mentioned, the NGOs have various roles to play with the support of government. These activities can lead to the generation of social capital consequently the impacts of HIV/AIDS may be alleviated. Before exploring how this can be done, however, it is important to consider how social capital is measured.

2.5 Measuring Social Capital

It must be borne in mind that measurements of social capital are contextual. As earlier discussed, in 2.0, social capital is concerned with social relations and the resources that can benefit people irrespective of whether they are part of organised networks. This study therefore, adopts measures associated with social relations including participation and level of participation in the network, those associated with trust including trustworthiness, social support, and cohesion. These measures were specifically selected because of their wider application in explaining people's health and related well-being (Berkman 1995; Campbell 2000; Hyyppa and Maki 2003; Kawachi, Kennedy, and Glass 1999; Kemenade 2002a; 2002b; Putnam 2000; Szreter and Woolcock 2004). The central measures will be explained below, as well as their theoretical relevance for this study.

2.5.1 Social Engagement and Participation as a Measure of Social Capital

The theoretical discussion above has demonstrated that network membership is important for both social and economic development. It has also shown that social relations and interactions are important for the improvement of people's health. The question that remains is how can the volume of social capital present in communities be measured? Blomkvist (2001) points out that, if one has data on trust and networks, one ought to be in a better position to say something on social capital. Thus, consideration should be given to associational membership and interaction – the nature of associational membership, the frequency of interaction and the structures of interaction.

a) The nature of involvement of engaged citizens. Consideration is given to the nature of associational membership and associational life. Various features of the interaction must be taken into consideration; for example, is the interaction formal or informal, face-to-face or non-face-to-face, and what the means of interaction are. Some scholars such as Putnam (1993; 2000) have considered face-to-face interaction to be more important, while others such as Wollebæk and Selle (2003), Wollebæk (2000) and Blanchard and Horan (1998) argue that non-face-to-face interactions are as good as face-to-face interactions. For the purpose of this study, a focus will be put on face-to-face interactions since many people in developing countries do not have access to facilities such as telephone and internet which would make non-face-to-face interaction possible. In addition, attention will be paid to both formal and informal interactions.

b) The frequency of interaction; i.e. how often interaction takes place. Respondents are often asked how often they engage in certain activities, the number of activities they are involved in, and the number of organisations and associations they participate in (Wollebæk and Selle 2003). In addition, it is also useful to ask who is interacting with whom; there are networks involving close friends and family members, networks involving distant friends, etc., and interactions involving state officials or people with more resources (Woolcock 2001). These studies draw upon Mark Granovetter's arguments regarding the importance of strong and weak ties. For example, social support should be considered in relation to the type of network that may result in that support (Kemenade 2002b).

c) Consideration should be given to the network types and resources embedded in them: some scholars have considered that analysis of social capital should not be isolated from the

benefits accrued from the particular networks (Burt 2000; 2001; Lin 2001b). This measure is important for the present study because of the interest in knowing the extent to which different networks mitigate HIV/AIDS challenges. I have earlier pointed out that different networks possess different resources, which benefit individuals and communities (see 2.3.4). With regard to mitigating HIV/AIDS, it is important to know the nature of benefits and resources embedded in particular networks³⁸.

2.5.2 Trust as a Measure of Social Capital and its Relationship with Health

Putnam (2001) argues that the levels of trust in the community may act as a proxy indicator of social capital. Blomkvist (2001) points out that if one has data on trust, norms and networks, one is in a better position to say something on social capital. Therefore, it is important that the levels of trust be taken into consideration.

Trust may be defined as the expectation that individuals will behave in the manner expected of them. It is an essential element in facilitating co-operative behaviour among individuals, as well as a means of enforcing social relationships and a lubricant of social life (Seligman 1997). It is the 'belief in the goodwill and benign intent of others' (Kawachi, Kennedy, and Glass 1999).

When using trust to measure social capital, the perceived trustworthiness of fellow citizens is often considered. Two conceptions of trust are put into consideration; a) generalised trust and b) particularised trust.

a) Generalised trust considers the extent to which people generally believe that engaged citizens and fellows are generally trustworthy. Such trust requires no prior knowledge of the trustee. It is usually associated with institutions and is often understood to refer to trust in institutions (Russell 2000). The argument is that when state institutions such as welfare, service and legal, are responsive to people's needs, people will trust them. This trust in such institutions will eventually make people trust fellow citizens (Rothstein and Stolle 2001; Szreter 2002). Generalised trust can also be associated with weak ties what others such as Granovetter (1973) identify as thin trust. Respondents are often asked the extent to which they trust members of the community who may not necessarily be members of the

³⁸ The discussion on this issue is made in chapter 6.

organisations to which they belong. They may also be asked whether they consider members of their community to be ready to offer help or whether they only care about themselves (Mayer 2003). In health-related studies, consideration of generalised trust looks at the extent to which people trust health care institutions and the professionals offering health care services. This trust is different from individualised trust. People go to hospitals and other health care units, not because they have a particular doctor they know, but because they trust that any doctor they find in the hospital will offer them the service they need.

There are ambiguities associated with the notion of generalised trust. In particular, this concerns the general interpretations of what a trusting relationship would entail and whether people should be trusted in every aspect of life, which may not be possible. For example, person A may trust person B to deliver a message on his behalf, but may not trust him to return money he has been lent. In other-words, it is possible for one individual to trust another to do something, but not to trust the same individual to do something else.

Thus, there is a need to consider the second conception of trust; b) particularised trust. This type of trust may exist between people who have known each other for some time. It usually develops out of increased face-to-face interaction and personal experiences of interacting individuals (Russell 2000). Another consideration may be trust based on social norms. For example, trust may develop due to sanctions existing in society; for example, the punishment and isolation of individuals who become untrustworthy, or withdrawal of financial support, may help to make such individuals and others in society more trustworthy. Coleman (1988) describes how people involved in the diamond trade could give their diamond to potential buyers to examine without any written agreement; he attributes this expectation that the potential buyers would be trustworthy, to the sanctions of exclusion that would be brought to bear on anyone who breached this trust.

Using particularised trust to measure social capital, respondents are often asked the extent to which they trust others they interact with, for example neighbours, workmates, friends or even relatives. Putnam (2000) argues that in communities where personalised trust is in abundance and people trust their neighbours, worries about straying children are minimal. Neighbours are each others' "police" and security, for example, watching each others' houses whenever a member of the community is away. It is interesting to note that, in such communities, where trust is high, people are likely to be in better health (Hyypä and Maki 2003; Putnam 2000).

Putnam (2000; 2001) has thus, considered that there has been a steady decline of social trust in America - implicitly a decline in social capital. Given this distinction between generalised and personalised trust, it is important to mention that personalised trust is more relevant and applicable in this study. The study will therefore, examine the extent to which this form of trust is generated through regular interactions and the extent to which such trust may affect HIV/AIDS mitigation.

Having established a working definition of social capital, the conditions under which social capital may be important for this study, and the different conditions for generating social capital, an approach and measures of social capital were adopted for this particular study; the next step is to develop an analytical framework.

2.6 The Analytical Framework

The concept of social capital defined as networks and associated resources which are meaningful for those affected by HIV/AIDS³⁹, is a reminder to observe the nature of networks and how such networks are meaningful. I have suggested that one of the approaches to the mobilisation of social capital is to create mechanisms that facilitate participation in the HIV/AIDS-related activities (see chapters 6 and 7). The analysis will focus, therefore, on the nature of participation (formal and informal); it will consider the time spent by individuals participating in the organisations' activities, the frequency of interactions and the nature of interactions in organisations and communities. In addition, it will consider the inter-organisational networks and relationships with government and donors.

With respect to the nature of interactions, the study will examine how these are relevant in the alleviation of the impacts of HIV/AIDS. It will examine the importance of face-to-face interactions and whether other kinds of interaction are also important. Because of the limited access to economic and technological resources⁴⁰, which facilitate non-face-to-face interactions, the study will argue that face-to-face interactions, of both formal and informal nature, are more important than non-face-to-face interactions. Thus, emphasis is placed on

³⁹ See 2.0 for the working definition for this study

⁴⁰ The World bank (2003; 2004) point out that in 2001, the Gross per capita income in Uganda was US\$ 1.255, while O'Manique (2004), points out that about 80% of Ugandans live on less than US\$1 a day. Similarly, access to communication technology such as telephone and internet services is limited by lack of funds.

understanding how often members meet their friends, relatives, fellow organisation members and people from other organisations, and how often they attend meetings.

I will examine the factors that enable interactions to take place. The study will analyse the processes through which interactions are facilitated (chapters 6 and 7). I will also examine the extent to which membership to HIV/AIDS NGOs results in increased trust relations among members, and whether the trust generated within these organisations may extend to other community members who are not members. This is particularly important because trust between individuals and groups may be seriously undermined by HIV/AIDS. People with HIV/AIDS or who are suspected of being infected with HIV, may be excluded from general social activities or stigmatised. This increases stress and demoralisation, and may undermine their trust of others (see stigmatisation in 4.2.2).

Several questions may be asked: How beneficial are such relationships for people with HIV/AIDS and other members of the organisations? Can they confide in their fellow members? Can they share their experiences? Can they trust community members because of their membership to organisations? Do people trust the service providers and staff who work in service organisations? Understanding these questions is important for the analysis of the extent to which the activities of TASO and PTC/PLI are able to alleviate the impacts of HIV/AIDS. The effect of interactions between different individuals and groups on the impacts of HIV/AIDS will be examined. Thus, using the measures of social capital developed above (2.5), the study will examine the extent to which TASO and PTC/PLI are successful in alleviating the impacts of HIV/AIDS (chapter 8).

Arguing that trust is important for a cohesive society, and that trusting societies will offer social support to their members, both social cohesion and social support are considered to be important analytical concepts in this study. It is important therefore to examine these two concepts and their relevance to this study.

Social Cohesion

Social cohesion involves building shared values and developing a sense of togetherness, based on a sense of trust, hope and reciprocity among members of a society (Kemenade 2002b). Indicators of social cohesion are the activities and behaviours that strengthen social unity and minimise social distance among individuals and members of a group. They include

a sense of belonging to the community and participation in various community activities. The greater the individuals' level of involvement with others, the greater the social cohesion and the greater the likelihood that they will be able to deal with personal or community problems which they are facing. People with higher levels of participation and integration are less likely to have self-rated⁴¹ poor health. This analysis is carried out at the individual level; self-rated feelings of health and community belongingness are two of the indicators of social cohesion (Hyypa and Maki 2003). The importance of these factors have been examined by Hyypa and Maki (2003: 771), who conclude that health among women participating in networks has improved in Sweden. They argue that the most important factors that contributed to improved health among participating individuals were the increased sense of belonging, participation in the process and mutual trust.

Social Support

Social support indicators include social activities and contacts with immediate networks. Social support provided by the community transcends narrow reciprocity (Barry and Scot 1990). It is perceived to consist of four elements based on people's perception of whether they have: a) someone they can confide in, b) someone they can count on, c) someone who can advise them, and (d) someone who makes them feel loved (Kemenade 2002b:9). As I discussed in chapter 1 and will elaborate in chapter 4, HIV/AIDS is associated with a lack of social support from immediate family members and the community. This is one of the major problems faced by people with HIV/AIDS and orphans in Uganda. In chapter 5, the development of HIV/AIDS NGOs in Uganda will also be related to this lack of social support from family members and relatives. Thus, understanding the extent to which NGOs can create or lead to a revival of such social support is necessary for this study. This partly explains why social support is considered a vital component of the analytical model of this study. To what extent do increased interactions and other social relations result into social support for people with HIV/AIDS and the needy such as the AIDS orphans?

2.6.1 The Empirical Model of the Study

The empirical model selected for this study is based on the synergy perspective on social capital generation. In this study it is perceived that the combination of efforts by the government and organised civil society is more appropriate for combating a phenomenon

⁴¹ Questions mapping social capital in relation to health are attitudinal and only individuals answering the question rate their own health status.

such as HIV/AIDS, which has psychological, physiological, sociological, political and economic consequences. Synergy in this study focuses on: a) how the formation of social networks in the community, such as of family and kin, are facilitated by the roles of HIV/AIDS NGOs and the state and, b) how NGOs' roles complement and are supported by the roles of government in fighting HIV/AIDS in Uganda.

Why was the Synergy Model chosen?

Evans (1996) argues that communities with pre-existing stocks of social capital are likely to enjoy the benefits of synergy. This study emphasises that the stocks of social relations at the family and community levels which existed before the advent of HIV/AIDS lends credence to synergy as an approach to fighting HIV/AIDS. The revival of social capital at these levels is likely to promote healthy state-society relations, which will make fighting HIV/AIDS possible. Apart from the social capital endowments, Evans further argues that short term construction of synergy is possible especially so with the responsive political regimes. As will be discussed in chapter 4 and chapter 7, Uganda's political response to HIV/AIDS makes a focus on synergy as an appropriate model of analysis in this study.

Further, there is little empirical research concerning how the actions of state and society (relations at the meso level) may be combined to provide an understanding of social capital generation and the impact of such a combination on a phenomenon such as HIV/AIDS with social, psychological physiological and catastrophic consequences. There is considerable research into the synergistic relationships between government and society in generating social capital and producing collective goods; for example, in maintaining water systems, enforcing law and order and improving educational performance of children (Evans 1996; 1996a; Lam 1996; Ostrom 1996). Nevertheless, there has been little empirical research, into community-state relations and take it beyond economic development realms and apply it in areas such as health.

It has to be emphasised that the meso level analysis examines the relationship between community organisations and middle level government institutions such as local governments and communes. Putnam (2000) proposes the creation of regional governments so as to increase people's participation. With the creation of regional, autonomous and self accounting local governments this level becomes important because different regions control different resources, they design their programmes and as such their relationship with society

are different. Policies might be the same for all local governments (emanating from the central government) but their application and enforcement may vary from region to region. The relationship between local governments and communities and organisations affects the impact such policies might have on social phenomenon. The meso level analysis has been applied in studies which looks at the relationship between society and local government institutions and government representatives in promoting development [see for example, Lam (1996; 1998) and Ostrom (1996)]. Nevertheless there is little empirical research relating the meso level analysis to public health and how this is beneficial to the individuals and communities.

In the present study, the model reveals how different actors, such as NGOs and government, can relate with each other in order to alleviate the impacts of HIV/AIDS. This model is intended to identify the social processes through which social capital may be generated, and applied to combat HIV/AIDS. The model reveals how the actions of government may facilitate the efforts of NGOs to mobilise social capital. Thus, I argue that the success of NGOs in mitigating HIV/AIDS is dependent on government support. This support may require that the government play a complementary role, by providing a favourable environment for the functioning of NGOs and other non-governmental actors, such as the business community. The support may also require that government integrates different actors in its programmes addressing HIV/AIDS.

Why is the Relationship between Government and NGOs Important for the alleviation of HIV/AIDS-related Problems?

Studies have revealed that governments cannot act alone in initiating change, and that they recognise this and have recently turned to the voluntary sector for help (Hall 1999). Moreover, a number of studies have suggested that NGOs' autonomy from government may not result in them having a greater impact on development, especially in developing countries (Bishwapriya 1997); and that a good and a cooperative working relationship with the government is the key to their success. This argument indicates that, for social, economic and political development to be realised, there is a need for the two to mutually reinforce each other. For example, Muriisa (2004) discusses that through cooperation between NGOs and the Ugandan government, rural development in Uganda was achieved.

First, NGOs in some developing countries lack the necessary connections that may grant them access to resources such as funds and technical personnel. They need to work with government agencies, therefore, so as to access such resources. In order to work with the government, it is necessary to develop forums through which NGOs and government can pursue development goals. Such forums encourage collaboration and communication between government and civil society, and when this happens, social capital is jointly shaped by private and public institutions (Woolcock and Narayan 2000).

Second, NGOs in developing countries are usually working in a turbulent political environment characterised by state takeovers and coups. This political instability may mean that governments are suspicious and feel threatened by any organised groups, especially those working with the grassroots and communities. Cooperation with government is, therefore, a step towards gaining legitimacy within the host government system. Such cooperation may produce the desired results; with the government creating an environment that facilitate involvement of NGOs and other actors, and NGOs getting involved into activities that would address problems which people face.

As mentioned, studies have shown the importance of family support for the needy, such as orphans, the unemployed and people with HIV/AIDS. There is also evidence of a decline in this support due to HIV/AIDS (Barnett and Whiteside 2002; Kayazze 2002; Marshall and Keough 2004; Orla 2004). Considering the importance of this social support in addressing individual and community problems, this study argues that there is a need for the revival of the declined social support. NGOs are currently involved in activities that focus on families and communities with a view of reviving the social support system at these levels. It is against this background that the present study seeks to analyse the synergistic relationship between the state and NGOs, the aim being to understand the role of HIV/AIDS NGOs in mitigating HIV/AIDS-related problems.

How does synergy work in this context? NGOs can serve many functions. At the micro level, there is a cross-section of communities, individuals, local and community based organisations that have a relationship with NGOs. The NGO's function is partially that of co-ordinating the various actors such as individuals and communities involved in HIV/AIDS activities. When communities and individuals are linked with each other in this way, they may access greater support.

NGOs may mobilise local initiatives to actively participate in alleviating the impacts of HIV/AIDS which are facing their communities. As mentioned, the traditional social support system in Uganda, which depended on the family caring for the sick, the needy and unemployed is slowly dying. It is hoped, therefore, that the activities of NGOs may revive this support. Similarly, with the involvement of NGOs, cross-cultural and community interaction, and individual and group networks may be developed at the micro level (see chapter 6). At the meso-level, NGOs are linked with various organisations and local government(s) that provide other forms of support. At the macro level, financial and technical resources, and personnel are mobilised through NGOs' connections with the government and the international donor community.

The roles of government in this synergistic relationship include making the rules that guide action and interaction between various actors, providing the resources and coordinating the various actors (see chapter 7). Evans (1996a: 1120) argues that emerging research on states and social capital generation reveal new kinds of complementarity between the state and society. He argues that effective states create environments, which strengthen and increase the efficiency of local institutions and organisations.

In this study, I argue that through its budgetary allocations, the government may provide resources for the implementation of various programmes, and through its international connections it may mobilise donor resources; these can be either allocated to different actors or utilised directly through government programmes in which fighting HIV/AIDS can be integrated. For example, integration of AIDS into the poverty alleviation strategies may have a wider ranging effect on the impacts of HIV/AIDS.

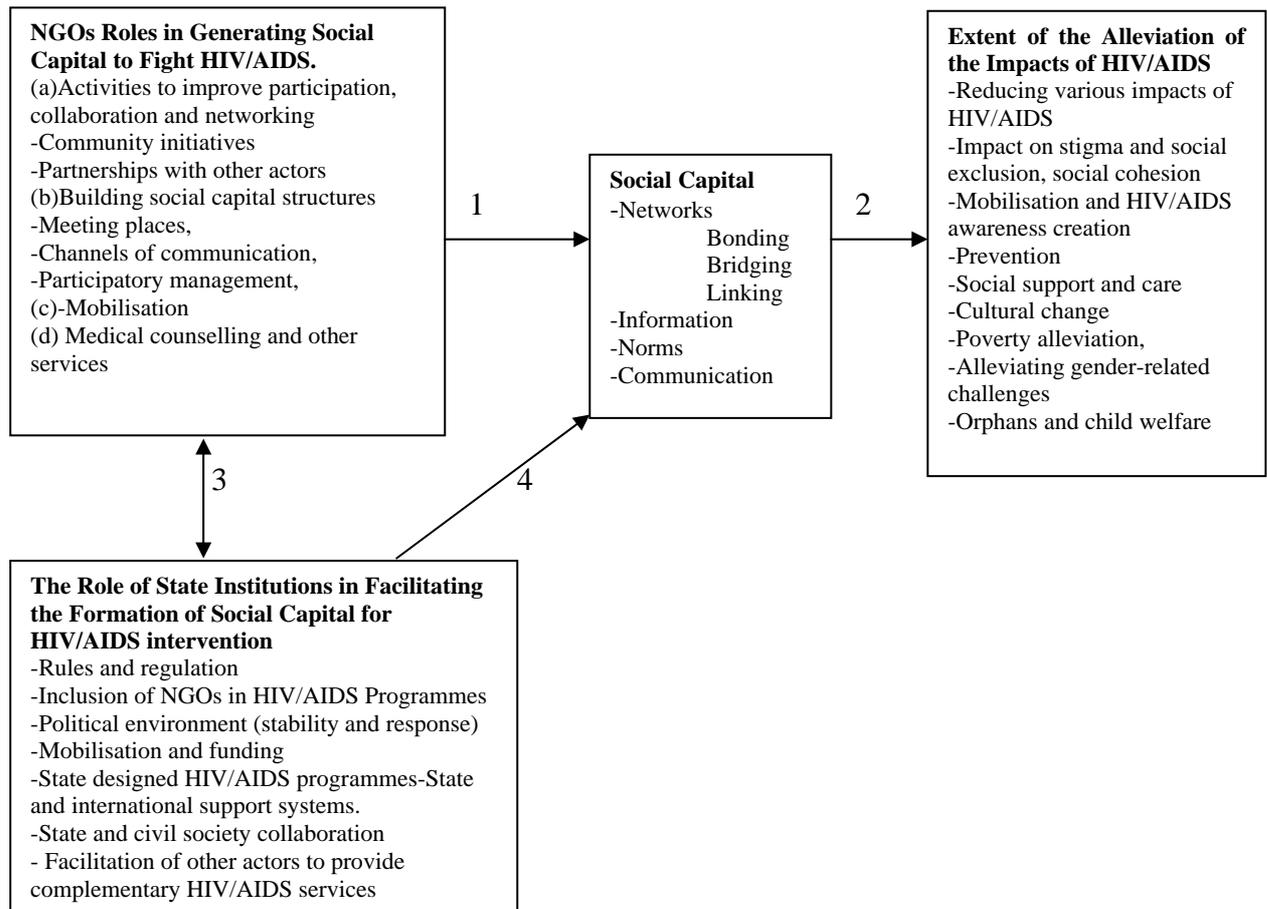
However, integration must take into consideration of other related factors that would limit the effectiveness of such strategies in the battle against HIV/AIDS. Most proponents of the integration of AIDS in poverty alleviation strategies, for example Ainsworth and Teokul (2000), have not considered that such strategies, especially those targeting the marginalised groups such as women, may not be effective unless social-cultural strategies are adopted. Such cultural factors limit the effectiveness of poverty reduction strategies. Within a favourable environment barked by the political institutions, therefore, NGOs involved in grassroots activities may target the cultural practices that may hinder success of various strategies (see discussion in 8.2).

In addition, the government can coordinate the relationships between the various actors involved in HIV/AIDS activities (see 7.7 in this thesis). Through this coordination, the competition and duplication of services and activities can be avoided. As an example of coordination and control, I have observed that, whereas HIV/AIDS NGOs operate with relative autonomy, this does not mean that they are outside the government influence. I argue that they operate within the limits of government HIV/AIDS policy, which emphasises prevention and control. The NGOs are required to register with the ministry responsible for their operation, also the process of negotiating access to the local communities involves initial contact with the Local Council 1(LC1)⁴² chairman of the area (chapter 7.3), who ensures that the NGOs programmes conform to government policy.

From the above discussion, figure 2.1, presents a hypothetical model of the relationship between NGOs, government, social capital generation and the extent to which utilisation of social capital by HIV/AIDS NGOs leads to the alleviation of the impacts of HIV/AIDS.

⁴² The Local Council 1 is the smallest administrative unit in the political system of Uganda. It is an equivalent of a village

Figure 2. 1 Hypothetical Framework: Synergy, Social Capital and the Alleviation of the Impacts of HIV/AIDS by NGOs



The figure indicates that the alleviation of the impacts of HIV/AIDS by NGOs is dependant on social capital (lines 1 and 2). However, as mentioned earlier, there is increasing evidence that social capital in Uganda, at individual, family and community levels, has declined considerably due to HIV/AIDS (see discussions in chapters 1 and 4). Therefore, for NGOs to effectively alleviate the impact of HIV/AIDS, it is necessary for them to mobilise and revive the declining social capital. This can be done in various ways: a) building structures that would encourage participation in HIV/AIDS-related activities, b) facilitating communication and cooperation, c) mobilising local and community initiatives, and d) providing an efficient service-delivery system that would improve trust-based relations between the service providers and the clients they serve.

However, for NGOs to effectively generate social capital, it is necessary for them to have a synergistic relationship with the government and other actors. Line 3 in the diagram indicates the interdependent relationship between government and NGOs; this implies that government actions may influence the performance of NGOs. Line 4 indicates that government may also

influence social capital generation by establishing institutions that may facilitate cooperative behaviour. For example, the role of political institutions, political leadership and improving the service delivery system would facilitate participation and interactions at various levels.

From the model above, the following hypothesis may be drawn:

1. Alleviating the impact of HIV/AIDS depends on the extent to which the activities of NGOs focus on improving people's relationships. The activities that improve social relations at individual, family and community levels are likely to have more effect on the impacts of HIV/AIDS. In this regard analysis of networks may be made at the informal and micro level

2. The extent to which NGOs' alleviate the impact of HIV/AIDS depends on the presence of social capital. For effective HIV/AIDS mitigation, therefore, it is paramount to build social capital. The effectiveness of NGOs depends on the existence of structures for interaction, such as meeting places, formal and informal meetings and various participatory activities. The analysis may be made at a more structural and formal level especially with regard to the interactions within the formal structures of the organisation. However, informal networks will also be examined

3. The generation of social capital depends on synergy between government and other actors, including NGOs, business organisations, faith based organisations, and community based organisations. For example, complementary roles rather than individual actor's roles facilitate the generation of more social capital. Here the analysis is on the meso level and more formal – state-civil society relations, State, NGO and donor relations

The extent to which NGOs will be able to alleviate the impacts of HIV/AIDS depends on their ability to facilitate the development of networks at individual, social and community levels. This in turn depends on the relationship between them and the state. The more the state supports the NGOs – either through complimentary activities or their integration in the phases of planning, implementing etc, of various HIV/AIDS-related activities – the more social capital can be generated and the more effective NGOs can be, in dealing with the impacts and challenges of HIV/AIDS.

2. 7. Conclusion

The purpose of this chapter was to explore how social capital may be conceptualised and used as a basis for developing an analytical framework for this particular study. The key argument was that social capital has become one of the most widely discussed concepts with relation to both academic and policy issues. Its ability to explain a number of issues that affect both individuals and society in general has won wide recognition.

Given the wider application of the concept of social capital and its importance in political, economic and social development, particularly in the field of public health, it was concluded that it may be important for the understanding of the roles of NGOs in mitigating HIV/AIDS in Uganda. In this chapter, social capital is considered to imply social relations and associated resources. The concept of social capital is widely debated and there are many definitions as presented by different scholars in this debate. For this study, however, social capital refers to social relations and associated resources which are meaningful for people's wellbeing, and in this case for the alleviation of HIV/AIDS challenges.

An analytical model was then developed based on the recognition of the fact that various social capital approaches have advantages which can be combined to build a model that can explain how the problem of HIV/AIDS can be addressed in Uganda. Thus, the synergy model has been adopted for this study. The chapter has discussed that synergy was chosen as a model for analysis partly because of the advantages that can be reaped by utilising state-society relations than the actions of either the state or civil society organisations each working in isolation. It was also chosen partly because of the limited research concerning this cooperation especially at the micro and meso levels and the relationship with health. The next chapter presents the methodology employed in the study.

CHAPTER 3

Selecting a Methodology to Study Organisations

3.0. Introduction

The purpose of this chapter is to discuss the methods employed in this study. In order to understand the role of Non-governmental Organisations in alleviating the impacts of HIV/AIDS, the study focuses on the activities of two NGOs: The AIDS Support Organisation (TASO) and Post Test Club/Philly Lutaaya Initiative (PTC/PLI). The study is guided by the methodology used in organisational and process studies.

Process studies often ask such questions as: what takes place, why does it take place and how does it take place (Saunders, Lewis, and Thornhill 1997; Yin 1994). Such questions can be answered when a study is based on only one or a small number of cases (Bryman 1989). Therefore, in order to accomplish the objectives of this study, the case study strategy has been selected and methodological pluralism has been employed in gathering information. The selected organisations (TASO and PTC/PLI) were purposively chosen because of their unique approach in tackling the impact of HIV/AIDS in Uganda⁴³. The study was carried out in Mbarara district of Western Uganda

3.1. Case study, Combined Methods and Organisational Studies:

Case⁴⁴ studies involve a detailed analysis of one or several cases. When studying organisations, the many variables that define the boundaries of the organisation must be taken into consideration. These include the context, the activities of the organisation and the environment within which it operates. The unit of analysis is the organisation, particularly the departments, sections or inter-organisational networks (Bryman 1989). Thus, the two organizations that are the subject of this study have been analysed in detail, in terms of their members, their activities, their orientation and the level of involvement of clients/members in the activities of the organisation.

The case-study strategy has been chosen not only because it allows an in-depth analysis of the cases, but also because it allows various methods of data collection and analysis to be combined. Both quantitative and qualitative methods are used in case studies for gathering information. It has to be mentioned however, that since the goal of the study is to understand

⁴³ The reasons for selecting these two cases are presented in chapter 5.4

⁴⁴ A detailed discussion of what is a case can be found in Yin (1994), and Ragin and Beker (1992).

the extent to which a social problem is addressed through social processes, it is important to get a detailed understanding of people's own views about the phenomenon being studied. This is obtained for example through narratives and people's own stories. The qualitative method is therefore, given a higher status than the quantitative method.

The tools for data collection employed in case studies include documents, interviews, questionnaires and observations. The combination of these different methods to study a problem enables the researcher to examine more closely the evidence gathered. Thus, the findings from one source can be checked against the findings from another source (Brewerton and Millward 2001; Punch 1999). This is in keeping with the principle of triangulation, in which different methods and data types are used in a single study. Thus it is argued that:

In case study research, the notion of combining qualitative and quantitative data offers the promise of getting closer to the 'whole' of a case, in a way that a single method could not achieve. This idea is based on the principle of triangulation which advocates the use of many different sources of information (e.g. questionnaires, observations, interviews, documents) on the topic with a view of obtaining convergence on an issue. (Brewerton and Millward 2001: 55)

3.2 Study Area and Selection of Cases

As indicated, this study was carried out in Mbarara district, which lies about 240 km South-West of Kampala, the capital of Uganda. The district borders the United Republic of Tanzania to the South, Rakai and Sembabule Districts to the East, Bushenyi and Ntungamo Districts to the West, Kamwengye and Kyenjojo Districts to the North (see figure 3.1)⁴⁵.

The average altitude of the district is 1800m; it receives an average rainfall of 1200mm per annum and has an average temperature range of 15° - 30° C. The terrain of the district is predominantly plains with some low hills in the north east. The village people in the district are predominantly Banyankore from two ethnic groups: the Bairu and the Bahima. They speak a common language, Runyankore. In the towns, there is a mixture of people including the local people, Baganda, Asians and those from other regions.

⁴⁵ At the end of 2005, the district was reduced in size by the subdivision of the original district into smaller districts. Ibanda and Kikagata sub-districts were made full districts, while Kazo and Nyabushozi counties were made into a district – Kiruhura. The new Mbarara District is composed of Rwampara, Sanga and Kashari counties (see figure 3.1 for the location of these areas).

During President Amin's regime in the 1970s the district flourished due to the flourishing cross-border illegal trade and its location on the main trade routes to Rwanda and Congo DR. This smuggling had some other impacts, including an increase in commercial sex which may have contributed to the spread of HIV/AIDS (Barnett and Whiteside 2002).

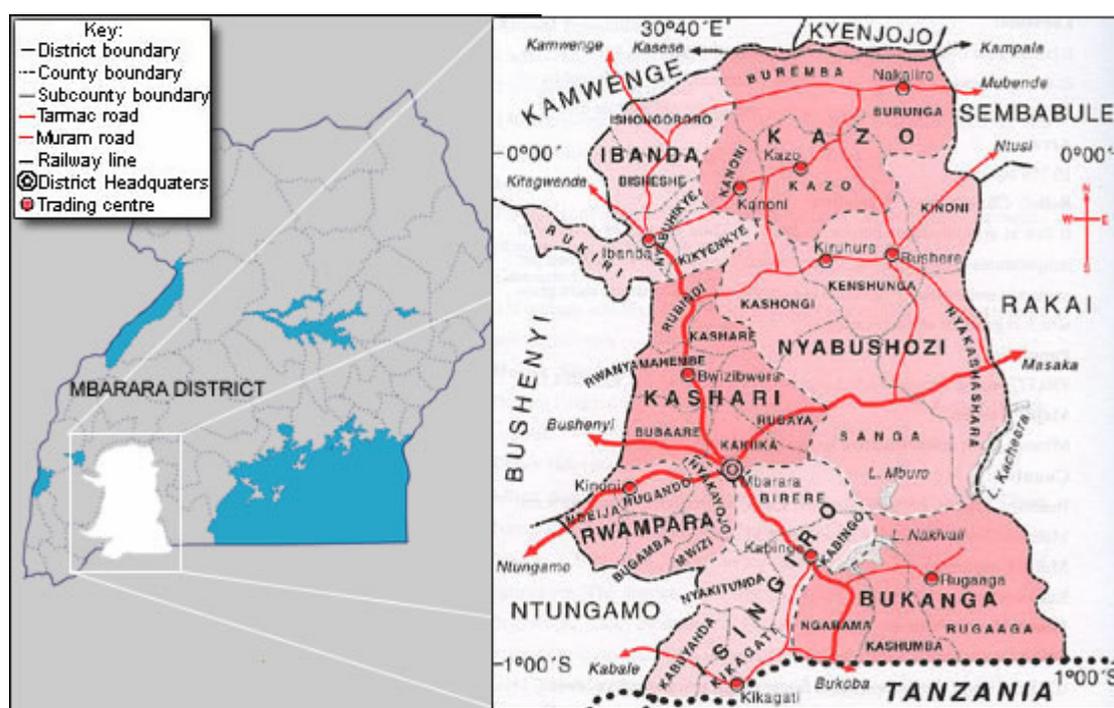
Because of its border with Tanzania, this region is home to refugees who fled from Rwanda through Tanzania to Uganda in the late 1950s and in 1994 after the genocide that took place in Rwanda. Like trade, this influx of refugees may also have contributed to the spread of HIV/AIDS (Barnett and Whiteside 2002; O'Manique 2004). These factors, together with others described below, led to the selection of this area for the study. In the discussions that follow, I shall highlight the specific factors that contributed to the selection of this area.

(1) At the peak of HIV infections in 1991, Uganda had a prevalence rate of about 18%, while Mbarara District had a prevalence rate of about 24.3%. By the end of 2001, Uganda's prevalence rate had declined to about 6.2% and for Mbarara, the rate had declined to about 10.8% (MDLG 2003a; Putzel 2004; Wendo 2004). This close relationship between the national trend for HIV infection and the trend for HIV in Mbarara was fundamental in the selection of this area for the study.

(2) Mbarara District neighbours on Rakai District (see figure 3.1 below), where the first HIV/AIDS cases in Uganda were identified in 1982. The main trade routes which connect Uganda to Rwanda, the Congo and Tanzania⁴⁶, pass through the district. These routes are channels that facilitated the spread of HIV from one region to another (Barnett and Whiteside 2002; O'Manique 2004). Given the decline in HIV which the district registered at the end of 2001, this area becomes interesting for this study.

(3) Another decisive factor was whether the selected NGOs had been active in the area, when they had operated in the region and what the nature of their activities had been. These considerations may provide a pointer to the impact the NGOs may have had on the social phenomenon in question. The area was selected because both organisations have been operating in the area for a long time; for example, TASO opened its branch in 1991, when the prevalence rate of HIV was at its peak.

Figure 3. 1. Position of Mbarara on Map of Uganda



Source: <http://www.mbarara.go.ug/> 13/04/06

(4) Accessibility of the field and data was another factor in the selection process. Since every study works with data obtained from someplace, consideration should be given to the ease with which the researcher can gain access to both the area and data (Field and Graham 2003; Saunders, Lewis, and Thornhill 1997). Two critical elements generally guide the selection; (a) resources in terms of time and finance; (b) data access in terms of language, response from host organisations, and research protocols to follow.

3.2.1 Resources

Data and field access are usually constrained by the time and other resources at the investigator's disposal (Stake 1995). This is the first consideration when selecting both the area and the cases to study. Investigators need to find areas which they can access without great impediments. In this respect, I considered Mbarara to be an appropriate area for research. Moreover, having lived and worked in the district for more than ten years, I am well acquainted with most of the region. This had the advantage of saving time and of facilitating the collection of quality data. Familiarity meant that my access to data was less constrained

⁴⁶ To the south of Mbarara District is Tanzania's Kagera region, the region of Tanzania hit hardest by HIV/AIDS in the 1990s.

by the language of the people studied, the means of communication or the procedures to be followed before being granted permission to carry out the study.

Language and Communication:

Uganda is multilingual and my study included both educated and uneducated people⁴⁷. As noted in 3.1, the strength of case-study research is its ability to get closer to the subjects, and this depends upon access to their responses and their narratives during interviews. Thus, my familiarity with and command of the local language was a decisive factor in selecting Mbarara as an area where the study could be carried out successfully. To locate the study in another area would have meant engaging interpreters to translate the questionnaire and the respondents' responses during the interviews. This intermediary link may have other implications: the presence of the interpreter may distort the meaning; may heighten the tension for respondents; and may breach the ethical norms for privacy and confidentiality⁴⁸. Moreover, the process would have been more time-consuming and expensive.

Research Procedures and Protocol

Different countries and organisations have different procedures to follow when scholars apply to do research in the country or to study organisations. These procedures may include seeking approval from relevant authorities. In Uganda, a research council [Uganda National Council for Science and Technology (UNCST)] controls the quality and nature of the researches carried out in the country. As required, I applied to the council to carry out research on selected organisations in a specific area (see, format of application forms in Appendix 2 A-i and ii). My application was approved by the council and a letter of approval and an identity card were issued. Introductory letters were also written to the Chief Administrative Officer of the district, instructing him to allow me to collect data from government officers, records and archives (see appendix 2 B- i, ii, and iii).

The AIDS Support Organisation (TASO) has a department of research that evaluates the research applications, to which I sent an application requesting permission to collect data about their organisation. The committee approved my application and gave me necessary clearance to carry out the study (also see appendix 2B- iv and v). The local branch manager introduced me to various heads of department, who in turn introduced me to clients of the

⁴⁷ This is in respect to formal education.

⁴⁸ See 3.3 for a discussion on ethical considerations in research involving vulnerable groups

organisation. In the case of Post Test Club/Philly Lutaaya Initiative (PTC/PLI), the manager has the prerogative of deciding whether a proposed study of the organisation may have serious ethical implications for the organisation and the people it is serving. I was interviewed in order to establish my objectives and the kind of data I wanted from the organisation. The manager requested that I give him a copy of my research proposal, in order to further investigate whether the stated objectives were in agreement with the interview he had held with me. On the basis of this material, it was decided that I should be allowed to carry out my study of the organisation. I was introduced to the heads of various sections in order to facilitate my data collection.

3.3. Methods of Data Collection

Studies about organisations may be interested in two types of data:

- (1) Primary data obtained directly from organisations through the use of different methods of investigation such as interviews, observations etc.
- (2) Secondary data obtained from organisation reports and other written sources.

To obtain primary data, I used a number of approaches, including interviews (structured, semi-structured and unstructured), observation, and focus-group discussions. To obtain secondary data, I examined a variety of reports, such as NGOs' reports, as well as activity and work schedules, government documents and studies and books written by various researchers.

3.3.1 Interviews

Face-to face interviews

In-depth face-to-face interviews were conducted over a period of six months with HIV and AIDS patients who were served by the two organisations (TASO and PTC/PLI). In addition, interviews were carried out with people who had been tested for HIV and belonged to the post-test club (PTC/PLI), whether the results were positive or negative. Interviews were also carried out with employees of both organisations. A number of interviews were conducted with selected government officials in the Mbarara district health department and people from the communities served by these organisations, other beneficiaries of these organisations such as the former apprenticeship students. The total number of respondents in this category was 165: TASO - 80 clients/members 10 officials, 10 AIDS Community Workers (ACWs), and 3 former TASO-supported students under the apprenticeship programmes; PTC/PLI - 45

members, 7 officials and AIDS Information Centre (AIC⁴⁹) workers; and 4 government officials (see table 3.1). Interviews lasted between 1 to 2 hours and were based on a set of questions that focused on selected themes (see appendix 1). In addition to the long interview above, short interviews lasting between 10-15 minutes were held with people selected randomly from people attending drama presentations in communities, 6 interviews of this nature were held.

Interviews with the staff of TASO and PTC/PLI, and government officials were unstructured. This data collection method was chosen because the study of the work process in organisations – of what they do and how they do it – requires that an extensive description of this process be made by people who are involved. Thus, unstructured interviews became an invariable tool for collecting data from organisational staff. Most of the staff members whom I interviewed were counsellors, whose task was to offer psycho-social support to the clients and members of the organisation. I also interviewed managers and heads of sections. Most of the interviews were done outside the main TASO centre during community outreach programmes. In addition to data gathered in direct interviews with the staff, I observed what they were doing in the field and how they were doing it.

Interviews with clients/members of organisations were both structured and unstructured. Most questions were structured, but in order to gain a deeper understanding of the whole situation, some of the structured questions were followed-up with more probing questions⁵⁰. These questions allowed respondents to construct meaning from their own perspectives and experiences. This generated more ideas and evidence about the research questions.

Profile of Respondents:

Respondents were drawn from different sections and departments of the organisations and the government institutions (see table 3.1). Government officials who were interviewed were selected from the Mbarara district directorate of health services and were involved in HIV/AIDS activities. These officials included: the Director of Health Services (DDHS),

⁴⁹ Home to PTC/PLI, AIC was formed in 1990 due to increased demand for HIV/AIDS counselling and testing services in the country. Its services include Voluntary Testing and Counselling services (VTCS) and, more recently, medical services for members of PTC/PLI.

⁵⁰ Narayan, Grootaert, Nyhan and Woolcock (2003) provide guideline for combining quantitative and qualitative approaches in social capital research.

District AIDS Focal Person (DAFP)⁵¹, District Health Educator (DHE), and Director of Social Services (DSS).

Respondents from TASO included the branch manager, social services officer, projects officer, director of counselling, 5 counsellors and 1 medical doctor, in addition to 80 clients who were drawing upon TASO's services in various ways. Interviews were also held with 10 AIDS community workers (ACWS) - volunteers who were working in TASO-aided communities⁵² and 3 former TASO supported students on apprenticeship programmes.

Respondents from PTC/PLI included the acting manager⁵³ of the AIDS information centre in Mbarara, the counsellor in charge of PTC/PLI activities, the head of the training department, and 4 executive members of PTC/PLI, as well as 45 members. Table 3.1 shows the number of respondents who were interviewed, and their position in the organisations. Table 3.2 shows the personal profile of members/clients of TASO and PTC/PLI who were interviewed.

Table 3. 1 Number and Placement of Interview Respondents

Respondents	TASO	PTC/PLI	Mbarara District Health Office	Members of community	Total
NGO officials	10	7			17
Government Officials			4		4
Beneficiaries	80	45			125
Graduates of Apprenticeship programmes	3				3
AIDS Community workers	10	-			10
Members of communities visited by drama groups				6	6
Total	103	52	4	6	165

Table 3. 2 Profile of Respondents from HIV/AIDS Organisations

Variable	Variable Category	Organisation	
		Members /Clients of TASO (%)	Members of PTC/PLI (%)
Gender	Female	70	64
	Male	30	36
Age	15-24	4	43
	25-34	33	34
	35-44	39	18
	45-54	19	5
	55	5	-
HIV Status	Positive	90	11
	Negative	4	82
	Do not Know	6	7
		N= 80	N= 45

Source: Field Notes

⁵¹ The HIV/AIDS focal person is selected by the Chief Administrative Officer (CAO) to coordinate all HIV/AIDS related activities, including evaluating proposals for funding, monitoring of fund disbursement.

⁵² These are communities in which HIV/AIDS programmes are implemented by volunteers. TASO only provides support supervision. Activities are run and sustained by AIDS Community Workers who are trained by TASO to handle different HIV/AIDS challenges.

⁵³ Before being appointed acting manager of the Branch, a post he had held for less than six month prior my field work, he had worked as the counsellor in charge of PTC/PLI activities for over two years

From Table 3.2 it is evident that the majority of interviewees (70% from TASO and 64% from PTC/PLI) were female. This is consistent with reports from both organisations (TASO and AIC) that there had been an increased demand for services by females, rather than males. *The AIDS Support Organisation information booklet (2003)*, for example, points out that the gender distribution of clients was 65% female compared to 35% male (TASO 2003a); at the Mbarara branch, 34% of the new clients served in 2003 were male and 66% female.

The table also reveals that the majority of respondents were in the 25-44 age category - 72% in TASO and 52% in PTC/PLI. This is also consistent with data obtained from these organisations. For example, *AIDS Information Centre Progressive Report for the Period July-September 2003* (AIC 2003b) reports that in the period July-September 2003, 66% of clients were in the 24-49 age category. Another difference was that while 90% of TASO respondents were HIV/AIDS positive, only 11% of PTC/PLI respondents were.

From the above discussion it can be deduced that these figures further help to define the boundaries and other significant features of the cases. For example, as mentioned, TASO's formation aimed at serving people who are infected with HIV/AIDS and their relatives, while PTC/PLI's formation aimed at serving and to follow up people especially those who tested HIV negative. In terms of gender, I have argued earlier that majority of women lack basic necessities for survival and depend on men for survival. With the existence of an organisation to provide free HIV/AIDS related services, it is no wonder therefore, that majority of the beneficiaries of these organisations and TASO in particular are females.

Telephone interview

In addition to face-to-face interviews discussed above I held a telephone interview with an official of the Joint Clinical Research Centre⁵⁴. The official is in charge of coordination of the Timetable for Regional Expansion of Antiretroviral Therapy (TREAT) Programme. The programme aims at expanding treatment and provision of ART to people with HIV/AIDS in all regions of Uganda. The objective of the interview was to get an understanding of the extent of the implementation of the programme to make ARVs accessible by PWHA. The interview lasted for about 10 minutes⁵⁵.

⁵⁴ Apart from pioneering the distribution of ARVs, JCRC is the largest organisation providing free ARVs in Uganda.

⁵⁵ The interview followed electronic mail correspondence between the official and I informing him of the kind of information which I needed from him.

3.3.2 Focus Group Discussions

Focus-group discussions have gained prominence in social research as another source of information. In such discussions participants may share knowledge about an issue, although they may have different opinions; thus, the meaning people attach to an issue may be clarified through the discussion. Through group discussions, members of the group express their opinions on the subject based on their experiences and the understanding they have of HIV/AIDS. In addition, focus-group discussions provide a rich source of data since the exchange takes place in the language of the people in the focus group and is not "translated into the terminology of the researcher" (Bloor et al. 2001: 7). These factors contributed to focus group discussions being selected as sources of information.

Since the purpose of the focus-group discussion is to allow interaction between group members, I acted as moderator and allowed them to interact with limited interference, occasionally providing guiding questions for interaction. Since they were not constrained by the researcher, they freely provided information about their experiences. This allowed a variety of responses and opinions to emerge on issues such as, the role of government and the way people with HIV/AIDS are perceived by the communities in which they live. From their discussions and conversations, I also learned the common views about government and community roles in addressing the problem of HIV/AIDS. During the discussions, group members supplemented each others' contributions in an interactive process that clarified and verified group meanings.

Apart from group discussions with members/clients of TASO and PTC/PLI, other members of the community were engaged in discussions in order to establish the way AIDS patients and people infected or suspected of being infected with HIV are perceived; and also the way the roles of NGOs and government in dealing with the impact of HIV/AIDS are perceived. Issues discussed in focus groups included: knowledge of HIV/AIDS as a problem in the community; government and community responses to HIV/AIDS; community perception of people who are HIV infected or AIDS patients; and NGOs' responses and interventions. Note was made of the participants' responses and later transcribed in order to construct meaning from what was said in the discussions. In all, three group discussions involving 7 to 10 people, and lasting 30 to 60 minutes, were conducted.

3.3.3 Observations

One way to find out about a phenomenon is simply to look at it in a systematic and scientifically rigorous way (Field and Graham 2003). Observations enable the researcher to study the behaviour and actions of respondents as they occur. This allows him/her to obtain first-hand information in a naturally occurring context (Nachmias and Nachmias 1996; Silverman 1993). There are many types of observational methods, but two categories are common in social research:

(1) Participant observation: the researcher gets involved and becomes part of that which is being observed. He/she participates actively in the activities of the studied population. The researcher takes note of everything that takes place as it occurs. The aim is to capture the subjects' point of view (Brewerton and Millward 2001).

(2) Non-participant observation: the observer stands at a distance and observes what is taking place. Usually the observer follows a kind of check list for what is observed.

In this study, I used the latter approach and observed what was being done directly. I observed formal and informal social interaction among different groups and individuals. Members/clients of organisations were aware of my presence and had been informed of my research objectives (see introductory note in Appendix 1). This made participants feel free to act normally, which in turn enabled me to observe them without the fact that they were being observed bothering them. As Nachmias and Nachmias (1996) point out, face-to-face interviews may create a kind of artificial environment and researcher/interviewee relationship that can be avoided using the observation method. As those observed get closer to the researcher, they tend to regard him/her less as an intruder, and will therefore act in a normal manner.

A number of activities taking place in the organisations were observed directly:

- (a) Frequency of meetings involving clients/members of organisations in the study,
- (b) Interactions through speech,
- (c) Games (indoor and outdoor) and drama activities, and
- (d) Informal activities apart from the formal interactions and activities.

In addition, I supplemented my observations of important events by using visual aids such as digital still cameras. This allowed me to collect data on events as they took place (see for example figures 5.1a-d, 6.1 and 6.2). In all the events captured in this way, the participants were aware of what was taking place⁵⁶. Through this method, I was able to observe how people interacted in a natural setting. At the TASO day and PTC/PLI recreational centres, I noticed that a client/member knew virtually all the others and was willing to offer support and assistance to them if it was needed and within their means.

3.3.4 Documentary and other Secondary Sources

Existing Studies

This study also drew upon existing secondary data. According to Skocpol (1984: 382), “if excellent studies by specialists are already available in some profusion, secondary sources are appropriate as the basic source of evidence for a given study”.

Documentary sources were selected on the basis of their relevance for the study. The long history of HIV/AIDS, especially in Uganda, has generated a wide range of studies that provided a wealth of background information and other relevant data regarding HIV/AIDS research in Uganda. This study used different written sources and studies from two categories of sources: general studies on HIV/AIDS, and those focusing on the TASO and PTC/PLI.

Studies done by Monico, Mukasa and Tanga (2001), and TASO (1995) provided a rich source of data. The former study describes the factors that contribute to stigma and to the other impacts of HIV/AIDS in Uganda. The latter study describes the set up of the organisation and provides an evaluation of its programme. Many writers, including Marshall and Keough (2004), Keough (2004), O'Manique (2004) and Barnett and Whiteside (2002), have addressed the problem of HIV/AIDS in Uganda. They have considered not only the impacts of HIV/AIDS, but also its deep roots. In addition, they provide useful background information that facilitates an understanding of the social, political and economic dynamics through which HIV/AIDS emerged, of what prevention approaches have been used and of how policy responses have evolved (see for example O'Manique (2004). Reference was also made to studies that have dealt extensively with, for example: the general social impact of HIV/AIDS,

⁵⁶ See the ethical consideration of informed consent

such as Crawford, et al (1997), and Aggleton, et al (1997); and the work of HIV/AIDS organisations, for example, Oketcho, et al (2001).

Documentary Sources

Documentary sources also provide a rich source of data and information in the field of organisational research. In order to understand the way organisations work, it is important to look at various documents relating to the organisations. These may include programme proposals, mid-term reviews and final reports; and procedure reports, such as memos and the minutes of meetings. Reports and documents were used to triangulate and support some of the data collected through interviews and observations. The Ministry of Health particularly the HIV/AIDS Surveillance Reports and HIV/AIDS policy documents, the Uganda AIDS Commission (UAC) and UNAIDS reports provided an invaluable data source. Other documents used were those produced by various government departments regarding HIV/AIDS and health-related issues. Particularly important for this study were The Health Sector Strategic Plan for 2000/01-2004/05, Mbarara District HIV/AIDS Work Plan and Budget for 2003/2004, The National Health Strategic Framework.

It should be noted however, that access to secondary material was not problem-free and I encountered a number of challenges. First, it was not easy to gain access to NGO records. Organisations work in a strained environment with few staff members, limited record-keeping facilities such as data bases, and sometimes limited space. In such an environment, document retrieval is slow and sometimes difficult. In one particular organisation, I was informed that, due to a change in branch management, none of the data regarding the previous management period was available. To overcome this problem, I had to contact the heads of various departments which had the data I needed. With no central data base, these heads of departments were the gatekeepers to the data in these departments and they were of great help to me to access the data. As Saunders, et al (1997: 166) point out: "...the information or data manager within the appropriate department is most likely to know the precise secondary data that are held. This is the person who will also help or hinder your eventual access to the data...and information".

The use of information obtained from sources other than a centralised data base had various implications. It was time consuming since I had to put together all the information obtained from the various departments in order to construct meaning. This exercise took more time

than expected, and would have taken a shorter time if I had had access to information compiled in a single report by the organization. In addition, some of the data fragments may be incomplete, not having reached the final stage of processing or awaiting qualification by other data from another department.

In government offices, access to reports was not easy since some reports are classified and outsiders are not allowed to use them; for example, financial records were not readily available. Most of the officials referred to the classified document clause when barring me from accessing certain data. This clause is cited in the guidelines for researchers who wish to use government documents and files as a source of information, and states that: “Only files and documents that are older than fifty years are available for researchers. More recent files and classified documents require fresh application to the Secretary for research” (see appendix 2A- ii). The bureaucracy involved in the process of getting approval is strenuous.

For this reason I was not granted access to the financial records documenting the receipt and disbursement of funds that The Global Fund to Fight AIDS, Tuberculosis and Malaria (GFFAMTB) donated to different CBOs to fight HIV/AIDS. I was forced, therefore, to rely upon the scanty data I was able to gather from the files and records to which I was granted access.

3.4 Ethical Considerations

Ethical considerations in research go beyond the formal procedure of obtaining the approval of different research boards for the research project. Seeking approval is part of the research process. Other phases of this process include the formulation of the problem, the design of the research, the collection of data and reporting of the study findings. At any point in the research process, the subjects of the research may be exposed to potential harm - physical, emotional, psychological and/or sociological. Such harm may actually constitute a violation of human rights. In order to prevent such harm from taking place, social research is very concerned about ethical considerations (Nachmias and Nachmias 1996). The focus is on ensuring that the research subjects are not placed at risk (Michael and Weinberger 1977).

Ethical considerations can arise if there is an imbalance between the interests of the investigator, and the costs and benefits that accrue to the research participants. The interests of the researcher are founded on the need to generate knowledge and understanding of the

phenomenon. However, such goals may put research subjects at risk, and it is important to avoid and guard against such potentially harmful situations. In the following discussion, central ethical considerations for conducting research on vulnerable groups will be presented. Vulnerable groups include people such as children, orphans, women and AIDS patients, who may be harmed by the project because of their social status in terms of their physical, psychological, physiological and/or cultural position in society.

How can the rights and welfare of research subjects be affected by the research? How can that harm be prevented?

The main negative effects that my research may have on the vulnerable persons in my study are the added psychological, sociological and emotional stress. All these effects result from the sensitive nature of the research problem - HIV/AIDS. The psychological impact may come as a result of the questions respondents are asked, which may be embarrassing to them. Such questions may also cause emotional stress if they are not well prepared to answer them. Sociologically, respondents may be affected if their HIV/AIDS status becomes known to society without their consent and knowledge.

Ethically, therefore, an effort had to be made to ensure that questions which could be psychologically and emotionally stressing were minimised or asked with proper knowledge of the impact they might have on the respondents. In this study there was a question asking respondents to reveal their HIV/AIDS status. However, revelation of HIV/AIDS status to another person may have serious psychological consequences for the individual. Since the diagnosis HIV/AIDS is considered shameful in some sections of society (Monico, Tanga, and Nuwagaba 2001)⁵⁷, many who are HIV positive would prefer to keep this a secret. In research, therefore, these people should be given choice to answer or not to answer. Moreover, participation in the study should be voluntary. Nevertheless, since the goals of every study are achieved by obtaining relevant data, such goals are not achieved if, for example, all respondents chose not to answer such questions.

The immediate concern, therefore, should be how to obtain such sensitive data without affecting the respondents negatively. There are steps which the investigator should take in order to protect respondents and prevent them from potential harm. Respondents must be informed about the research objectives and about the way results will be disseminated, so they

can make a well-grounded decision whether they should respond or not. Confidentiality should be guaranteed; for example, the use of names in the final report should be avoided. One option here is to use 'blind' reference.

There are many ethical issues that may be considered by investigators, but in this study the focus is predominantly on two central issues: (a) informed consent and (b) privacy of research subjects.

3.4.1 Informed Consent.

The notion of informed consent in research requires that the subjects' participation in the research should be voluntary. Participants should be informed of the aims, benefits and potential risks of their involvement in the research project. They should also be informed of the main elements of the research project so that they can make autonomous decisions as to whether or not to participate. Nachmias and Nachmias (1996: 83) define informed consent as the procedure by which individuals choose whether to participate in an investigation after being informed of facts that are likely to affect their decisions. There are various ways that informed consent can be obtained. One approach is to contact respondents directly and obtain their consent to participate.

Informed consent however, may not be directly obtained from individuals but rather from the organisations which represent these people. Clients/members of organisations are represented by the organisation officials whom it is assumed will protect their clients from harm. Thus, organisations "filter" research to be carried on the organisation and clients. A key element in this "filtering" process involves the submission of research proposals for evaluation before being allowed to proceed. As mentioned in 3.2.1, my research proposal passed through several filters before being approved by both the Uganda National Council of Science and Technology (UNCST) and the two organisations I studied.

Once the project has been approved, the protection of clients is further ensured by giving the branch managers the opportunity to assess the research proposals. Finally, at the grass-roots level, I was requested to clarify my research objectives to the clients before commencing with data collection (see introductory note to appendix 1). All these procedures are meant to get the consent of the research subjects and consequently to protect their interests.

⁵⁷ See also religious fundamentalism in 7.4.1

3.4.2 Privacy of Respondents

Every researcher should guard against invading the private lives of respondents, and if by some chance (through the methods employed to gather data) the researcher breaches the privacy of respondents, it is the researcher's duty to protect their subjects from any harm that may result. Invading respondents' privacy may pose a threat to their integrity and may cause emotional, physiological and psychological stress. This should be avoided at all costs.

It should be pointed out however, that the invasion of the privacy of the respondents may easily pass unnoticed because of the many ways in which it is manifested. It is necessary, therefore, to consider in some detail the different ways in which the privacy of respondents may be invaded and the ways in which such invasions were guarded against in this study.

Data Collection Approaches and Tools

The privacy of respondents may be invaded through certain approaches used to collect data. For example, in the interview process respondents may voluntarily or involuntarily disclose private and sensitive information about their life. Similarly, the use of observation methods such as hidden cameras may invade the privacy of respondents by allowing access to data which the respondents would not wish to be accessed without their consent. Such approaches should be avoided when conducting social research.

In order to balance the needs of my research and those of the respondents, observation methods were restricted to activities related to my research questions. The respondents were informed when tools such as cameras were to be used to capture events, and they consented to this since the events had no negative implications for their private life. According to them, such events were activities connected with their work concerning the problem of HIV/AIDS. For example, the drama and recreation activities which I observed and photographed were open activities in the communities.

The problem related to interview questions was addressed by discussing issues of a general nature in focus-group discussions and addressing more sensitive, personal matters in face-to-face interviews with individuals. Caution was taken when introducing sensitive questions, such as the question regarding respondents' and HIV status. Respondents were first advised about the sensitivity of such questions and informed that they could choose whether to answer or not if they found them difficult to answer. Respondents were also assured that

confidentiality would be ensured. Moreover, respondents were informed that to ensure confidentiality, the study did not require any identifying information such as names of the respondent.

The Type of Data Collected

The data collected should be in line with the research proposal. Researchers often collect data and information beyond what was initially proposed, and this is unethical. Secondly, data gathered through open-ended interviews may encourage respondents to provide more information than required when responding to the question, revealing even personal and private information. The researcher therefore, should guard against this. The questions should be made clear and straightforward, so as to be understood by the research subjects. Another way of guarding against respondents' providing excessive information is to employ structured questions so that they are restricted to the options provided. In my research proposal, most questions directed to the clients/beneficiaries of organisations were structured so as to prevent them from going beyond the required information.

The Setting of the Investigation

The place where the data collection takes place may encourage potential research subjects participate in investigations to which they might not have otherwise consented. It may also encourage them to respond to questions to which they would not otherwise have responded. It is therefore, important that data collection especially from the interviewees be made in a friendly environment.

Because of the sensitive nature of my research problem, the study settings varied, including the centres and respondents' homes where medical and care services were provided by the organisations staff. In most cases, the clients had had counselling about their conditions and they had relaxed minds. In addition, respondents were informed of the ongoing research and research objectives, and had consented to the mode of investigation. HIV/AIDS patients care activities go beyond the clinical and hospital settings, extending into the home environment. Since the study was interested in the work process of organisations, it was essential to carry out the study in this setting as well.

At the organisation's community outreach centres, interviews were held in a relaxed and friendly environment, for example, sitting outdoors in the shade. Holding the interviews in a

positive environment meant that respondents were less strained, both physically and psychologically. They had time to relax and were attentive in responding to research questions. The interviews were face-to-face and I personally administered the questionnaires and conducted all the interviews so as to avoid misinterpretation of the questions and the tension that would be caused by a third party in the form of an interpreter.

Confidentiality during Data Collection and in Reporting the Study Findings

Confidence building is a very important ethical consideration when conducting studies on HIV/AIDS. The researcher has to make respondents feel confident in themselves and prove to them that their integrity is being respected. If not provided with proper information, many potential respondents may refuse to participate in the research project. In their study on the provision of HIV services in East London, Feldman and Colm (1997: 124) note that, in most studies of that kind, accessing respondents and getting their agreement to be interviewed is very difficult, because of issues of confidentiality, and lack of proper information about the purpose of research.

My strategy for dealing with this ethical issue was to first introduce myself, explaining my institutional affiliation and the intentions of the research project⁵⁸. I then explained how they (the clients of organisations) could benefit from this kind of research. I emphasized that my study was purely academic and had no commercial aims⁵⁹. I stressed that respondents may indirectly benefit from academic studies, when the organisations respond to the findings presented in the final report. Since I was required by the UNCST and organisations to submit final reports to their research departments⁶⁰, this feedback could influence organisation policies, thereby benefiting clients/members indirectly. However, I had to stress that the state and the organisations were not obliged to act upon my findings since the study was not commissioned by them. This openness encouraged my respondents to respond freely without expectations beyond those I had explained. An effort was also made to ensure that respondents were informed that confidentiality will be observed when reporting the findings as well (see the discussion below).

⁵⁸ See introduction to Appendix 2

⁵⁹ Studies done by consultancy firms for big organisations, donors or the government, for example, provide some financial benefits for the investigators who are paid handsomely to collect data for the consulting firm.

⁶⁰ See Appendix 3B i and v

Reporting and Dissemination

The privacy of individuals may be invaded not only at the data collection stage, but also at the stage of reporting or presenting the findings. For example, study findings which involve information such as names may reveal the identity of respondents.

Where such information is disclosed, the respondents' identity should be excluded from the analysis and presentation of data, unless the respondent is aware of this and is informed of the implications of such disclosure. Where disclosure of identifying information cannot be avoided, the respondents must agree that such disclosure does not violate their privacy and is not a breach of confidentiality. For example, as earlier stated, the use of photographs of TASO and PTC/PLI members in the final report was agreed to by the members and clients of these organisations as not damaging to them in any way. They said that there is no harm with this form of reporting, since publicity is their mode of campaigning against HIV/AIDS. Therefore, it was agreed that if their photographs appeared in my dissertation, it would not constitute a potential risk to their private lives. The use of identifying information in the thesis is limited. Where respondents may be identified, for example in the responses from the Chairman Clients' Council, it was agreed that such information was not damaging since "they are proud of disclosure"; these are people who champion HIV/AIDS disclosure as a way of fighting HIV/AIDS.

3.5. Data Analysis and the Reporting of Findings

Data analysis is a matter of examining, categorising, tabulating and arranging evidence in accordance with the hypothesis or subject of the study. The data collected in this study were analysed using both quantitative tools, such as statistical packages for social scientists (SPSS); and qualitative methods, such as progressive analysis of data⁶¹.

Analysis of data was done in a four-stage process:

- (a) Qualitative responses from the clients/members, the staff of the organisations and the government officials was analysed progressively at each stage of data collection. Interviews were content analysed for different themes and these themes were analysed for meaning. The intention was to generate a pattern relating hypothesis to data.
- (b) Quantitative data obtained from clients/members of organisations, in particular, was

analysed using SPSS after the completion of data collection.

- (c) Results from the qualitative and quantitative sources were matched against each other in order to identify agreements or disagreements in data on particular variables of interest. This involved triangulating quantitative results and qualitative responses, as well as data from secondary sources.
- (d) Finally, connections were established among data sources and these were related to the general research questions. An intensive triangulation of data from different sources in relation to the research problem and questions was undertaken.

To obtain a proper understanding of the phenomena, I carried out an in-depth analysis of each case and an extensive cross-case analysis. The former analysis followed a strategy of pattern matching, which focused on relating several pieces of information or evidence from the same case to the theoretical propositions. The establishment of such a relationship helped to strengthen the theoretical arguments on which the selection of cases had been based.

Cross-case analysis, on the other hand, involved relating evidence found in one case to evidence found in another. This too, followed a strategy of pattern matching to see whether what was found in the first case was found in the other. For example, data about building social capital in each case was analysed by linking it to the types of networks which were discussed in chapter 2, and then the two cases were compared. This comparison of cases widens the scope for making theoretical generalisations.

3.5.1. Validity

Validity in social research is concerned with the extent to which findings are consistent with what the study was intended to do. It refers to “correctness or credibility of a description, conclusion, explanation, interpretation or other sorts of account” (Maxwell 1996: 87).

The focus of validity is not an objective truth against which the credibility of results and conclusions can be evaluated. It is not necessary for a study to identify the ultimate truth in order for it to be useful and believable; it is enough to identify a basis for making conclusions. To determine the validity of research or findings one may ask: do the tools developed to carry

⁶¹ One attribute of qualitative research methods is that it allows flexibility in analysing data during the data collection process.

out the study measure what they were intended to measure? Are the tools consistent with tools used in similar or related studies? Are the conclusions consistent with the research questions?

In order to obtain valid data, the following measures were taken in this study.

(a) In order to have valid conclusions, I based my research tools, including the questionnaires and tools for measuring social capital, on other empirically tested tools. I used measures of social capital which have been tested elsewhere in studies by researchers such as Putnam (2000; 2001) and Kemenade (2002a; 2002b). Kemenade, for example, was concerned with health determinants in Canada and developed an approach for measuring social capital as a health determinant. My questionnaire was also developed on the basis of other studies and on existing social-capital databank questions such as those proposed by Ruston and Akinrodove (2002), Narayan, Grootaert, Nyhan and Woolcock (2003), and Szabo (1999). Narayan, Grootaert, Nyhan and Woolcock (2003) show how to combine qualitative and quantitative approaches in social capital research. Based on these data banks, I consider the tools I used and conclusions drawn by the study to be valid.

(b) Second, to increase the validity of my conclusions I used different sources of information as part of the triangulation approach. For example, I gathered data about the performance of HIV/AIDS NGOs from the members and personnel in these organisations. To corroborate these findings, I obtained data from government officials on the government's view on the performance of HIV/AIDS NGOs. I also used different methods of data collection, such as interviews, focus-group discussions, documentary sources and existing research works. These approaches supplemented each other.

3.6. Limitations of the Study

The study is limited in two ways: a) the research process and the data access procedure, and b) generalisability of the study.

Data Access

In the case of The AIDS Support Organisation (TASO), access to secondary data was limited. As mentioned, the lack of a centralised record system and data base meant that data had to be accessed at various departments. This data may not be consistent with the general data published in final reports. However, it should be noted that these inconsistencies would be

reflected in differences in numbers, rather than in the quality and process. Such inconsistency between the figures obtained from different departments and final reports would most likely arise as a result of double counting. This inconsistency can be dealt with by comparing the figures with evidence from other sources.

Generalisability:

Critics argue that the disadvantage of case studies is the fact that they lack general applicability to the whole population (see for example, Yin's (1994: 10) discussion). This argument stems from the fact that these studies are generally based on few cases. Critics may argue that, in a study of two cases, the findings may not be applied to all the NGOs involved in HIV/AIDS activities. As mentioned earlier, it has to be emphasised that qualitative methods were strongly emphasised over quantitative approaches. Usually, in a qualitative case study the purpose is to develop the fullest possible understanding of the case. The evaluation of case studies should be based on the theoretical construct, not on the size of the sample, as is done in conventional quantitative strategies (Yin 1994). In this case, theoretical generalisation, as opposed to statistical generalisation, applies.

In initiating this study, my interest was in generalising the results to a broader theory, as opposed to generalising them to a broader population. A sample is selected not on the basis of its representativeness for the general population, but on the basis of the purpose of the study. Thus, "Case studies should be evaluated in terms of the adequacy of the theoretical inferences that are generated. The aim is not to infer the findings from a sample to a population, but to engender patterns and linkages of theoretical importance" (Michell 1983, cited in Bryman (1989: 173).

By focusing on an in-depth study of each case and then putting together how each case addresses the impacts of HIV/AIDS, I was able to identify what conditions are associated with the generation of social capital and how social capital was utilised by the two NGOs (TASO and PTC/PLI) to tackle the HIV/AIDS problem. By identifying such conditions in each case therefore, it was possible for me to make theoretical generalisations about the importance of social capital in tackling a social phenomenon.

3.7. Conclusion

The purpose of this chapter was to discuss the methods used to study the role of HIV/AIDS NGOs in alleviating the impacts of HIV/AIDS. The study was placed in the mainstream of organisational research and therefore, the tools for data collection were designed in accordance with organisational research principles. This chapter has argued that case study research requires a detailed understanding of the phenomena and that this understanding can be obtained through obtaining data from various sources and using a variety of approaches. Thus, methodological pluralism was found to be more appropriate than any single method. Different methods of data collection therefore, were employed and were important for obtaining valid information for the study. These methods included; interviews, observations, documentary sources and focus-group discussions.

CHAPTER 4

The Problem of HIV/AIDS in Uganda

4.0 Introduction

HIV/AIDS has had an enormous effect on many countries and its impacts in developing countries are alarming. After two decades of existence, it stands unequalled in terms of its impact on humanity. In general, the impacts of HIV/AIDS include: the rise in adult and child mortality, resource depletion (human and physical) for both individual and state, and social consequences such as stigmatisation, discrimination and stress. UNAIDS (2001b: 619-620) summarises the impact of HIV/AIDS in the following statement:

It is...uniquely devastating in terms of increasing poverty, reversing human development achievements, eroding the ability of government to provide and maintain essential services, reducing labour supply and productivity and putting a brake on economic growth. It affects social unity and limits governance.

In order to address the above problems, organisations involved in HIV/AIDS-related activities (HIV/AIDS NGOs) have focused their efforts on a holistic approach including both care and prevention. The core of this approach is to prevent HIV from spreading, and to address the existing impacts which may fuel its further spread and cause increased human suffering. This study is interested in those NGOs that focus on the integration of different social groups – such as families, youths and individuals – for the purpose of limiting HIV/AIDS. This involves employing social interaction as a means of breaking down the walls of stigma, discrimination and self denial, and of creating avenues for the participation of different groups and individuals into HIV/AIDS related activities.

The purpose of this chapter is to contextualise the problem of HIV/AIDS and to investigate why HIV/AIDS has had a devastating impact in Uganda. An understanding of these factors may help in the development of approaches that will reduce the HIV/AIDS-related problems and impacts which societies are facing.

4.1 The Socio-Economic Dynamics of HIV/AIDS

It is only recently that the spread and impact of HIV/AIDS have been related to the political, social and economic environments in which people and communities live (Barnett and Whiteside 2002; Hankins et al. 2002). HIV was recognised to be the cause of AIDS, but there was little understanding of why some societies faced more severe HIV epidemics and impacts

than others. Early studies emphasised the biomedical and epidemiological patterns that associated HIV/AIDS with 'high risk groups' such as sex workers, truck drivers and intravenous drug users. Little attention was paid to the social, economic and political environments and their contribution to the exacerbation of HIV/AIDS impact.

Similarly, approaches to the battle against HIV/AIDS also remained dissociated from the social and economic factors facilitating the spread of HIV. The modes of HIV transmission are now clear and recognised, and include having sex with HIV infected persons, infected blood transfusions and intravenous drug use. These are all globally recognised modes of HIV/AIDS transmission, and may be found in many societies around the world, although in varying degrees. What is not clear, or was not clear until recently, is why HIV/AIDS transmission is escalating in some societies (Sub-Saharan Africa and Asia) and not in others (for example, Western European countries).

At the end of 2001, about 70% of people with HIV/AIDS were in Africa; the percentage of new infections that were diagnosed was equally high in this region (UNAIDS 2002b). Similarly, by the end of 2003, almost two thirds of the people with HIV/AIDS were living in Africa, with the majority of HIV/AIDS victims being found in Southern Africa. Asia is now following in the footsteps of Sub-Saharan Africa. In Asia, about 7.4 million people have the diagnosis HIV/AIDS, and the rate of increase is about 1.1 million every year. The incidence rates are particularly going up rapidly in countries like China and India (UNAIDS 2004: 5 - 6). The task of examining the implications of these rising HIV/AIDS infection rates for the societies involved remains to be done. There is a need to understand peoples' way of life and their social, economic and political contexts. It is possible that these contextual factors may offer an explanation for the spread of HIV, as well as the means of fighting against it (Barnett and Whiteside 2002). In the next section, the relationship between HIV/AIDS and the social, economic and political environments will be examined.

4.2 Patterns of HIV/AIDS

As mentioned, since its identification in the 1980s, the spread of HIV on the African continent has taken place more rapidly than in any other part of the world, although it is now increasing rapidly in Asian countries as well. There are various explanations offered to account for these variations. In Africa, for example, the gender imbalance and poverty that exacerbate the

severity of the HIV/AIDS epidemic can be traced back to the history of colonialism, neo-colonialism and global trade patterns, and can be located, therefore in time and space.

Colonialism emphasised the production of cash crops such as coffee, cotton, and tea, and negated the production of food crops. In colonial history, cash crops were those that had direct forward linkage with the industrialised Europe; for example, cotton was grown to “feed” the Lancashire textile industry. This policy meant that the production of cash crops reduced the labour and land available for the production of food crops (Youe 1979). In Uganda, the introduction of cash crops went hand in hand with the introduction of taxes. The introduction of taxes was intended to; a) raise money to sustain the colonial office, and b) force men to produce cash crops as a source of income to pay the tax. In terms of gender imbalance, cash crop production was controlled by men, although both women and children were engaged in the process. This has had negative consequences for both food security and gender relations.

Historical processes such as colonialism depleted African resources, and created a divided and marginalised society (Barnett and Whiteside 2002). Under the yoke of colonialism, African communities were more actively engaged in anti-colonial strategies than in the construction of developmental infrastructure⁶². Since independence and even up to the present, many independent African states have enjoyed only a limited political and economic stability. If they are not engaged in a war⁶³, they are generally engaged in reforming their agrarian economies in the forlorn hope of competing with the industrial economies of the developed world. This situation creates an environment in which HIV/AIDS is able to grow and thrive (Barnett and Whiteside 2002).

Barnett and Whiteside (2002) have described the political economies of Uganda, South Africa and Tanzania, and relate their findings to the spread and impact of HIV/AIDS. They suggest a possible causal relationship between the spread of HIV and the unstable political and economic environment. Although these countries have different political and economic histories, they have one element in common – colonialism and the colonial legacies. The political and economic legacies of the pre-independence period still dominate these countries.

⁶² Infrastructure such as roads and railways were only constructed in areas producing cash crops.

⁶³ Since independence in 1962, Uganda has experienced six military coups and military state take-overs that are characterised by the destruction of property and bloodshed (Muriisa 2001).

The political economy of colonialism split countries and such divisions are still evident in countries like Uganda. Fanned by the civil strife and graft emanating from colonial history, Uganda, for example, continues to be torn apart⁶⁴. In addition, new divisions have emerged that are increasing social disintegration, divisions between rural and urban areas, between north and south, between rich and poor and between men and women; in each case the weaker party is marginalised. These factors contribute significantly to the spread of HIV.

In the war-torn northern Uganda, HIV transmission in Internally Displaced People's Camps (IDPC) is accelerated by the practice of unprotected sex with multiple sex-partners, and by the total disruption of people's social life (Hankins et al. 2002). In the south, Barnett and Whiteside (2002) describe the spread of HIV in Rakai as a result of the flight of war refugees from Rwanda to Uganda between 1959 and 1964, and of the movement of the liberation army from and to Tanzania in the late 1970s. This was the area where HIV/AIDS was first reported in Uganda in 1982.

The effects of globalisation⁶⁵ on present-day modes of life, production and distribution help to explain the magnitude of the HIV/AIDS problem in various countries. Barnett and Whiteside (2002) and O'Manique (1996; 2004) have discussed the relationship between HIV/AIDS patterns and globalisation. They demonstrate how the spread of HIV/AIDS was facilitated by global trade patterns involving the transfer of the products of multinational companies, such as petroleum and gas, from one place to another.

There is no doubt that the outbreak of HIV/AIDS might have first taken place in one or more, and it might even have remained for a long time in those particular places. For example, HIV was first identified in parts of United States and on the shores of Lake Victoria in Uganda. Hence, the fact that it is very widespread, covering almost the whole world, needs to be explained. According to Barnett and Whiteside (2002) the internationalisation of trade, combined with rapid urbanisation and the development of the road networks, may provide some answers. In Tanzania, the population explosion and increased urbanisation, in addition to various economic shocks, resulted in urban migration; those who were young and well-

⁶⁴ For example, since 1986 Uganda seems to be divided into two parts; a politically stable South with a flourishing economic base, and a politically unstable North where an unending civil war has been waged for over 20 years. This has caused homelessness, poverty and impoverishment in the region.

educated migrated in search of a new way of life and employment. For example, a large number of young Chagga men migrated to urban areas (Barnett and Whiteside 2002). This disrupted their social lives, and exposed them to the unfamiliar social conditions and sexual behaviours of urban centres. As a result, they were exposed to HIV infection.

Along the international road networks that link trading centres and cross countries in Africa as well as regions in India and in Pakistan, truck drivers became the major transmitters of HIV (Tushabe et al. 2002). In East Africa for example, the spread of HIV/AIDS followed a distinctive pattern; it first spread to the main trading centres such as Rakai⁶⁶ in Uganda, where truck drivers slept during their long trips from Mombassa and through Uganda to Rwanda and the Congo (DR). From these centres, HIV spread to other parts of these countries.

In trading centres along the main roads, sex-trade became a lucrative business for women who had been marginalised economically, socially and culturally. There was increased rural-urban migration of women who wanted to tap this “easy” source of money by meeting the increased demand for commercial sex in urban centres. With this increase in the sex trade, other people, including the locals, became trapped in the system; for example, businessmen and traders started sleeping with sex-workers on their business trips. It did not take long, therefore, for HIV/AIDS to find its way to the countryside.

In addition to the historical processes that shaped the production relations in which women were disfavoured, the neoliberal demand for privatisation and market allocation mechanisms creates a situation where individuals and communities have to face the impacts of HIV/AIDS individually, with limited support from the government (O'Manique 1996; 2004). O'Manique (2004) maintains that neoliberal policies originating in western countries have exacerbated the effects of the disease, since they emphasise private response. Dealing with HIV/AIDS has become an individual matter, a market-regulated response with little or no state intervention. The role of the World Bank and its Structural Adjustment Programmes (SAPS), and the role of the WHO in designing AIDS policies, leave little room for African countries to manoeuvre and design their own policy responses. Almost three-quarters of the national budget in many African countries are donor funded. Thus, Van de Walle points out that,

⁶⁵ Globalisation implies the erasure of regional, economic and cultural differences through the removal of country “borders”. The related diffusion of goods and services means that a homogeneous pattern of consumption and cultural expression emerges (O'Manique, 2004: 7).

In Uganda, for example, donors financed 77 percent of health spending in fiscal year 1992/93 while the government's share was 23 percent. In the case of expenditures on hospitals, however, the government's share was 64 percent, suggesting the often noted preference of governments in the region for city-based curative care that benefits the better off. (Van de Walle 2001: 101)

Policy responses often follow foreign dictates as for example the WHO demand that HIV/AIDS responses should be focused on education and behaviour change (O'Manique 1996; 2004). Thus, policy responses have focused on behavioural change rather than on the social-economic factors, such as poverty, cultural practices, gender and stigmatisation, which aggravate the spread of HIV. The behaviour change-focused policies take time to make an impact and may be short term.

The above discussion provides the basic premises for understanding the social, economic and political dynamics of HIV/AIDS and the social explanations of the cause and spread of HIV/AIDS. It stresses the fact that globalisation has shattered many African societies, leaving them susceptible and prone to HIV infection and the various impacts of AIDS. The explanations highlight issues such as poverty that are symptoms of a divided and marginalised society, the product of historical and current patterns of commodity production and distribution. These issues facilitate the spread of HIV/AIDS within and between communities. Nevertheless, such issues remain largely unaddressed by current policy responses, which have focused on prevention, education for behavioural change and control. These policies mainly target sexual behaviour, although sexual behaviour may not be the real problem. Sexual behaviour that leads to the spread of HIV is more likely to thrive where poverty, social patterns and institutional structures create a suitable environment. Some of the key factors and their relationship with the spread of HIV/AIDS are discussed in the following sections.

4.2.1 Poverty

The Uganda AIDS Commission has stated that "poverty, underdevelopment, and illiteracy contribute to the spread of HIV/AIDS in the developing world"⁶⁷. However, such statements do not elaborate on how poverty increases the transmission of HIV and the impacts of AIDS.

⁶⁶ A small trading centre on the shores of Lake Victoria where HIV/AIDS was first identified in Uganda.

⁶⁷ <http://www.aidsuganda.org/aids/index.htm>, 21/11/04

O'Manique (2004), and Barnett and Whiteside (2002) have argued that unequal resource distribution, widespread poverty and economic dependence of women upon men affect the spread and impact of HIV/AIDS on different individuals, groups and communities. Poverty drives women to engage in unprotected sex. In some cases this is because of their dependence on men for survival; in other cases, they enter prostitution as a way of earning a living. Although they may be aware that this is the major cause of HIV/AIDS, they take the risk of getting infected when the option is to go hungry.

Fassin and Schneider (2003), and White (2002) demonstrate how poverty may drive young girls to move from rural areas to towns where they generally sell their bodies to survive. Kelly (1995: 346) argues that efforts to prevent HIV/AIDS should be aimed at the social and interpersonal contexts of risk. Poverty and social stress are considered to be important contributors to risky sexual behaviour, although adequate attention has not been paid to the link between HIV/AIDS prevention and the social context of risk.

In addition to facilitating the spread of HIV, poverty limits access to drugs and health care services. Many people living in rural areas in Uganda cannot access medical services because they cannot afford the cost of transport to these facilities (Garbus and Marseille 2003; TASO 2002a). Nor has the introduction of ARV drugs helped the majority of those with HIV/AIDS for a number of reasons. First, the existing levels of poverty and unequal income distribution limit access; people cannot afford to buy the required combination of ARV drugs. Second, even if they could afford them, they cannot sustain this expense over time. Third, poverty prevents people from using the drugs in accordance with the prescribed doses. Fourth, there are nutritional requirements associated with the use of ARV drugs which the poor find difficult to afford. Finally, there is a lack of trained technical personnel to monitor patients on ARV drugs (Barnett and Whiteside 2002: 340-342; O'Manique 2004: 165). All these factors hinder the successful use of ARV drugs. Moreover, misuse of the drugs may have disastrous side effects, including the development of a resistance of the virus to other drugs. Barnett and Whiteside (2002) argue that ARV drugs are a necessity but not the answer; they are part of the answer and the other part involves tackling problems in the environment.

In Uganda, there are about 170,000 people with HIV/AIDS who are in need of ARV drugs; only 75,000 of these are being provided with the drugs, and of these, 45,000 treatments are donor funded. This reliance on the external funding of HIV/AIDS programmes cannot be

sustained in the long run, especially if the donors withdraw their support. Indeed the withdrawal of the global fund support in 2005, left people who were already on ARVs hopeless until the programme was restored later in the year. Another example showing the problem with heavy reliance on donor support is the failure of the full implementation of the plans for District AIDS Coordination Committees (DACC) due to withdrawal of the United Nations Development Fund support (UAC and NHACP 2002)⁶⁸.

4.2.2 Stigmatisation

Stigma is defined as a significant discrediting attribute possessed by a person with an undesired difference⁶⁹. HIV/AIDS-related stigmatisation has its roots in the social and economic structures of society. The way in which HIV/AIDS is transmitted promotes a negative attitude towards the disease. For example, epidemiologists first identified HIV/AIDS with gay men (in the USA). In Africa it was (and still is) identified with high-risk groups such as prostitutes, truck drivers and promiscuous men and women. Above all, HIV/AIDS is portrayed as a self-inflicted disease that is contracted through carelessness and one's own negligence⁷⁰. For example, religious groups consider HIV/AIDS to be the result of immoral behaviour and a punishment sent by God⁷¹. The development of this stigmatisation pattern threatens the social wellbeing of people who are HIV positive. They are afraid of being identified with promiscuity and prostitution, and fear of being blamed for their illness. Small (1997) argues that people with HIV/AIDS do not share their experiences or talk about HIV/AIDS because they feel rejected by society.

In Uganda, as elsewhere, AIDS is associated with promiscuity, infidelity, endless illness and inevitable death (Monico, Tanga, and Nuwagaba 2001; Muyinda et al. 1997). Because of this association with promiscuity, the HIV/AIDS diagnosis is considered demeaning and shameful (Monico, Tanga, and Nuwagaba 2001). It is also associated with discrimination in the work place, and termination or denial of employment opportunities to those infected. People are afraid, therefore, to disclose their status if they have taken the HIV test, or in extreme cases they are afraid to take the test.

⁶⁸ See 7.4.2 for a discussion on the implementation of the sexual transmitted diseases, HIV/AIDS (STD, HIV/AIDS) programme by Uganda AIDS commission.

⁶⁹<http://www.heart-intl.net/HEART/Stigma/ST-Index.htm> 18/04/06

⁷⁰ See the discussion on religious fundamentalism in 7.4.

⁷¹ see for example, http://www.christianaction.org.za/GDL/Newletters/2000-jun_jul.htm 18/04/06

Stigmatisation also results from the physical effects of AIDS on patients. In Uganda, AIDS was given the nickname “Slim” because it causes loss of body weight and increased emaciation. Such attitudes mean that HIV/AIDS victims often feel rejected by society, so they may choose not to participate in social activities. Thus, this stigmatisation is a threat to their psychological and social well-being.

Strangely enough, stigmatisation may heighten HIV transmission. In the first place, stigmatisation makes people afraid of finding out whether they are infected or not. Second, if they find out that they are HIV positive, they may keep this secret and not seek medical attention for fear of being discriminated against by care givers and the people around them including their sexual partners (TASO 2002a: 35; UNAIDS and WHO 2003: 31). Third, stigmatisation discourages people from practicing safe sex for fear of being considered to be HIV positive by their sexual partners.

From the above discussion, it is evident that people who discover that they are infected may resort to self-denial, isolation and self-discrimination. These strategies may cause stress and depression. Therefore, many prefer not to know, preferring to live in “false security”⁷². This increases the risk of transmission of the disease.

On the basis of the above discussion, it can be asserted that stigmatisation is a social creation. It emanates from the way messages about HIV/AIDS are delivered, the way HIV transmission is perceived and the association of HIV/AIDS with particular social groups. There is little room for effective HIV prevention programmes, therefore, if stigmatisation is addressed, without also addressing the factors that cause it (White 2002). It should be noted that the focus on contextualising HIV/AIDS by considering people’s living conditions is relatively recent; this has enabled people to talk about it. For example, it is now acknowledged that HIV can affect anybody, irrespective of age, gender, religion and status in society.

4.2.3 Gender Relations

There are few studies such as Gisselquist, Rothenberg et al (2002), which contradict existing data that relate HIV/AIDS transmission to heterosexual relationships, especially in Africa. The transmission of HIV/AIDS in Uganda is mainly through sexual relations with the

opposite sex (UNAIDS 2002b: 23). At the outset and with its increased spread, HIV/AIDS made its impact felt in Rakai district, where entire households were almost wiped out. Although there were various explanations offered regarding the causes of the disease, ranging from witchcraft to sexual behaviour, it was the latter that took precedence over other explanations (Putzel 2004). The cultural practice of widow inheritance contributed significantly to its spread. Barnett and Whiteside (2002: 133-136) argue that commercial sex in Rakai district in Uganda resulted from the susceptibility and vulnerability of women in the district.

The possession of economic resources is a fundamental feature of gender relations in Uganda. In this context, men possess more economic resources than women. According to the World Bank (2000a: 139), countries with high gender inequality also have high HIV infection rates. O'Manique (2004), explains how women were disadvantaged by the Uganda's colonial and post-colonial political economies. She demonstrates how women were disadvantaged in relations of commodity production and distribution, leaving them vulnerable to disease and modern-day HIV/AIDS. Furthermore, she illustrates how Ugandan HIV/AIDS policy, which has followed the World Health Organisation (WHO) and World Bank (WB) policy design, has ignored the socio-economic and political conditions of developing countries, thereby further undermining the position of women and rendering them more vulnerable to HIV infection. O'Manique (2004) brings to light the gender implications of this political economy and its consequences for HIV/AIDS transmission.

In Uganda, this gender imbalance was exacerbated by post-independence economic and political policies. The 1970s and 1980s were characterised by economic collapse. The illicit and often high-risk businesses such as “magendo⁷³” that flourished during President Amin's regime in 1970s were dominated by men. Women's economic marginalisation and total dependence on men for survival and support grew. The relationship between men and women became cash driven. It was a relationship in which women married or engaged in sexual relations in exchange for cash or for financial security. Prostitution, although illegal, grew out of this imbalance and has continued to contribute to the transmission of the disease.

⁷² It is a shadow of ignorance mixed with fear and doubt about individuals HIV/AIDS status. It prevents people from seeking medical help and testing (See <http://www.avert.org/aidsstigma.htm>, <http://www.faceaids.org/learnmor/stigma.html> 21/04/06)

⁷³ The term Magendo referred to cross-border smuggling, a common phenomenon during Amin's (1971-1979) and later during Obote II (1980- 1985) regimes.

The problem of gender inequality is compounded by cultural and social institutions which define the commodity production relations between men and women. This relationship is explained in terms of the property relations between men and women. In most parts of Uganda, property ownership is defined by the family of the husband, and women have only limited property rights⁷⁴. Socially, women are considered to be their husband's property because of the customary bride price that men pay to parents before they allow their daughter to marry (Leistikow 2003). Furthermore, it is culturally accepted that men take care of and provide for their families, in which case women do not need to own property. This results in a gender relationship in which women are the underdogs.

Women's vulnerability therefore, is largely due to the social institutions which deny them the right to own property. Ultimately, women do not have the right to determine when to have sex and what type of sex to have, and to negotiate for safer sex (Kelly 1995; Monico, Tanga, and Nuwagaba 2001; Oruboloye 1993). Thus, they cannot protect themselves against HIV infection. According to Human Rights Watch's - HRW (2003) Report *Just Die Quietly: violence and Women's Vulnerability to HIV in Uganda*⁷⁵, many women expressed fear of repercussions if they demanded fidelity from their partners or use of protective measures against HIV. This is because the legal framework has not addressed issues relating to domestic violence. Consequently, HIV/AIDS prevention approaches focusing on fidelity do not achieve desired results. Thus, the report argues that;

Current approaches focusing on fidelity, abstinence, and condom use do not address the ways in which domestic violence inhibits women's control over sexual matters in marriage, minimize the complex causal factors of violence, and incorrectly assume that women have equal decision-making power and status within their intimate relationships. (HRW 2003: 3)

Domestic violence against women impedes their access to HIV/AIDS information, HIV testing and HIV/AIDS treatment and counselling (Mbabazi, Mookodi, and Parpart 2005). A study carried out in Ssembabule district in Uganda revealed that women were abused and sexually assaulted by their husbands, who did not want to use condoms when they were drunk (Batard and Ouma 2005). A similar finding was made by Wilton and Aggleton (1991) that in

⁷⁴ With the failure of the domestic relations bill to gain parliamentary approval, women's efforts to acquire equal property rights were denied.

⁷⁵ <http://www.hrw.org/reports/2003/uganda0803/uganda0803full.pdf> 20/01/06

the USA women who attempt to negotiate safer sex with male partners risked abuse, physical violence or the loss of that partner and that this has social and economic consequences.

In addition, many Ugandan men have multiple sexual relationships which are "legitimate"⁷⁶, since this is supported by the existing social institutions. For example, polygyny is a social institution recognised in Africa and most men and women accept that men should have sexual relations with different women (Caldwell 2000: 118). However, women are not allowed to have sexual relations outside their marriages.

The above factors partly explain why the prevalence of HIV/AIDS among adults remains higher for women than for men. In 2001, the number of infected adult women in Uganda was reported to be 49,092, while the number of men was significantly lower, 40,533 (UAC 2003). Mbabazi, Mookodi and Parpart,(2005: 120) point out that the male to female ratio of AIDS cases in the 15 to 19 years age group is 1:5⁷⁷ and argue that women in Uganda are considerably more susceptible to AIDS than men. In addition, they stress that women constitute more than half of the 1.2 million people with HIV/AIDS in Uganda.

From the above discussion, it becomes clear that successful HIV/AIDS intervention cannot be achieved without addressing gender issues. To deal with HIV/AIDS, a variety of approaches are required, including behavioural change to prevent new and re-infections, treatment measures for those with HIV/AIDS, and approaches that target gender relations as a factor contributing to the spread of HIV/AIDS. These issues provide a basis for developing successful mitigating approaches.

4.3. HIV/AIDS in Uganda

In 1982, two cases of HIV/AIDS were identified in Kasensero village in Rakai district on the shores of Lake Victoria. The disease had characteristics similar to those of a disease identified in the United States in 1981, including high fever, diarrhoea and emaciation. It was not easy, however, to establish a link between the USA and Ugandan cases. In the US, the disease was first identified among the homosexuals and drug users. This produced controversy regarding whether the two cases (USA and Uganda) were similar, since there

⁷⁶ Ugandan law recognises different kinds of marriage: traditional, civil, and religious. There is no established law that prevents men from having multiple marriages at the same time, although women are restricted to being married to one particular man. Until this marriage is annulled, a woman cannot marry another man.

were no known cases of homosexuality in Uganda at the time. The Ministry of Health ordered that further investigations be carried out regarding the possible linkage. In 1983, 17 more cases were identified and the disease was found to be more prevalent among the high-risk groups such as sex workers (Barnett and Whiteside 2002; Putzel 2004) and small traders engaged in smuggling goods across Lake Victoria (Okware et al. 2001). As in other countries in Africa that feared a decline in tourism and international prestige, the initial response to HIV in Uganda was denial by the Ministry of Health officials (Putzel 2004). Eventually, this denial was no longer credible since the number of people diagnosed as having the disease was increasing rapidly.

Uganda is considered to have been the first African country to collect data regarding the scale and extent of the AIDS epidemic (Barnett and Whiteside 2002: 343). Citing several early studies of HIV/AIDS, Putzel (2004: 23) traces the development of research into HIV/AIDS in Uganda. According to Putzel, research began in the late 1983 and early 1984 with a joint effort by Ugandan and foreign doctors. When the disease was first identified in Rakai, the medical officer began studying the impact of the disease on the traders and smugglers who were crossing the Kagera River. In 1984, a report was submitted to the Ministry of Health and in January 1985, President Milton Obote ordered the disease surveillance committee to investigate further the prevalence of the disease in Rakai. The committee reported that the outbreak in Rakai was due to poor sanitation. In June 1985, a team of doctors mapped the disease by sampling households in Rakai. The results of the study indicated a clear pattern: disease occurrence rates were high in sexually active households. This report contradicted the earlier report of the disease surveillance committee appointed in January 1985.

The June study was the first in Uganda to link HIV and sexuality, and the first anywhere in the world to link HIV and heterosexuality (Putzel 2004). This study was published in the British Medical Journal *The Lancet* in 1985. With increased research into the disease in late 1985, it was confirmed that the disease was actually the same as that found in the USA. Further research was carried out on a sample of 65 patients admitted to Mulago Hospital⁷⁸ between October and November 1985. The results of the study were compiled into a report entitled “AIDS in Uganda” that was published in *Health Information Quarterly* in early 1986.

⁷⁷ citing the *New Vision* 8 March 2004

⁷⁸ The national referral Hospital

In Uganda, the AIDS pandemic emerged at the time when the regime of President Obote II was facing political challenges in the form of internal and external political pressure from rebels. The government therefore, had little time for HIV/AIDS since it was more concerned with maintaining its crumbling regime. The regime was overthrown in 1986 by one of the army commanders, Tito Okello Lutwa, and later by the national resistance army led by the current president, Yoweri K. Museveni. When the National Resistance Movement (NRM) government took over power in 1986, it faced severe economic problems, including resource constraints resulting from the poor economic management of the former regimes. There were breakdowns of major economic and political structures during this period, so the pandemic received little attention. It was not until almost a decade after the NRM take-over, that effective political involvement in HIV/AIDS was realised. Museveni became deeply involved in 1996, when he was informed by the Cuban president that the army was infected. Of a group of 60 officers who had been sent to Cuba for military training, 18 (30%) were found to be HIV positive (Putzel 2003; Tumushabe 2005).

4.3.2 HIV/AIDS Policy in Uganda

Although HIV/AIDS had been identified in Uganda in 1982, and the establishment of various programmes through which HIV/AIDS could be fought⁷⁹ –such as the establishment of the Sexual transmitted Diseases/HIV/AIDS Control Programme (STD/ACP) in 1986, it was not until 1993 that HIV/AIDS policy guidelines were drawn up (Asingwire and Kyomuhendo 2003). These guidelines were revised in 1996 and have since provided a reference point for policy proposals. This late coming of policy guidelines was due to two factors: the political crisis that the country was facing, and the underestimation of the virulence of the HIV virus, which in the meantime was developing into an epidemic. With regard to the first of these, the country had been devastated not only by the political crisis associated with the fall of Obote's regime, but also by an economic crisis that had begun in the 1970s. Even after the establishment of the new regime under Museveni, therefore, the government was still preoccupied with the work of rehabilitation rather than with a single virus.

Another factor explaining the government's reluctance to become involved in this problem was the nature of the illness. When it became known that HIV was largely sexually transmitted, it was clear that any efforts at prevention would tread on sensitive cultural,

⁷⁹ See 7.4

personal and religious issues. Thus, the government was reluctant to discuss these issues for fear of rousing the opposition of various religious and cultural groups (Ainsworth and Teokul 2000; Putzel 2003).

HIV/AIDS was initially treated like any other disease that had to be dealt with under the established health policy. The long latency period of the HIV infection was misleading and hindered the prompt reaction of government agencies. As Ainsworth and Teokul (2000) argue, with an outbreak of a new disease, governments are reluctant to act until many people are visibly affected since there are other health problems that require immediate attention.

Given the increasing spread of the virus, the government came up with policy proposals in 1996, which centred on four themes: a) prevention and control, b) care, support and mitigation, c) organisation and co-ordination of HIV/AIDS activities, and d) research and publication (Asingwire and Kyomuhendo 2003). The continuation of practices that caused the spread of HIV, such as promiscuous sexual behaviour and blood transfusions, meant that preventive measures dominated in mitigation approaches. Consequently, mitigation and control efforts, as well as HIV/AIDS policies, have focused mainly on prevention and behavioural change for a long time.

The government's multisectoral strategy stresses the importance of involving various actors, including government ministries and departments, religious and faith based groups, NGOs, individuals and the private business sector in fighting HIV/AIDS. This openness and the multisectoral approach encouraged the participation of a variety of actors, and it was the government's role to coordinate interaction between them. Most importantly, it is partly thanks to this policy that HIV/AIDS programmes in Uganda⁸⁰ have been so successful.

It should be noted that, although policy proposals regarding how to deal with HIV/AIDS are in place, and various ministries are supposed to implement HIV/AIDS programmes, HIV/AIDS has remained a health issue⁸¹. Only the Ministry of Health has specific HIV/AIDS programmes in place; for example, Prevention of Mother to Child Transmission of

⁸⁰ See chapter 7 for a more detailed discussion of the multisectoral approach

⁸¹ Although dealing with HIV/AIDS was made an integral part of different ministries duties through the multisectoral approach, there have been conflicts between the ministries regarding how programmes should be implemented (Putzel, 2003). Ministries have continued to focus on their main programmes, leaving HIV/AIDS

HIV (PMCTH) and antenatal surveillance of pregnant mothers. Other ministries have not been vigilant in implementing programmes to address HIV/AIDS directly.

The government only recently introduced Anti Retroviral Therapy (ART) into the treatment of HIV/AIDS due to the high cost of antiretroviral drugs (ARV) and the lack of capacity (personnel and equipment) to monitor the effects of the drugs⁸². Uganda's HIV/AIDS policy has generally been limited to preventive measures, such as promotion of condom distribution, sex education and PMCTH. A policy of openness about HIV/AIDS has also been implemented, although the initial proposal to use the condom was supposed to be 'quiet' (Asingwire and Kyomuhendo 2003), condom use is now being promoted openly.

The quiet introduction of condoms was meant to avoid direct conflict with religious groups. Only when the attacks and controversy surrounding this issue had diminished, did condom use become an open policy. The involvement of religious and cultural leaders in the discussions about HIV/AIDS and in control efforts was intended to minimise opposition from these groups.

Currently, the approach taken to promotion of the use of condoms in the prevention of HIV has not attracted much negative attention from these groups, nor has it divided the population. Even religious groups now accept the government's policy regarding the use of condoms, although they may personally disagree with their use (Parkhurst and Lush 2004). The government's policy of Abstinence, Faithfulness and Condom use (ABC) has not met major opposition from major religious groups, such as the Anglicans and the Catholic faiths. The religious groups have instead modified the approach to suit their followers and beliefs. Thus, the slogan, 'love carefully' that is used by the government in preventive messages was replaced by 'love faithfully' by religious groups to de-emphasise the use of condoms. The argument is that if partners are faithful to each other, there is no need to use condoms.

4.4. Impacts of HIV/AIDS in Uganda:

At present, there is no part of the country, village or community that has not been affected by this disease. In the early 1990s, HIV/AIDS reached its peak with a prevalence rate of about

at the periphery. For example, poverty eradication strategies have tended to be general and not specifically focused on HIV/AIDS concerns.

18% for the country as a whole, and in some areas around Kampala, the prevalence rate was around 30% (MOH 2003: 10). Although the prevalence rate has declined since 1991, the disease has made itself felt in many sectors.

People who become infected with HIV continuously lose their immunity and become susceptible to various opportunistic infections. This condition is what is called AIDS. AIDS often results in death. The immediate impact was related to the number of people dying. Soon it became clear that the impact goes beyond the high death rate. AIDS has affected households' means of survival and the overall way of life. As mentioned earlier, its impacts range from demographic and socio-economic to political. The discussion that follows is about these impacts.

4.4.1 HIV/AIDS Related Deaths

As noted above, the ultimate impact of HIV/AIDS is death: HIV/AIDS is the leading cause of death in Sub-Saharan Africa and the fourth biggest global killer (UNAIDS 2002b; World Bank 2000a). The World Health Organisation (WHO) report of 2003, *Shaping the Future*, notes that;

Acquired immunodeficiency syndrome (AIDS) is the leading infectious cause of adult death in the world....in hard-hit areas, including some of the poorest parts of the world, HIV has reversed gains in life expectancy registered in the last three decades of the 20th century. HIV/AIDS is a major global health emergency.⁸³

In the absence of affordable treatment, the impact of HIV/AIDS on demography is unstoppable (Barnett and Whiteside 2002: 169). As of the end of 2001, at least 15% of the adult population in 9 African countries was infected with HIV/AIDS (highest figure 38.8% in Botswana). In 2002 alone, the epidemic killed about 3 million people and it continues to kill more, as the global figures indicate. At the end of 2002, a global total of 60 million people had been infected by HIV/AIDS since its detection; 42 million were living with HIV/AIDS, of which 29.4 (70%) million were in Sub-Saharan Africa. In 2002 alone, 5 million people in the world were newly infected, of which 3.5 (70%) million were in Sub-Saharan Africa (UNAIDS 2002b). In Asia, the disease is slowly picking up pace. About 7.4 million are living with HIV/AIDS, and the infection rate is about 1.1 million every year. The infection

⁸² The use of ARVs was limited to those who could afford to pay for both the drugs and the accompanying cost of monitoring their effectiveness, especially the well-educated and businessmen and women.

⁸³ <http://www.who.int/whr/2003/chapter3/en/index.html> 03/08/06

rates are now rising in countries like China and India (UNAIDS 2004: 5 - 6)⁸⁴, as well as in the Ukraine and the Russian Federation “which has the biggest AIDS epidemic in all of Europe” (UNAIDS 2006: 9).

The demographic impacts of HIV/AIDS in Uganda are enormous. At the end of 2001, 1,050,555 cases (individuals, adults and children) of HIV/AIDS were on the records, while 84,000 AIDS deaths occurred in 2001 alone. A total of over 940,000 HIV/AIDS-related deaths are reported to have occurred in Uganda between 1982 and 2001 (UAC 2003). In 1995, *The Burden of Disease* study in Uganda reported that AIDS accounted for 9.1% of premature deaths; and that for the people in the 15-49 age bracket, HIV/AIDS remains the leading cause of death (Wakhweya et al. 2002: 11-12). The president of Uganda, Museveni, stated that about 50% of recorded deaths in hospitals were HIV/AIDS-related⁸⁵.

HIV/AIDS has not only led to increased death rates, but has generally reduced the life expectancy of Ugandans from 60 to 40 years (Fredland 1998: 554). Table 4.1 shows the number of deaths, new infections and orphans in selected African countries.

Table 4. 1 Estimated HIV/AIDS Cases in 11 Selected Sub-Saharan African Countries by the end of 2001

Country	Adults and Children	Adults	Adults (15-49) rate %	Orphans Living with HIV(0-14)	AIDS Deaths (Adults and children) 2001	Total Population (000s)
Botswana	330,000	300,000	38.8	69,000	26,000	1,554
Kenya	2,500,000	2,300,000	15.0	890,000	190,000	31,293
Lesotho	360,000	330,000	31.0	73,000	25,000	2,057
Malawi	850,000	780,000	15.0	470,000	80,000	11,572
Namibia	230,000	200,000	22.5	47,000	13,000	1,788
South Africa	5,000,000	4,700,000	20.1	660,000	360,000	43,792
Swaziland	170,000	150,000	33.4	35,000	12,000	938
Uganda	600,000	510,000	5.0	880,000	84,000	24,023
Tanzania	1,500,000	1,300,000	7.8	810,000	140,000	35,965
Zambia	1,200,000	1,000,000	21.5	570,000	120,000	10,649
Zimbabwe	2,300,000	2,000,000	33.7	780,000	200,000	12,852

Source: (UNAIDS 2002: 190)

The above table reveals that, by the end of 2001, about 5% of the adult population in Uganda was infected with HIV/AIDS. The above table also shows that Uganda has the lowest adult HIV prevalence rate in Africa. Other reports have also indicated that Uganda’s national HIV prevalence rate declined from 18% for the whole population in the early 1990s to about 6.2%

⁸⁴ UNAIDS (2006) reports that in India, the number of cases is declining, but maintains that the number of cases is rising in China and some other Asian countries such as Indonesia, Papua New Guinea, and Vietnam, and that, there are possible HIV outbreaks in Bangladesh and Pakistan.

⁸⁵ <http://www.museveni.co.ug/reader.php?process=speechesandspeechSpec=5> 24/10/04

at the end of 2002 (MOH 2003: 9). For the worst hit areas, the decline was from around 30% to around 10%. However, there are indications that HIV infection may not actually be declining, but rather that HIV/AIDS-related deaths are levelling off new infections, thus creating stability in the prevalence rate⁸⁶. The Uganda AIDS control programme reports that an estimated 73,830 Ugandans died of the disease in 2002 and there were 70,170 newly infected (MoH 2003: 29; Wendo 2004: 3). These figures are mere estimates and, because of constraints in HIV/AIDS reporting and sentinel surveillance system, the death rate and prevalence rate may be much higher than actual figures for the disease, and therefore may not provide a true picture of HIV/AIDS in Uganda (MoH 2003; Ouma 2004)⁸⁷.

According to Rubaramira, an HIV/AIDS activist and the Executive Director of the National Guidance and Empowerment Network of People Living with HIV/AIDS (NGEN), HIV/AIDS surveillance estimates are based on hospital statistics, yet many people are not hospitalised. Rubaramira argues that Uganda's prevalence rate has ranged between 12-20%. This is at least double the reported prevalence rate of 6.2% (Rubaramira 2004). The Ministry of Health (MOH) *HIV/AIDS Surveillance Report* (MoH 2003), also acknowledges the disadvantage of using hospitalised cases as a basis for generalisation in prevalence reporting. The report notes that in some centres where pregnant mothers are tested for HIV, figures were too small for any generalisation to be made to the whole nation⁸⁸. These examples show that HIV/AIDS in Uganda might be having worse impacts than can actually be known since the number of HIV/AIDS infected persons might not be known.

Because of the controversy surrounding the use of prevalence rate as an indicator of countries HIV/AIDS status, scholars have pointed out that the incidence rate would provide a more accurate picture of the problem in the countries concerned. For example, Parkhurst (2002) argues that it is not possible to claim that prevention of HIV has been successful until a decline in the number of new infections (incidence) each year is recorded. He argues that the prevalence rate will decline when incidence is declining or stabilising if mortality increases

⁸⁶ Since HIV prevalence rate shows the total number of people infected with HIV/AIDS in a country at a particular time, if the HIV/AIDS infected equalled the number of infected who die in that period, the prevalence rate would not change. However, the true picture would be that infections are still taking place. A true picture would be shown by the new HIV infections (incidence) not the prevalence (which shows old and new HIV infections).

⁸⁷ See also, <http://www.aidsuganda.org/aids/index.htm> 03/05/06

⁸⁸ see <http://www.avert.org/aidsuganda.htm> 17/10/04).

above the incidence rate. The incidence figures therefore, are more realistic and should provide a truer picture of the national HIV/AIDS situation than the prevalence figures.

All across Uganda, there is increasing evidence that the incidence of HIV/AIDS is declining among people in the 15-24 age group (Mbulaiteye et al. 2002; Parkhurst and Lush 2004). In a study carried out in western Uganda between 1989 and 1994, Mbulaiteye, et al (2002) found that HIV prevalence reduced from 8.2% in 1990 to 7.6% in 1994. They found that there was a significant drop among the 13-24 age groups: males from 3.4% to 1% and females from 9.9 to 7.3%. They argue that such declines have been sustained. Parkhurst (2002) suggests that, since it takes time for people who contract HIV to die, a decline in HIV incidence among the youth, who have recently come of age in terms of sexual activeness, would be a good indicator of programme success. Therefore, a fall in the prevalence in this age group is likely not related to mortality, since the average number of years a person can live after contracting HIV ranges between 5 and 15 years (Barnett and Whiteside 2002). In general, the number of new cases of HIV/AIDS in Uganda has been declining since 1995. This is evident in the figures in Table 4.2.

Table 4. 2 New and Cumulated Reported AIDS Cases in Uganda by Year (1983-2002)

Year of Reporting	New Reported Cases (HIV incidence)	Cumulative cases
1983	17	17
1984	11	28
1985	440	468
1986	441	911
1987	2,914	3,824
1988	3,425	7,249
1989	6,090	13,339
1990	6,616	19,955
1991	10,235	30,552
1992	6,362	36,552
1993	4,641	41,193
1994	4,927	46,120
1995	2,191	48,312
1996	3,032	51,344
1997	1,962	53,306
1998	1,406	54,712
1999	1,149	55,861
2000	2,303	58,165
2001	2,008	60,173
2002	801	60,974

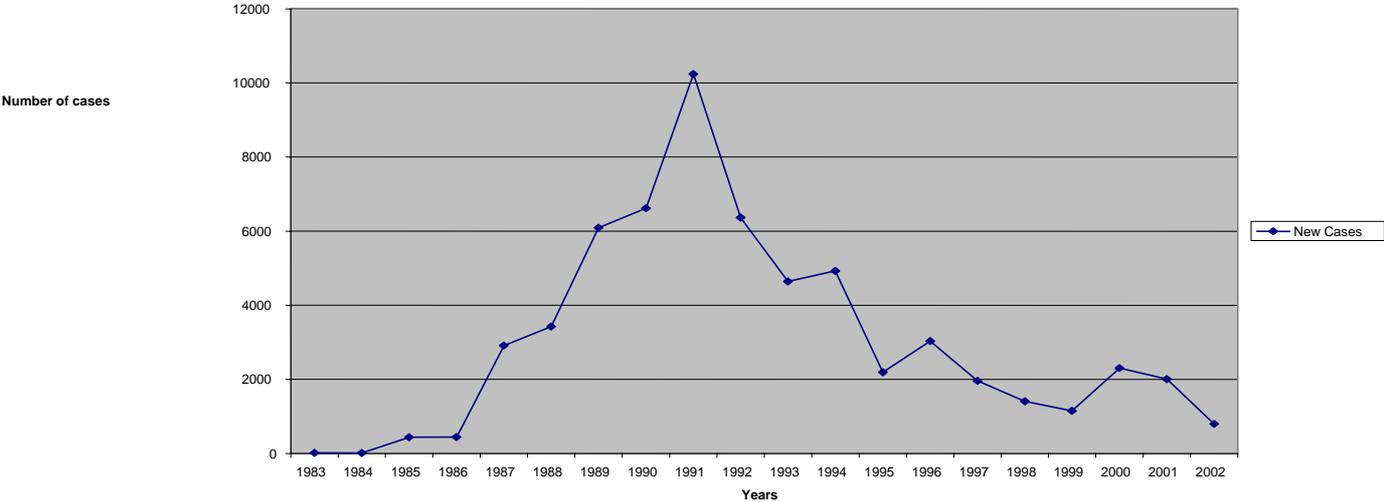
Sources: 1. Figures gathered from various reports such as Uganda AIDS Commission⁸⁹, Uganda Epidemiological facts sheets on HIV/AIDS and Sexually transmitted infections, 2002 Updates, UNAIDS⁹⁰, MOH (2003: 23).

⁸⁹ http://www.aidsuganda.org/analysis_2002.htm 23/03/4

⁹⁰ http://www.unaids.org/hivaidsinfo/statics/facts_sheets/pdfs/Uganda_en.pdf 23/03/2004

Table 4.2 reveals an overall decline in the number of new cases reported annually since 1991. The data presented in this table, when presented graphically (figure 4.1), illustrates the trend in the HIV/AIDS infection.

Figure 4. 1 HIV Incidence in Uganda, 1983-2002



Data source: Table 4.2 above

Figure 4.1 above is based on the data presented in table 4.2. The figure demonstrates that the incidence of HIV was steadily increasing until 1990, when there was a sharp increase in the number of new cases: the peak was reached in 1991 when there were 10,235 new cases. After 1991, there is a steady decline followed by a dramatic decline until 1995 and then a steady decline. There are several reasons for this trend in the HIV/AIDS infection rate:

- 1 From 1983 to 1991, the rapid increase is explained by the uncertainty regarding the means (at that time) of transmission and the general lack of awareness about the HIV/AIDS in the community, and hence increased transmission.
- 2 From 1991 to 1995, there is a sharp decline, mostly due to increased knowledge about the way HIV/AIDS is transmitted. From 1995 onwards, the number of cases reported has been stable and low. This is due to the greater involvement of various actors, including civil society, and other means used to combat HIV/AIDS. Since 2000, there has been a downward trend in the number of new cases reported, and by 2002, the prevalence was estimated to be 6.2% (MoH 2003)⁹¹.

⁹¹ Since 2002, there has been a steady increase in the HIV/AIDS prevalence stabilising at around 6.5% (UNAIDS, 2006; Allen, 2005).

Child Mortality

The majority of children who are born with HIV/AIDS die before the age of five, having been infected by their parent(s). In countries where HIV/AIDS spreads primarily through sexual transmission, such as Uganda, the peak age for infection is 20-40 years, and the peak age of death is 5-10 years later (Barnett and Whiteside 2002). This means that the age group with the highest rate of infection is also the most economically productive and the most fertile category. In the absence of PMCTH, AIDS accounts for about 30% of infant mortality. Therefore, this would imply that almost all the babies born to parents within this age bracket would be infected, and would likely die before the age of five (Barnett and Whiteside 2002).

4.4.2 Orphans

Orphans in Africa and Uganda in particular are an enormous problem. An orphan is defined as any person below the age of 18 who loses one or both parents (Wakhweya et al. 2002). UNAIDS (2002b) estimated that there were about 880,000 orphans with HIV/AIDS in Uganda at the end of 2001 (see table 4.1). The total number of orphans in Uganda is estimated by the Uganda Bureau of Statistics- 2001 to be about 1.65 million (UAC 2001: 2). UNDP (2002a: 38), citing Demographic and Health Survey (DHS), suggest that one in every four families has an orphan. Although orphan-hood in Uganda may be due to a variety of causes, including war and insurgency in the northern region, AIDS is responsible for a significant percentage, about 80-90% of the total, of the orphans in the country (Wakhweya et al. 2002: 17). UAC (2003) estimates that 2 million children below the age of 15 have lost one or both parents to AIDS.

The problems faced by AIDS orphans ranges from a general lack of care to total homelessness and life on the street. Since the parents often die when the children are still young, there is seldom anyone to care for them except their elderly grandparents. The traditional family system, which provided care and support to the sick and orphans, is very much weakened with the death of its able-bodied members; left behind are the elderly, who are in need of support themselves (Barnett and Whiteside 2002; Marshall and Keough 2004). Marshall and Keough (2004) claim that the African social fabric is unravelling rapidly due to the strain of stigmatisation and discrimination, the increase in the number of orphans needing attention, and the decline in the number of care givers. Garbus and Marseille (2003) also indicate that the success indicated by the reduced prevalence rate is not matched by positive

progress in meeting the needs of the increasing numbers of orphans and others requiring care and support. These orphans are cared for by relatives, some of whom may be sick themselves, or by various organizations. Many who have no relatives to take care of them, lack basic necessities of life and take to the streets, adding to the growing population of street children (White and Robinson 2000). Yet others find work in domestic environments and are doing heavy domestic work. In this situation, girls are more likely to be infected by HIV/AIDS due to early marriages, sexual abuse and defilement (UNDP 2002a).

Child-Headed Families

HIV/AIDS has given birth to a new family system: the child-headed family structure. This is a system in which the eldest child heads the family, which usually consists of his/her sisters and brothers, if there is no relative to take care of them following their parents' deaths. This has become an institutionalised system in countries severely affected by HIV/AIDS, such as the countries of southern Africa (Foster 1998). Child-headed families are a relatively new phenomena and are therefore still being researched (Ntozi and Mukiza-Gapere 1995; Ntozi and Nakayiwa 1999), but they characterise societies as in Rakai which were severely affected by AIDS. The child-headed family system is symbolic of the ongoing disintegration of the social system. As will be discussed below, most of these families live on margins with limited resources to cater for basic needs since most of the property holdings of the family were sold by their sick parents before they finally died.

4. 5 Socio-Economic Impacts:

4.5.1 Impact on the Extended Family and the Community

In Africa in general and Uganda in particular, social structures such as the family and community are important for the contribution they make to the well-being of community members. Social networks at community and family levels have long existed in Uganda and have played an important role in the people's way of living. For example, social networks of women groups and farmers have played and continue to play a central role in rural agricultural communities in Uganda. In addition, small revolving funds, which are highly dependent on personal trust, have helped rural communities to thrive. Moreover, the extended family has acted as a safety net for individuals during hard times. It also acts as the main source of care for members who are vulnerable: the elderly, orphaned children, the disabled, the destitute, the incapacitated, the victims of disaster, the sick and the unemployed.

Families, neighbours, friends and relatives provide material and moral support, which can be drawn upon when individuals are hit by crises (Woolcock 2001: 23). In Uganda, this is particularly true, since families provide an important form of social security (Kayazze 2002; Marshall and Keough 2004; Tumwesigye 2003). Marshall and Keough (2004:135-156) have argued that, the deep-rooted kinship system that exists in Africa -the extended family networks of aunts and uncles, cousins and grand parents - is an age-old social safety net for vulnerable children, and that this system has long proved resilient even in circumstances of major social change.

Tumwesigye (2003: 1) notes that, before the introduction of a formal social security system in Uganda, “the extended family system served as a security mechanism. Socio-economic structures were such that each person was related to another and there were family responsibilities and values”. Apart from social support, rich societal ties of family, kinship and community are important for poverty alleviation, information access and job placement.

Globalisation and the social instability it has caused, such as the urban migration of young men and women in search of employment, has left the family system somewhat disorganised. However, in certain aspects as in burial and ritualistic moments individual members of the family continued to support each other. In addition, occasionally, young men and women who had moved to the cities would bring their children to the village to be cared for by their parents. These children were often the product of extra-marital relationships and had single parents. Grandparents were often happy, at least initially, to receive these grandchildren, who replaced their “lost” sons and daughters. However, these ties, which held the social systems of the family and community together, have been seriously affected by the spread of HIV/AIDS.

HIV/AIDS changed the order of who should care for whom; the sick replaced the children as dependants. Instead of taking children back to the villages, it was sick men and women who were taken back, often by their friends, to be taken care of by their relatives (usually their parents), until they finally died. In addition, the dead left behind orphans to be taken care of by grandparents. Given the increased number of HIV/AIDS-related deaths and the increased spread, coupled with the problem of segregation, a new response developed: a decline in the social support available to the sick. The initial trigger for this decline in social support was the fear of contracting the deadly disease. Later, when the number of people infected

increased, there was a more general lack of support. There was a disruption of social unity and of interpersonal relationships involving people infected with HIV/AIDS or suspected to being infected. The social relationships became characterised by discrimination. The number of orphans increased, while resources dwindled and could not be stretched to support an additional member (Nyonyintono et al. 2001; O'Manique 2004). The practice of sending orphans to their relatives is slowly diminishing, as the role of the extended family is giving way to the individualisation of the care and support roles, or is being left to specialised organisations. The extended family system exists almost solely in theory now (Barnett and Whiteside 2002: 187).

4.5.2 Declining Care and Support for People Infected With HIV/AIDS

The biggest challenge facing AIDS patients is the lack of care and support. This problem is inseparable from the other impacts of AIDS, such as poverty, discrimination and stigmatisation. However, the difference is that lack of care and support is life-threatening for those with HIV/AIDS, therefore it warrants independent attention. The provision of care and support calls for services, financial assistance and emotional support, and these are not generally available to those with HIV/AIDS. They are stigmatised and or discriminated against due to the fear of transmission of the disease (Monico, Tanga, and Nuwagaba 2001). For example, in her study in eastern Uganda, Christiansen (2005) found that widows and orphans were harassed and sometimes chased away from their homes by relatives following the death of the husband.

As mentioned in the preceding section, the African social support system, which depends on family members acting as safety nets, is overstretched. With the increased number of deaths, especially where older members of the family die of HIV/AIDS, there is no one to take care of those remaining, i.e. the sick and orphaned (Treichler 1991). There is often not enough food in the home and is seldom money for medication (O'Manique 2004: 159). Nor can they depend on neighbours for support, since the neighbours themselves are affected and cannot provide the required support (Orla 2004). With increased poverty, AIDS patients cannot meet their own basic needs, let alone gain access to the medical care that is essential for their survival.

It should be noted that, since people with HIV/AIDS do not live independently of the whole community, care and support requires that everybody becomes involved. As mentioned, the amount of social support provided to those infected with HIV/AIDS is affected by the level of stigmatisation and social discrimination. Earlier in this chapter, I discussed stigmatisation as a social construct, largely created by the way messages about HIV/AIDS are delivered and received by different people in the community, including family members. In chapter 2, I stressed that in the absence of a welfare system that is functioning effectively, social support is provided by families and the community. Therefore, in order to deal with the impacts of HIV/AIDS, families and communities must be involved. This requires that organisations target those not infected (usually family members of the infected person) since they are the major providers of social support (see 6.2.3).

4.5.3 Impact on Poverty and Income

Apart from the demographic impact, the social and economic impacts of HIV/AIDS are widespread. A study of three countries (Burkina Faso, Rwanda, and Uganda) predicted that AIDS will not only reverse efforts to reduce poverty, but will increase the percentage of people living in extreme poverty from 45% in 2000 to 51% in 2015 (UNAIDS 2002b: 47).

The impact of HIV/AIDS on the victims' ability to work productively is one of the most widely recognised short and long term impacts. The majority of those infected are in the 15-49 age bracket (UNAIDS 2001b), which constitutes the productive labour force of the country. Their infection implies total or partial withdrawal of their labour input from the productive sectors.

In many developing countries, and Uganda in particular, most of the people with HIV/AIDS are the bread winners of their families. When they withdraw from active engagement in productive work, therefore, their families become dependant on handouts and external support if this is available.

In my study, 90% of TASO beneficiaries were living with HIV/AIDS. They all decried the impact of HIV/AIDS on their ability to work; and they all reported that one way of prolonging their life was to reduce the effort they put into work. Responding to the question: *In your*

opinion do you think your HIV status affects your ability to work? One of the respondents answered that;

Living with HIV/AIDS causes a lot of strain; I cannot predict my health status. One day I am feeling well and ready to work, the next day I am ill. In addition, there are many opportunistic diseases to which we are exposed; fevers and colds, diarrhoea and TB. Malaria is the notorious one and it attacks any time. But all these diseases are waiting for an opportunity to attack. To guard against them, I have to guard against anything that causes more body strain than is caused by HIV. Therefore, I have to do light work in order to live longer. (Interview with an HIV positive person)

The reduction in efforts put into work affects not only output, but also leads to low incomes, which increases dependency and poverty.

The fact that AIDS aggravates poverty is evident from the findings in various studies. For example, a study of 232 urban and 101 rural families that were affected by AIDS was carried out in Zambia by Namposya-Serpelle in 2000. Their findings revealed that the most significant effect of AIDS on these families was the rapid transition from relative wealth to relative poverty. The monthly income of more than two-thirds of these households fell by more than 80% (Whiteside 2002: 322).

The annual per capita income in half of the Sub-Saharan countries is estimated to be reduced by 0.5-1.2 % as a direct result of HIV/AIDS (UAC 2003: 2). Expenditure on HIV/AIDS treatment and prevention is very high. According to UNAIDS (2004: 9), “on average, AIDS care-related expenses can absorb one-third of a household's monthly income.” UNDP (2002a: 21) states that HIV/AIDS poses the most serious challenge to future success in reducing poverty in Uganda. The report maintains that HIV/AIDS has contributed to the low levels of human survival in Uganda. In addition, the report argues that the national human poverty index (HPI) declined from 39% in 1996 to 34% in 1998. However, between 1998 and 2000, an increase from 34% to 37.5% was registered. This increase in the proportion of the population considered to be deprived is due to the increase in the percentage of the population

not expected to survive to the age of 40; this is directly linked to the life expectancy and mortality levels in the population⁹².

Output and production are also affected when death strikes. In addition to the decline in the labour force due to deaths, the mourning period affects work and output. During the period when the dead person is accorded the last respects, work is suspended and virtually no productive activities take place, in spite of the fact that the existing food supplies are being depleted. As a result of HIV/AIDS-related deaths, households have reported spending up to 50% more on funerals than on medical care (Whiteside 2002). In Africa and Uganda in particular, the mourning ritual is a social event which requires that members of the community and close relatives stay at the home of the deceased for a minimum of 4 days. If the deceased is the head of the family, the ritual takes 7-10 days. The resultant expenses leave the bereaved family almost penniless and sometimes with no food, which compounds the problem of food security (see discussion in 4.5.4 below). In addition, in Uganda, some traditions require that the dead be buried at specific places (usually the ancestral grounds) irrespective of where the death occurs. The cost of transporting the dead body may be enormous, for example, in the case of people who die while employed as migrant workers. Sometimes, the sale of the deceased's property is necessary in order to raise money to transport the body home.

4.5.4 Impact on Food Security

The time spent caring for the sick, attending funerals and otherwise lost to productive labour has a profound effect on output and production in the agricultural sector. This threatens food security and sustainability. This problem is compounded by the increasing number of dependants, particularly orphans who are below the working age. As already noted, the number of orphans in Uganda below the age of 15 is over 1 million. This constitutes a challenge for production and output. Monico, Mukasa and Tanga (2001) suggest that the production of cash crops such as coffee in the Northern part of the country has declined due to the time spent caring for the sick. Kirumira(1993) argues that the rise in adult mortality rates will affect the ability of many households in Uganda to cope and or even survive.

⁹² UNAIDS, (2001b: 3) projected that by 2005-2010 the average life expectancy at birth in 11 countries worst hit by HIV/AIDS would be reduced to 44 years of age instead of increasing to 61.

The impact of these factors on food security is significant in many parts of the country. At present, many families are dependant on the food aid solicited from international donor agencies by NGOs such as TASO. TASO has established a social support programme that provides food aid to families that have a minimum of 5 members (interview with the project officer). In 2003, 1,452 registered clients received food aid at the Mbarara TASO centre. This food is estimated to have indirectly benefited some 5,808 people.

4.5.5 Social Exclusion and Stigma

As mentioned, stigma is a social construction. The importance of this section for the present discussion is how HIV/AIDS-related stigma affects HIV/AIDS prevention and control. Stigmatisation has a negative impact on social interaction, employment opportunities, emotional well-being and self-perception, resulting in withdrawal from social interaction (Fife and Wright 2000). According to the World Bank (2000a: 131), discriminatory practices create barriers to upward mobility, constraining people's ability to take advantage of economic opportunities, and benefit from and contribute to economic growth. Fife and Write (2000: 51) note that: "due to the reaction of others, as well as internalised self feelings, stigmatised person's life chances and opportunities are lessened, they are set apart from others, and they are considered to be inferior and represent a danger to society all of which lead to social rejection".

Social exclusion and stigmatisation remain major problems faced by people infected with HIV and as such pose a threat to social unity. UNAIDS (2001b) stresses that HIV/AIDS poses a threat to social stability through its impact on social unity. During the 1990s in many Ugandan communities, those with HIV/AIDS were regarded as social deviants who had acquired HIV/AIDS through immoral behaviour, because both cause and transmission were mistakenly associated with promiscuity and immoral sexual relationships, which are regarded as shameful acts (Monico, Tanga, and Nuwagaba 2001). Thus, the stigmatisation, rejection, suspicion, and isolation of persons with HIV/AIDS were common responses (Muyinda et al. 1997). In the 1990s, HIV/AIDS related stigmatisation and discrimination were serious problems in Uganda. Some findings have indicated that AIDS patients did not always receive support from their communities or even from family members (Garbus and Marseille 2003: 59).

A study conducted by the Ministry of Health in 1995 found that 53.5% of the respondents in the study felt that people infected with HIV/AIDS should not be allowed to work alongside those who were not infected (Monico, Tanga, and Nuwagaba 2001: 8-9). Self-exclusion was also an indicator of stigmatisation in the early period of HIV/AIDS in Uganda. Keough (2004: 17) points out that in the early days of the epidemic, being “slim” was enough to cause shame and withdrawal from family and community. In addition, stigmatisation and discrimination undermine prevention, care and treatment. When people are stigmatised, they hesitate to seek treatment for fear of further stigmatisation and discrimination. It has to be emphasised that these indicators of stigma characterised almost all parts of Uganda which were affected by HIV/AIDS – slim. As will be discussed in chapter 8, these conditions are changing with the increased involvement of various actors in HIV/AIDS activities.

4.6 Political Impacts of HIV/AIDS

Whether it is a matter of protecting the country’s borders, fighting internal wars and civil strife, strengthening the army or building a strong and political system, the issue of human security for the country’s population is central. Yet little research has been done to examine the relationship between HIV/AIDS and human security. This section discusses human security as a major political challenge of HIV/AIDS.

The politics of the nation depends on the stability of the economy, the army, and the population of the country. Therefore, in a situation where an epidemic such as AIDS affects all sectors of life, the political impact is clearly evident. One field, in which HIV/AIDS affects the stability of the country directly, is when its army dies. As earlier discussed, political response to the disease was intensified in Uganda when it was discovered that 18(30%) of 60 army officers who had been sent to train in Cuba were found to be HIV positive (Putzel 2003; Tumushabe 2005). This might have been a tip of the iceberg.

The second concern is related to the impact of HIV/AIDS on government expenditure. An increase in HIV/AIDS exerts pressure on the government through expenditures on HIV/AIDS-related research, treatment and prevention, and loss of personnel through HIV/AIDS-related deaths. As Barnett and Whiteside (2002: 298) summarily put it, “governments face special challenges from HIV/AIDS: greater calls on their resources and a disease that cuts away at financial and personnel capacity”. In the next section the focus will be on HIV/AIDS and human security as a critical political impact.

4.6.1 HIV/AIDS and Human Security

The issue of human security today goes beyond concerns about war and peace; it goes beyond the traditional security considerations of military threats, global order and peace. It involves a multitude of issues that threaten the well-being of humanity (UNDP 1994). Deaths resulting from poverty, malnutrition, malaria and HIV/AIDS, as well as from natural calamities such as earthquakes, hurricanes and the tsunamis, are all factors which threaten human life sustenance. In this context, HIV/AIDS has been recognised as one of the greatest challenges to human security.

Human security includes the impacts of HIV/AIDS which affect the sustainability of human well-being. The increasing levels of poverty resulting from HIV/AIDS, and the increasing stigmatisation and discrimination, threaten not only human life, but also the safety for people affected by HIV/AIDS. People affected by HIV/AIDS, particularly AIDS patients, are increasingly excluded from social and economic activities, or ostracised due to their HIV status. Similarly, AIDS orphans are neglected because of the fear that they may infect other children if they are taken in by their relatives.

The withdrawal of those with HIV/AIDS from social activities is one example that illustrates how HIV/AIDS threatens human security through stigmatisation and social discrimination (Alkire 2002; Caroline 2001; Leaning 2004). Stigmatisation and social discrimination are factors that promote the withdrawal of people from participation in social and community activities. This failure to identify with common group interests may create a limited feeling of community belongingness among the infected in the communities in which they live. These factors may contribute to early deaths and sometimes to suicide tendencies (Kausch 2004).

In terms of mortality trends, HIV/AIDS threatens the very existence of mankind. As mentioned, in 2002 alone, about 73,830 deaths are reported to have occurred in Uganda due to HIV/AIDS or related causes (UAC 2003). These figures are alarming and people live with a feeling of hopelessness, not knowing who will be the next victim or when they themselves may be infected.

4.7 Conclusion

The purpose of this chapter was to contextualise the problem of HIV/AIDS in Uganda. Placing Uganda in the wider context, and finally zeroing on Uganda, the chapter has discussed the factors that facilitate the spread of HIV and deepen the impact of the AIDS. This discussion provides an understanding of the background to the main impacts of HIV/AIDS. It also facilitates a deeper understanding of why different mitigation responses have evolved. In this chapter, I have discussed the relationship between gender, stigma, poverty and the spread of HIV. Furthermore, I have demonstrated that the impacts of HIV/AIDS cut across all sectors of life, including the political, economic and the social spheres. To address such impacts may require a multi-dimensional approach.

The discussion in this chapter highlights the importance of reviving the traditional social support system, which appears to be declining due to the increasing pressure of HIV/AIDS. The role of HIV/AIDS organisations in reviving the social support system, through strengthening the social networks at the family, community and individual levels, is further emphasised in the chapter. The discussions concerning the role of social relations at providing various benefits for individual and community members further indicates the need for social capital (see chapter 2) to mitigate HIV/AIDS in Uganda. The next chapter will consider the growing number of NGOs involved in HIV/AIDS activities in Uganda.

PART 2:

BUILDING SOCIAL CAPITAL

FOR

HIV/AIDS INTERVENTION IN UGANDA

CHAPTER 5

The Evolution of HIV/AIDS Focused Non-Governmental Organisations in Uganda

5.0. Introduction

The development of Non-Governmental Organisations engaged in fighting HIV/AIDS (HIV/AIDS NGOs) in Uganda was a response to the declining social support at the organisational and community levels and the increasingly market-oriented approaches to HIV/AIDS related problems. These approaches which were supported by international donors and implemented by the government, favoured individualised responses rather than social responses. This, combined with the pressure HIV/AIDS put on families, communities and government, led to a decline in the support offered to those infected with HIV/AIDS and those affected by the disease. NGOs emerged, therefore, to fill gaps left by family and government withdrawal from the task of providing for the poor and the vulnerable, such as AIDS orphans and AIDS patients. This chapter focuses on these NGOs and their growing interest in HIV/AIDS. Following a general discussion of the conceptual background of NGOs, the growth and development of HIV/AIDS NGOs is considered. The reasons for choosing The AIDS Support Organisation (TASO) and Post Test Club/Philly Lutaaya Initiative (PTC/PLI) as cases are also discussed, before examining these two NGOs in greater detail.

5.1 The Conceptual Background of NGOs

There is a lack of consensus regarding the concept of NGOs and views differ as to whether they should or should not be completely separated from government in terms of funding, governance and/or programme design. Definitions range from being taken as voluntary organisations (Hulme 1994; Jamil 1998), to being conceptualised as organisations which are outside the spheres of government, although they may be government funded (Tvedt 1998)⁹³. In general, these studies have conceptualised NGOs as organisations that are autonomous from government and are not engaged in activities motivated by profit⁹⁴.

The lack of consensus that characterises the conceptualisation of NGOs, also applies to their categorisation. The first categorisation system is on the basis of origin (Hulme 1994). In this

⁹³ A discussion on definitions and conceptualisation of NGOs is made elsewhere in Muriisa (2001).

⁹⁴ That NGOs close relationship with government does not always imply loss of autonomy (Tvedt 1998).

system, NGOs are either Northern (NNGOs), Southern (SNGOs) or indigenous. NNGOs are those which have their headquarters in developed countries; they may work directly with local communities or indirectly, funding local agencies in these countries. The Southern or indigenous NGOs are those whose formation was a result of local problems in developing countries, and at the initiative of local people in these countries. The SNGOs may operate at the national, regional, and community levels. Their funding is primarily from local sources, including membership contributions, but they may also receive funds in the form of grants and donations from NNGOs.

Within the SNGOs category, a further distinction may be made between community-based organisations (CBOs) and NGOs⁹⁵. Community-based organisations operate within specified boundaries, having been developed to serve these communities. In addition, CBOs are membership organisations. In contrast, NGOs are not bound by locality, and can operate at international, national, regional, local or community levels. They may be membership organisations, but the benefits from such organisations largely accrue to people who are not necessarily members. NGOs are largely service and advocacy organisations (Barr, Fafchamps, and Owens 2005). For the purposes of this study, NGOs are considered to include all non-profit initiatives, including grassroots associations and groups which are engaged in development work. These organisations are not part of the government, although they may receive government support to carry out their work effectively.

The second categorisation of NGOs is in terms of what they do, their level of operation, their organisational structures, their goals and the nature of their membership (Ball and Dunn 1995; Dicklitch 1998; Fisher 1997; Fowler 1997; Jamil 1998). NGOs are categorised as relief and welfare NGOs, advocacy NGOs, human rights NGOs, environmental NGOs and Non-governmental Development Organisations (NGDOs) (Fowler 1997). In contrast to the first categorisation, this conceptualisation does not include the origins of the NGOs and the sources of funding.

For the purpose of this thesis, I have categorised the NGOs involved in HIV/AIDS related activities in terms of what they do and their origin. In order to understand their impact on HIV/AIDS, I have focused on the organisations whose formation was precipitated by the HIV/AIDS situation in Uganda. These organisations receive funding from governments,

international organisations and the Ugandan business community. They depend on the voluntary participation of members/clients, whose main contribution takes the form of unpaid work for the organisations.

5.2. The Growth of NGOs

The growth of non-governmental organisations in Uganda can be traced back to the rise in global interest in the role of the non-governmental sector in the development process in the 1980s. The development of NGOs and their involvement in development at both international and national levels has been discussed elsewhere in *NGOs and Rural Development in Uganda* (Muriisa 2001: 34-39). Citing various scholars such as Tvedt (1998), and Riddell and Robinson (1995), the study reveals that, until the 1970s, the development work of NGOs was granted little recognition and NGOs were considered marginal actors in the development process (Muriisa 2001). However, this changed in the 1980s and 1990s when NGOs began to be viewed as channels through which international aid could reach the poor in the south. Citing *Organisation for Economic Cooperation and Development (OECD)*, the study points out that in 1991 about \$6 billion was channelled through NGOs into developing countries by development agencies. These transfers increased by 5% to \$6.3 billion in 1993 (Muriisa 2001: 5).

In Uganda, only 18 NGOs were registered at independence⁹⁶, but by 1980 the sector had expanded to include 51 registered NGOs and by 1986 the number had doubled to 106. In the 1990s, the number of NGOs increased even more rapidly to about 3, 471 (Riddell, Gariyo, and Mwesigye 1998). Because of poor monitoring and evaluation procedures, there are also many unregistered NGOs working in different fields in Uganda (Gariyo 1996). In the following discussion the rapid growth of the NGO sector will be outlined. The objective is to contextualise the development of NGOs working with HIV/AIDS, particularly in Uganda.

According to Korten, NGOs have evolved through three stages (Korten 1990; 1987). The first generation NGOs were primarily concerned with relief and welfare. These were the organisations which developed in the 1940s in the aftermath of the great wars to address the war damage. The second generation NGOs, which undertook small-scale local development projects appeared in the 1960s and continued through the 1970s and 80s. Their focus was on

⁹⁵ A more detailed discussion of the distinction between CBOs and NGOs has been provided in Muriisa (2001).

⁹⁶ Uganda became independent in 1962.

self-reliant local development, and they often sponsored small-scale community improvement projects. In this period they concentrated on raising the income levels and reducing poverty by developing credit facilities, increasing crop production and improving rural infrastructure.

The number, the scope and the scale of second-generation NGOs have expanded rapidly. In the 1960s and 1970s, there was only a small number of NGOs involved in development work, especially relief. The 1980s saw an explosion in the number of NGOs, and in the variety of activities, including community, regional, national and international initiatives. Tvedt (1998) has named this period the NGO decade.

The third generation of NGOs included community organisations that were interested in establishing partnerships and coalitions with the overall objective of influencing decision making processes. These organisations emerged in the 1980s to address issues of governance and new development concerns such as environmental degradation; and to target institutional constraints that hinder development and self help. They focus on creating awareness through mass campaigns, and have become channels through which development NNGOs fund local initiatives. It is in this category that the NGOs concerned with HIV/AIDS belong.

5.2.1 The Growth of HIV/AIDS NGOs Global Trend

The development of HIV/AIDS NGOs in Uganda followed a pattern that can also be observed globally. HIV/AIDS organisations emerged as a distinct group as a result of a grass-roots need: people infected with HIV and AIDS patients felt a pressing need to respond to the exclusionary practices society had adopted. In the USA, the Gay Men's Health Crisis (GMHC) was the first response to the needs of those infected with HIV. In order to respond to the special needs of various groups living with HIV/AIDS, other organizations such as women with HIV/AIDS were established (Small 1997: 19). The initial focus of HIV/AIDS NGOs was on counteracting the problem of exclusion and helping HIV/AIDS patients to sustain their lives. People with HIV/AIDS found themselves rejected by society and this motivated them to find others with whom they could identify.

Thus, the HIV/AIDS organisations were founded on the basis of solidarity, and had as their overall objective, how to cope with the various HIV/AIDS-related problems which their members were facing. As Uehara (1990) stresses, a sense of identity and solidarity often

finds expression in formal and informal support in times of stress and danger. In Uganda, the founding of TASO was an expression on the part of people affected by HIV/AIDS of the need to find support and identity. Thus, “the founding of The AIDS Support Organisation (TASO) was based on people that were unified by common experiences faced when encountering HIV/AIDS at a time of high stigma, ignorance and discrimination”⁹⁷.

The founding of organised self-help groups to take care of the sick has moved HIV/AIDS out of the medical and biological realms and put it into the social realms, and highlighted the social aspect of the disease. In his study, Small (1997) points out that, beyond the medical interventions, the social responses of care and support bring to light the sociological implications of HIV/AIDS. In Africa, many organisations were formed in both southern and eastern regions, which were the most seriously affected. It is thanks to the initiatives of people with HIV/AIDS and the publicity attracted by their plight that the sociological impacts of the disease, such as discrimination and lack of support by family members and the community, were made public and started appearing on government agendas. These organisations were soon recognised by international organisations such as the World Health Organisation (WHO).

The recognition and the legitimisation of the non-governmental sector in HIV-related activities first came in the late 1980s with the establishment of the World Health Organisation Global Programme on AIDS (GPA). The GPA facilitated the establishment of international networks dealing with AIDS, including Global Network of People Living with AIDS (GNP plus) and International Council of AIDS Service Organisations (ICASO) (Altman 1999: 566). These organisations became linked to existing local and national organisations that were dealing with HIV/AIDS in various countries. HIV/AIDS NGOs soon gained recognition both as contributors to international policy decisions concerning HIV/AIDS (Mohga 2002)⁹⁸ and as implementers of policy programmes (UNAIDS 2002b). At present, the HIV/AIDS NGOs sector is large and is recognised by donors as the champions of success. In Uganda, and other parts of Sub-Saharan Africa, NGOs such as TASO are considered to be effective in managing HIV/AIDS (O'Manique 2004; Webb 2004). Indeed, Webb (2004: 23) notes that,

⁹⁷ <http://www.tasouganda.org/index.php> 05/11/04

⁹⁸ http://www.oxfam.org/en/files/pp0206_false_hope_or_new_start.pdf,
http://www.oxfam.org/eng/policy_pape.htm 10/10/03

The critical role played by mission hospitals in galvanising this response is recognised (such as the Salvation Army hospital in Chikankata in southern Zambia), but it was not until the establishment and formal recognition of secular AIDS focused NGOs, led by TASO in Uganda from 1986, that the potential and relevant NGO response was evident. The crucial ability of NGOs to mobilise communities and foster interpersonal dialogue is gaining recognition in epidemiological analysis.

There are now new (second-generation) organisations being formed, based not on social exclusion and isolation as first-generation organisations were, but on the needs and problems of particular groups and society in general. Cases in point are the involvement of CBOs and other small local initiatives in the implementation of HIV/AIDS programmes funded by Global Fund to Fight Tuberculosis, Malaria and HIV/AIDS (see 7.5.1). This general trend is exemplified in the following discussion of the rise of NGOs in Uganda.

5.3 The Growth of HIV/AIDS NGOs in Uganda

5.3.1. An Overview of the Organisations Working with HIV/AIDS in Uganda

In 2003, there were estimated to be over 2,500 NGOs and CBOs working only with HIV/AIDS, and the numbers are continually increasing. However, there are varying reports as to how many NGOs there are working in this field, which makes it almost impossible to establish the correct number. Already in 1997, the Uganda AIDS Commission (UAC) had registered more than 1,020 agencies, mostly NGOs working with various aspects of HIV/AIDS (UNDP 2002a). UNAIDS (2000: 10) reports that 1,050 NGOs and Community based organisations are working in the AIDS field. Oketcho et al (2001: 10) identified 546 NGOs, including 156 community based organisations (CBOs), 9 United Nations Agencies, 86 international NGOs, 115 Faith Based organisations, 123 National NGOs, and 57 Local NGOs working in HIV/AIDS related activities. Coutinho, cited in Garbus and Marseille (2003), noted that there were about 2,500 NGOs involved in HIV/AIDS work in Uganda.

These reports include not only the number of NGOs, but also the varied nature of the organisations. They include international, national, local and CBOs HIV/AIDS NGOs, and have been categorised in various ways by different scholars. An overview of this categorisation will help to locate HIV/AIDS NGOs in the mainstream discussion about NGOs.

From the discussion in the preceding section, some categorisations of NGOs have been clearly identified; for example, NGOs can be categorised as local, national or international. Another categorisation which is useful is based on time and the activities of NGOs. In this respect HIV/AIDS NGOs can be divided into two groups⁹⁹.

(a) First-generation HIV/AIDS NGOs. These were the primary organisations formed to provide support and care for AIDS patients, people infected with HIV and their relatives. An example is TASO. In addition, there are those organisations which were developed to undertake research and investigation of HIV/AIDS; for example, AIDS Information Centre (AIC¹⁰⁰).

(b) Second-generation HIV/AIDS NGOs. These organisations were created later and their activities extended beyond welfare provision. These organisations are largely involved in advocacy and sensitisation of the public to the dangers of HIV/AIDS. They target specific groups of people in society affected by HIV/AIDS. For example, NACWOLA was found to address problems such as widow inheritance, property grabbing and violence against women. Also included in this category are other organisations such as Faith Based Organisations (FBOs) which took up HIV/AIDS work as a secondary activity, in addition to their primary activities – missionary work.

There is no clear-cut boundary between the activities of first-generation and second-generation NGOs. In general, HIV/AIDS NGOs provide a range of services including care and support, advocacy and policy shaping, and community sensitisation and education campaigns related to HIV/AIDS transmission and prevention. The organisations operate at different levels and include:

- National NGOs with branches in various districts; for example TASO, PTC/PLI, NACWOLA and AIC;
- District or regional based organisations, and faith based organisations (FBOs);
- Community-based organisations that emerged within specific community boundaries in order to address problems faced by that community due to HIV/AIDS; for example, the increase in funeral requirements has resulted in a number of small village organisations

⁹⁹ This is only meant for analysis. The divide cannot be clearly seen in empirical world. Moreover, some of the activities of first and second generation organisations overlap.

¹⁰⁰ AIC is the mother organisation of the PTC/PLI

formed to help one another during the mourning period.

- International NGOs, including Action AID, Oxfam and Save the Children, and
- Networks (Umbrella organisations) such as, Uganda National Association of AIDS Organisations (UNASO).

Having established the number and type of NGOs working in Uganda, it is interesting to explore the factors that facilitated their growth.

5.3.2 Factors Explaining the Growth of HIV/AIDS NGOs in Uganda

As mentioned, the growth of HIV/AIDS NGOs was a response to the declining welfare of people affected by HIV/AIDS, and to the need for those affected to identify with each other. This is in accordance with Katz and Bender's (1976) suggestion (cited in Putnam, 2000: 151) that the emergence of self-help groups can be viewed as a means through which isolated people can develop new identities¹⁰¹ and address specific problems which they face .

Apart from the need to create identity, the growth of these HIV/AIDS organizations can be explained by several other related factors associated with the general political economy and social conditions. As discussed in chapter 4, the colonial and neo-colonial political economy of Uganda had created a system in which women became economically marginalised and dependant on men. In the 1980s, the political economy was dominated by a move towards state rollback from the provision of public services (Dicklitch 1998). There was break down in major infrastructure; roads, hospitals, schools and all other service sectors in the country. The poor and the needy are left to fend for themselves in terms of access to social services within an increasingly market-oriented economy.

Socially, HIV/AIDS disrupted the social fabric and the social cohesion which had existed before AIDS (Orla 2004) due to the increased burden of orphans, the fear of contracting HIV from the infected and the lack of general social support. HIV/AIDS NGOs emerged as new social support providers to fill this gap. In addition, there was a growing global trend in the international donor community to recognise the "failure" of governments in developing countries and the need to support the non-governmental sector in implementing development

¹⁰¹ see also Uehara (1990)

programmes. These three factors contributed to the development of the HIV/AIDS NGO sector in Uganda. I will examine each factor in turn.

Declining Family Support for People Affected by HIV/AIDS

The emergency of TASO and other organisations such as National Community Organisation of Women Living with AIDS (NACWOLA) was a direct response to the global trend described above. These organisations were interested in addressing the challenges which people affected by HIV/AIDS were facing.

In chapter 1 and 4, it was stressed that the emergence of HIV/AIDS put a lot of pressure (in terms of orphans and other HIV/AIDS-related problems such as stigma and poverty) on the victims' families, which had previously provided economic, social and psychosocial support to its members. Since the family was unable to cope with this pressure, organised social groups began to replace families.

AIDS came with a strong divisive force. It threatened social unity and increased suspicion, mistrust and discrimination against people with HIV/AIDS in the workplace, the community and, above all, in the home. In response, people with HIV/AIDS began to meet and form groups that could replace the lost care and support from the community and families. Orla (2004) echoes Nanyondo Christine of World Vision in stating that "AIDS has broken all the social norms. The weekly meetings of women are a kind of 'interpersonal psychotherapy group'. In practice, it resembles community support and friendship, the kind of network which has been destroyed by the HIV/AIDS pandemic."

At the individual level, HIV/AIDS led to withdrawal of social support. The sick were neglected because of stigma and blame, or because there was no one to take care of them (O'Manique 2004: 159). Orla (2004) notes that "Before, there were relatives, they could give you suggestions. Relatives have died, even the neighbour you run into, he is depressed... AIDS has broken all the social norms."

At the community level, assistance commonly provided by members of the community in caring of the sick and taking them to hospital, has now been left to individual efforts; there has been a decline in collective behaviour and responsibility vis-à-vis those infected with

HIV/AIDS. Contributions to and membership in the local voluntary “ambulance”¹⁰² group are almost non-existent. This is partly due to the increased monetization of services and partly due to the reduction in the number of able-bodied men and women available to carry the sick to the hospital. In addition, there are new social pressures on widows, who are considered to have brought AIDS into the family; their property is often grabbed by relatives, and they are not always given the support traditionally provided by the family and community. This decline in the social support offered to the sick and the needy can be explained by two HIV/AIDS-related factors:

- Conflicting views regarding the cause and means of transmission of HIV/AIDS. Most people believed that HIV is transmitted through socialising, sharing food and even shaking hands. This led to a withdrawal of social/community engagement in supporting and caring for the sick. New organisations and social groups emerged to replace community support.
- The perceived link between promiscuity and HIV/AIDS. This led to the decline of social unity due to the withdrawal of those infected from social activities and the community because of stigmatisation. It also led to social segregation of the sick due to the misguided belief that HIV victims are promiscuous, which is considered socially deviant behaviour (Monico, Tanga, and Nuwagaba 2001). Given this situation, groups formed, mainly made up of people with HIV/AIDS or who had lost their spouses and loved ones to the disease, to cope with the HIV/AIDS-related problems which they were facing.

Other types of organisations have since been formed to take the fight against HIV/AIDS beyond the personal level; to shift the focus from those who are directly affected by HIV/AIDS to others who need support. For example, the PTC was formed, not on the basis of social exclusivity, but to provide support services such as counselling to all those who have been tested for HIV, irrespective of their test results.

It should be noted that, the government of Uganda acknowledges the importance of these organisations in the fight against HIV/AIDS. The state is funding or mobilising funding for

¹⁰² The ambulance is a stretcher which is used to carry the sick to the hospital. Four people carry the patient at a time others in the group relieving them in turn.

some HIV/AIDS activities to supplement those being carried out by NGOs. However, such funding is still very small (TASO 2002a).

Inadequate Provision of Health and Related Services by the Government

In Uganda, HIV/AIDS NGOs emerged in the late 1980s following the realisation that HIV/AIDS was no longer just a medical problem but a social one as well. The care and support required by those infected with HIV/AIDS led to the realization that HIV/AIDS has multiple faces; the sociological face had gone unattended while the medical or biological face was already being attended to by medical interventions and biological research. In addition, pressure from the international donors for governments to cut down public expenditure meant that the government committed fewer resources to the health sector in general, and to the HIV/AIDS sector in particular.

Reduced public spending can be linked to the adoption of neoliberal economic policies, under which market forces increased, compelling the state to reduce expenditure in the service sector. As discussed in chapter 4, the impact of these policies on health and social services was enormous, and it is closely linked to the emergence of NGOs in the HIV/AIDS sector.

In 2000, Uganda's public expenditure in health was 1.5% of Gross Domestic Product (GDP), while private health expenditure was 2.4% of GDP (Garbus and Marseille 2003: 8). According to the Ministry of Health (MOH), *Health Policy Statement 2001/2002*, the per capita expenditure on health in Uganda is only US\$ 9-10; it should be US\$ 19. The total government funding to the Ministry of Health covers half of the ideal budget. The government allocates a small percentage of this to organisations running complementary HIV/AIDS programmes; for example, the Ministry of Health funds only 3% of TASO's annual budget. This allocation only meets less than 30% of the requirements of people infected with HIV/AIDS who are supported by TASO (TASO 2002a: 17 - 18); the rest is mobilised from external sources such as international donors and the business community within and outside the country.

Because of low public expenditure in health sector, the market is taking the lead in providing health-care services, and as a result, even the poor are left to privately finance their health care. Tables 5.1 and 5.2 below summarize government expenditures in the major sectors between 1990 and 2005.

Table 5. 1: Percentage of Total Government Expenditure by Ministries (1990/91-1994/95)

Ministry	1990/1991 (%E)	1991/1992 (%E)	1992/1993 (%E)	1993/1994 (%E)	1994/1995 (%E)	Average of total budget (%)
Finance and econ. Planning	11.3	32.7	42.2	9.1	20	23
Defence	29.1	18.5	15.6	22.8	17.4	20.7
Education and sports.	2.2.	13.1	10.3	11.1	7.2	8.7
Foreign affairs	6.1	4.3	4.2	3.2	3.6	4.3
Health	4.3	3.4	3.2	4.2	2.5	3.5
Works Transport and com.	2.4	2.1	1.9	3.4	1.9	2.3
Agriculture animal industry and fisheries	2.7	2.0	1.7	1.5	1.5	1.9
Public service	1.8	1.0	0.5	2.3	1.8	1.5
Justice and constitutional. Affairs.	1.0	0.6	0.4	2.3	2.7	1.4
Lands, housing and urban development.	1.8	0.8	0.4	0.9	1.2	1
Labour and social welfare	1.4	0.7	0.4	1.2	0.6	0.9
Trade and industry	0.7	0.5	0.4	0.5	0.4	0.5
Information	0.4	0.3	0.2	0.2	0.3	0.3

Source: Ministry of finance and economic planning (budget reports) as cited in Muriisa (2001: 53).

Table 5. 2: Percentage of Total Government Expenditure by Ministries (1998/99-2004/05)

Years	1998/99	1999/00	2000/01	2001/02	2002/03	2003/04	2004/05
Sector (Ministry)	Actual (%)	Budget estimates (%) **	Budget Projections (%)*				
Education	26.9	26.3	24.9	24.4	23.3	23.0	24.4
Public Administration	20.7	20.3	20.2	19.2	17.4	15.9	16.0
Security	19.9	15.4	13.9	12.7	14.1	14.4	13.4
Health	6.5	6.5	7.4	8.7	9.0	9.5	11.0
Interest Payments Due	7.1	7.7	8.5	8.1	8.6	9.9	7.9
Economic Functions and Social Services	2.7	4.6	5.0	6.4	7.2	7.4	7.8
Roads and Works	6.2	8.1	8.5	8.1	7.3	7.3	7.2
Law and Order	7.2	7.3	6.5	6.3	6.9	6.5	6.5
Water	1.2	1.5	2.4	2.6	2.9	2.7	2.4
Agriculture	1.0	1.5	1.5	2.2	2.3	2.1	2.1
Accountability	0.6	0.8	1.1	1.2	1.2	1.3	1.3

Source: MFPED (2002: 24), * Source: MFPED ((MFPED 2002), ** Source: MFPED (2004), (<http://www.finance.go.ug/econtrends.htm> / 26/11/04)

Comparing the data presented in Tables 5.1 and 5.2, it is evident that, apart from increased expenditures in education between 1990 and 2000, public administration and defence continue to account for a large percentage of the government budget. Table 5.1 illustrates that

between 1990 and 1995 government expenditure on welfare services such as health, education, pensions and retirement benefits was extremely low compared to defence and finance, and planning and economic development.

According to O'Manique (2004: 139), in 1992 “the public sector [in Uganda] contributed approximately \$2 per capita per annum to health, the lowest in the region”. Compared to public administration and security, expenditure on health remained relatively low in later years, as the 1998-2005 budget estimates reveal (table 5.2).

Not only is the public expenditure on health in general low; public expenditure on HIV/AIDS is also limited. Most expenditure comes from donors, the rest is privately funded. Table 5.3 below analyses the nature of HIV/AIDS-related expenditure and the sources of funding.

Table 5. 3 Funding of HIV/AIDS Programmes (Uganda Shillings in Millions¹⁰³)

<i>Programmes/Project</i>	<i>2000/2001</i>		<i>%</i>	<i>2001/2002</i>		<i>%</i>
	<i>Donors</i>	<i>GOU</i>	<i>Donors</i>	<i>Donors</i>	<i>GOU</i>	<i>Donors</i>
<i>UAC Secretariat</i>	-	108.5	-	-	280	-
<i>Uganda AIDS Control Project</i>	-	-	-	10640	800	93.0
<i>ACP /Survey/Research</i>	2375	-	100.0	-	-	-
<i>HIV/AIDS and Right to self protection</i>	2546	-	100.0	-	207.9	-
<i>Strategies for HIV/AIDS and Girl Education</i>	-	-	-	-	420	-
<i>Decentralised HIV Testing and Counselling</i>	3040	525	85.3	5700	-	100.0
<i>Sexually Transmitted infections</i>	-	-	-	8170	1000	89.1
<i>AIDS Palliative Care Project</i>	1026	-	100.0	76	-	100.0
<i>Support to TASO</i>	1653	-	100.0	2432	-	100.0
<i>Total</i>	10640	633.5	94.4	27018	2707.9	90.9

Source: Adapted from MFPED, *Development and Expenditure, 2000/1 and 2001/2, as cited in Tumushabe (2005: 12)*¹⁰⁴

According to this table, the government contributed only 5.6% of the total budget to HIV/AIDS in the 2000/2001 fiscal year, and this was granted to the Uganda AIDS commission secretariat and decentralised HIV/AIDS testing. However, the plans for a decentralised HIV testing and counselling programmes were abandoned and never implemented (interview with the District Director of Health Services and the manager AIDS information Centre Mbarara), so government in this sector was reduced still further by the failure to implement this programme. It can also be asserted that the government expenditure in this period was only on administration and not directly on activities that affect people living with HIV/AIDS.

¹⁰³ The exchange rate stood at around 1500 Ugandan Shillings for one US\$ in 2001.

¹⁰⁴ Cited with Permission from United Nations Institute for Social Development (UNRISD)

In the 2001/2002 fiscal year, the government contributed only 9.1% of the total HIV/AIDS budget, the remaining 90.9% was contributed by donors. The principle source of funds is the UNAIDS Global fund to fight tuberculosis and malaria (discussion in 7.5). Research funding is also provided by other donors; for example, the Bill and Melinda Gates Foundation is funding various research projects in collaboration with Ministry of Health and Makerere University. Another source of funds is the USA Presidential Emergency Plan for AIDS Relief (PEPFAR). It should be noted that most of the donor funding is channelled through the government to NGOs- the implementing agencies for HIV/AIDS activities.

Government support is limited not only in terms of financing major HIV/AIDS activities and health care, but also fails to recruit sufficient technical and professional health personnel. According to the Ministry of Health *Annual Sector Performance report (2001: 66)*, the health sector is not adequately staffed. There is a shortage of health personnel with the required skills, and those who have the necessary skills do not want to work in the rural areas (see also O'Manique (2004: 146). In addition, the limited public expenditure in health also has implications for the wages paid to health-sector employees. Staff wages are low compared to what would be paid elsewhere in the private sector and abroad, and the wages are not usually paid on time. It is not surprising, therefore, that the sector cannot attract qualified personnel. Most of qualified people have abandoned their professional positions in Uganda and are now working in developed countries that can offer better pay. According to an article entitled "Africa's Health Shortage" in the *International Herald Tribune (July 27/2006)*, the shortage of qualified medical personnel throughout Africa is limiting effective HIV/AIDS control. The gaps left are being filled by NGOs that train volunteers to provide care and support in family and community settings.

In addition to the lack of qualified personnel, there is a limited supply of drugs in the health care units. O'Manique maintains that poor health policy implementation is due to the inadequacy of government infrastructure. For example, the deliveries of drugs often fail to reach their destination or, if they do so, they are sold by the poorly paid health workers to private sector buyers. She argues that corruption in the public health care system is a systematic problem which limits the implementation of health policy (O'Manique 2004: 146).

It has to be noted however, that the conditions stated above also have their foundation in the poor and dilapidated economy inherited from the previous regimes. As mentioned, in chapter

4, when National Resistance Movement (NRM) government took over power in 1986, the economy was in poor state. The government has since been undertaking rehabilitation of the main infrastructure including health. Currently there is a programme going on to provide a health facility with a medical doctor at every sub-county in the country. And the NGOs continue to rely on government facilities for some of their operations (see 6.5).

In spite of the above rehabilitation drive, the effect of the poor facilitated welfare system on the organisation drive by the people is recognisable. Faced with little state support and exclusion from the employment sector and the community, people with HIV/AIDS formed organisations, primarily as safety nets and sources of livelihood. Less expenditure on social and welfare services implies that many of the social welfare activities must be privately funded by individuals. The majority of Ugandans are poor; over 80% live on less than one United States dollar a day (O'Manique 2004). This means that people cannot afford private health-care services. Much of the welfare sector, therefore, and particularly the health sector, is increasingly dominated by NGOs.

Provision of a Supportive Environment for the Formation of NGOs

In spite of the shortfall in the government's response to directly fund HIV/AIDS activities, there is a positive contribution of the government for the formation of these organisations. Thus, the rise of NGOs in Uganda was a result of the support provided by the government. In other Sub-Saharan African countries, for example South Africa, tension has arisen between HIV/AIDS NGOs and the governments. In contrast, HIV/AIDS NGOs in Uganda have enjoyed a favourable environment that has encouraged their growth and participation (see 6.5 and 7.8.2). This environment has three key features operating on national, international and local levels: an active and positive political leadership; access to international funding for NGO activities; and civil society engagement in various HIV/AIDS activities. It must be stressed that the government of Uganda was active in facilitating the establishment and growth of HIV/AIDS NGOs, as is discussed in greater detail elsewhere in this thesis (see, for example, 7.1, 7.2 and 7.4). Basically, government recognition of the role of NGOs in the fight against HIV/AIDS and provision of the necessary support has made them legitimate actors (Webb, 2004).

The Role of the International Donor Community:

International donor support is another element that facilitated the development of HIV/AIDS organisations. With minimal or failing state responsibility for HIV/AIDS programmes, the HIV/AIDS NGOs have gained prominence and recognition in the international donor community, which increasingly channelled development aid through them (Webb 2004). The development of HIV/AIDS NGOs is related to the general international donor requirement that the south implement the new policy agenda¹⁰⁵, a trend that started in the 1980s. NGOs were to be the new implementing agencies, and the donor community redirected their support through these. International donors such as the World Bank and Oxfam therefore, have considered NGOs as viable options for making their HIV/AIDS funding more effective. The formation of HIV/AIDS NGOs was partly due to this consideration.

The Multi-Country AIDS Programme for Africa explicitly aims to use non-governmental organizations (NGOs) as implementing partners for approximately 50% of the funding provided. The role of NGOs in advocacy, programme design, implementation and provision of services at community level is well documented (UNAIDS 2002b: 178). In 2002, a global fund was established to mobilise and raise money from countries, individuals and other donors to fight AIDS, Tuberculosis, and Malaria. These funds are granted to countries, but only if they fulfil certain requirements. The “Global Fund” requires that countries establish Country Coordination Mechanisms (CCMs)¹⁰⁶ that is made up of diverse groups including government and civic organisations. All applications for funding must pass through the national CCM. Before any application is approved for funding, it should be assessed with regard to whether it involves civic organisations and whether there is an NGO-government partnership in the fight against HIV/AIDS. According to Mohga (2002), NGOs should contribute to the global decision-making process on AIDS. He also argues that CCMs should give a strong voice to NGOs in decision-making, programming, implementation, monitoring, and evaluation. These arguments are in line with the neoliberal requirement of involving the private sector in programmes implementation (O'Manique 2004).

¹⁰⁵ Governance, Accountability and Transparency (Hulme and Edwards 1997, Muriisa 2001, Muriisa 2005)

¹⁰⁶The fund requires that organisations intending to utilise the funds make applications in which they describe their programmes. The CCMs role is to help organise applications and to monitor the implementation of programmes in which the funds are utilised. The CCM is composed of representatives from government agencies, NGOs, CBOs and FBOs, individuals working in the field and private sector institutions (<http://www.avert.org/global-fund.htm> 15/05/06)

The role of the state is to provide support and strengthen private initiatives from communities and families. With the involvement of the private sector, health services became monetised, which alienated the poor who could not afford to pay for the services. NGOs acted as alternative health care providers, especially for those with HIV/AIDS.

The funding allocated to Uganda by the Global Fund to Fight Malaria and TB to develop Community HIV/AIDS initiative (CHAI) is passed through the UAC, but the programmes is coordinated by the local governments (Asingwire et al. 2003a: 24). The programme requires that the implementing agencies provide:

- (a) Participatory activities involving HIV/AIDS victims,
- (b) Community-based information, education and communication (IEC) initiatives,
- (c) Education of orphaned children.

These requirements have their foundation in the World Health Organisation's strategy, which stresses training and "empowerment" of local communities. This was spelt out in 1993 in the AIDS assessment and planning study of Tanzania (O'Manique 1996: 6).

These requirements have led to the establishment of groups at the local and community levels. There has been a dramatic growth in this category of HIV/AIDS organizations, which cuts across gender, class and social units, as well as the HIV-positive - HIV-negative divide¹⁰⁷. It is believed that these small local initiatives are likely to have a greater impact on HIV/AIDS than other types of initiative (Barnett and Whiteside 2002).

The international donor community also includes international bodies, such as various UN organisations, which have facilitated the formation of many organisations that have continued to support people with HIV/AIDS (PWHAs). For example, United Nations International Children's Education Fund (UNICEF) played an important role in the establishment of the Philly Lutaaya Initiative (PLI). The United State Agency for International development (USAID) and Agricultural Cooperative Development International/Volunteers Overseas Cooperative Assistance (ACD/VOCA), is sponsoring the nutrition programme for HIV/AIDS patients through TASO.

¹⁰⁷ See discussion in 7.5.1 for the number and formation of community based organisations responding to CHAI programmes

5.4. The Selection of Case Studies

The preceding discussion provides an overview of the HIV/AIDS NGO milieu in Uganda, and has indicated that there are a large number of HIV/AIDS NGOs in Uganda (see 5.2.2 above). This poses a selection problem for anyone wishing to carry out a study of the roles and impact of the NGOs. The selection of cases for the present study followed purposive sampling procedures typical of the case study strategy (Creswell 1998: 62). It should be emphasised that the cases were selected because of their uniqueness in terms of the theoretical relevance and their activities, and not on the basis of their representativeness in terms of the general population of either NGOs or people living with HIV/AIDS in Uganda¹⁰⁸. The selection process was guided by the theoretical debates developed in chapter 2 and the methodological considerations discussed in section 3.2, such as time, resources and access to data.

Before selecting the cases, I contacted several NGOs through the electronic mail system and telephone calls. I used the internet to obtain an overview of the operations and activities of different organisations. Following these preliminary initiatives, I received a positive response from two organisations: The Aids Support Organisation (TASO) and Post Test Club/Philly Lutaaya Initiative (PTC/PLI). It was considered advantageous that these NGOs were involved in different activities, which focused on groups, communities and individuals, compared to other organisations, which focused on individual responses as the case of faith based organisations and religious fundamentalism (see for example 7.4.1). The selection was based on several criteria.

In the first instance, the criterion for selection was that the selected NGOs should be engaged in activities that bring their members together on a regular basis. Many organisations have stressed the provision of welfare or other service to individual clients and beneficiaries without focusing on building structures that encourage regular interactions among group members. This characteristic was central in the selection of the type of organisation to be studied. The theoretical questions asked in the selection process were: How are the activities of organisations organised? What is the level of involvement of members/clients in the activities of the organisations? What is the composition of the membership – does membership cut across social groups or is it exclusive?

¹⁰⁸ See discussion on generalisation in 3.6

The second concern was that the selected NGOs should be working directly with those suffering from HIV/AIDS. Many of the organisations that are involved in HIV/AIDS activities do not work with this group, for example, organisations involved in sensitising the youth. Such organisations target a specific group they consider to be vulnerable to HIV/AIDS but do not work directly with those who actually have HIV/AIDS.

A number of other factors were also taken into consideration: (i) Years of operation: The number of years an organisations had been providing services in the selected area was important, in order to determine the extent of the impact they may have made. As mentioned, TASO has been operating in Mbarara since 1991 – at a time when HIV prevalence of the district was at its peak; (ii) Area of operation: This factor had an impact on accessibility, both to the area and data (see 3.2 for a discussion of the criteria for choosing a study area); and (iii) Indigenous in origin: Indigenous NGOs are those that are established within the country of their operation. Their formation is often precipitated by conditions within a particular country. Indigenous HIV/AIDS NGOs were formed as a result of the poverty, stigmatization, and cultural practices to which their founders were subjected. As earlier mentioned the founding of both TASO and PTC/PLI was precipitated by the conditions in the local environment.

5.4.1 Why Only Two Cases?

The answer to this question is to be found in the general methodological perspective of comparative research. The comparative study focuses first and foremost on what is being compared. In this respect, this study compares two organisations (TASO and PTC/PLI). These two organisations are distinct in terms of their membership (see table 5.4), but have a similar focus. The two cases are also different in terms of their structure, composition, and targets. TASO targets people infected with HIV, AIDS patients and others who are closely linked to victims of AIDS, such as orphans¹⁰⁹. In contrast, PTC/PLI targets everyone affected by HIV/AIDS, provided they have taken an HIV test.

By studying the group composition of two different organisations that have a similar focus, it should help us to understand the effect of social capital on the impacts of HIV/AIDS. Methodologically, the goal of the study was to explore the role of NGOs in dealing with the

¹⁰⁹ An AIDS orphan will be defined as an orphan whose parents died due to some HIV/AIDS-related cause.

impacts of HIV/AIDS. In order to understand the extent to which NGOs fulfil this role, therefore, it is important to compare two organisations and their approaches. This makes it possible to determine whether success depends on the structure of the organisation. Table 5.4 outlines the differences between TASO and PTC/PLI.

Table 5. 4 Similarities and Differences between TASO and PTC/PLI

A: Differences: TASO	PTC/PLI
Targets people who have tested positive for HIV, AIDS patients and their close relatives	Targets those who have been tested for HIV, irrespective of the status.
The philosophy of TASO stresses openness and disclosure of one's status	PTC/PLI philosophy is non-disclosure of one's status
Life-long membership and beneficiary; provides care and support to those living and not living with HIV/AIDS; community based approaches	Fixed term of two years for members or clients to benefit from the services
B. Similarities: TASO	PTC/PLI
Focus on addressing the ills of society such as poverty, gender imbalance, and cultural practices, as part of a control and prevention programmes	Focus on addressing the ills of society such as poverty, gender imbalance, and cultural practices, as part of a control and prevention programmes
Indigenous	Indigenous
Community sensitisation through drama	Community sensitisation through drama
Focus on strengthening social relations through regular face-to-face interaction of members	Focus on strengthening social relations through regular face-to-face interaction of members
Educational talks and role playing	Educational talks and role playing

5.5. The History of TASO in Uganda

The AIDS Support Organisation (TASO) was founded in 1987 as a response to numerous problems such as stigmatization and social exclusion, which people with HIV/AIDS were facing (TASO 2002a: 1)¹¹⁰. This vulnerable group needed to provide support for one another. The organisation grew out of the small gatherings of individuals affected by HIV/AIDS who were seeking solutions to the problems they were facing; in particular, they were facing discrimination in the workplace and neglect in the home. These meetings took place in the offices and homes of individuals who had lost their loved ones. Soon it became evident that they were not the only ones experiencing these problems; that there were many more like themselves throughout the country. It was out of this recognition that the original members founded an organisation that would address such problems.

The main objectives of TASO were to provide care, prevention advice, and support for people with HIV/AIDS and/or their families. The guiding philosophy of TASO is known as “positive living”¹¹¹. TASO has grown from being a small organisation in 1987 that was

¹¹⁰ See also, <http://www.tasouganda.org/index.php/> 05/11/04

¹¹¹ Positive living is a concept developed by AIDS care and support organisations. The concept implies having positive attitudes towards living with HIV/AIDS. It is stressed that people should not despair because they have contracted HIV, but should learn ways of living with it: avoid alcohol and unsafe sex, regulate or even stop

housed in the national referral hospital, to a national organisation with services all over the country and with international fame and recognition (TASO 1995: 9).

The first funding received by TASO was from Action Aid. This was followed by funding from USAID in 1988 and 1991, and from the United Kingdom government (Monico, Tanga, and Nuwagaba 2001: 7).

By 1993, TASO had opened seven branches: Mulago –TASO headquarters in 1987, Masaka in 1988, Mbarara and Tororo in 1989, Mbale in 1990, Jinja and Entebbe in 1991 (TASO 1995: 5-6)¹¹². Although most of these branches are named after specific districts, the branches operate beyond the geographical boundaries of the districts after which they are named. For example, the Mbarara branch in western Uganda serves Bushenyi district, Ntungamo and parts of Rukungiri¹¹³. Besides the major branches, there are “mini-TASOs” that are the result of collaborative efforts with private organisations such as private hospitals and in districts where TASO does not have a branch. For example, TASO collaborates with Kilembe hospital in Kasese district (Western Uganda), Mutolere Hospital in Kisoro district (South Western Uganda) and has a fully funded programme in Gulu Hospital (Northern Uganda).

As the impacts of HIV/AIDS have increased, TASO has scaled up its efforts through a regionalisation programmes. This programme began in 2003 and involved the establishment of regional offices. TASO’s area of operation is divided into four zones: Northern region, South-Western region, Eastern region and Central region. The role of regional offices is to coordinate TASO activities in respective regions¹¹⁴.

5.5.1 Activities of TASO

TASO is involved in various activities ranging from the care and support of its clients and people directly under their care, to education and prevention. By the end of 2003, the number of clients registered with TASO Mbarara was about 29,000. These clients receive a number of

reproduction, seek prompt health care, and ensure good nutrition. If these suggestions are followed, their quality of life improves and they live longer (Kiirya 1999).

¹¹² See also, <http://www.tasouganda.org/index.php/> 05/11/04

¹¹³ At the time of data collection, it had been proposed that Rukungiri district get its own branch to serve the district of Kanungu, Rukungiri and parts of Kabale, Bushenyi and Ntungamo.

¹¹⁴ http://www.tasouganda.org/index.php 10/11/04

services from the organisation, including medical and counselling services, nutrition advice, and care and support.

TASO has a medical clinic and counselling centres in the areas in which it operates. The area of coverage for each TASO branch is currently a radius of 35km. However, because of the increased number of HIV/AIDS victims, patients travel as much as 80km to obtain these services. Because of this challenge, TASO branches operate mobile clinics, called community outreach programmes, that cover a radius of between 35-70 km, (TASO 2002a: 59). People who are outside this radius can travel to the outreach post instead of going to the branch clinic. The activities in these community outreach programmes (except for pre-testing counselling and testing for HIV¹¹⁵) are similar to those carried out at the centre, including counselling and medical care (see figures 5.1- a, b, c, and d, below).

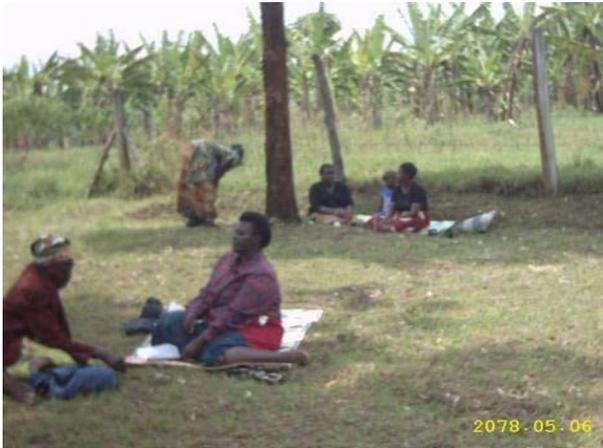
The mobile clinics rotate from one location to another, however, in the course of a month. Each outreach post is served once a month. Such an approach has the limitation that clients do not have access to services precisely when they need them. To address this problem, the centre (branch) clinic is open on working days in order to receive any serious cases that might come up. Any client, therefore, may access these services during the week should a problem arise before the outreach day – always provided that they can afford to come to the centre.

The community outreach approach has increased the number of clients who have access to TASO services. TASO reports that by 2003, the organisation had served about 90,000 registered clients, that 1,865 children had benefited from the education and apprenticeship programmes, and that nutritional support had been provided to 28,140 beneficiaries (<http://www.tasouganda.org/output.php/> 05/11/04).

Other than providing services to people infected with HIV/AIDS and their relatives, TASO paved the way for, or even facilitated, the founding of other service organisations; for example, Uganda National Association of AIDS organisations-UNASO (an umbrella organisation for organisations engaged in HIV/AIDS activities), NACWOLA, POMU, AIC and THETA.

¹¹⁵ Note however, that testing is done by another organisation but in collaboration with TASO. In 2004, Family Planning Association of Uganda (FPAU), had been hired to provide this service on behalf of TASO in the field.

Figure 5. 1. TASO's Community Outreach Programmes



(a): Counselling Session in the community.



(b) Chairman Clients' Council Addressing Clients



(c): Clients receiving medication in the community



(d) A counsellor addressing new Clients

Source: Fieldwork

At the international level, TASO's training programme has benefited other countries in Africa. In 1994, TASO provided training in basic help and care skills to various initiatives and organisations throughout Africa; for example, the WAMATA and UPENDO projects in Tanzania, the Catholic Secretariat in Nigeria, KENRI in Kenya, Project Hope Manzini in Swaziland, the AIDS/STD Unit in Botswana, the Kasana AIDS Initiative in Zambia, and the AIDS control programme in Ghana (TASO 1995:9).

5.6 The History of PTC/PLI

The Post Test Club (PTC) and Philly Lutaaya Initiatives (PLI) are groups formed under the auspices of the AIDS Information Centre (AIC) to tackle HIV/AIDS problem. These organisations began as separate organisations with separate objectives in 1992 and 1993 respectively. In 1999 PLI was merged with PTC to form PTC/PLI due to funding problems and the need to provide PTC members with correct, first-hand information regarding HIV/AIDS from people with the disease.

The members of PTC/PLI may be HIV positive or HIV negative. The organisation is based on the principal of non-disclosure, which means that the sero-status of an individual is a personal issue, although it does not discourage members from sharing their sero-status with their friends if they so wish.

5.6.1 The Post Test Club (PTC)

The Post Test Club is a nation-wide club operating under the supervision of the AIDS Information Centre (AIC). It is a social support group for all clients tested for HIV/AIDS, irrespective of their test results¹¹⁶. After AIC was established in 1990, it became evident that there were a number of issues that needed to be addressed if HIV/AIDS prevention was to be successful. In an interview with the manager AIC Mbarara, the following issues and benefits were identified as the reasons for founding PTC:

(i) There was a realisation that people who had passed through the testing and counselling process, especially the youth, remained vulnerable to HIV infection and re-infection if not monitored. The establishment of PTC was intended to create a structure that would facilitate the follow-up of these individuals, facilitate interaction of the youth and stimulate discussions about HIV/AIDS among themselves. This would prevent them from engaging themselves into activities that would expose them to the risk of HIV infection¹¹⁷. The club was to act as an internal organisation under AIC, to which those who had been tested for HIV, especially the youth who constitute the majority of the members (see table 3.2), could be referred for further monitoring and follow up. According to the manager, these people needed care, support and monitoring through an established referral system within the organisation.

¹¹⁶ <http://www.aicug.org/PostTestClub/> 06/11/04

¹¹⁷ See for example, <http://www.id21.org/insights/insights64/art00.html> 15/11/2006, for a discussion on the benefits of youth groups and interactions with regards to HIV infection.

Because of this, a health clinic was established at each AIC centre to provide health care support for clients.

The organisation was also intended to help members to access medical services and to facilitate their participation in the organisation's activities. Such activities were expected to increase the involvement of other people as well, who would be encouraged to take the HIV test. The activities of PTC were to be partly funded by AIC in the short term. PTC was to design its own programme, which were to be demand-responsive and self-sustaining. According to AIC (2003a: 10), members of PTC were to initiate projects for self-support and the funds realised from these projects should be partly used for follow up; a record was to be kept of where each member lived so as to be able to offer any social support that might be required.

(ii) There was a realisation that the level of stigmatisation was still high and people who were HIV positive needed care and support. In spite of the many referrals made to TASO, it was evident that a number of HIV positive clients still felt stigmatised and did not want to be identified with TASO- an organisation perceived to be exclusively for AIDS patients. The club would act as a social support group, which would focus on developing a positive identity and close contact among its members.

These two issues led to the starting of the Post Test Club in August 1990; the Mbarara branch was formed on 22/08/1992 (AIC 2003a). It has grown from a small club that gathered at the Mbarara AIC centre, to a multi-branch organisation. Three of these branches are in Ruhoko, Rushere and Itojo, and were started by members who broke away from the main arm of PTC/PLI in order to reach more youths in the rural areas. Moreover, under the new AIC strategy, PTC membership in mother organisation is supposed to end after two years. In an interview, the counsellor in charge of PTC activities Mbarara AIC branch revealed that the objective is that former members should start other organisations elsewhere so as to reach as many people and communities as possible. These branches are autonomous but may continue receiving support and supervision from the AIC main branch at Mbarara. By March 2004, Mbarara branch had registered 3,010 members (AIC, Mbarara records).

5.6.2 Philly Lutaaya Initiatives (PLI)

The founding of PLI in 1993 followed in the footsteps of late Philly Lutaaya. In 1989, Philly Bongole Lutaaya, a Swedish-based Ugandan musician, became the first known Ugandan to publicly declare that he was HIV positive (Birikwija 2000: 1; Maholo 2003: 12). This announcement came at a time of high stigmatisation, discrimination and HIV denial by people living with or suspected of having HIV/AIDS. His declaration later became an inspiration for organisations engaged in HIV/AIDS activities such as TASO and AIC, to focus on voluntary disclosure of HIV/AIDS status as a mode of HIV/AIDS intervention. These organisations realised that speaking out would save those not yet infected, while reassuring the infected that they can play a role in minimising the spread of HIV and the impacts of HIV/AIDS. These people also needed courage and hope to cope with the problem of HIV/AIDS. When Lutaaya first spoke out, he was ostracised, shunned, stigmatised and excluded, even by members of his church in his home community (Maholo 2003).

Lutaaya's courage and stamina made him popular. He gained confidence and sympathy, and was finally considered a hero. When he visited Makerere University, he talked to the community about sex as the cause of HIV/AIDS. He stressed that death is eminent when one contracts HIV (Birikwija 2000: 1). This was the first time someone had boldly addressed these issues. Since talking about sex openly in public impinges on people's life styles and questions people's morals, it is likely to lead to conflict with certain sections of society. No one, including the government, had risked taking up this issue as far (Putzel 2004).

Lutaaya's objective was to save others from becoming infected with HIV. As a result of his open approach, three NGOs – AIDS Information centre (AIC), World Learning Inc (WLI) and TASO and one UN agency-UNICEF – got together and formed a group that would encourage those infected with HIV/AIDS to come to terms with the disease through talking about it openly and giving testimonies voluntarily. This approach was called the Philly Lutaaya Initiative (PLI). The funding of its activities was provided by UNICEF and World Learning Inc., while AIC was responsible for implementing the PLI programmes and housing the group. TASO and AIC were responsible for recruiting members for the group, and this was done by counsellors from within the two organisations (TASO and AIC). The PLI recruits are trained in public speaking and equipped with other communication skills to enable them share their life experiences.

The objective of PLI was to change public attitudes towards HIV/AIDS. The focus was to develop a positive attitude to HIV/AIDS in the community. Thus, the philosophy of PLI was to give HIV/AIDS a "human face" through education and sensitisation of the public. Activities included community outreach and regular interaction of members (Birikwija 2000; Maholo 2003).

In 1999, UNICEF pulled out as a direct funding body for PLI activities. According to the Mbarara branch manager of AIC, this threatened the future of PLI activities (interview). TASO had already initiated a drama group to work with the sensitisation, and AIC's Post Test Club was doing the same. AIC realised that PTC was handicapped due to their philosophy non-disclosure (AIC 2003a). The AIC branch manager stressed that, "without disclosure, HIV/AIDS messages remained abstract and unconvincing, and the public would not trust such testimonies" (interview). The involvement of people with AIDS in education campaigns seemed to be an effective means of making AIDS a reality to the general population (Muyinda et al. 1997: 147). When it became evident that the activities of PTC and PLI were overlapping, PLI was fully incorporated into PTC and the two clubs became one under a new name: PTC/PLI.

There is a general meeting of all members of PTC/PLI every Saturday, at which plans and decisions are made for the organisation. The meetings are also intended to bring members together on a regular basis. Apart from these meetings, there is a recreational centre where members are encouraged to gather.

5.6.3 Activities of PTC/PLI

The PTC/PLI is engaged in various activities aimed at disseminating information about HIV/AIDS. The activities that take place at Mbarara PTC/PLI centre include educational talks, community outreach programmes, and recreational activities for its members. Such activities include music and dance rehearsals, watching HIV/AIDS films, and indoor and outdoor games. Sports activities are considered particularly important for the youth because of their ability to unite and shape the character of participants (Seippel 2006); they are also important for stimulating social relations among individuals and particular groups (see chapter 6 for a full discussion). The PTC/PLI has some income-generating activities, including a tailoring project. The income from this project reduces the organisation's dependence on external funding. In addition, the project benefits youths who are

recommended by any PTC/PLI members for training in tailoring and cloth-design. Income is also generated by hiring out of music and public address systems to the public.

5.7 Conclusion

The purpose of this chapter was to outline the development of non-governmental organisations in the field of HIV/AIDS. The role played by local context and impact of HIV/AIDS in the formation of the organisations involved in HIV/AIDS activities was discussed. It was stressed that these organisations were founded in response to a need to collectively address impacts of HIV/AIDS which were being faced by individuals or the community in general. Finally, the activities of these organisations were described and related to the main focus of the study, i.e. the need for social capital to address the challenges of HIV/AIDS. It is on the issue of social capital and the process by which it is generated by HIV/AIDS NGOs that the next chapter focuses.

CHAPTER 6

Building Social Capital: The Role of Non-governmental HIV/AIDS Organisations

6.0 Introduction

The purpose of this chapter is to explore the process by which non-governmental HIV/AIDS organisations (HIV/AIDS NGOs) facilitate social capital formation. There is wide agreement that social capital plays an important role in facilitating social and community development, and improving people's health. In the African context, and Uganda in particular, social networks at the community, family and individual levels have been essential in providing care and support for the needy during hard times. However, it is argued that HIV/AIDS has affected these social networks negatively, causing them to decline, particularly within the family and the community (Barnett and Whiteside 2002; Marshall and Keough 2004; Orla 2004)¹¹⁸. This chapter discusses the activities employed by NGOs working with HIV/AIDS in order to mobilise, revitalise and generate social capital at individual, community and organisational levels in Uganda. In this chapter I contextualise different types of networks, discuss the process of building these networks by NGOs, and the limitations of NGOs in building these social networks. The chapter will also discuss the role of the private sector in the fight against HIV/AIDS in Uganda.

6.1 Types of Networks

In chapter two I discussed different types of networks through which economic and social development may be influenced. The discussion showed that there are networks at all levels: personal, community, intra-organisational, inter-organisational and, not least, state-agency. Thus, bonding, bridging and linking networks were observed. This section will discuss the various types of networks which exist as a result of NGO activities. The objective of this section is to put these networks into context with respect to HIV/AIDS. Such contextualisation will make it possible to analyse (in chapter 8) the extent to which the impacts of HIV/AIDS are alleviated by HIV/AIDS NGOs.

¹¹⁸ See discussion in chapter 4.5

6.1.1 Bonding networks.

Bonding networks take place when people who share similar interests or social and economic backgrounds interact with each other. In the context of this study, bonding networks are those in which members of the same organisation interact. The daily activities (both formal and informal associations) that take place in the two organisations studied represent a form of bonding network. For example, when TASO or PTC members interact at their organisation's day and recreational centres, this is a form of bonding network. It has been mentioned that these networks provide a basis of identity formation. For example, it is such networks that encourage TASO members to identify themselves as members of the same "family". One reason people with HIV/AIDS relate to each other is to obtain psycho-social support, since they seem to understand each others' HIV/AIDS-related problems.

The discussion in 6.2.2 stresses that interpersonal networks which take place within organisations are important for trust building. As discussed in chapter two, trust provides a basis for sharing experiences and a foundation for communication. It is through such communication that members of organisations develop positive attitudes towards relating to each other and other people, such as family and community members outside the group. At family and community levels, bonding networks are observed when the members of the organisations interact with their family members. However, this may also be a form of bridging network, especially as those with HIV/AIDS obtain both information and financial assistance from family members.

At the intra-organisational level, bonding networks can be observed when interdepartmental relationships exist within the same organisation. Most organisations, although divided into separate departments, work as one organic unit in which departments are interdependent. There are interdepartmental meetings, which are aimed at achieving the objectives of the organisation. These relationships facilitate the learning and sharing of knowledge and exchanging information, and consequently, make the coordination of activities easier.

It is important to note that interpersonal connections among AIDS patients have led to the emergence of sub-organisations. A number of NGOs that have been formed exclusively by people with HIV/AIDS are involved in HIV/AIDS-related activities in Uganda. These organisations emerged with the recognition that different categories of people with HIV/AIDS face different problems. For example, the Positive Men Union (POMU) was formed to

address issues faced by HIV-positive men. This followed the formation of National Community Organisation of Women Living with HIV/AIDS (NACWOLA). One may predict that an organisation for HIV-positive youth may emerge to deal with HIV/AIDS impacts exclusively faced by the youth and adolescents. The formation of such organisations makes it possible for the HIV/AIDS-related problems faced by particular groups and individuals to be quickly identified, shared and addressed.

The objective of these organisations is to provide psycho-social therapy to their members and act as channels through which issues exclusive to a certain group can be addressed. For example, the formation of National Community Organisation of Women Living with HIV/AIDS (NACWOLA) was aimed at addressing the problems which most women with HIV/AIDS were facing; issues such as widow inheritance and HIV/AIDS-related domestic violence were exclusively female problems and could not be addressed within an organisation such as TASO, which encompassed all the people with HIV/AIDS.

6.1.2 Bridging networks

Bridging networks are those networks which take place between people with different backgrounds and interests. These may include broader interactions between different community members or communities involved in the battle against HIV/AIDS. NGOs work goes beyond the individuals who belong to it and benefit directly from it; they also benefit members of the community who are not members of HIV/AIDS organisations. In this regard therefore, bridging networks are; at individual level, they are the interactions between members who belong to different organisations, interactions between members of organisations and other people in the communities. At organisational level they may include inter-organisational networks. It should be noted that the development and functioning of bridging networks at the micro and personal levels have not been thoroughly studied. These networks have implications for the impacts of HIV/AIDS, for example, in minimising stigmatisation and social exclusion; the chances of success are better when people with different backgrounds interact.

Therefore, networks which link organisations, individuals and groups are important. As mentioned, one of the advantages of bridging networks is access to HIV/AIDS-related knowledge. In chapter four, it was stressed that one of the greatest contradictions regarding HIV transmission is lack of knowledge about modes of HIV transmission. It is for this reason

that bridging networks are important. Members of NGOs are provided with correct knowledge regarding spread, control and prevention of HIV/AIDS. Therefore, their interactions with people outside the NGOs result in the dissemination of this knowledge at a lower cost than would be incurred through other means.

In addition to the interaction between members of the NGOs which I studied, there are personal relationships which develop when members of these organisations interact with members of other organisations. The participation of members in inter-organisational activities, such as sports and joint HIV/AIDS-related activities result in bridging networks.

At the organisational level, bridging networks are observed when interactions between different organisations take place. At this level, these networks involve organisations with more-or-less the same volume of resources. For example, inter-organisational networks may be involved in human resource sharing. For instance, TASO employs Family Planning Association of Uganda (FPAU) to carry out HIV/AIDS testing during their outreach programmes. Similarly, Population Service International (PSI) hires the TASO drama group to perform in those areas where it operates. Bridging networks have also developed an organisational referral system (see 6.2.6 and 6.6.2).

Bridging networks are also active in the formation of splinter groups in addition to exclusive groups such as NACWOLA and POMU, there are groups which are all-inclusive; for example, Makenke AIDS Initiative, Amatsiko Foundation and Katete New Hope(see 6.2.5).

6.1.3 Linking networks

Linking networks are a special type of bridging network that exists when the interacting partners – individuals, groups and communities – have unequal access to resources (Woolcock 2001). Because of unequal resource distribution, individuals and groups with fewer resources may tend to associate with those having more resources in order to improve their situation. In some cases, groups and organisations may initiate a policy of associating with people who have fewer resources. For example, institutions like the World Bank and other donor agencies are the ones who often initiate the process. This is because these organisations focus on helping the poor to improve their lives. Moreover, the poor may not know of the existence of these organisations. Through such relationships, disadvantaged people and communities, such as those affected by HIV/AIDS, benefit in terms of financial resources made available to support various activities.

Linking networks are significant because it is through them that individuals, communities and organisations can access the external resources needed, for example to finance programmes addressing HIV/AIDS-related problems. O'Manique (2004) compares Hope Clinic in Kisoro to TASO. She argues that Hope Clinic has programmes similar to ones carried out by TASO, but that Hope clinic has not managed to offer the high-quality services as offered by TASO. She claims that those local NGOs that manage to secure funding from the northern NGOs, can often provide more extensive services than organisations such as Hope Clinic, which do not have access to funding from international agencies (O'Manique 2004: 162). The lesson to be drawn from this comparison is that organisations that lack linking social capital cannot make much head-way in successfully combating the impacts of HIV/AIDS.

The relationship between HIV/AIDS NGOs and the government is important since the latter is an important actor in HIV/AIDS intervention in Uganda. The state's role is to provide a favourable environment for the various organisations participating in the battle against HIV/AIDS. The government establishes rules and guidelines to guide and coordinate the interaction process. The government controls the established physical infrastructure and personnel in various districts. Although these facilities are quite lacking in terms of medical personnel and medical supplies (see 5.3.2), the rehabilitation process which is currently taking place is likely to improve the quality of services. Moreover, the NGOs still rely on these facilities for referrals and other activities (see 6.5). In addition, the government has better access to international donor agencies. It should be noted that, international donor agencies such as the World Bank prefer NGOs to implement their programmes, but ironically, do not directly fund these agencies. Instead, funds are passed through governments, to be distributed to NGOs. Therefore, without close interaction with the government, NGOs access to such external finances would be limited. Given this situation, it is of paramount importance that organisations establish links with the state if their HIV/AIDS interventions are to succeed.

Other linking networks are evident in interaction with international donor agencies, such as the UN agencies and the World Bank. NGOs are channels through which resources from the government and donors are dispersed to those involved in HIV/AIDS activities and to people such as AIDS patients who need those resources.

It should be noted that, in addition to financial access, the linking networks are channels through which the preferences of people with HIV/AIDS can be communicated to government and other support groups such as donors.

Although a distinction can be made between various types of networks theoretically, this may not be possible in practical terms. For example, as the discussion above indicates, bonding, bridging and linking networks are intertwined and may exist at the same level (personal and organisational levels).

The discussions above have shown that, bonding networks may be activated when the members of NGOs interact with their families because of shared backgrounds and for psycho-social therapy. Similarly, bridging networks may be activated when family members interact with members of NGOs for knowledge acquisition. Likewise, linking networks may be activated when HIV/AIDS-related knowledge and resources are unevenly distributed between family members and AIDS patients. These examples show that bonding, bridging and linking networks are not mutually exclusive in practical terms. As pointed out in chapter two, the distinction is for analytical purposes. Moreover, for purposes of analysis, these networks are contextualised with respect to HIV/AIDS. A distinction is made on the basis of their structure and composition, and of the likely benefits they can provide to PWHA (see table 6.1 below).

Table 6. 1 Contextualising the Differences between Bonding, Bridging and Linking Networks in the Study

Type of Network	Structure	Implication for people with HIV/AIDS
Bonding	-Composed of people with the same ethnic background; family members, same community, people faced with similar problems such as HIV/AIDS. -They may be exclusive	- Sources of services; relationship with family and kin can be the source of these services. - Sources of psychological support -Influence policy. For example, TASO works closely with the government and is involved in discussions about HIV/AIDS intervention. -If people with HIV/AIDS limit their relationships to fellow victims, this may cause further stigmatisation, denial and selfexclusion.
Bridging	These are horizontal associations composed of people with different social backgrounds but with comparable economic and social resources. These are cross-cutting networks	-Sources of new forms of HIV/AIDS-related knowledge -Encourage tolerance -Inclusive -Avenues for knowledge sharing and communication -They facilitate disclosure and make individuals less stigmatised.
Linking	-Vertical in nature -Composed of people with different social backgrounds and unequal social and economic resources	-Access to resources outside the community to alleviate the impacts of HIV/AIDS. -Individuals link up with people, organisations and/or institutions that may respond faster to the problems they face.

Table 6.1 distinguishes different types of networks and the impact they may have on HIV/AIDS mitigation. If we take an example of people with HIV/AIDS, it can be observed that bonding networks result in services and psychological support. Bridging networks are sources of new forms of HIV/AIDS-related knowledge and can facilitate discussion and disclosure of one's HIV/AIDS status, thus making people less stigmatised. Similarly, linking

networks make it possible to gain access to financial resources. These examples demonstrate that all types of networks can be important for the individual, and should not therefore, be taken as exclusive and one as being better than others. As mentioned their importance depends on context. The next section will discuss how NGOs facilitate the above social relations.

6.2. Building Networks by HIV/AIDS Organisations

Based on the theoretical discussions presented in chapter 2 about the measurement of social capital, I argue in this chapter that social capital generation by NGOs is mainly through the creation of channels for regular interactions between their members/clients and members of society. In the following discussion, the focus is on the process by which two NGOs working in this field in Uganda, The AIDS Support Organisation (TASO) and Post-Test Club/Philly Lutaaya Initiative (PTC/PLI), facilitate social relations.

Social capital generation may be observed at three levels: micro-, meso- and macro-levels. At the micro-level, it involves facilitating the development of personal networks. At the meso-level, it involves facilitating the development of networks between local government and organisations, groups and associations. At the macro-level, it involves facilitating the development of networks between NGOs and national government or international organisations. All these levels are important for successful HIV/AIDS intervention. Chapter 2 discussed the different types of networks and their importance. In this chapter, these networks are contextualised (see 6.1.1 – 6.1.3) and the way they are constructed by HIV/AIDS NGOs will be examined. On the basis of this discussion, the implication of these networks for the impacts of HIV/AIDS will be discussed in chapter 8.

6.2.1. Interpersonal Networks and Their Relevance to HIV/AIDS Intervention

Building interpersonal networks involves confidence building. Bringing people into regular face-to-face contact promotes norms of reciprocity and trustworthiness of the individuals, and builds confidence (Hall 1999). The HIV/AIDS organisations are important in building interpersonal networks through a system of regular contacts. For example, TASO has a day centre where people meet regularly. The day centre allows clients to develop a spirit of fellowship. This encourages clients to share their experiences and manage HIV/AIDS-related problems they face. Similarly, PTC/PLI has a recreation centre, where clients and members meet twice a week to learn and rehearse songs, engage in different sports activities, and

discuss HIV/AIDS-related issues. Through sharing experiences, rehearsing and performing dramas, HIV/AIDS prevention and coping with difference can be achieved (Kayazze 2002; Kelly 1995). When people share their experiences and communicate about AIDS, they learn from each other and their fears regarding the disease are laid to rest. The impact of such a strategy, however, depends on the frequency, nature and sustainability of interaction. Irregular meetings often result in a breakdown of communication, so their effect on HIV/AIDS may be limited.

I asked respondents about the frequency of their interaction with different groups of people. Results are presented in table 6.2 below.

Table 6. 2 Frequency of Meetings with Members of Organisations and Other Groups

Frequency of meetings	Weekly (%)		Once a Month (%)		Never (%)	
	TASO	PTC/PLI	TASO	PTC/PLI	TASO	PTC/PLI
Formal meetings	88	26	7	70	5	4
Informal meetings	94	73	5	23	1	4
Family and relatives	80	87	15	5	5	8
Neighbours	82	82	9	15	9	
	N= 79	N=43	N=79	N= 43	N= 79	N=43

Note: Respondents were asked *how often they meet members of their organisation, their family, and neighbours.*

From the above table, it is evident that 88% of TASO members, compared to 26% of PTC/PLI members, reported that they were meeting formally each week. In an interview with the members of PTC/PLI, it was revealed that most members are school going and some of the meetings take place during school days. It was not possible therefore to have formal meetings with fellows weekly. But, it was also revealed that, HIV/AIDS peer groups are already being formed in schools and they get additional knowledge from these groups. Nevertheless, 70% of PTC/PLI members were meeting formally once a month. In both organisations, members were meeting informally, for example, visiting friends or hanging out together. In addition, 80% of TASO members/clients and 87% of PTC/PLI members were interacting with family members on a weekly basis. This is important since families and relatives are sources of social support in times of trouble. In both organisations, 82% of the members were meeting their neighbours weekly. Interactions in the neighbourhoods are also a source of social support (see 8.8), as well as serving to increase trust and access to knowledge regarding cause, transmission and mitigation of HIV/AIDS.

The above findings demonstrate two things: a) that TASO and PTC/PLI members meet one another regularly both formally and informally, as well as meeting their relatives, families and neighbours frequently, and b) that the majority of respondents meet other people weekly.

The implication of the above findings is that members of these organisations were not isolated, but were in close contact with other people. These interactions are a source of knowledge, as well as of financial, psychological and emotional support, which may, in turn, improve the health and welfare of interacting individuals. Interactions also result in people getting to know each other and provide a basis for collective action. Kilpatrick and Falk (2003), and Fafchamps and Miten (1999) argue that when farmers get to know each other through interaction, this results in increased access to information about where to obtain better prices for their crop. Similarly, interaction involving people with HIV/AIDS results in communication about HIV/AIDS (Low-Beer and Stoneburner 2004a; 2004b; 2004c).

On the individual level, clients of TASO develop a sense of identity through regular talks and face-to-face contact. They refer to one another as “belonging to the same family”, and most of them know one another well (interview with a counsellor, TASO). They provide support for one another; for example, taking each other to the hospital if there is a need. It was evident that both TASO and PTC/PLI foster identity formation through the regular contact of members.

Formal meetings at organisation centres and outreach programmes often lead to the development of close and friendly relationships among members. Tables 6.3 and 6.4, respectively, present percentage responses to the question about the number of close friends that individuals have and how many of these friends belong to the same organisation as the respondents.

Table 6. 3 Number of Close Friends Claimed by Members of PTC/PLI and TASO

Number of close friends	TASO (%)	PTC (%)
Two or More	67	76
One	21	16
None	12	8
	N= 80	N=44

Note: The following question was asked: *About how many close friends do you have these days? These are people you feel at ease with, or can talk to about private matters, or call on for help.*

In table 6.3, it can be observed that 88% and 92% of members of TASO and PTC/PLI respectively, had one or more friends who were close to them. These results indicate that the majority of members of organisations had someone they could talk to. Talking and communicating about HIV/AIDS is a form of psychological therapy, especially if the talk focuses on sharing experiences. In the course of such conversations, HIV/AIDS-related information about medicine, sources of financial support and access to medical care can be accessed.

However, the question does not elicit whether these friendships are limited to members of the same organisation, and does not, therefore, distinguish between relationships involving members of the organisation and those involving non-members. In this respect, a second question was posed to ascertain the number of friends belonging to the same organisation. The intention was to reveal the nature of the respondents' networks and the people with whom they interact. As discussed in chapter 2, an understanding of the type of networks in which people participate, and by examining how and with whom interactions take place, it may be possible to understand the nature of resources that might be accessed through such interactions. The results are presented in table 6.4.

Table 6. 4. Friends of TASO and PTC/PLI Members who are Members of the Same Organisation

Number of Friends	TASO (%)	PTC (%)
None	32	68
One	24	15
Two or more	44	17
	N=71	N=40

Note: I asked them to respond to the question: *Of these friends, how many belong to the same club or organisation (TASO or PTC) as you do?*

Table 6.4 indicates that the majority of TASO members, who had friends, had them in the same organisation-TASO (68%); the rest of the friends were non-members (32%). In contrast, only 32% of the PTC/PLI members' friends were from their organisation. The majority (68%) of members had friends who were not members of PTC/PLI. The above findings imply that friendship is not limited to members of the same organisation. On the one hand, the finding suggests that the majority of TASO members had bonding relationships, since the majority (68%) associated with fellow members. On the other hand, the findings suggest that majority of PTC/PLI members had bridging relationships since they associated

most with people who did not belong to the same organisation. However it was found that in both organisations, respondents had friends who resided close by. This finding indicated that people tend to associate with people who can be called upon any time for assistance and these should not be residing far away.

It has to be emphasised however, that the observation in Table 6.4, that 32% of TASO members and 68% of PTC/PLI members have friends outside their organisation may imply that PTC/PLI has a greater potential for creating bridging relationships with the outside world than TASO. Moreover, TASO's clients are largely people infected with HIV/AIDS, so relationships will necessarily develop into interpersonal relations of bonding nature for them to share experiences regarding HIV/AIDS¹¹⁹. The situation is different with PTC/PLI since organisation membership cuts across the division between HIV positive and HIV negative persons; bridging ties are likely, therefore, to be more easily developed.

The importance of the above analysis lies in the fact that people will tend to develop relationships with people from whom they may expect some benefit and ones who are easily in their reach (see table 6.5). In this regard, since most of the members of TASO have HIV/AIDS, they may grow closer to people with the same problem. Associating with people infected with HIV/AIDS may provide a form of psycho-therapy that those not infected cannot provide.

On the other hand, the majority of PTC/PLI members are HIV negative, which means that these friendship networks differ greatly from those of TASO members. The type of resources expected from such a network may also differ from those expected by TASO clients. Since most PTC/PLI members are youths, they want to make connections with people who may provide information or offer them jobs. I have stressed that bridging networks are important for information access, and for this they must look beyond the organisation. In an interview, one youth who was about to complete a technical education said that:

I associate with different people outside my group. As you can see, the majority of the members are the youths like me. I play and joke with them, and learn how to deal with the problem of HIV/AIDS which threatens our future. But I need a job after school. For that, I look outside.

¹¹⁹ As Lin (2001 b) argues, people having similar problems such as people facing a divorce will tend to associate with people like themselves, since these are the people who understand their suffering (see discussion in 2.3.4)

The above example clearly demonstrates that people tend to associate more with others from whom they expect benefits. It should be noted, therefore, that interactions with people outside the organisation is likely to lead to easy transfer of HIV/AIDS-related knowledge from organisation members to non-members, including members of community and friends.

In addition to the interactions that takes place both in organisations and communities, therefore, closeness between organisation members and their friends is likely to be strengthened by residential proximity. Residential proximity facilitates easy sharing and exchange of knowledge between friends, including talking about their sero-status, how to avoid HIV/AIDS infection/re-infection and their position in communities and the relationships which they had with other people. The following table indicates the residential proximity of friends.

Table 6. 5 The Residential Proximity of Organisation Members and Their Friends

Residential Distance (Km)	TASO (percentage response)	PTC/PLI(percentage response)
1-2	70%	71%
3-10	19%	16%
Above 10	11%	13%
	N=80	N=45

Note: The question asked was: *How many close friends do you have these days...of these friends estimate how far it is from where you live to where they live*
 1. 1-2 km, 2. 3-10km, 3 above 10km

Table 6.5 above reveals that 70% of TASO members and 71% of PTC/PLI members have friends who reside close by. As mentioned, residential proximity among friends facilitates the sharing of knowledge by facilitating communication.

6.2.2 Interpersonal Networks and Trust Building

As mentioned in chapters one and two, the trust which develops out of regular interaction by individuals may provide a basis for communication about HIV/AIDS. Consequently, I have suggested that this may be useful in meeting the challenges of HIV/AIDS. In chapter 2, I considered how trust facilitates cooperation and interaction. In the present section I will bring these two lines of thought together in a discussion of the extent to which NGOs can generate trust. In the interviews, questions related to trust were asked so as to measure the level of generalised and personalised trust. HIV/AIDS is a sensitive issue which is shrouded in

secrecy once one contracts it (see stigma in chapter 4). This is because, as previously discussed, a person who is diagnosed as HIV positive may sometimes be shunned by society. This segregation hinders efforts to control the spread of the disease. For the spread of HIV to be controlled, it is important that people talk about HIV/AIDS. However, since it can be argued that the extent to which people are willing talk about HIV/AIDS will depend on the extent to which they trust both friends and society not to reject them, therefore, the extent to which HIV/AIDS NGOs foster trust among their members is examined. The following table indicates the percentage of respondents who answered ‘yes’ to the questions asked about the extent to which membership to such organisations results into trust among them and their neighbours.

Table 6. 6 Trust in Organisations and Neighbourhoods

Trust Relationship	TASO (% positive response)	PTC (% positive response)
Members willing to offer help and support	94	86
Trust in their neighbours	50	48
	N=80	N=44

Note: Respondents were asked to respond to the following questions:

- a) In the organisation you belong to are most members willing to offer you support or do they only care about themselves?
- b) In your neighbourhood can most people be trusted?

Table 6.6 reveals that the vast majority of members of TASO trusted fellow members of their own organisation to provide support to fellow members. Similarly, a slightly smaller majority of the PTC/PLI respondents claimed that they trusted members of their own organisation to offer support to fellow members. The above responses are significant. In the first place, they demonstrate that membership in organisations with regular face-to-face interaction leads to trust among members of the organisation. However, in spite of high trust among members of the same organisation, the level of generalised trust is only average for members of both organisations; 50% of TASO and 48% of PTC/PLI members felt that they could trust members of their own community. Regular interaction within associations lead to increased trust among members of the same organisation, but such trust does not spill over to the rest of the community. These figures show that whereas trust between members of NGOs and community members is relatively low compared to that between members themselves, but it is not far from average. I can assert that there is a relatively better relationship than earlier perceived, since for example Muyinda et al (1997) found that there were high levels of stigma and discrimination in the past. Moreover, as the discussion in 6.2.3 and 6.2.4 below show,

these NGOs are engaged in activities which improve the relationships between members/clients of these NGOs and the community and their family members.

6.2.3 Networks at Family and Community Levels

The importance of communities and families as safety nets for people with HIV/AIDS is widely recognised¹²⁰. TASO and PTC/PLI have focused their efforts on the community as a mechanism for addressing HIV/AIDS problems. The social ties and networks at community level are considered particularly important as channels through which the effects of HIV/AIDS can be alleviated. The social ties – which were broken first, as a result of the forces of globalisation, and later further damaged by HIV/AIDS (see chapter 4) – need to be mended if HIV/AIDS intervention is to be successful. It is the vision of both TASO and PTC/PLI to create harmonious relations between community members and HIV/AIDS infected persons. Interviews with people in the community emphasised the positive role of NGOs in creating social unity. According to one community member,

The NGOs bring together and unite people, especially those affected by HIV/AIDS. They give such people confidence and a positive attitude towards life. People infected with HIV/AIDS know now that they are not alone; together with other members of the community they fight HIV/AIDS. (Respondent in the community)

A respondent from TASO stresses that

When we join the organisation we learn many things. We learn how to keep close relations with others and how to avoid any encounter that may develop into stress. Thus, we eventually cope and get along with everyone in the community. (Interview with TASO Client at Katungu)

Organisations make it possible for their members and people in the communities to meet and participate jointly in drama activities, and to ask questions and interact. These activities encourage community members to associate with people with HIV/AIDS without fear of contracting the disease. All the presentations that I attended emphasised the importance of the united efforts on the community and family level for a successful intervention. The role of the family in caring for the sick was emphasised. The informal interaction that takes place

¹²⁰ The importance of the family in Africa as safety nets is discussed in chapter 4 (4.3), but see also, Kayazze (2002) and Marshall and Keough (2004).

between the members of the drama group and the community further facilitate closeness between the two groups (see discussion in 8.7.1 for the role of drama).

6.2.4 Informal Interactions in the Community

Informal interactions are not limited to organisation members, but include other social groups. In the previous discussions I have shown that there are various interactions (formal and informal) which take place between members of TASO and PTC/PLI. It was also revealed that these interactions are not limited to members but they go beyond the organisation to include their families, people in other organisations and from the communities in which they live. All these networks are important for alleviating the impacts of HIV/AIDS.

The role of HIV/AIDS organisations in building the above relationships is significant. Respondents were asked to describe the relationship they had with other people such as friends and neighbours, relatives and family. The majority of respondents (86 % of TASO and 84 % of PTC members) responded that they had good relationships with their relatives and neighbours.

I asked respondents to comment on the contribution that the organisation they belonged to (PTC/PLI or TASO) made to their relationships with different people. Both organisations were found to be facilitating relationships between members of the organisations and their relatives, as well as their neighbours. Table 6.7 presents the respondents’ impressions of the contribution of NGOs to the improvement of the relationships of organisation clients/members to their relatives and neighbours.

Table 6. 7. The Contribution of TASO and PTC/PLI to Improving their Members’ Relationships with their Neighbours and Relatives

Type of Persons	TASO (% response)	PTC/PLI (% response)
Neighbours	88%	69%
Relatives	85%,	76%
	N=78	N=43

Note: The question I asked was: *Using a 5 point scale from 1 to 5, where 1 represents “to a very small extent” and 5 represents “to a very large extent”, determine the extent to which belonging to the PTC/TASO has contributed to your relationships with different people; Neighbours, relatives, family members, members of the organisation in which you belong.*

From table 6.7 it is evident that the majority of respondents in both organisations were of the view that the positive relationship they have with their neighbours, friends and relatives is largely due to their membership to these organisations.

In order to understand why there was such a high positive response regarding the contribution of organisations to relationships existing between organisation members (TASO and PTC/PLI) and their neighbours and relatives, I asked respondents to explain why the organisation they belonged to had been so significant. Answers varied. Some members of PTC/PLI and TASO answered that they had learnt to share with others what they discuss in their meetings. One of the clients claimed that; “the organisation has taught us that the only way to deal with this problem (AIDS) is to share it with others and to associate well with people” (interview with TASO client).

PTC/PLI and TASO employ counsellors who advise their members and clients about the way they should relate with other people. Most clients with whom I discussed this, maintained that inter-personal relations with their relatives and families, neighbours and other people had improved since they joined PTC or TASO as a result of such counselling.

It has to be emphasised that regular interaction and sharing personal experiences about HIV/AIDS helps the members of the organisations build self confidence. This confidence results in a willingness to share experiences with others outside the organisation. Therefore, personal relations develop between members and outsiders, both members of the community, and relatives and friends. As will be discussed in chapter 8, such relations constitute a positive impact that the NGOs have on HIV/AIDS.

6.2.5 Group Formation

Realising the need to keep in touch and continued interpersonal relationships, organisations encourage their clients/members to form independent groups outside the mother organisations. Within TASO at the national level, numerous groups have been formed; for example, Positive Men Union (POMU) and National Community Organisation of Women Living with HIV/AIDS (NACWOLA). Membership to these organisations is exclusive for people with HIV/AIDS.

At the local level, for example in Mbarara, there is Lugazi AIDS women group, Makenke AIDS Initiative, Katete New Hope and Amatsiko Foundation. Membership in these groups is open to both HIV positive and HIV negative persons and/or those who have not yet been tested for HIV. To this effect, therefore, it can be argued that the founders of these groups, while belonging to TASO, have formed bridging groups which cut across HIV boundaries.

Similar findings were observed in PTC/PLI. The AIDS Information Centre (AIC), which oversees the activities of PTC/PLI, encourages its members to go out and form new groups in their communities. AIC continues to play a supervisory role vis-à-vis the newly formed groups. According to the counsellor in charge of PTC/PLI activities at the Mbarara AIC centre, the organisation is introducing a phase-out plan so that membership in PTC/PLI is only for a period ranging from 6 months to 2 years, after which members are expected to form their own groups and phase out of the parent organisation. This has encouraged the establishment of a number of organisations; for example, Kakika AIDS Group, Ndejja Post Test Club, Rushere Post Test Club, and Ruhoko Post Test Club. These groups facilitate cooperation among individuals and are a means of keeping contact, as well as of accessing important information, sharing experiences and extending services and information regarding HIV/AIDS to rural areas.

By encouraging people with HIV/AIDS to form such associations and groups, NGOs enhance their capabilities to learn from each other; for example, about what medicine (especially herbal medicine) works and what does not work, or what works on what ailment and how to use it. With no cure forthcoming, AIDS patients are relying on local herbs. Respondents acknowledged the importance of different herbs; they gather these together and teach one another about their use.

The importance of herbal medicine is also recognised by both TASO and AIC. One of the organisations which TASO helped to start is the Traditional and Modern Herbal Practitioners Together against AIDS (THETA). THETA was formed to streamline the use of local herbs in a more refined and scientific way. Other organisations which TASO has helped to establish include: Uganda Network of AIDS Service Organization (UNASO) and Kumi AIDS Support Organization (KASO) (<http://www.tasouganda.org/output.php/> 05/11/04

As mentioned, these offshoot organisations assist in the extension of NGO activities into the rural areas and in the spread of services to more people. This would be one way of scaling up NGOs activities. In addition, the benefits of belonging to the organisation, such as acquisition of more knowledge about the disease, would spill over to other members of the community. Such knowledge is likely to ease the tension between the community and those infected with HIV/AIDS and their relatives, thus increasing social unity. In addition, such knowledge, as it will be discussed in chapter 8 it helps to demystify issues such as witchcraft, which are perceived to be causes and of HIV/AIDS.

Social unity reduces intolerance and creates harmony between people. This study reveals that both TASO and PTC/PLI foster social unity among their members, as well as within their community. As discussed above (see 6.2.3 and 6.2.4), it is evident that inter-personal relationships between different groups, such as relatives, family members, neighbours and clients/members of TASO or PTC/PLI, are good. In turn, social unity may result in increased support for members of the community (see chapter 2). This issue will be discussed further in chapter 8 with regard to alleviating impacts of HIV/AIDS.

6.2.6 Intra- and Inter-organisational Networks

Intra-organisational networks refer to those networks within the organisation. Generally, these relations are realised at department or section levels. Within organisations, departments work together in close collaboration. Both TASO and PTC/PLI were found to work as one organic unit, with close-knit intra-organisational networks. At AIC, almost 50% of PTC/PLI executive members were also working as volunteers in the parent organisation, and some were engaged in counselling or other activities of the organisation. In TASO, the departments are well networked through a system of management meetings. At the personal level, intra-organisational networks may include relations between members of the same organisation, either within the same department or from different departments (see, formal and informal networks above).

Inter-organisational networks refer to relationships between organisations. At the organisational level, relations with other NGOs that are engaged in HIV/AIDS activities vary. It should be noted that social capital is not limited to interconnections between persons, but extends to other forms of networks, including networks between different organisations.

Most organisations have horizontal networks that link them to other organisations engaged in AIDS care and service provision. HIV/AIDS organisations are engaged in specialised activities that also benefit other people who are outside that particular organisation. Specialised services are accessed through a system of inter-organisation referrals; for example, TASO refers clients to other organisations for specialised care services that it does not provide, as in the case of clients with cancer, who are referred to Hospice. Such referrals are an important link in ensuring that clients can access better services (TASO 2002a). In addition, clients are sometimes referred to the Uganda Association of Women Lawyers (FIDA) for legal counselling and assistance (interview with a TASO counsellor). Networking with other organisations helps clients to access different services one can get. Through inter-organisation networks, therefore, clients of these organisations are able to access information and acquire knowledge about other organisations providing specialised health and care services. It is such information and knowledge that facilitates access to better services in these organisations.

The following referrals were received by TASO from different organisations. In 2001, 1,278 referrals were received from the community, 693 from health units, 653 from hospitals, 74 from other HIV testing sites, and 98 from AIC (TASO 2001: 17). In 2003, reports from AIC (Mbarara) indicate that AIC made 496 referrals to TASO in the 3rd quarter of 2003. TASO's quarterly report (January to March 2003) indicates that about 3,534 clients were referred to TASO by other agencies, including AIC, health units and hospitals, and others (TASO 2003a). Similarly, TASO makes referrals to other organisations. Between January and March 2003, TASO referred 172 clients to other agencies for more specialised services.

Organisations also have some joint activities. For example, they hold inter-group drama performances during national and international events such as women days, AIDS day, independence days and other international celebrated annual days. These examples are indicators of inter-organisational networks which are important for HIV/AIDS mitigation.

Inter-organisational networks are also realised through partnerships in the form of contracting out certain services by one organisation to another. Rather than viewing each other as competitors, they consider each other to be partners in the battle against HIV/AIDS. An organisation may hire the services of other organisations to carry out certain activities on its behalf. For example, in 2003, Population Service International (PSI) hired TASO's drama

group to run a public sensitisation programmes on its behalf because they did not have such a group. TASO records indicate that a total of 8 drama performances (HIV/AIDS related songs and plays) were presented to different communities in which PSI operates. This was so successful, that 8 more performances were scheduled for 2004 (interview with the counsellor in charge of the day centre and drama activities). Moreover, TASO (2002a) anticipates that the AIDS/HIV Integrated Model District Programmes (AIM¹²¹) may hire them to provide training in selected districts.

Activities at Organisations' Branch Centres

Both TASO and PTC/PLI have activities including singing, drama and recreation, held at their branch centres. The aim of these activities is to socialise their members and to provide psychological and emotional support to their clients/members.

At TASO centre, clients engage in drama activities and other performances such as songs. In addition to holding community drama performances, the TASO and PTC/PLI Drama groups occasionally sings for TASO clients who come for medication (see, figure 6.2 a, and b, below). For the members of TASO who are infected with HIV/AIDS, they often find their songs about living with HIV/AIDS encouraging, rather than the feelings of hopelessness associated with the HIV positive diagnosis, and for the youths and others who have tested HIV negative, engaging in drama and singing allows them to avoid risks of getting the infection. As Kelly (1995) argues, rehearsals and role playing increases chances of avoiding risks of infection with HIV¹²².

Another form of networking is through recreational activities. This is heavily emphasised by PTC/PLI. In addition to holding drama performances, PTC/PLI members organise recreation activities, including singing, drama and sports such as indoor games and friendly inter-organisational matches. The organisation sponsored 1164 recreational activities in 2002 and 1076 in 2003. For example, on 15/05/2004, the members of PTC/PLI held friendly matches with students from the Mbarara Institute for Social Development (MISD); the day's activities included: netball, volleyball, bottle racing, sack racing, football and tug-a-war (see figure 6.3 for some of these activities). Members of PTC often spend their time engaged in such

¹²¹ AIM is a 5 year programme jointly funded by USAID and Centre for Disease Control-CDC. It is a district programme aimed at developing approaches to HIV/AIDS multisectoral management (TASO 2002a).

¹²² See also, <http://www.id21.org/insights/insights64/art01.html> 20/11/06

activities. They socialise with their peers and this limits their engagements in risky behaviours that might lead them to contract HIV/AIDS. The following figures show some of the activities of TASO and PTC/PLI.

Figure 6. 1 TASO Drama Group Singing for the Clients at TASO Centre Mbarara



Figure 6.2 (a) TASO Drama Group Singing



Figure 6.2(b) Clients waiting for medication listens to the TASO Drama Group

Figure 6. 2 PTC/PLI Recreational Activities (Netball and Volleyball)



Figure 6.3a, Girls playing Netball

Source: Fieldwork



Figure 6.3b, Boys Playing Volleyball.

6.3 Participatory Management in NGOs

It has been stressed that the process of building social capital should involve, among other things, the creation of avenues for interaction and participation; that participation can be encouraged through relaxing the rules of engagement; and that encouraging participation is a form of legitimising action that creates feelings of having a stake in the programmes. It is through such a process of legitimating activities that successful HIV/AIDS intervention can

be achieved. In this section the focus will be on participation in management as one of the approaches employed by the NGOs to achieve such success.

The process of building social capital involves a multitude of activities aimed at confidence building for both the clients and staff of organisations, so as to enable them to alleviate the impacts of HIV/AIDS. Involving clients and staff members in the decision-making process is one such approach. TASO and PTC/PLI have created flexible channels of communication and organisational management structures in order to respond to people's needs. Flexibility implies that there are no strict rules to follow, in contrast to the traditional bureaucracies. Such flexibility not only allows members to interact directly with those in power, but also strengthens their networks. In the following section, I will consider how participatory management functions in these organisations, and the implications for meeting the challenges of HIV/AIDS.

6.3.1 Staff Involvement in Decision Making

Interviews with the management of TASO and PTC/PLI indicated that employees are recognised as key actors and are allowed to participate freely in the decision-making process. There are weekly management meetings in which staff members participate and make a valuable contribution to the running of the centre. Every week, employees meet to discuss and share their experiences from the previous week. In addition, there are monthly staff meetings. In the course of these meetings, staff members discuss how to handle certain cases. This focus on sharing experiences facilitates learning from each other.

In addition, NGOs approaches to management tend to be informal. An employee of TASO revealed in an interview that it was unnecessary to wait for a meeting to bring an important matter to the attention of the branch manager. "The manager can be reached any time and is always available to listen" (employee).

In addition, the organisations' sections and departments are autonomous. The granting autonomy of decision-making powers to various section heads, means that this takes place at different levels, and that decisions may be arrived at through informal discussions. This may result in decisions being made quickly, without bureaucratic delay. When asked about the extent to which members of staff are involved in decision making, the branch manager of TASO-Mbarara responded as follows:

Staff meetings are held at department level in order to review the performance of various departments. We hold weekly assemblies to review the week's activities. Above all, our meeting schedules are not as fixed as it may seem; we may call a meeting whenever issues arise. This helps the organisation to deal with problems and other issues without allowing them to accumulate. In addition to these meetings, there are monthly staff meetings where every staff member participates.

In addition, our organisation deals with emergencies and sometimes crises that require response without delay. If a driver is on his way to the centre and is informed of a patient somewhere in the community who needs immediate medical help, the driver is not required to come and get permission, as long as he has fuel and his schedule for the day is relaxed. He makes the decision and takes the patient for medical treatment. This is how we work. Everyone is a manager and contributes to the success of our organisation. (Interview with the Manager, TASO Mbarara)

The above response displays flexibility in management and relaxation of rules. Such flexibility is an effective management tool. Relaxing rules and routines also facilitates effective communication between management and staff of the organisation. This also facilitates effective implementation of programmes of the organisation.

6.3.2 Clients' Involvement in Decision Making

Recognising the contribution that beneficiaries (clients/members) make to decisions that affect their wellbeing, organizations allow them to contribute to the formulation of policies that affect them. Solutions are not only handed down by those at the top, but are formulated by those who are directly affected in cooperation with other experts. Clients of TASO, for example, are involved at all levels of organisation management and governance through various committees. When asked about the extent of client involvement in decision making, the branch manager of TASO-Mbarara responded as follows:

Our organisation is demand driven. We try to respond to the needs of clients as much as possible. This is done by allowing clients to identify their problems and provide solutions or proposals as to how such problems can be solved. For example, when preparing budgets and work plans for the centre, clients are consulted; they give us their proposals and their feelings about the organisation's programmes. Clients meet quarterly (in the clients' council). In order to make decisions regarding the branch, representatives of clients are invited. In

addition, clients are represented on various boards and committees. (Interview with Manager, TASO Mbarara)

At PTC/PLI the same views were reiterated. Moreover, the above views are supported by findings from interviews held with members of TASO and PTC/PLI (see table 6.8 below)

Table 6. 8 Clients'/Members' Participation in Decision Making

Level of Participation	Organisation	
	TASO (% response)	PTC/PLI (% response)
High	56	51
Low	44	49
	N= 79	N= 43

Note the question that was asked was: *To what extent do you participate in the organisation's decision making, such as participation in meetings?*

The figures in table 6.8 indicate that 56% and 51% of the members of TASO and PTC respectively answered that their level of participation in the decision making of the organisation was high. Other sources revealed that clients of TASO, for example, participate in and are represented at various levels of the management structure.

Participation at the Centre (Branch)

A TASO branch is headed by a branch manager who is responsible to the Chief Executive Officer (CEO). Below him/her there is the clients' council. The Clients' Council is a body through which clients voice their views regarding management and air their complaints to management. The council is respected by all the employees of the organisation. It has a full-fledged administrative structure composed of the chairperson, vice chairperson, secretary, treasurer and board members. The committee is democratically elected by clients at the annual general meeting (interview with Chairman Clients' council). Representatives from Clients' Councils at various branches of TASO form a clients' committee which gives feedback to the Chief Executive Officer (CEO) about clients' grievances, contentment and requirements.

In addition, there is the Centre Advisory Committee at each centre, which is composed of local leaders and other knowledgeable people who can provide advice about fighting HIV/AIDS. This body is elected by the clients and other registered members of the organisation at the annual general meeting (TASO 2002a: 45). The committee represents yet another bridging body, since it involves both local leaders and people not infected with

HIV/AIDS and those infected with HIV/AIDS. Clients advise management through the Centre Advisory Committee and the Clients' Council, thereby contributing to organisational decisions. For example, they can recommend the dismissal or suspension of any counsellor or doctor who mistreats them or is rude to them (interview with counsellor at TASO Mbarara branch).

Like TASO, PTC/PLI has an autonomous clients' committee¹²³ which has a chairman, vice chairman, secretary and the board members. The committee is elected by members and represents members to the AIC board.

Both TASO and PTC/PLI have decentralised internal management frameworks that depend on the participation of clients/members. For example, the Clients' Council at a TASO branch is autonomous, independent of the TASO branch management. This also applies to PTC/PLI's Clients' Committee. These committees ensure that members exercise certain freedoms; freedom to access resources, and freedom from influence, i.e. freedom to decide.

Freedom to access: A decentralised framework enables clients and members of the organisation to voice their needs, such as fund requirements, and to access information and new resources through their elected committees.

Freedom to decide: A decentralised framework gives local committees and organisations autonomy. As discussed earlier, AIC plays a supervisory role over local PTC/PLI clubs, but does not influence the way their activities are selected. Similarly, TASO plays a supervisory role over the activities of AIDS Community Workers (ACWs)¹²⁴. Local committees and ACWs arrange their activities, implement them and make periodic reports to the mother organisation - TASO.

Client Participation at Senior Management Level

Participation in decision making is not limited to the branch but continues up to the highest level of management. At this level, clients advise the chief executive officer through their elected Clients' Committee members.

From the above discussion, it can be argued that clients' participation is generally recognised in all the management structures of TASO, from the branch up to the highest level of

¹²³ This is an equivalent of the clients council at each TASO branch

¹²⁴ See, 8.7.2.

management. The management approaches mentioned above have the effect of allowing members and communities to make contributions to decision making. At AIC, PTC/PLI members also participate in decision making. Through their elected body, PTC/PLI members can contribute to the running of the organisation. Such approaches to decision-making reduce hierarchy and the centralization of authority, and encourage more participation and access to resources since they can decide how resources should be distributed among various activities. In addition, participation creates an enabling environment in which individuals are free to communicate the needs, grievances and problems which they face, without fear of being punished or sanctioned for that they report. Therefore, both individuals and organisations receive information immediately, which facilitates quick response and immediate problem solving. This type of management is widely practiced in TASO and PTC/PLI and may be the cause of their success in fighting HIV/AIDS (see chapter 8).

6.4 The Limitations of TASO and PTC/PLI in Building Social Capital

In spite of successes NGOs have had in building social capital, they have some limitations. These limitations include the failure to scale up their operations. Scaling up in this context may include expanding: a) inputs (process) and, b) outputs (activities and their impact). It means increased NGO involvement in terms of wider coverage and resource input.

This process involves increasing the scale of organisation activities, including a) reaching more people, for example through expanding the geographical coverage and, b) reaching other target groups¹²⁵. Such activities may extensively combat the impacts of HIV/AIDS (see discussion in chapter 8). Organisations may focus on widening the scope of activities; for example, targeting their population by increasing the volume of products such as condoms, which are given out to prevent HIV transmission or increasing drama sessions and information delivery mechanisms. The following discussion explores some of the limitations of HIV/AIDS NGOs with particular reference to TASO and PTC/PLI.

6.4.1 Lack of Capacity

HIV/AIDS NGOs are handicapped in terms of their capacity to handle the overwhelming numbers of clients. Although they have invested in training and expanding their staff and community volunteers, their capacity to handle the ever-increasing number of HIV/AIDS cases is still inadequate. Both the staff and clients of TASO have expressed concerns over the

¹²⁵See <http://www.aidsalliance.org/sw21874.asp> 14/04/06.

high ratio of clients to personnel. Interviews with TASO counsellors revealed that each counsellor at the centre has between 1000 to 1500 clients assigned to him for counselling; and on each counselling day, the counsellor meets between 6-10 clients. The logical implication is that it would take between 150-167 days for each counsellor to counsel all the clients assigned to him (assuming that all clients require counselling). This means that client-counsellor contact is limited.

6.4.2 Lack of organisational Routine

Another challenge was evident in the organisations' failure to keep records of the death rate of their clients. With no cure for AIDS, its long term effect is death. However, there is no data base at the organisations' centre for recording deaths. When the manager of Mbarara TASO branch was asked about the death rate of their clients, she claimed that she was aware of this problem and said that the organisation lacked the necessary staff to follow-up their clients closely. She said that the organisation relies on the relatives of the sick to report the death of clients, but that relatives rarely report these deaths. Thus, it has been difficult to build a data base for these cases. This information was confirmed by the lack of data on deaths in TASO reports¹²⁶. Ultimately, this makes it difficult to draw conclusions regarding the impact of the NGOs ability to scale up.

TASO has met the above challenges, by becoming increasingly encouraging client-to-client counselling, encouraging AIDS Community Workers' (ACWs) participation and involving volunteers. Moreover, clients face the pain and suffering inflicted by AIDS, in this respect they are in better position to provide advice to fellow patients. In addition to counselling fellow members, clients also report the deaths of other clients. However, they have not followed the reporting procedure consistently.

According to the manager of TASO Mbarara, voluntary work is important for the implementation of certain programmes. The Mbarara branch had a staff of 48 members: 7 volunteers, 4 part-time employees, and 27 full-time employees (interview with the manager TASO Mbarara branch). In addition, the drama group is composed of 25 voluntary members. Their work involves sensitising people through drama about HIV/AIDS.

¹²⁶ See for example, http://www.tasouganda.org/uploaded_files/11485384692004%20Annual%20Report.pdf, and http://www.tasouganda.org/uploaded_files/11485390392005%20annual%20report.pdf,

Similarly, some members of PTC/PLI work as volunteers in AIC, in addition to running their club. They receive and guide clients to counselling and other service departments, and they act as counsellors if a counsellor is absent or when the organisation is overwhelmed by a large number of clients. The manager of Mbarara AIDS Information Centre (AIC) branch had the following to say about the work of PTC/PLI volunteers.

They are very important to us. They save the situation with their voluntary work. On a day like Monday, as you can see for yourself, we are overwhelmed by clients. The counselling department cannot handle such a large number without external support. Yet, we cannot employ additional counsellors, because this only happens one or two days a week. To solve this problem, I do counselling myself (refers to himself), and PTC members fill the remaining gaps. (Interview with Manager AIC – Mbarara branch)

There are problems, however, which are associated with employing volunteers in HIV/AIDS NGOs as counsellors. For example at TASO, the problem with client-to-client counselling is that some of the clients have tended to present themselves as employees of TASO. The head of the counselling department at TASO Mbarara expressed his concerns regarding client involvement in the activities of TASO, such as counselling, in an interview:

They distort information, and may blemish the work of TASO since they have not been fully trained in counselling. These people are only given basic training in counselling to fill emergence gaps in communities but not a comprehensive training in counselling. However, some of them have taken it up as their job to offer counselling services to every HIV/AIDS patient. This is not our objective when we employ the services of volunteers. (Interview with the head of counselling department, TASO -Mbarara)

6.4.3 Lack of Funding for Volunteers

Recognising the important work volunteers do, these organisations face a challenge of how to reimburse them. TASO volunteers decried the appalling conditions under which they were facilitated as volunteers. While clients are aware that they are doing voluntary work for TASO and for themselves, they are disgruntled over the incentives provided for their work. According to clients, the amount they receive is far below the amount required to keep them alive. According to one respondent, TASO pays them less than US\$20 (Uganda Shillings 36,000) per month, in comparison with the over US\$400 (Uganda Shillings 750,000) as monthly salary that permanent employees of the organisation are paid.

Like other volunteers, the members of the drama group receive very little remuneration. The group is engaged to sensitise the public about the dangers of HIV/AIDS and related problems such as stigmatisation. For each day they work, the members are given about, US\$ 3, to cover the cost of transport (interviews with both clients and staff of TASO).

The above concerns were also expressed by PTC/PLI volunteers assisting in AIC activities. When asked how much PTC/PLI volunteers are paid for their services, the manager of AIC Mbarara said, "I cannot disclose the sum, but it is not much. We only motivate them; the organisation is strict about additional expenditure" (interview with manager, AIC Mbarara).

6.4.4 Lack of Infrastructure

HIV/AIDS NGOs face yet another challenge in the form of poor infrastructure. They are largely dependent on the government infrastructure, such as buildings, and on donor support. With an increasing number of clients registering to receive services at their centres, it is very difficult for these organisations to find the necessary space and personnel to cope with the new clients. It is likely that these organisations will have to start sending new clients away or overcrowding may hamper their operations. In addition, they lack the capacity to support programmes for all their clients who are needy. In an interview with an official of TASO, I asked the following question: *What are the failures of the organisation?* The response was:

We are growing everyday. We do not have enough personnel and space. There are increasing numbers of AIDS patients in need of food, but the supplies from the ACD/VOCA and USAID are not enough. Our policy is to give food aid only to a family with a minimum of 5 needy members. This is a challenge, since even if there is only one hungry member of the family he/she needs to survive. We cannot provide food to all these needy families.

We are also facing an influx of orphans. There are so many. We can only help a handful because of limited funding.

The other failure is that we cannot extend our services to those who live far from the TASO centre. We do not have the capacity to reach them. (Interview with the counsellor in charge of day centre)

TASO operations are limited to places within a short distance from the main TASO centres. Field activities outside the centre are now carried out within a radius of 35-70 Km; in 1993, the radius of operation was 20 miles or 32 Km from the centre(O'Manique 2004; TASO

2002a). Ten years have passed, but it still operates within the same distance from the main centre. The credit which can be given to the NGOs for reaching the poor, the needy, and in particular, the great number of people with HIV/AIDS who are outside the project area, is limited.

In order to address the multiple impacts of HIV/AIDS, TASO has an integrated service delivery system. Centres provide counselling, medical care, AIDS education, home care and social support to clients, orphans and vulnerable children. However, counselling orphans is still only a small component of the programme; it is only provided to those who are sponsored in schools, and even this is not adequately done. The head of social support services claimed that,

With limited staff in the department (they are only two), we have not managed to visit these children at school as required. We may only be able to afford one visit in a school term. We rely on the schools to do what is necessary. However, school officials' training in counselling is general and may not address AIDS-related issues such as stigmatisation, discrimination and the trauma caused by loss of parents. Such problems are unique, and specific to AIDS orphans. This calls for special counselling, which we are unable to provide regularly due to lack of personnel. (Interview with the head of department for TASO social support services-Mbarara branch).

The discussions above have shown that HIV/AIDS NGOs such as TASO and PTC/PLI have limited capacity to successfully fight HIV/AIDS alone. This calls for the involvement of other actors in the fight against HIV/AIDS. It is important therefore, to point out that, mutually reinforcing relationships (synergy) between government, NGOs and other actors such as the private care givers are important in meeting the challenges of HIV/AIDS. Through collaboration with different government departments, and other actors, the NGOs role in addressing HIV/AIDS-related problems is strengthened. The discussions in the rest of the chapter will focus on these relationships and their relevance for addressing HIV/AIDS challenges.

6.5 State-NGO Relations

Existing literature about the NGO-state relationship indicates that governments in many developing countries fear that the existence of NGOs may erode state political power and threaten national security (Hulme and Edwards 1997). Jamil (1998: 10) suggests four distinct ways in which NGOs relate to government: a) Benign neglect: the government is not

concerned about NGOs activities, which creates a state of peaceful coexistence. He argues that this kind of relationship existed in Bangladesh in the early 1980s. b) Cooperation: NGOs relate to government through consultation and collaboration. Consultation implies that the NGOs are advised on development issues, and collaboration implies partnership, c) Competition: the NGOs and the government are considered to compete in the implementation of development programmes. The state's performance is often judged in relation to that of the NGOs; and the NGOs are viewed as competitors for funds from donors and as the "darlings" of the donors. Such relationships breed disharmony and conflicts. d) Confrontation: Often there is a clash between governments and NGOs. In this situation, there is considerable mistrust between the two, which interferes with the effective functioning of NGOs.

With respect to service organisations, the government of Uganda has preferred the second relationship with NGOs, and recognise their importance in development, and have therefore opted to allow their contributions in the mobilisation and delivery of services. However, these governments monitor and watch what NGOs do in order to harmonise their activities with those of government and to objectively achieve development goals. It should be mentioned however, that with regard to other forms of NGOs especially those engaged in advocacy and human rights, conflict and confrontation is the form of relationship between them and government¹²⁷.

By means of control, monitoring and co-ordination mechanisms, the government of Uganda is able to watch what NGOs are doing (Muriisa 2004). The monitoring and control apparatus set up by the government requires NGOs to register their programmes and their activities are monitored through registration, government representation on their boards, etc (Muriisa 2001). This kind of relationship often causes tension between the government and the NGOs. Co-ordination, on the other hand, allows the NGOs to operate under the guidance of government. Thus, NGOs are usually required to follow guidelines stipulated in the national policy, which creates harmony between governments and NGOs.

It has to be stressed that in the context of this study state-NGOs relationship is characterised by cooperation. As discussed in chapter 5, government provided a favourable environment for the formation of HIV/AIDS NGOs. It will further be discussed in chapter 7 that

¹²⁷ Since I am concerned with service organisations, I will not discuss these issues regarding advocacy NGOs.

government recognises the role of NGOs and CBOs in fighting HIV/AIDS. In this section, I explore how the NGOs relate to the government with respect to HIV/AIDS problem.

As stressed, the government of Uganda recognises the importance of partnership with NGOs in order to fight HIV/AIDS. There is widespread recognition that no single actor (individual, organisation or state) can successfully solve the HIV/AIDS problem without involving others (MoH 2003; TASO 2002a). Recognising the potential of the state, NGOs have focused on developing synergistic relations rather than working in isolation.

TASO (2002a: 5), for example, notes that political goodwill and support are vital for the success of HIV/AIDS service delivery. The manager of TASO-Mbarara said that, “the government of Uganda has always provided a favourable environment as far as HIV/AIDS is concerned” (personal interview).

HIV/AIDS organisations refer some of their clients to government hospitals for treatment. Although the government health care system continues to be plagued by inadequate medical supplies (Garbus and Marseille 2003; O'Manique 2004), hospital staff give people the necessary care. They offer them whatever assistance they can. According to one TASO client:

We are always treated well in government hospitals, although there is no medicine sometimes. Doctors and nurses provide what they can; they are compassionate and will give you the medicine if it is available. They do not sell the medicine to you. In contrast, the policeman will tell you that there is no paper in the office to write your statement on, so that you pay him to go and “buy” the paper. (Interview with respondents)

Furthermore, there is widespread recognition on the part of the HIV/AIDS organisations that they need interdependent relationships with the government. The nature of the state-NGO relationship is symbiotic and is enacted in a reciprocal way. In this respect, the NGOs have created linkages with the state at both administrative and operational levels.

At the administrative level, government and NGOs plan some of the HIV/AIDS activities together. For example, the commemoration of international AIDS day 2003 in Mbarara district was a jointly planned programme involving the government, TASO, AIC and West Ankole Diocese. For planning and coordination purposes, NGOs are represented on the

District AIDS Committee (DAC) and Parish Aids Committee (PAC). While the representative on DAC is an employee of the organisation, the PAC representative is drawn from the local community. As will be stressed¹²⁸, the involvement of the people's representatives on government committees not only increases the legitimacy of the programmes, but also promotes a trusting relationship between government and citizens.

At the operational level, organisations sign memoranda with government authorities committing themselves to provide various services and use the available health facilities. Thus, TASO and PTC/PLI operate in health facilities owned by the government. For example, apart from the Mbarara TASO centre, which TASO built on independently owned land, nearly all other centres are housed in government health facilities. Even the headquarters of TASO, although constructed by TASO, it was built on land allocated to it by the government within the country's largest hospital's compound.

Likewise, although AIC rents premises for their branches, the testing and counselling carried out in satellite areas, as well as PTC/PLI activities are conducted in public and sometimes in private health facilities. An interview with both managers of TASO and AIC revealed that, where there are no public health sector facilities, they are handicapped. They refer difficult cases which they cannot handle to these facilities. In addition, they use them as mobile clinics and outreaches; and in some instances, the hospital and health centre staff participate in the arranged programmes. For example, AIDS community workers (ACWs) who offer counselling and perform HIV/AIDS dramas in communities do so at government health centres on clinic days, in addition to Sunday presentations at churches. The aim is to obtain the assistance of the government health officials. In an interview with both TASO counsellors and AIDS community workers, it was revealed that they count on the services offered by the government health workers: for example, according to one counsellor, "government workers will offer treatment as well as do counselling" (interview with counsellor in charge of Nyakayojo community).

At the local level, both TASO and PTC/PLI seek the assistance of local leaders and the church to mobilise the population for their drama presentations. Usually, the organisation has to seek the local council chairperson's permission in order to access the local communities.

¹²⁸ See 7.4

When the person in charge of counselling services at TASO-Mbarara was asked “*How does government feature in your programmes?*” he responded:

We are interacting with leaders at different levels. At the national level, we get technical support from the Uganda AIDS Commission (UAC), which is the supervisory body. We are under Uganda AIDS Control Programme, which is directly controlled by the Ministry of Health. We work hand in hand with the District Directorate of Health, as well as political officials. District officials have to be made aware of what is taking place. Before we do anything, we hold a sensitisation workshop involving all the stake-holders at district and sub-county level. We go to communities that invite us with the knowledge of the local council chairpersons who some times does the mobilisation of local people. TASO and Government are working together to alleviate HIV/AIDS. (Interview with head of department, counselling services)

The above response summarises the nature of the government-NGO relationship with regard to HIV/AIDS, while the example of NGO collaboration with other actors is presented in table 6.9 showing the different organizations collaborating with TASO.

Table 6. 9 TASO Collaborators

Category	Organisations	Area of Collaboration
Government departments	Uganda Aids Commission, Ministry of Health, Government Hospitals, Districts/Local Governments, Uganda Virus Research Institute	Coordination, referrals, funding, research, and joint planning
Care and Support	Hospice, Kitovu Hospital, Midway, Nsabya Hospital, AIDS, Widows, Orphans, Family Support (AWOLFS), Mengo, Lubaga and Kamwokya	Referrals,
People Infected with HIV/AIDS	National Guidance and Empowerment of People with HIV/AIDS (NGEN), NACWOLA, POMU	Information dissemination and advocacy
Research and Academic institutions	Makerere University, Centre for Disease Control and Prevention, Joint Clinical Research Centre, Medical Research Council, Academic Alliance, Institute of Public Health	Research and knowledge sharing
CBOs and Grassroots Communities	St Francis Counselling	Referrals
Others	Plan International, Uganda Network of Aids Service Organisations (UNASO), THETA, ACTIONAID, World Vision, Uganda Business Coalition, Regional AIDS Training Network (RATN)	Capacity Building and Training

Source: TASO (2002a: 3).

6.6 The Role of the Private Sector in Fighting HIV/AIDS

The Ugandan government policy on HIV/AIDS is all inclusive. It has focused on a wider involvement of different types of actors, out of which a vibrant private sector involved in HIV/AIDS has evolved. The involvement of the church, the media, the business community and other NGOs such as Hospice is related to this emphasis. The purpose of this section is to discuss the role of the private sector in the fight against HIV/AIDS. It must be borne in mind that the private sector is part of the wider non-governmental sector. The actors involved in the private sector provide complementary services to those of the government and the NGOs. In this section I will discuss the role of the business sector, and care and service organisations such as Hospice in the fight against HIV/AIDS.

6.6.1 The Role of Business Organisations

In the face of the rapid growth of multinational companies and their rush into the growing markets in Africa, India and China, the prevalence of AIDS is also increasing in these countries. In Africa, the HIV/AIDS situation has been alarming for the last twenty years; in Asia, particularly in India and China, HIV/AIDS is more recent, but unless something is done, they will soon catch up with Africa. The business community, threatened by the rate of infection among their employees and the loss of a potential market, are now focused on fighting the spread of the disease. In order to effectively fight HIV/AIDS, they have established The Global Business Coalition (GBC) to fight HIV/AIDS. The coalition currently has about 200 members. In Africa, most of the members are based in South Africa¹²⁹. Although membership to the GBC is limited, business organisations in various countries are nevertheless taking an interest in the battle against HIV/AIDS. They either act in partnership with other actors and the government, or they engage in complementary activities. For example, by taking HIV/AIDS messages to the workplace and providing HIV/AIDS-related services for their workers, they complement other actors.

In Uganda, both local and multinational companies have developed an interest in the social service sector, identifying themselves with the problem of HIV/AIDS, in particular. Obviously, the response from the business sector is not purely philanthropic; it is motivated by a “more comprehensive understanding of corporate interests” (Trevor 2004). Nevertheless, their role in fighting HIV/AIDS cannot be ignored.

¹²⁹ See, <http://www.businessfightsaids.org/site/apps/nl/newsletter.asp?c=gwKXJfNVJtFandb=1009205> 18/08/06.

HIV/AIDS has had an impact on many companies; this may be due to the loss of employees, to the increased expenditure and absenteeism due to sick workers, and to dwindling markets due to the high death rate of PWHA. These factors all have an effect on the production and profitability of business corporations. As a result, business organisations have become key actors in HIV/AIDS prevention; they constitute a source of funds, since they make donations to organisations involved in HIV/AIDS activities, and they bring HIV/AIDS services to the workplace. Through such activities, funds that were once privately owned are now finding their way to the people who are needy, such as AIDS patients. These funds can help to solve some of the problems which these people face due to HIV/AIDS.

Private sector policy targets those involved in programmes which can reverse the trend of HIV/AIDS spread. Building awareness and strengthening preventive strategies remains central to the private sector programme in this field. In Uganda, companies such as Coca-Cola sponsor major events in which HIV/AIDS organisations are involved. For example, in Mbarara, Coca-Cola has provided refreshments at performances put on by the TASO drama group at a number of social and political events. For example, on the International Labour Day (01/05/04), Coca-Cola provided all the refreshments¹³⁰. It is on such occasions that the government usually announces its partnership with civil society organisations. Apart from funding TASO in this way, Coca-Cola is funding other activities in other organisations. In an interview with *The New Vision* reporter, the manager of Coca-Cola Uganda was asked the following question: “Do you have social investment programmes”. He responded: “We are very committed to fighting AIDS. We have teamed up with Uganda Women’s Effort to Save Orphans-UWESO” (Olaki 2004)¹³¹.

Other companies are also supporting HIV/AIDS initiatives. Celtel Uganda Limited (a cellular phone service provider) is sponsoring the schooling of orphan children registered under TASO. In 2004, the company paid the school fees for 50 (22 male and 28 female) children who are registered in TASO’s social support programmes (TASO records). Donations from such companies to NGOs like TASO have enabled them to expand their programmes to fight HIV/AIDS.

¹³⁰ I attended this function and observed the support TASO was given by Coca-Cola

Beyond the level of individual company initiatives, private companies have developed network organisations with the aim of fighting HIV/AIDS. Supported by USAID, the private sector in Uganda formed an umbrella organisation, The Uganda Private Sector Alliance on HIV/AIDS (UPSAA), which brings together all private sector employers that are dedicated to bringing the battle against HIV/AIDS to the work place. Membership in the organisation includes the Uganda Manufactures Association (UMA), the National Trade Unions Organisation (NOTU), the Federation of Uganda Employers (FUE) and Midway Centre. The terms of reference for membership in UPSAA include bringing HIV/AIDS prevention, treatment and support programmes into the workplace¹³².

6.6.2 The Private Sector and Care Giving

In the face of biting poverty and limited public health services, the private sector has developed into an important health and care provider. The founding of private sector organisations was facilitated by the passing of laws that facilitated this process (see Hospice below). Among the prominent health and care givers are orphanages and Hospice Uganda. Although these two institutions are not widespread in Uganda¹³³, they nevertheless provide care to the needy. For example, the *Friends Orphanage School*, located in Kampala, takes care of HIV/AIDS orphans and street children. It provides free education, food, housing, and medical supplies to about 72 HIV/AIDS orphans. In a situation where there are about 1 million orphans, such coverage is obviously limited. In addition, such orphanages are concentrated in the urban areas and not in rural areas where majority of HIV/AIDS orphans are living. Nevertheless, these orphanages complement the efforts of families and relatives who are taking care of orphans, including AIDS orphans.

Like orphanages, the hospice movement in Uganda provides care and support, in this case to terminally ill AIDS patients. The role of Hospice Uganda in addressing the HIV/AIDS problem in Uganda warrants closer examination.

¹³¹ UWESO is a nongovernmental organisation that was founded in 1986 by a group of women who had lived in exile and wanted to address one of the side-effects of the war - orphans. With the increasing number of orphans, including HIV/AIDS orphans, the organisation has diversified to include all orphans, irrespective of their origin.

¹³² http://kampala.usembassy.gov/ugandan_business_to_fight_aids.html 15/04/06.

¹³³ Orphanages as an institution are not fully developed. Most orphans are taken care of by family members and other relatives, and most NGOs such as TASO have preferred to take care of orphans in their homes or foster families instead of establishing orphanages. Likewise, the hospice movement has limited coverage, with only three centres in Uganda.

Hospice Uganda

Hospice Uganda began as an NGO to provide palliative services and care to patients and their families in 1993. The founding and operation of Hospice Uganda has been indirectly supported by the government through the passing of favourable laws (Spence, Merriman, and Binagwaho 2004). These laws were essential to the establishment of Hospice in Uganda, in contrast to Nigeria where no such encouragement was offered¹³⁴. Hospice has three branches: in Kampala, Mbarara and Hoima. The Mbarara and Hoima branches were opened in 1998. Although Hospice does not target HIV/AIDS as its main focus, it incorporates HIV/AIDS in its programmes. Given the rapid spread of HIV/AIDS, there has been an increase in the number of people suffering from the infection, especially those with full-blown AIDS. Thus, the involvement of Hospice in HIV/AIDS activities was driven by the need to provide care and support to those in the late stages of the disease. This is a specialised service which was previously lacking in Uganda. Hospice collaborates with other NGOs working in the service sector. For example, it receives referrals from government hospitals, TASO, and other health institutions¹³⁵.

Activities of Hospice

(a) Home-based Care

Hospice Uganda provides palliative care to about 3.5 million people in Kampala, Mbarara and Hoima. About 178 patients in Mbarara were receiving direct home-based care in 2004. The initiation of this home-based care is in line with the cultural needs of the patients, since most cultures prefer patients to be buried from their homes in their ancestral lands. Equally important is the fact that, in view of the prolonged final stage of cancer or HIV/AIDS, the cost of maintaining patients in their home is less than it would be in institutionalised settings such as hospitals. Home care may also solve the problem of increased funeral expenses due to the cost of transporting the body (see chapter 4 - 4.5.3) which is one of the social economic impacts of HIV/AIDS. Thus, home-based care can reduce both the expenses incurred when patients require long-term care and those involved in transporting the body to the burial ground when the patient finally dies.

Secondly, home-based care has implications for stigmatisation and social discrimination. Because patients are in their homes, hospice staff train family members to care for the patient.

¹³⁴ See <http://www2.edc.org/lastacts/archives/archivesMay02/intlpersp.asp> 16/04/06

This training involves dissemination of practical knowledge about the dangers of contracting the diseases and preventive measures to be taken during care giving. Fears of contracting the disease and other myths regarding the contraction of HIV/AIDS are overcome in this manner. This training also helps to minimise stigmatisation.

Finally, home-based care constitutes an avenue for social unity and support, especially for those who are ill. Such support has positive psychological benefits for patients, engendering confidence and peace. Thus, the patients may live longer than they would live without that kind of care.

(b) Teaching and Training

The goal of Hospice in Uganda was not to provide direct palliative care to the whole country. Their main goal was to provide training to health professionals at various levels. People with such training would be able to provide care to people who need it throughout the country. The training programme has focused on medical professionals at both undergraduate and graduate levels at Mbarara University and Makerere University. Training is also offered to staff, nurses and physicians in various districts in Uganda. By 2002, Hospice had trained about 800 health professionals to provide such care. Their students gain practical experience working with various organisations involved in HIV/AIDS activities such as TASO and Midway. Such experience exposes them to the needs of people suffering from HIV/AIDS. Clearly, the involvement of Hospice in training programmes and providing care services to PWHA reflects the synergy between government and the private sector and the non-governmental sector in general (see chapter 7). It is important to mention that the training offered to families of the HIV/AIDS patients facilitates integration and interactions between individuals with their families and other people in the community. This improves the life conditions of PWHA.

6. 7. Conclusion

The purpose of this chapter was to discuss the process by which HIV/AIDS NGOs build social capital, and how such a process might be linked to their ability to alleviate the impacts of HIV/AIDS (see discussion in chapter 8). The chapter has considered various ways of creating social capital, including: increased interaction between members and clients through regular meetings, family support and sensitisation, inter-organisational networks, community mobilisation and training. Moreover, it is dependent on flexible organisation management

¹³⁵ <http://www2.edc.org/lastacts/archives/archivesMay02/intlpersp.asp> 16/04/06

which allows the clients/members and staff to participate in the decision-making process, which facilitates cooperation and communication in the organisation. The chapter concludes that such cooperation and communication are vital if organisations are to meet the challenges of HIV/AIDS.

A critical examination of the role of NGOs, with particular emphasis on their ability to scale up their operations, leads to the conclusion that they have only limited capacity to scale up. These limitations make it clear that no single actor can successfully address the problem of HIV/AIDS without the support of others (either in direct or indirect collaboration). Therefore, the conclusion is that NGOs alone cannot address the problem of HIV/AIDS; by implication, the need for synergy is even more crucial. Given this observation, a discussion about the importance of NGO-state partnership and the role of the private sector in the fight against HIV/AIDS is made. The discussion shows that with the limitations of HIV/AIDS NGOs such as TASO and PTC/PLI, the private sector is filling the gaps by not only providing complementary services, but also providing both material and financial support to these NGOs. The next chapter examines the role of the state in facilitating the involvement of various actors, particularly the non-governmental sector, in the battle against HIV/AIDS.

CHAPTER 7

The Role of Government in Facilitating the Development of Social Capital to Fight HIV/AIDS in Uganda: Evidence of Synergy

7.0 Introduction

Uganda is one of the countries that have managed to control the spread of HIV/AIDS. Compared to other Sub-Saharan African countries, HIV/AIDS interventions in Uganda have been successful. This success has been possible because of many factors, but of particular interest for this study is that there is more social communication with regard to HIV/AIDS in Uganda than any where else in Africa. For example, Low-Beer (2004a; 2004b) asserts that it is easy to talk about HIV/AIDS or to know someone with HIV/AIDS in Uganda, and president Museveni asserted that success in Uganda was because of social immunisation. Several questions may be raised in this context: how has it been possible to develop relationships between people with HIV/AIDS and those without; how is communication about HIV/AIDS maintained; and why is it possible to get to know someone with AIDS more easily in Uganda than elsewhere in Africa? Another question that may be raised concerns the reasons why Uganda, which is a poorer country than South Africa for example, has been more successful in fighting HIV/AIDS than countries considered economically prosperous (Ainsworth, 2000; Parkhurst, 2004). Moreover, one may also ask how the harmonious relationship that prevails between the various actors and the government has been established in the fight against HIV/AIDS in Uganda.

The previous chapter presented the contributions by HIV/AIDS NGOs in facilitating formation of social capital, this chapter will try to answer the above questions by focusing on the role of the government in fighting HIV/AIDS and, more specifically, by considering the role of the government not only in facilitating and sustaining the social networks necessary for HIV/AIDS intervention, but also the active involvement in other activities such as making drugs for HIV/AIDS patients available and provision of health care infrastructure. In addition, the ways in which the government and civil society, and in which the state, NGO and donors interact with each other, will be examined. This cooperation may take the form of either complementarity or embeddedness, as mentioned in chapter 2 (2.4.1).

As mentioned in chapter 2, “complementarity is more relevant for the case of Uganda with respect to HIV/AIDS, since embeddedness requires complex institutional settings to allow sustained relationships across the public-private divide. According to Evans (1995), this can be achieved if robust bureaucracies are in place. And this entails achieving internal coherence across and within departments, while remaining both externally autonomous from dominant class factions and yet embedded in society. It has therefore to be stressed here that the state has tried to create avenues for interaction and collaboration and creating an environment that facilitates strengthening social relations between individuals, groups and communities and between various actors (see for example the role of local councils – 7.3 and the multisectoral approach – 7.4), but there is still a long way to go since, there is evidence¹³⁶ showing that there is still political influence in allocation of funds for HIV/AIDS intervention. Nevertheless, the chapter will try to discuss how state society interactions facilitate cooperative behaviour of citizens and how this cooperation promotes effective mitigation of HIV/AIDS challenges.

7.1 Initial Response to HIV/AIDS: The Role of Government

Until recently, ARV drugs had contributed only marginally to Uganda’s success. The majority of Ugandans who are HIV positive do not have access to antiretroviral therapy (ART). The cost of treatment is high and only a few businessmen and the elite can afford it. Furthermore, ARVs are a life-long treatment, therefore, the maintenance and follow up of people on Antiretroviral drugs (ARV) requires highly qualified medical personnel, advanced laboratory equipment and technicians (Barnett and Whiteside 2002); these are in short supply in Uganda. It is only recently that – thanks to the joint efforts of United States Agency for International Development (USAID), the Ministry of Health (MoH) and the Joint Clinical Research Centre (JCRC) – free antiretroviral drugs (ARV) have been given to HIV positive persons through various implementing agencies, including government and private health centres, such as mission clinics. By March 2006, over 41,000 AIDS patients were receiving treatment in 35 centres nationwide (telephone interview with a JCRC official).

At the heart of Uganda’s success story is the preventive focus in fighting HIV/AIDS and the integration of this approach with other mitigating approaches that target the social and economic environments. Preventive measures, coupled with the involvement of various

¹³⁶ see for example, Nyanzi and Luggya (2006); <http://www.newvision.co.ug/D/8/12/488577/muhwezi> 22/03/06 and <http://www.newvision.co.ug/D/8/12/534446/muhwezi> 26/05/06

actors in the fight against HIV/AIDS, have contributed to the decline of HIV prevalence which was registered in Uganda between 1991 and 2002.

It should be noted that a strong government commitment is crucial in this battle, particularly in developing an environment that favours mobilisation of the necessary resources to successfully combat HIV/AIDS. As mentioned in 4.3, in Uganda, the AIDS pandemic emerged at the time when the country was facing political and economic challenges. As a result, the government played a minimal role in fighting HIV/AIDS during this period, simply initiating preventive education programmes. Given the international economic climate at the time¹³⁷, there was increasing international pressure for the government to roll-back. Thus, preventive approaches were emphasised, and behavioural change education as a means of preventing transmission of HIV/AIDS was prioritised. Meanwhile, funding of health care was left to the private sector to be financed by individuals. The initial focus of preventive approach was on the sexually active groups such as the sex-workers and the youth prone to HIV infection. This was because, as Barnett and Whiteside (2002) argue, there are new cohorts of young people reaching adulthood and becoming sexually active every day that need to be kept free of HIV/AIDS.

The initial government response to HIV/AIDS was marred by the long window period of HIV before the signs of AIDS appear. This meant that AIDS was not immediately recognised as a major problem. Eventually, however, HIV/AIDS was placed high on the agenda of the government development programmes (Allen and Heald 2004; Oketcho, Kazibwe, and Were 2001; Okware et al. 2001). In 1997, it was integrated into the mainstream poverty eradication programmes through the provision of funding to local communities for specific programmes targeting poverty and income generation.

At a time when many African governments such as Kenya and Zimbabwe were denying the existence of HIV/AIDS (Fredland 1998; Kayazze 2002), the Ugandan government openly declared to both people at home and abroad the existence of HIV/AIDS. Within Uganda, the strategy was to spread the message to all parts of the country that HIV/AIDS was on the advance. The initial messages focused on the modes of transmission and its dire consequences, including death. Messages were spread across the country through radio

¹³⁷ During the 1980s there is increased demand for privatisation and limited public expenditure.

programmes. Because of the devastating impact HIV/AIDS had on its victims, it was likened to a beast which the population needed to guard themselves against. Mukasa (2004)¹³⁸ quotes President Museveni; “Having identified the causes, our first line of defence was to shout and let the population know that a lion was on the loose and the lion is AIDS and it spreads like this.” Outside Uganda, on the international scene, the declaration that HIV/AIDS was on the rise in Uganda was one strategy for attracting international assistance.

The response by the government of Uganda in combating the AIDS pandemic, rather than denying its existence, remains unparalleled and unmatched on the African continent (O'Manique 2004). It has been such openness, especially on the part of the president, that enabled Uganda to succeed in the battle against HIV/AIDS (Barnett and Whiteside 2002: 116).

Having acknowledged the presence of HIV/AIDS, the government of Uganda had to formulate strategies to deal with the problem. The government focused on creating an environment that enabled and encouraged the activities of various individuals and groups – including HIV/AIDS NGOs, Faith Based Organisations, and private individuals such as herbalist, and on providing policy guidelines and procedures for coordinating and monitoring these agencies. In addition, the government established agencies for example, the Uganda AIDS Commission and the National HIV/AIDS Partnership Forum and various committees such as the District AIDS Coordination Committees (DACC), that would encourage interaction between different actors involved in fighting the HIV/AIDS epidemic, and between these actors and government agencies such as ministries. However, as mentioned earlier, HIV/AIDS has largely remained a health issue as such interaction between various ministries has remained minimal (see also Putzel (2003).

7.2 Political Leadership

The importance of senior political leaders in promoting and sustaining the fight against HIV/AIDS cannot be ignored (Parkhurst and Lush, 2004), although it is usually found to be the missing link. President Museveni once claimed that, where AIDS is a big problem, it is mainly due to leadership (Cobb 2002)¹³⁹. Considering the importance of leadership in fighting HIV/AIDS, TASO (2002a: 9) asserts that, “It has been demonstrated that a lot of

¹³⁸ <http://www.newvision.co.ug/D/8/13/393145/HIV/AIDS> 13/10/2004

¹³⁹ <http://fr.allafrica.com/stories/200205080152.html> 08/05/03

difference can be made in fighting the epidemic if correct stewardship is present in the form of senior political leaders with a vision of freeing its people from HIV/AIDS". This commitment of senior political leadership is crucial for the provision of resources necessary for fighting HIV/AIDS. As the World Bank observes,

Not all African leaders and development agencies are convinced of the seriousness of the epidemic nor do they realise the potential impact it will have on the country. A strong political commitment to the fight against HIV/AIDS is crucial to provide the needed resources, strong leadership and enabling environment that are critical to controlling the epidemic, spread and caring for the nation. (World Bank 2000b: 25)

In Uganda today, HIV/ADS activities have the full support of government from the highest political office – the presidency. The Ministry of Health report, *Annual Health Sector Performance Report for the Financial Year 2000/2001*, notes that

HIV/AIDS has causes and consequences far beyond the health sector...HIV/AIDS affects all strata of population and poses a serious threat to the socio-economic life and development of the country...the national response has therefore been characterised by a policy of openness backed by effective political and resource support from the highest level of government. (MoH 2001a: 1)

According to Webb (2004), the president of Uganda – Museveni, has taken fighting HIV/AIDS as a personal commitment. Under Museveni's guidance, the initial information campaign was followed by an offensive to mobilise stake holders in the fight against the disease. Museveni argues that in Uganda, the effective strategy for combating HIV/AIDS is through political meetings. When he goes to political meetings in villages, he talks about HIV/AIDS; this is necessary because, when they say a doctor is coming to the village, very few people will come to the meeting, but when they say he (Museveni) is coming, nearly everybody will turn up. In this way, the message will reach many people. On the subject of the political debate model, Museveni has reiterated the message of political leadership on many occasions in his public speeches around the country. He maintains that Uganda's success in combating HIV/AIDS has been due to the implementation of this policy in collaboration with many partners, including NGOs and the civil society.

In my interviews, various respondents, especially clients/members of TASO, acknowledged the importance of political leadership in facilitating effective prevention of HIV/AIDS. I asked respondents the question “mention any of the government-aided HIV/AIDS programmes you know”. Some of them mentioned “Museveni”, as one of the programmes (see 7.9). This indicates how deep his commitment goes and how closely people identify him with the battle against HIV/AIDS. This recognition increases the confidence which people have in the government’s efforts in this field.

Uganda’s political leadership is not limited to Museveni, but also includes other government officials who talk about HIV/AIDS at all their political meetings and public addresses. In 2000, the then Minister of Health Dr. C. Kiyonga urged political leaders to talk about HIV everywhere they hold meetings or attend functions. He implored them, saying: “No function or meeting should pass without a word on AIDS. The fight is not over. There is still a long way to go” (Busharizi 2000)¹⁴⁰. This philosophy has continued up to the present. For example, during the International Labour Day celebrations in 2004¹⁴¹, the local council five (LCV) chairman in Mbarara District, decried the rate at which HIV/AIDS was depleting human resources. He pledged the government’s commitment to fight HIV/AIDS and called upon everyone to join this fight. In his address he mentioned that plans are underway to make a law that would make employers to start programmes to fight HIV/AIDS at the work place so that workers who become/or are infected with HIV/AIDS can be cared for. He noted that discussions with employers, including private businesses had begun with a view of making these companies to realise the importance of getting involved in fighting HIV/AIDS before a law is put in place. According to him,

“when you put a law in place before the implementers are sensitised, it will appear to be an imposition on them, and implementation is likely to fail. Therefore we began with the sensitisation and dialogue process. So far this is going on well and some companies like Coca-Cola are already involved”. (Transcribed from the speech of the LCV Chairman Mbarara Addressing congregation on Labour Day 01/05/2004)

He also recognised the work of TASO and other organisations such as PTC/PLI which are already involved in the fight against HIV/AIDS. Such announcements of the government’s

¹⁴⁰ <http://www.aegis.com/news/re/2000/RE001205.html> 15/06/06

¹⁴¹ I attended the celebrations and took notes about how government is fighting HIV/AIDS with respect to workers.

commitment to fight HIV/AIDS and the recognition of NGOs' role increases the confidence people have with such organisations and their expectations of government action.

As will be discussed in chapter 8, political support has positive implications for people's attitudes to those with HIV/AIDS, which may make a positive contribution on reducing stigmatisation and social discrimination, and to recognising the rights of those affected by HIV/AIDS.

7.3. The Role of Local Councils (LC)

Uganda has a decentralised administrative structure in which districts are given autonomy in designing their own programmes. In combating HIV/AIDS, the decentralisation policy promotes coordinated partnerships between religious, political and educational institutions, and NGOs, in planning and implementing programmes through a central coordinating body; initially the District AIDS Coordination Committee-DACC (UNDP 2002a) and later the District AIDS Committee. The formation of these bodies facilitated the formation of a formal structure of communication through which politicians could interact with other actors and monitor programmes in their respective districts. It has to be stressed however, that these bodies although actively involved in fighting HIV/AIDS, they receive limited funding from the government.

Within the decentralised framework, the Uganda AIDS Commission (UAC) links up with the politicians at all levels of government down to Local Council One (LC1), which is the lowest administrative unit in the political system of Uganda. The LC system is a hierarchical administrative structure extending from village to district levels. At each level, there is a governing committee composed of nine elected members, including secretaries for health, women and youth. With the help of the district HIV/AIDS focal person and the district coordinator of health services, training in AIDS-related issues is provided to LC officials at the district and in some cases, sub-county levels; the officials in turn train their counterparts at lower levels. This approach is intended to encourage the officials to design and implement their own strategies to cope with the problem. Participation into HIV/AIDS activities by the local people creates a sense of independence and ownership of the programme. The involvement of representatives elected by the citizens in health (as for example the LC1 secretary for health) and HIV/AIDS programmes intensifies the relationship between the government and citizens, and improves service delivery. Lam (1996) provides evidence that involvement of officials who are part of society in the programme management process

increases trust between government and citizens, and such trust leads to improved delivery and management of services.

Through the Uganda AIDS Control Programme, knowledge is disseminated to local communities. The Local Councils (LCs) are used as channels through which messages about HIV/AIDS are spread down to the grassroots level. The LC system not only facilitates the dissemination of HIV/AIDS messages to every village, but also ensures that anti-AIDS activities are initiated and implemented at the lowest level. It should be emphasised that the role of LCs in fighting HIV/AIDS is strongly evidenced in the northern region. Whereas the local councils have worked with civil society organisations to promote HIV/AIDS awareness in the central and southern regions, they have worked almost alone in the northern region, where war has limited the operations of NGOs and other civil society organisations (Allen and Heald, 2004).

Since 1996 when the government adopted the policy of decentralization, 65% of tax revenues collected have remained at the sub-county level, and some of these funds are committed to health-related activities which may also include fighting HIV/AIDS. LC committees are provided with information leaflets, condoms and, in some cases, HIV testing services. The role of the politicians in this initiative is mainly advocacy and resource mobilisation. Although the government provides limited funding of HIV/AIDS activities, the involvement of its officials in HIV/AIDS activities serves to improve the relationship with citizens and result in a positive reception for messages about HIV/AIDS in communities.

7.4. Multisectoral Approach

Barnett and Whiteside (2002: 337) conceptualise of a multisectoral approach as one that goes beyond prevention to focus on all aspects of the epidemic. “It includes treatment, policies and programmes to mitigate the impact of HIV/AIDS and policies that will change the societal factors that influence long term susceptibility and vulnerability to HIV/AIDS”. The multisectoral approach combats AIDS on a number of fronts, involving various government ministries, and civil society organisations, such as local and international NGOs, the business sector and individuals. This remains a central government approach, and may explain Uganda’s success in fighting HIV/AIDS.

As early as 1986, the Ugandan government set up the Sexually Transmitted Diseases/AIDS Control Programme (ACP) to fight HIV/AIDS through information dissemination, blood transfusions and epidemiological surveillance. The ACP was established under the Ministry of Health. By 1991 the HIV/AIDS programme was fully incorporated in six public ministries: Defence, Education, Information, Labour and Social Affairs, Local Government and Health (UNDP 2002a). The rationalisation of the HIV/AIDS programme in the public sector began in 1993 with the appointment of programme managers in various ministries, such as Education and Sports, Defence, Information, Labour and Social Affairs, Local Government, Gender and Community Development, Agriculture, Justice, Finance and Economic Planning, Internal Affairs (Police and Prisons) and Health (UNDP 2002a). This approach was a forerunner since other African countries were still denying the existence of the disease on the continent. However, as mentioned apart from Ministry of Health, other ministries have not fully implemented the HIV/AIDS programme. Putzel (2003) argues that one of the factors affecting the implementation was the conflict over resource utilisation with other ministries arguing that it should remain under Ministry of Health.

In 1992, the Uganda Aids Commission (UAC) was established under the Office of the President by the Parliamentary Statute No. 2 of 1992. The commission was appointed on a five-year tenure, which could be renewed or suspended, and its role was to coordinate the multisectoral response to HIV/AIDS. Representatives to the UAC were drawn from religious organisations, different government ministries, other civil society organisations and the medical profession (see table 7.1). These commissioners had the necessary technical knowledge and expertise for the implementation of HIV/AIDS programmes, and worked under the commission chairman. The UAC was intended to ensure harmonisation of intervention, to foster collaboration, to establish effective linkages between various agencies, and to facilitate the sharing of experiences (Oketcho, Kazibwe, and Were 2001: 15). It is for this reason that it embraces the principle of participatory coordination, which aims at ensuring shared perspectives on the various issues of the national programmes, while at the same time promoting a feeling of ownership among the various stakeholders. The coordination mechanism has evolved over the years through partner consultation to ensure harmony while focusing on a common problem.

Since the Uganda AIDS Commission was under the office of the President, it was the President who had the authority to appoint the commissioners. This gave the body

prominence and signified a strong government commitment (UNDP 2002a: 86). In order to coordinate activities and effective programme implementation, the UAC developed a National Strategic Framework (NSF), the purpose of which is to relate the fight of HIV/AIDS to national development goals, and to facilitate and integrate the participation of all stakeholders in the planning and management of HIV/AIDS activities (Oketcho, Kazibwe, and Were 2001).

Within the multisectoral framework, HIV/AIDS activities were decentralised and embedded in different ministries, responsible for designing programmes for implementation. Thus, the UAC had policy making as its main duty and evaluation, while implementation was left for the line ministries and civil society organisations. In order for the policy to be successful, widespread popular support was required because of the involvement of people representing different categories and groups of citizens (see table 7.1). As VanMeter and VanHorn (1975) argue, successful policy implementation depends on the wider acceptance of policy goals.

Table 7.1 Variation in Composition of UAC Membership

Categories of members	Designation of Members	Members of Uganda AIDS Commission		
		1992 (n=27)	1994 (n=13)	2001(n=20)
Government	Minister	11	1	1
	Permanent Secretary	1	3	-
Religious Leaders ¹⁴²	Retired	-	1	2
	Active Clergy	3	1	2
Politicians	Parliamentarians	4	2	1
	District Councils	-	-	1
Civil Society	Medical Doctors	5	3	5
	Academic/researchers	1	1	4
	People infected with HIV and AIDS patients	-	-	1
	HIV/AIDS-NGOs	2	1	1
	Community Members	-	-	2
Gender	Male	23	10	18
	Female	4	3	2

Source: UNDP (2002: 87).

In table 7.1, it is evident that the importance of civil society is well recognised by the government of Uganda. Although about 59.3% of the AIDS commission in the early 1990s was composed of politicians, civil society was also recognised and constituted the remaining 40.7% of the commission. In later years, civil society becomes more dominant in the commission, constituting 53.8% in 1994 and 85% in 2001. By 2001, the number of

¹⁴² These are also part of civil society, but I have maintained the table as presented by UNDP

politicians on the commission had been reduced significantly and replaced by the people from the community and people with HIV/AIDS.

From the table, it can be deduced that people from civil society were purposely selected: the medical doctors had the technical skills related to HIV/AIDS, the NGOs were involved in the mobilisation of people and the delivery of services¹⁴³ and the religious leaders had a mobilisation role to play¹⁴⁴.

This involvement of various categories of people increased the exchange of knowledge about HIV/AIDS, as well as participation. It should be emphasised that although fighting HIV/AIDS was not fully implemented by other ministries apart from Health Ministry, with a multisectoral approach, Uganda became the first African nation to openly declare the presence of HIV/AIDS and to report declining trends in HIV/AIDS infection. This decline put the country on to the international scene and recognition. The multisectoral approach succeeded with involving other actors as the following discussion will show.

7.4.1 The Relationship between Government and Faith Based Organisations (FBOs) in Fighting HIV/AIDS in Uganda

Religious organisations are one category of civil society organisations involved in the multisectoral strategy that plays an important role in mobilising communities for behaviour change. The focus of this section is on how the government has facilitated the involvement of religion and religious leadership in fighting HIV/AIDS.

Uganda is predominantly a Christian country. According to the 2002 national Census, Christians of all denominations made up 85.1% of Uganda's Population. The Catholic Church accounts for the largest number (41.9%), followed by the Anglican (31.9%). Other Christian groups include Pentecostal churches (4.6%) and Seventh-Day Adventists (1.5%), while 1% was grouped under the category 'Other Christians'¹⁴⁵.

The government considered religious groups to be important actors in the fight against HIV/AIDS because of their large congregation. Religious congregations serve as a channel

¹⁴³ See discussions in chapters 5, 6 and 8 about the formation and roles in fighting HIV/AIDS

¹⁴⁴ See discussion in 7.4.1 on the role of religion and why the government focused on involving religious leaders in HIV/AIDS prevention strategy

¹⁴⁵ <http://en.wikipedia.org/wiki/Uganda#Religion> 10/06/2006

for delivering messages. In addition, they play a vital role in the health care system in Uganda, having developed numerous health facilities throughout Uganda. At the time when the government hospitals lacked qualified personnel and medicine, the mission hospitals offered quality health services to people at a subsidised fee, thanks to donations from countries such as France and Germany. The religious founded health establishments still provide these services, especially in rural areas. The involvement of the church in the fight against HIV/AIDS strengthened the trust people had in government institutions such as the UAC that was established to fight HIV/AIDS. In addition, this inclusion made discussions about HIV/AIDS within the church and religious circles legitimate.

The involvement of religious leaders opened up the discussion about HIV/AIDS. HIV/AIDS had always been considered as a disease affecting immoral people and transmitted through immoral behaviour, and discussions about HIV/AIDS were initially not allowed in churches. Such attitudes heightened the differences among people and the stigmatisation of those with HIV/AIDS. The involvement of top church leaders in the commission broke this myth about HIV/AIDS. This increased the integration of people and minimised differences.

The introduction of HIV/AIDS discussions into the church forum served, in the first instance, to legitimise and acknowledge the presence of the disease among the congregation, and encourage an acceptance of the problem. The inclusion of religious leaders as part of the team fighting HIV/AIDS was one way of overcoming the cultural and religious tendencies to view people with HIV/AIDS as immoral social deviants. This was part of the move to make a collective attack against HIV/AIDS. In addition, since HIV/AIDS had been identified as a sexual transmitted disease, behavioural change was necessary to combat its spread. Open discussions about sex involved touching issues related to people's personal life, and religious beliefs. Involving the church would not only legitimise such discussions, but also limited opposition from the church (Putzel 2004). Most public officials had hesitated to address issues related to sex and sexuality because they feared strong opposition from religious leaders and interest groups who regarded such issues as matters of individual behaviour and not for public discussion (Putzel 2003).

However, religious congregations have taken a different approach to fighting HIV/AIDS. The church, especially the Anglican Church, did not openly support or criticise the use of

condoms in HIV/AIDS prevention. Thus, the key messages embodied in the AIDS campaign slogan – Abstain, Be careful and use a Condom (ABC) – have been modified by the church; for example, “love carefully” has been replaced by “love faithfully”. Such a substitution implies the recognition of the presence of HIV/AIDS amongst their congregation, which facilitates the discussion of HIV/AIDS and sex related matters in the church.

Religious Fundamentalism and the AB Approach to Fighting HIV/AIDS

Recently, fundamentalist movements have grown up in both the Anglican and the Catholic churches that are vehemently opposed to the use of the condom in fighting HIV/AIDS. The fundamentalists focus on abstinence until marriage (AB) as the only acceptable approach. This approach has evolved particularly in the charismatic and Pentecostal sects, and has government support. The programme targets the youth, who are brought together for prayer meetings. With the recent involvement of the first lady – the wife of the president (Mrs. Janet Museveni), who has called upon today’s youths to maintain their virginity until marriage, the AB strategy is becoming almost a catch word for the religious fundamentalists¹⁴⁶.

It is not unusual to hear that religious groups are preaching about the dangers of failure to abstain from sex until one is married, and of infidelity. These two moral principles have constituted the pillars of Christian morality since its inception in Uganda. Nevertheless, the approach of religious fundamentalists to fighting HIV/AIDS needs a closer look and a critique.

In its religious teachings condemning sin, the fundamentalists criminalise all other programmes which have proved successful in Uganda and other parts of the world such as Thailand. For example, it condemns condom use, implying that this promotes immorality, exposes individuals to high risk of infection and therefore should be avoided. Thus, the programme fails to address both cultural and social issues that have led to the increased spread of HIV/AIDS. In addition, the approach individualises the problem of HIV/AIDS and this may heighten blame and stigmatisation. They portray HIV/AIDS as a self-inflicted punishment, and the acquisition of HIV/AIDS as a matter of personal choice. Messages such as abstain and be faithful have strongly been emphasised and these have deeper implications, since those who acquire HIV are blamed for their failure to abstain and to be faithful. Ultimately, such an approach may mean that those with HIV/AIDS will be isolated and

stigmatised, and lose their social identity. This is a challenge to the efforts to fight HIV/AIDS.

It has to be stressed that religious fundamentalists in Uganda borrow their ideas from abroad. The following extract demonstrates the external influences that shape the views of fundamentalists. In June 2000, a newsletter was posted on the web page of a religious group – the Gospel Defence League, stating that:

AIDS is the result of immoral living. ... AIDS is the result of apostasy, of denying God and disobeying His commandments. AIDS is God's judgement for disturbing His order... To advocate the mass distribution of condoms is to promote defiance of Gods commandments. It is a call to sin. It is an invitation to death. In telling youngsters to “love life” and be "sexy, savvy and sensitive”, while installing condom dispensers in their schools is "to send them down to the chambers of death.”¹⁴⁷

The use of condoms has been effective and, in combination with other approaches, condom use has contributed to the decline of HIV/AIDS prevalence. Deemphasising the use of the condom, therefore, is likely to lead to more HIV/AIDS infections. In addition, the approach does not address the socio-economic factors that promote sexual vigilance. For example, poverty, gender and cultural practices, such as widow inheritance, which facilitate the spread of HIV, are ignored. Without addressing these problem areas, it is unlikely that women will be able to negotiate relationships based on abstinence and faithfulness (Wilson 2004: 848). The cultural practice in Uganda, for example, does not criminalise men who have sex with young girls¹⁴⁸. The narrow focus of religious fundamentalists, who vehemently opposes condom use (C) leads to creation of stigmatised individuals, may plunge the country into the pit from which it came. The Ugandan success story in fighting HIV/AIDS may be reversed (Sekabira 2005). Thus, it is not surprising that the *Economist*, September 8, 2005, reports that a Ugandan Ministry of Health survey indicates that the HIV/AIDS infection rate may be on

¹⁴⁶ <http://hrw.org/reports/2005/uganda0305/5.htm> /15/04/06

¹⁴⁷ http://www.christianaction.org.za/GDL/Newletters/2000-jun_jul.htm 18/04/06

¹⁴⁸ Although the law prohibits having sex with anyone below the age of 18, putting such a law into practice has always been frustrated by the cultural practice that allows the marriage of children to adults, and by the abundance of poor parents who want to settle cases outside the court and cannot escape corrupt government officials.

the rise, to 7% for men and 9% for women. The study blames the abandonment of condom use in favour of the AB strategy¹⁴⁹.

In spite of the impediment posed by religious fundamentalism to the battle against HIV/AIDS, there are lessons that can be learned. First, the fact that HIV/AIDS can be discussed in religious institutions is a success for Uganda's policy. Moreover, the government's focus is on allowing multiple actors to fight HIV/AIDS, each in their own way, as long as their approaches lead to a reduction in HIV prevalence rates. Second, the fact that such religious groups can be facilitated to create their group of followers lends credence to the applicability of the synergy approach in fighting HIV/AIDS.

7.5 Government Funding and Mobilisation of funding

The government also plays a decisive role in the provision and mobilisation of funding for HIV/AIDS programmes. The Government makes annual financial allocations to the combating of HIV/AIDS. This amounted to US\$ 4.8 million in 2000/2001 and US\$ 3.9 million in 2002/2003 (Kayazze 2002). Part of this fund is to run projects directly under government ministries such as research, information dissemination, making anti-AIDS campaign billboards, brochures and charts. From this amount the government also funds different organisations involved in the fight against HIV/AIDS. For example, the Government funds about 3-5% of TASO's annual budget (TASO 2002a).

7.5.1 Community Response

The government has created an enabling environment for association and participation (Oketcho, Kazibwe, and Were 2001: 14). The participation and engagement of people working in various fields and at all levels, has been encouraged by the decentralised health reforms involving the creation of AIDS Coordination Committees (ACC) at various levels in the district.

Beginning with 1992, the Uganda Aids Commission (UAC) established District Aids Coordination Committees (DACC) in all districts of Uganda. Within each District, three levels of committees were established: Sub-county Coordination Committees (SACCS), Parish AIDS Coordination Committees (PACCS) and Village Aids Control Committees (VACCS). The creation of such bodies was meant to facilitate the coordination of HIV/AIDS

¹⁴⁹See, http://www.healthgap.org_releases/05/091905_Uganda_condoms_press_clippings.doc 11/08/06

activities in the Districts. However, this structure was not fully implemented due to lack of technical leadership and funding (UAC and NHACP 2002).

The failure of UAC to fully implement this overall programme meant that different districts implemented HIV/AIDS-related programmes through different sectors. In order to coordinate such programmes, the UAC allowed the Chief Administrative Officers (CAO¹⁵⁰) to form District AIDS Committees (DAC) in their districts in 2001. Unlike the DACC, the DAC was relatively autonomous, and independent of the influence of UAC. These committees are chaired by district HIV/AIDS focal persons who are appointed by the district CAOs. The district HIV/AIDS focal person coordinates the various HIV/AIDS activities including training, mobilisation and coordination of different stake holders.

Through the creation of these HIV/AIDS coordination structures, especially the DAC, there is a new category of community-based organisations emerging. The government of Uganda has been instrumental in facilitating the growth of these organisations, and of social networks among people affected by HIV/AIDS and between organisations involved in HIV/AIDS-related activities.

The government recognises the need for community participation, especially that of the people affected by HIV/AIDS. As mentioned, community participation creates a feeling of ownership of the problem among community members. These communities, therefore, take it upon themselves to fight HIV/AIDS collectively. It is against this background that there has been a spontaneous growth of Community-Based organisations (CBOs) and other local initiatives to fight HIV/AIDS. This has been facilitated by the government's approach of allowing interested organisations, individuals and groups to participate in the battle against HIV/AIDS and mobilisation of funding for the control and mitigation projects such as Community HIV/AIDS Initiatives (CHAI) – a project financed by the global fund to fight AIDS, TB and Malaria. In their study, Oketcho, Kazibwe and Were (2001: 30-31) argue that:

Although no specific laws or regulations on HIV/AIDS have been enacted, government acceptance of the HIV/AIDS problem and commitment to the HIV/AIDS control programmes have encouraged spontaneous and positive response...this has provided a strong foundation for actions on HIV/AIDS: - mobilization of financial and technical support from donors to the

country programmes, establishment of diversity of interventions through multisectoral involvement of players at many levels including community groups.

Under the CHAI project, funding is provided to people who get together and form a group. In order to qualify for funding, the group must be composed of people with HIV/AIDS or must be engaged in activities that are focused on reducing HIV/AIDS through the creation of awareness.

This project has led to the emergence of community responses in the form of CBOs and other local initiatives. In Mbarara district alone, about 201 groups had been formed prior to March 2004. TASO recommended that 39 of these groups be financed by the district CHAI project. (District reports). An interview with the district HIV/AIDS focal person revealed that in order to assess the credibility of these organisations, the district often seeks the assistance of other organisations working with the communities such as TASO and the local council officials in the areas of the applying organisation. He said that, “the evaluation process of these organisations is complex, slow and an interactive one between government and different stake holders including, local communities”. Through this process, in addition to the 39 groups mentioned above, about 162 more applications had been processed by the district health office and would be submitted to UACP. The *New Vision*, 13/11/04, reported that the district had recently received about US\$ 93,000 (160 million Ugandan shilling) from Uganda HIV/AIDS Control Programme and that this would benefit 50 HIV/AIDS groups.

The involvement of different stake holders including local communities and leaders in the evaluation of CBOs to be funded is an indicator of government’s commitment to work with society in the fight against HIV/AIDS. In addition, funding groups rather than individuals, facilitates interactions, communication and collective responsibility towards fighting the disease.

I asked the HIV/AIDS district focal person in Mbarara district why they insisted on funding groups instead of individuals. He responded that:

Because our guidelines require beneficiaries to form groups composed of people of their own choice, it is expected that these people will work together to fulfil their goals- fighting

¹⁵⁰ The CAO is the Administrative head of the District.

HIV/IDS. This has another implication – programme ownership of the communities involved. In addition, groups facilitate easy monitoring and effective utilisation of funds. Because the group is composed of various people, each member becomes responsible and acts as a control mechanism for the others. This increases control and quality, transparency, efficiency and accountability, in addition to stimulating social support that would develop in-group support from some members to others. (Interview with district HIV/AIDS focal person)

The government's role in this process is not limited to provision of funding, and it also provides the beneficiaries with training in project design, evaluation, budgeting and progressive accountability of funds (interview with district HIV/AIDS focal person).

7.6 Government Procurement of HIV/AIDS Medicine

The introduction of the Highly Active Antiretroviral Therapy (HAART) services in 1996 (Lucchini et al. 2003), brought hope to people affected by HIV/AIDS. However, the high cost of these services and monitoring tests, and lack of qualified personnel, meant that people living in developing countries did not have access to these services especially the ARVs. In Uganda in 1998, the cost of treatment was US\$ 1000 per month for brand drugs (Martinez-Jones and Anyama 2002), while about 80% of Ugandans live on less than US\$ 1 a day (O'Manique 2004). Thus, Atwiine Agweng and Takubwa (2001) note that less than 1% of AIDS patients in Uganda were accessing ARVs in 2001.

Recognising this disparity of access, the United Nations (UN) organisations set out to negotiate a way of making these drugs accessible to people in developing countries. Thus making these drugs cheaper was the starting point. As a result, the UN organisations, governments and non-governmental organisations began negotiating with the major pharmaceutical companies producing ARV drugs for a reduction in their prices. The pharmaceutical companies negotiated with governments on country by country and drug by drug basis. According to the Ministry of Health *Annual Health Sector Performance Report for the Financial Year 2000/2001*, continuous negotiation by government has reduced the cost of the drugs by 80-90% (MoH 2001a: 14). This is confirmed by the findings that, between 1996 and 2001, the price of ARV drugs decreased to between 5%-20% of their price in developed countries (Lucchini et al. 2003).

As early as 1996, Uganda pioneered the importation of antiretroviral drugs in Sub-Saharan Africa. Drugs were imported and distributed to those who could afford them, through private and government hospitals under the supervision of qualified health personnel. The government commitment to making ARV drugs available to its citizens caught the attention of international AIDS bodies such as UNAIDS. Between 1998 and 2000, therefore, Uganda was one of the countries being sponsored in a pilot project under the UNAIDS Drug Access Initiative (DAI) programme (Martinez-Jones and Anyama 2002). In order to increase access to the drugs, the government established an advisory board to oversee the implementation of the programme. In addition, a non-profit autonomous organisation, Medical Access Uganda Ltd, was established to import the medicine and distribute ARV drugs to pharmacies at subsidised prices. Lucchini, et al (2003) note that, in other countries such as Kenya and South Africa, there was no clear commitment of government to facilitate the delivery of ARV drugs, except for preventive use for example, for the prevention of mother to child transmission of HIV.

Apart from the DAI project, Uganda is one of the countries that have been active in developing a hybrid mechanism of drug procurement, that combines the Accelerated Access Initiative (AAI) international framework, with competitive tendering procedures vis-à-vis the generic producers (Lucchini et al. 2003: 190). In 2002, the UN signed an agreement with five pharmaceutical companies (Boehringer Ingelheim, Bristol-Myers Squibb, GlaxoSmithKline, Merck and Hoffman-la Roche) to provide ARVs to developing countries through the AAI. The aim of the programme was to rapidly increase access to ARVs in developing countries. To supplement this, UNAIDS offered technical training to various centres in Uganda in dispensing the ARV drugs. The biggest centre dispensing these drugs is the JCRC, a non-profit organisation established by the Ministry of Defence, the Ministry of Health and Makerere University to carry out research in HIV/AIDS (Martinez-Jones and Anyama 2002).

Although Medical Access Uganda Ltd was given the exclusive rights to import ARV drugs in Uganda, this monopoly did not apply to the hybrid mechanism. By 2002, JCRC was dispensing about 2,500 doses of generic drugs to patients in Mbarara referral hospital. Similarly, Médecins sans Frontières (SMF) is importing generic ARVs directly from pharmaceutical companies and is initiating a HAART project in the Arua District of Northern Uganda. As a result of taking away the monopoly rights of provision of ARVs from Medical Access Uganda Ltd, and allowing other companies to provide these drugs, their prices have

declined significantly. Between September 2000 and February 2001, there was a sharp decline in the price of the eight major types of ARV drugs on the Ugandan market. The cost of a single dose of ARV drugs, which had ranged between US\$ 100 and 400 in 2000, was between US\$ 20 and 300 in 2001¹⁵¹.

The reduced prices made it possible for an increasing number of patients to access ARV drugs. As indicated above, JCRC alone was dispensing about 2,500 doses to patients in Mbarara. Prior to the DAI programme which ended in 2001, less than 400 patients had had access to ARV drugs. However, by the time the programme closed down, about 1,700 patients had received treatment in seven centres (Cains et al. 2003: 32).

In 2003, the government negotiated with various organisations regarding the provision of treatment for HIV/AIDS patients in various districts and centres. In 2004, Uganda implemented the Presidential Emergency Plan for AIDS Relief (PEPFAR); this is President Bush's five year plan to address the problem of AIDS in developing countries. The programme in Uganda focused on making ARV drugs available to patients free of charge in selected hospitals. About 2,700 HIV/AIDS patients received the drugs at 11 referral hospitals and 11 district hospitals throughout the country. This was a joint programme initiated by JCRC, the Ministry of Health (MoH) and the United States Agency for International Development (USAID, and is still being run.

How does the government's involvement in the negotiation of drug access relate with social capital formation

To access ARV drugs, people have to know their status, and for people to know their HIV status, they have to take an HIV/AIDS test. Since the government does not carry out HIV testing (except for pregnant mothers and some others on the special request of medical personnel), testing is done by NGOs such as AIC and Family Planning Association of Uganda (FPAU). The assignment of testing services to specialised NGOs by the government is a sign of recognition of the importance of these organisations and their relationship with government. In addition, testing for HIV/AIDS is a point of entry into specialised HIV/AIDS organisations such as AIC and TASO. As discussed, these organisations are engaged in activities which socialise their clients and members, and are therefore generating social capital. It is possible, therefore, to argue that, without government recognition of the

¹⁵¹ The highest price represents the brand product, while the lowest price represents the generic product.

complementary roles of these organisations, social capital generation by these organisations would be limited.

Apart from negotiations to access HIV/AIDS medicines, the government is involved in the procurement of condoms to be distributed through health units and NGOs. The Ministry of Health procured about 150 million condoms between 1997 and 2000 (Garbus and Marseille 2003: 90). In 2002, over 50 million condoms were distributed and the government projected that about 80 million would be distributed in 2003. Condom use and behaviour change are among the reasons why HIV/AIDS intervention has been successful in Uganda (Low-Ber and Stoneburner 2004a; 2004b; 2004c). It should be noted, however, that government recognition of the NGOs involved in HIV/AIDS activities to distribute condoms to people, especially those it cannot reach, made this exercise successful.

It should be emphasised that the government relies on the health units (government hospitals and other government health establishments), for the implementation of various health programmes. However, these units are understaffed, they lack essential drugs and very few people visit them because they lack the funds to enable them to access the health care services (Garbus and Marseille 2003; O'Manique 2004; TASO 2002a)¹⁵². There is no doubt, therefore, that synergy between HIV/AIDS organisations and government made condom distribution and provision of other HIV/AIDS related services successful.

7.7 State, NGO and Donor Relations

In chapter 6 (6.5), I discussed state-NGO relations. In this section, I focus on relationship between government, NGOs and donors in the fight against HIV/AIDS. The purpose is to understand the importance of this relationship and to discuss how the state features in, or facilitates this relationship to take place.

The international donor community is an important actor in the network that is fighting against HIV/AIDS. These bodies provide funding for various programmes intended to tackle the HIV/AIDS problem. In the financial year 2001/2002, for example, the USAID grant to fight HIV/AIDS in Uganda was about US\$ 2 million (Kayazze 2002). As mentioned, Uganda is a beneficiary of PEPFAR. Funding is provided to the government, while the programme is implemented by USAID, Centre for Disease Control (CDC), Peace Corps, The Department of

¹⁵² See, for example, the discussion on poverty in 4.2.1 and the discussion in 5.3.2 of the fact that inadequate health provision by the government is one of the reasons for the growth of HIV/AIDS NGO sector in Uganda.

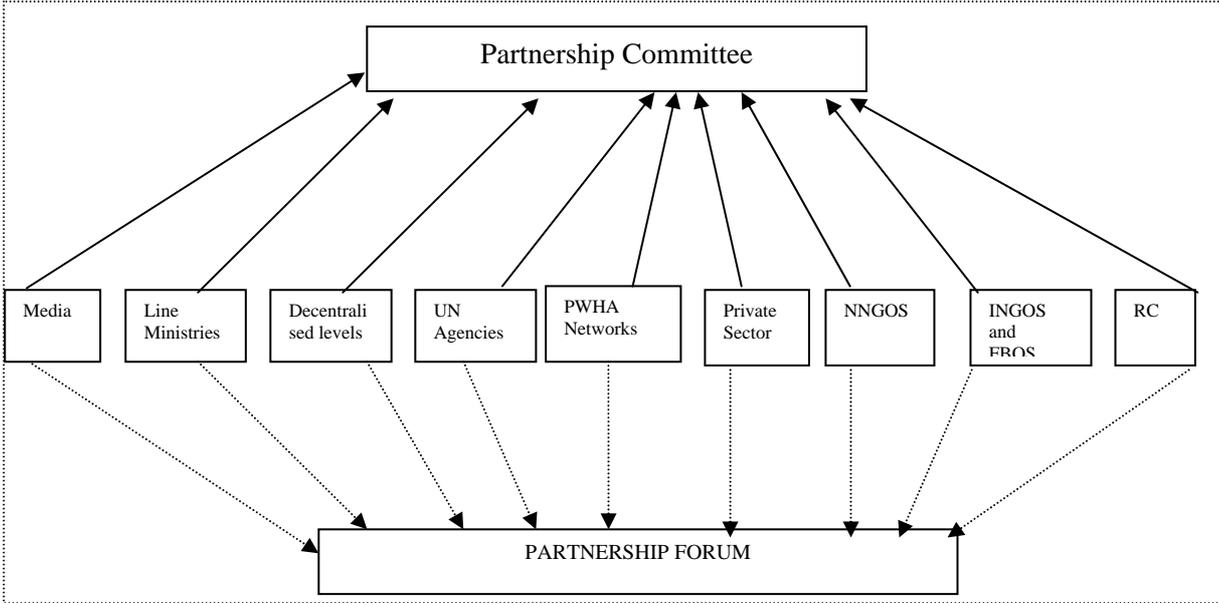
Defence and National Institutes of Public Health, CBOs and NGOs¹⁵³. As earlier mentioned, the government also benefits from the Global Fund to fight HIV/AIDS and TB.

It should be noted that donor agencies continue to fund government HIV/AIDS programmes, but with the NGOs as the implementers. To a large extent therefore, one can rightly say that there is a government-donor-NGO partnership in the fight against HIV/AIDS. Specific examples of such partnerships and their influence on fighting HIV/AIDS are presented below.

As discussed in 5.3.2, the importance of NGOs is gaining recognition in the international arena as the failure of governments to provide social services increases. Nevertheless, governments are recognised by donors, and it is required that they become part of the programmes to fight HIV/AIDS. The government’s role is to monitor and coordinate the activities of other agencies. In order to perform this role, donors channel funding through government ministries and the NGOs are required to be implementers of the programmes (see 7.5).

Through the UAC, the Ugandan government coordinates a partnership of different organisations and other interested parties involved in fighting HIV/AIDS. There is a formal HIV/AIDS partnership coordination structure in Uganda (see figure 7.1) including various interest groups.

Figure 7. 1 National HIV/AIDS Partnership Coordination Structure



Source: Adapted from (UNDP 2002a: 101)

¹⁵³ See, <http://usembassy.state.gov/posts/ug1/wwwhfaqs.html> 13/08/06.

Key to figure 7.1

RC –Research Community
NNGOs- International NGOs
INGOs- Indigenous NGOs
FBOs –Faith Based Organisations
UN United Nations organisations

In figure 7.1 above, it can be observed that the state has involved state institutions such as ministries, districts and the research community such as those funded by government, the private sector including the business community, traditional healers and international organisations such as United Nations agencies and international NGOs (INGOs) that constitute the donor community. There is the involvement of Faith Based Organisations (FBOs) and networks of People with HIV/AIDS (PWHA). These institutions are Self Coordinating entities (SCOs) which are brought together in a partnership committee. Each body sends one representative to the partnership committee which meets monthly under the chairmanship of UAC. All members however, form the partnership forum which meets twice a year also under the chairmanship of UAC. Through these meetings, there are interactions between different actors who share different ideas and knowledge they possess about how to deal with the problem of HIV/AIDS. From this structure of relationships, one can rightly argue that NGOs are integrated in activities of government to fight HIV/AIDS in Uganda.

7. 8 Comparing Government Responses in Uganda and South Africa

Many countries in Africa have employed similar strategies to those used in Uganda, stressing preventive approaches such as education targeting behavioural change and condom distribution. These approaches have not had the same effect, however, and HIV/AIDS prevalence in these countries has remained alarmingly high. It is evident from the preceding discussions that Uganda's successful HIV/AIDS intervention has depended on synergy between the government and the non-governmental service providers. The government's role is to establish a favourable environment for other actors to participate in the battle against HIV/AIDS and to integrate them in this process. Its role is to provide the necessary leadership, in the form of committed political leaders, mobilisation of funding and shaping the environment for them to participate. Such an environment has enabled approaches such as the behavioural change campaign to be effective (see chapter 8). Are there lessons for other countries to be learned from Uganda? To answer this question without simply repeating the preceding discussions, I will compare the political responses to HIV/AIDS in South Africa and Uganda, and consider the implications of these responses for the implementation of

HIV/AIDS programmes. In particular I will focus on the role of political leadership and the government-NGO relationship.

There are characteristics with respect to HIV/AIDS that highlight the similarities and differences between Uganda and South Africa. In South Africa, HIV/AIDS was identified in 1982, the same year as in Uganda. At the time when HIV was identified, both countries were facing political transitions. Uganda was undergoing reconstruction following the 1986 takeover by the National Resistance Movement (NRM), and South Africa was in the midst of the transition from apartheid to popular democratic government. South Africa, compared to Uganda, had more resources which could have been used to fight the spread of HIV/AIDS. The economies of both countries had been destabilised by economic and political colonisation, but the magnitude of this was greater in South Africa. This was partly due to the fact that it took longer for South Africa to gain independence¹⁵⁴. In both countries vibrant civil society organisations emerged in response to the disease.

A number of factors might have suggested initially that the South African HIV/AIDS policy would be more successful than the Ugandan. South Africa was relatively rich, compared to Uganda. With a per capita GDP of about US\$ 2,941 in 2000, South Africa was considered the richest country in Africa. In contrast, Uganda, with a per capita GDP of about US\$ 249 in 2001, was one of the impoverished African countries (Parkhurst and Lush 2004). In addition, South Africa had an established and functioning health service structure after the political transition, which Uganda lacked. For example, the ratio of medical doctors to people was 56 to 100,000 in South Africa (Parkhurst and Lush 2004: 1918), compared to less than 5 to 100,000 in Uganda (Ainsworth and Teokul 2000: 56).

In spite of advantages South Africa enjoyed with regard to income and health care facilities, compared to Uganda, this is not reflected in the statistics regarding HIV/AIDS infections in the two countries. About 5 million people in South Africa are infected with HIV/AIDS. With a prevalence that rose from 0.7% in pregnant mothers to about 25% in 2000, South Africa is ranked as the country with the highest number of people with HIV/AIDS (Fassin and Schneider 2003). By 2004, AIDS was considered the greatest threat to post-apartheid

¹⁵⁴ Barnett and Whiteside (2003) discuss the political economy of South Africa and Uganda, and its relationship with HIV/AIDS transmission. Uganda gained independence in 1962 while South Africa overthrew apartheid in 1994.

reconstruction and development (Heywood 2004). In contrast, with a declining prevalence rate among pregnant mothers from about 18% in 1991 to about 6.2% in 2001, Uganda is considered as one of the most successful countries in fighting HIV/AIDS (Barnett and Whiteside 2002; Low-Beer and Stoneburner 2004b; Okware et al. 2001). The differences in HIV/AIDS prevalence rates in the two countries can be explained by a number of factors, including: (a) the political commitment of the top leaders, and (b) the involvement of civil society organisations.

7.8.1 A Comparison of the Political Responses in Uganda and South Africa

Political leadership and the involvement of civil society organisations (NGOs, CBOs, private sector organisations and religious organisation) have been identified as the key to successful HIV/AIDS intervention (Friedman 2000; Putzel 2004). In sections 7.2 and 7.3, the positive impact of political leadership in creating an environment for the successful fight against HIV/AIDS was discussed; important factors were the positive response to the creation of institutions to respond to the epidemic, and the commitment of the President of Uganda and other politicians, who openly discussed HIV/AIDS. For the present discussion, the important point is how the Uganda response differs from that in South Africa.

When HIV was identified in Uganda, the government became interested in research about the disease (Putzel 2004). Success was spearheaded by political leadership, led by the president and top politicians (see 7.2). In addition, the critical elements in Uganda's fight were openness and political mobilisation of various stake-holders such as religious leaders (see discussion in 7.4). The involvement of religious leaders and political leadership not only established the legitimacy of the programme, but also a forum for instruction. People were being told what to do by their leaders (Barnett and Whiteside 2002). The situation was different in South Africa.

There was lack of openness about HIV/AIDS in South Africa. At the community level, awareness about AIDS remained limited and was characterised by myth, conspiracy and denial for several years (Fassin and Schneider 2003)¹⁵⁵. The means to prevent the transmission of HIV such as open discussion remained highly stigmatised so this was not translated into changed behaviour (Parkhurst and Lush 2004).

¹⁵⁵ AIDS was first seen as a means of controlling the expansion of the Black race by the Apartheid regime (Fassin and Schneider, 2003).

Moreover, South Africa lacked political leaders who were committed to fighting HIV/AIDS. The initial response was to create a partnership between civil society organisations and the government. As a result, the initial response to fighting problems such as discrimination in employment was successful. For example, National Association of People with HIV/AIDS (NAPWA) launched a successful campaign to fight HIV/AIDS in the workplace, which was later transformed into government policy in 1998. This policy ended the mandatory pre-employment HIV/AIDS test in both public and private sectors, except in the armed forces (Heywood 2004).

The state-NGO partnership in South Africa was short-lived, however, and came to an end with the election of Thabo Mbeki as president. The president was unwilling to listen to the experts who possessed knowledge about HIV/AIDS. In his opening address to the 3rd international conference on AIDS in Africa, Thabo Mbeki continuously questioned the linkage between HIV and AIDS (Schoofs 2000), particularly the validity of the scientific findings. Twisting WHO statements which described the status of poverty in South Africa as the root causes of misery and disease, Mbeki used it as a weapon to discredit the scientific basis for the HIV/AIDS link. He insisted that poverty not HIV caused immune deficiency (Fassin and Schneider 2003)¹⁵⁶.

Mbeki missed the point (Friedman 2000). There is no denying that poverty has an impact on the rate of transmission of HIV/AIDS by increasing the vulnerability of people, as discussed in Chapter 4. The poor may engage in activities such as commercial sex in order to meet their needs, while the relatively rich – such as migrant workers, truck drivers and businessmen on their shopping and business journeys – may have sex with sex-workers when they are away from home (Barnett and Whiteside 2002; Whiteside 2002). In war situations, men who are exposed to potential danger and away from their families may end up with sex-workers, and women may be raped (Barnett and Whiteside 2002; Hankins et al. 2002). Nevertheless, although poverty may aggravate the problem of HIV, scientists have proved that HIV causes AIDS. Mbeki was provided with all the evidence, which he denied¹⁵⁷. Thus, South African HIV/AIDS policy during the Mbeki era was dominated by hostility, confrontation and conflict between the government and other major actors, including the civil society organisations that

¹⁵⁶ See also, *The Politics of HIV/AIDS in South Africa* <http://www.journ-aids.org/politicsofhiv.php#virodene> 18/04/06.

¹⁵⁷ <http://www.journ-aids.org/politicsofhiv.php#virodene> 18/04/06

were contributing to the successful fight against HIV/AIDS in countries like Uganda. Barnett and Whiteside (2002: 335) echo the above argument and claim that the absence of clear and decisive leadership damaged HIV prevention efforts in South Africa.

The failure to involve civil society in major decision making processes regarding HIV/AIDS in South Africa limited the legitimacy of the government as an information source. There is likelihood, therefore, that information provided by the government might not be considered correct, so people might not act upon it. In extreme cases, people might get the wrong message and become confused. Due to lack of political leadership, there was an information/knowledge crisis in South Africa, while in Uganda the political leadership has spearheaded the dissemination of HIV/AIDS related knowledge to the public. The most recent example of this information crisis in South Africa was when Jacob Zuma, a former Deputy President of South Africa, testified in court in a rape case against him that he took a shower after having sex with an HIV positive woman to minimise the chances of getting HIV¹⁵⁸. Jacob Zuma was acquitted of the rape charges on May 8th, 2006. However, the impact of his testimony is likely to be felt in the South African HIV/AIDS battle for the years to come. Zuma's high political profile gives him a large following among the people of South Africa. The example he set by having a shower after having sex with an HIV positive person may be followed by some of his supporters. Critical of Zuma's action, an editorial in the Ugandan daily, *The New Vision* 9th May 2006, commented that;

“...South Africa was just starting to catch up on HIV awareness when Zuma muddied the waters by giving the public the impression that mere washing can clean off the HIV virus. Zuma is a hero of the labour movement and the Zulu people, but he has now misled his followers”¹⁵⁹.

7.8.2 A Comparison of the State-Civil Society Relationships in Uganda and South Africa.

The impact of HIV/AIDS has been enormous in both Uganda and South Africa since its identification. However, the two countries have responded differently. In both countries, civil society involvement has been among the highest in the region. However, there are marked differences in how civil society organisations have been perceived by government and

¹⁵⁸ http://www.mg.co.za/articlePage.aspx?articleid=267293&area=/zuma_report/zuma_insight/

¹⁵⁹ <http://www.newvision.co.ug/D/8/14/497585/zuma>

their engagement in the fight against HIV/AIDS. Both cases provide important lessons for other countries in this era of HIV/AIDS.

In Uganda, there has been a peaceful co-existence of civil society and the government in the fight against HIV/AIDS, while this was not the case in South Africa. This in part explains the difference in the levels of HIV/AIDS infection rate in South Africa and Uganda. When HIV/AIDS was discovered in Uganda, the first political response was to involve religious leaders at different levels (see 7.4.1). Unlike Uganda, the South African government excluded mainstream NGOs, including religious organisations, from policy debates about HIV/AIDS. For example, there were no HIV/AIDS NGOs represented on the National Council of AIDS in South Africa (NACOSA), and no representatives for the vast number of people with HIV/AIDS (Powel 2000)¹⁶⁰.

Civil society organisations work with people at the grassroots. The exclusion of such organisations from policy debates and/or the relief arena, contributes to the failure of the government to transmit messages about HIV/AIDS to the people. Civil society involvement is a precondition for successfully combating an epidemic such as HIV/AIDS, which affects all social and economic forums.

In the Mail and Guardian (Johannesburg) - June 20, 2000, Steven Friedman wrote about the success of Uganda, Thailand and Cuba in controlling the spread of HIV/AIDS, and attributed it to political leaders who rallied civil society organisations behind fighting HIV/AIDS.

It is simply impossible for any government to fight Aids on its own: society must co-operate not only by changing attitudes and behaviours, but also in its willingness to support and help those who live with the virus or are orphaned by it. The key goal of political leadership in the three countries was to rally society around the battle against AIDS. The government needed to take the lead, but its task was to get everyone who could contribute to a solution to work together to achieve it. (Friedman 2000)¹⁶¹

In Uganda, the relationship between NGOs and government has been harmonious. Policy proposals have always developed through a cooperative process with no major opposition

¹⁶⁰ This was different in Uganda where civil society was represented by both NGOs and individuals such as medical doctors, drawn from society (see table, 7.1)

¹⁶¹ <http://www.aegis.com/news/dmg/2000/MG000601.html> 20/04/06

from either the government or civil society. For example, HIV/AIDS NGOs in Uganda were viewed as channels through which counselling and care, and HIV/AIDS messages on behavioural change, could reach the communities (see for example, 8.7). The government of Uganda provided a stable environment in which NGOs could evolve and coexist with the government in the fight against HIV/AIDS (Putzel 2004: 27). This kind of cooperation made it possible to send the right messages to communities and people at the grassroots in Uganda, but this kind of cooperation is lacking in South Africa. It is possible that people will get incorrect and confusing messages about the disease, as in the cited case of Zuma.

In South Africa, the government did not provide a favourable environment for the peaceful coexistence of government and civil society organisations; in fact, these relations have always been characterised by conflict. The establishment of a large number of HIV/AIDS organisations was a result of this hostility. For example, the Treatment Action Campaign (TAC) grew up to fill the need for a lobbyist and advocacy organisation defending the rights of people with HIV/AIDS. This organisation has been influential in shaping the way the state and society respond to HIV/AIDS. For example, in July 2002, TAC won a court case against the South African state. The government had been taken to court for its refusal to provide Nevirapine to pregnant women in order to prevent the transmission of HIV to their unborn children. As a result, the use of Nevirapine was permitted outside the initial 18 pilot sites (MacLennan and Grobler 2002). In August 2003, the South African government agreed to introduce other ARV drugs, in addition to Nevirapine, and also to mobilise funding to obtain these drugs for AIDS patients¹⁶². In June 2002, NACOSA was criticised by TAC for being ineffective and excluding representatives from civil society; TAC called for the restructuring of NACOSA to include AIDS activists and scientists on its board. The conflict between government and civil society organisations has continued. For example, TAC planned to reject the government's invitation to participate in the United Nations General Assembly Special Session on AIDS (UNGASS) at the end of May 2006 unless its ally, the AIDS Law Project, was also invited (Thom 2006).

From the above discussion, it can be argued that, unless a reciprocal relationship is forged between government and civil society organisations, the fight against HIV/AIDS in South Africa may not be successful. The comparison of Ugandan and South African cases offers a

¹⁶² <http://news.bbc.co.uk/1/hi/default.stm 9/08/03>

very vivid picture of the need of synergy between government and civil society in fighting HIV/AIDS in Africa. A discussion of the two cases reveals that success has been achieved in Uganda where synergy is practiced. This comparison offers some lessons for HIV/AIDS intervention: (a) a supportive political environment is required for successful intervention; (b) partnership between actors is important for successful intervention; and (c) the work of civil society organisations should be recognised and supported by the government.

7.9 Critical Perspectives on the Role of Ugandan Government in Fighting HIV/AIDS

The main critique of the Ugandan government response to the challenge of HIV/AIDS is largely related to the rollback policy. As indicated in chapter four, this has its foundations in the neoliberal policy that favours minimal state involvement in development, and greater involvement of private and local initiatives. As mentioned, Uganda's policy response to HIV/AIDS is shaped by neoliberalism. Government involvement therefore, has been kept in the background. This is confirmed by the limited funds allocated by the government for HIV/AIDS activities, and the concomitant dependence on foreign funding for these. As a result, some programmes have stalled because of the withdrawal of foreign funding. For example, the suspension of the Global Fund project meant that people who were already on the programme faced a crisis until the donors were petitioned to allow the programme to go on while they look for solutions. In addition, there is limited allocation in the budget at the local level to specifically address HIV/AIDS (although funding is available for health programmes which HIV/AIDS form part), and as a consequence, HIV/AIDS programme implementation at the district level has not taken off due to poor funding or no funding at all (interview with district officials in the DHS office).

Under the decentralised governance system, the local governments design their own development programmes. Although 65% of total taxes remain at the sub-county level, in addition to central government allocations, HIV/AIDS is not prioritised. HIV/AIDS is a threat to development, yet it has not been given priority on the local development budget. A community volunteer in Nyarubungo¹⁶³, who is also a local council official, indicated in an interview that there was no funding for HIV/AIDS specific activities in local council development programmes. Worse still, he stressed that expenditure guidelines came from the local government office at the centre, and that HIV/AIDS was not mentioned in the guidelines

apart from being considered as a health issue. He stressed that “HIV/AIDS is part of the overall health programme and has remained so in the local government programmes”.

Interviews with other respondents confirmed that there is little or no government funding for HIV/AIDS programme in their local communities. Clients and members of TASO and PTC/PLI were asked if they knew of any government aided HIV/AIDS programme at the community level; 61% of TASO clients, compared to 42% of PTC/PLI clients, perceived to know of such a programme (table 7.2).

Table 7.2 NGO respondents’ Knowledge of Government HIV/AIDS aided Programmes

Response Type	Members of TASO (%)response	Members of PTC/PLI (%)
Yes	61	42
No	39	53
Do not know		5
	N=77	N=44

Note: The question asked was: *Do you know of the existence of a government HIV/AIDS aided programmes?*

Table 7.2 above would suggest that most of the respondents from TASO (61%) knew of a government HIV/AIDS funded programmes in their area. However, when I asked the respondents to mention the type of programmes being run by government, they talked about the Community HIV/AIDS Initiative (CHAI) and the provision of free anti-retroviral drugs (ARV) to HIV/AIDS patients, and others mentioned “Museveni” as a programmes and condom distribution (see table 7.3). They also mentioned radio programmes. Table 7.3 indicates what respondents mentioned as government aided HIV/AIDS programmes.

Table 7.3 Perceived HIV/AIDS Government Aided programmes

Programmes	Members of TASO's Response (%)	Members PTC/PLI Response (%)
Radio	36	-
CHAI	32	25
ARV drugs	18	38
Others	14	37
	N=77	N=42

Note: Respondents were asked to *name a government HIV/AIDS aided programmes which they know.*

From table 7.3 above, it can be observed that 36% of TASO respondents mentioned radio programmes, 32% mentioned CHAI and 18% mentioned ARV drugs. Similarly, respondents

¹⁶³ One of the 12 communities where volunteers implement HIV/AIDS programmes with the support and supervision of TASO.

from PTC/PLI mentioned CHAI (25%) and ARV drugs (38%). However, the programme to provide free ARV drugs was still at the proposal stage. Second, the radio programmes mentioned were those broadcast on FM radio, and were sponsored by HIV/AIDS NGOs; for example, the programmes, *Omushaho wawe* (Your Personal Doctor) on Radio West is sponsored by AIDS Information Centre. CHAI is not a government-aided programme either; it is financed by the Global Fund to Fight TB and Malaria and is implemented through NGOs, CBOs and FBOs under the supervision of government. Finally, in “others” category, “Museveni” and condom distribution were mentioned as some other programmes aided by government to fight HIV/AIDS. But it has to be pointed out that Museveni is not a programme. In general, therefore, there was no clear knowledge by respondents of any government-aided HIV/AIDS programmes.

With the limited government funding available for HIV/AIDS programmes, the dominance of the CHAI programmes requires closer scrutiny. The programme has limitations; there are reports that government officials are misallocating funds meant for HIV/AIDS activities. For example, in August 2005, the Global Fund Project in Uganda was suspended due to mismanagement of funds by officials in the Global Fund Project Management Unit (GFPMU), who are believed to have siphoned off around US\$ 280,000 through various fraudulent means ranging from the use of false exchange rates to allocation of funds to programmes not covered under the fund (Nyanzi and Luggya 2006)¹⁶⁴. The project is also silent on gender issues.

Findings from other sources also indicate that the government commitment to supporting HIV/AIDS programmes in the districts is inadequate. For example, the implementation of Voluntary Counselling and Testing (VCT) by AIDS Information Centre (AIC) is hampered by the lack of political will in the districts. AIC (2000: 15) highlights the following challenges that limit VCT service in districts;

- a) Lack of outreach and mobilisation due to inadequate involvement of district officials
- b) During the allocation of district funds, VCT is not given priority since district officials think that NGOs such as AIC have a lot of money.
- c) Lack of support and supervision by district officials.

¹⁶⁴ See also, <http://www.avert.org/global-fund.htm> 15/05/2005

Government support of HIV/AIDS NGO programmes is often criticised *The New Vision*¹⁶⁵ noted that organisations dealing with HIV/AIDS in Mpigi district had accused the government of not supporting them in their fight against HIV/AIDS in the district. NGO officials complained that the government had not set up HIV/AIDS control projects in the district.

In Mbarara district, the same story is told by government officials. Interviews with officials from the District Health Educator (DHE) acknowledged that government programmes at grass roots level have not done much. I asked various government officials at the Directorate of Health in Mbarara the following set of questions:

Do you have or know of any government-aided programmes dealing with the HIV/AIDS problem?
Probing questions followed:

**What is the nature of the programmes?*

**Are there any government-aided community programmes?*

To what extent have the communities benefited from these programmes in general?

This question was followed by the following probe questions:

**How many communities have been visited and what is the impact of these programmes on the effects of HIV/AIDS?*

**How is the programme implemented at the community level?*

**How would you compare the effectiveness of NGOs with that of government in fighting HIV/AIDS?*

**How do you perceive of NGOs work with HIV/AIDS?*

According to the Director of Health Services, government programmes such as community sensitisation and health units are poorly funded and, therefore, not well implemented. He reported that:

We have been poorly funded. This has hampered programmes implementation by the government... NGOs have done more work than the government. NGOs have directly contributed about 80% to the fight against HIV/AIDS. NGOs have done better than the government. But we work with them; for example, they use government facilities during their outreach programmes, the local councils are used to mobilise people to go for these services. (personal interview with district health educator, Mbarara)

¹⁶⁵ <http://www.newvision.co.ug> 25/6/03

He further noted that the Uganda AIDS Commission, which was established in 1992, was supposed to support boards up to the community level. However, these committees were not yet in place in Mbarara.

The District Health Inspector had no positive comments to say either. He attributed the effectiveness of the battle against HIV/AIDS to NGOs rather than government programmes. He observed that NGOs such as AIDS Information Centre (AIC), TASO, and Family Planning Association of Uganda (FPAU) are more focused on specialised tasks. They target specific groups, while the government covers a wider area. He argued however, that the government cannot simply select one activity or one programmes or region to serve or one problem to address at a time. This would be committing development “suicide”.

I asked the respondents from the community to compare the government response with that of the NGOs: *How would you compare NGOs’ HIV/AIDS aided programmes with that of the government?* Most respondents were of the opinion that the performance of NGOs is better and more effective than that of the government. The following is the reply of one of the respondents:

NGOs are far better in delivering services to the needy and especially to local communities. This is because, on the one hand, government programmes are spearheaded by doctors and health workers who educate people. On the other hand, organisations use volunteers who are the real victims of HIV/AIDS. People listen to them more than to government officials (doctors). The government does not offer much. It only distributes condoms, especially to the youth. NGOs go deep into the village even to fetch the seriously sick, and take them to the hospital or the TASO centre for treatment at no cost to the sick, or their relatives. (Interview with respondent from the community)

One of the officials of the NGO noted that it is still a challenge for the government to fund programmes at the district, and that NGOs almost work alone in fighting HIV/AIDS. He noted that:

We work with government, but literally, we are doing the work of the government and almost working alone. Around 2001, the government trained counsellors who worked for few months. The government promised to introduce HIV testing kits in government hospitals, but the kits were not in place until 2003. These were used for few months and abandoned; instead

we receive patients sent to us from government hospitals. (interview with an official at AIC – Mbarara branch)

This view is supported by Uganda Aids Commission (UAC), which asserts that the government has not a strong commitment to funding HIV/AIDS activities (UAC and NHACP 2002).

As mentioned, the government relies heavily on external funding for HIV/AIDS programmes and rarely commits any funding to sustaining programmes after donor withdrawal. For example, the programme of establishing the District AIDS Coordination Committees (DACC) in every district in Uganda was not implemented. Their performance has been very poor. UAC and National HIV/AIDS Control Programmes, UAC and NHACP (2002), reported that the DACC only performed in districts which received United Nations Development Programmes (UNDP) funding, but ceased to be effective when funding stopped. Given this background, it may be predicted that the organisations being formed under the Community HIV/AIDS Initiatives (CHAI) programmes may not be operational when funding is withdrawn.

7.9.1 The Human Rights of People with HIV/AIDS

The Uganda National Health Consumer Organisation (UNHCO) notes that the rights of disadvantaged people such as those with HIV/AIDS are often abused in the matter of accessing health services, and there is no law to guarantee the rights of people as regards HIV/AIDS in Uganda (Garbus and Marseille 2003). It should be borne in mind, however, that the right to health services is only one of the basic human rights; others include the right to employment, to life and to freedom of association, just to mention a few. These human rights are often implied in government documents and emphasised in official statements, especially in those concerning people with HIV/AIDS, and the right to health is guaranteed by the constitution of Uganda (chapter 4 of the constitution). In spite of the lack of a specific law to protect the rights of people with HIV/AIDS, the government has addressed this issue (TASO 2002a: 10). The rights of people with HIV/AIDS are respected, which explains the greater openness about HIV/AIDS in Uganda than in any other country in Africa.

However, it should be noted that there are still many people with HIV/AIDS who do not know their rights, especially among the poor and the semi-illiterate. People whom I

interviewed indicated that they did not know their rights, especially those related to treatment, harassment and discrimination, which were some of the problems they faced.

In general, neither the rights of people with HIV/AIDS nor the specifics of these rights are clearly stipulated in government documents. The general constitutional rights are considered to be comprehensive, so there are no specific laws to protect the rights of those with HIV/AIDS. For example, there is no law to protect people against loss of employment due to their HIV/AIDS status, and there are no laws regarding inheritance and custody of children (Garbus and Marseille 2003). And, as O'Manique (2004: 136) asserts, the Ugandan government has ignored the role of violence, particularly the issue of forced sexual relationships in marriage¹⁶⁶.

The United Nations- UN (2002: 11), guideline no. 7 states that, “States should implement and support legal support services that educate people affected by HIV/AIDS about their rights, provide free legal services to enforce those rights...”. This has not been put into practice in Uganda, however, and human rights awareness is relegated to NGOs such as The Uganda Association of Women Lawyers (FIDA). FIDA works with vulnerable groups such as orphans and widows. Problems such as domestic violence, eviction from land and other maltreatment of widows have led the organisation to establish legal clinics in both rural and urban areas. As mentioned in 6.2.6, FIDA is one of the referral NGOs for TASO clients who need specialised services.

The discussions in this chapter have revealed that government has played a major role in facilitating the formation of the social capital required to fight HIV/AIDS. Table 7.4 provides a summary of this role.

¹⁶⁶ See also HRW (2003).

Table 7. 4 The role of Government in Facilitating Social capital to fight HIV/AIDS: The Quest for Synergy

	The Role of Government in Facilitating the Formation of Social Capital
Establishment of a favourable environment for other actors to participate in fighting HIV/AIDS	<p>Creation of an institutional framework that favours participation of different actors in HIV/AIDS activities</p> <ul style="list-style-type: none"> -Establishment of Uganda AIDS Commission to coordinate HIV/AIDS activities; Membership to the commission includes politicians and civil society representatives. - Multisectoral approach which allows participation of different actors -Political leadership -The involvement of the President -The role of Local Council system
Facilitating NGOs' Performance	<ul style="list-style-type: none"> -Funding NGOs activities such as provision of preventive materials; condoms and brochures - Mobilisation of funding such as from Global Fund to Fight HIV/AIDS Malaria and TB and from the United states Presidential Emergency Plan for AIDS Relief (PEPFAR) -Negotiating reduction in prices for Antiretroviral drugs, consequently people with HIV/AIDS access ARVS through their membership to NGOs -NGOs relationships with other actors through the Partnership committee and Partnership forum. These facilitate interaction and dialogue about HIV/AIDS by different actors. -Human rights for PWHA allows them not only to open up but also to have access to medical services and care-giving organisations (see stigma in chapter4)
Relationships with other Actors	<p>Collaboration through the partnership forum and partnership committees</p> <ul style="list-style-type: none"> -Collaboration through physical and human resource utilisation; the use of health facilities by HIV/AIDS organisations during their outreach programmes, - Provision of complementary services consequently collaborating through a referral system -Integration; for example, through joint activities and programmes. For example, the involvement of FBOs in management of UAC, involvement of NGOs in joint planning for HIV/AIDS activities, the use of government health facilities and the staff of government by NGOs and ACWs to implement programmes

7.10. Conclusion

The purpose of this chapter was to map the importance of government and state institutions in facilitating the generation of social capital necessary to fight HIV/AIDS. The role of the government in providing political leadership, mobilising funding and establishing an enabling environment not only for the operation of NGOs but also for the participation of other actors including individuals, in the fight against HIV/AIDS, were identified as important contributions to the success registered in Uganda with regard to fighting HIV/AIDS. The discussion also revealed that the government has been instrumental in forging partnerships between government, donors and NGOs through the establishment of formal institutions of collaboration. These institutions not only enable actors to engage with each other, but also enable the government to coordinate multiple actors with diverse HIV/AIDS programmes. This chapter has shown that through different programmes, social relations have been strengthened at different levels. At the organisational level, interorganisational communication and collaboration are strengthened. Through its international collaboration, funding has been mobilised. This funding is allocated to the local NGOs and other actors involved in the fight against HIV/AIDS. The chapter has shown that through government programmes, for example, political leadership, mobilisation and allocation of funding, local initiatives have been stimulated. These networks, as the discussion in chapter 2 premised, and

as the next chapter will show, have contributed to the extent to which HIV/AIDS organisations alleviate the impacts of HIV/AIDS.

The comparison with South Africa reveals that one of the reasons why South African AIDS policy has had little success was the gap that was created between government and civil society organisations. The failure to forge a partnership with these organisations in the fight against HIV/AIDS continues to dominate HIV/AIDS politics in South Africa. Although the Ugandan government was criticised for its shadow involvement, its partnership with civil society exemplified how synergy between government and society can have an impact on a social phenomenon.

The arguments raised in this chapter therefore, lead to a conclusion that in spite of the missing gaps as those identified in chapter 5 and the last part of this chapter, in government's effort to fight HIV/AIDS, the government of Uganda has made a big contribution to fighting HIV/AIDS. In the next chapter the role of TASO and PTC/PLI in combating HIV/AIDS and its impacts will be considered in more detail.

CHAPTER 8:

Alleviating the Impacts of HIV/AIDS: The Role of The AIDS Support Organisation (TASO) and Post-Test Club/Philly Lutaaya Initiative (PTC/PLI)

8.0. Introduction

The purpose of this chapter is to discuss the extent to which non-governmental organisations involved in HIV/AIDS activities (HIV/AIDS NGOs) alleviate the impact of HIV/AIDS. In particular, the discussion will focus on two organisations of this study. In chapter 1, I stressed that the overall purpose of the study is to explore the role of non-governmental organisations in alleviating the impacts of HIV/AIDS in Uganda. Consequently, in chapter 4, the various impacts of HIV/AIDS on individuals and society were discussed. It was stressed that strengthening social relations at individual, community and organisational levels, was a precondition for successful HIV/AIDS intervention by NGOs. In chapter 6, various approaches used by NGOs to strengthen these social relations were discussed, while chapter 7, discussed the role of the government in facilitating social relations. Based on the discussions in the chapters aforementioned, which have stressed the processes through which HIV/AIDS is addressed, this chapter will focus on the extent to which the two NGOs – The AIDS Support Organisation (TASO) and Post Test Club/Philly Lutaaya Initiative (PTC/PLI), have succeeded in addressing HIV/AIDS-related problems in Mbarara district of Western Uganda. In this regard, the general question being raised in this chapter is; Have TASO and PTC/PLI alleviated HIV/AIDS related problems? Throughout the chapter, a discussion of findings vis-à-vis this question is presented.

8.1 Access to Medical and Counselling Services.

In chapter 4, I discussed that acquiring HIV often results into AIDS, consequently death of these individuals because there is no cure of AIDS. As mentioned, because HIV causes loss of immunity and consequently making victims susceptible to opportunistic infections, both TASO and PTC/PLI members receive free medical services from the medical clinics established at their centres. The establishment of these medical clinics was aimed at making their members have access to HIV/AIDS medical services which were lacking in established health centres and hospitals. In addition, the members receive preventive treatment for infectious diseases such as tuberculosis. Further, they receive counselling services from specialised and trained personnel in HIV/AIDS counselling.

In 2002, a total of 26,065 individuals visited the seven TASO clinics countrywide (TASO 2002b: 7). In 2003, a total of 17,311 individual clients received medical services at the Mbarara TASO clinic (TASO records). In addition, TASO employs community nurses to take care of the sick in TASO supported communities¹⁶⁷.

The provision of free medical and counselling services improves the health conditions of people With HIV/AIDS (PWHA) and other members of these organisations. In addition the members get psychological and emotional support. As discussed, majority of people in Uganda are handicapped by poverty and therefore, do not have access to medical services which are largely privately funded. The provision of free medical care by these organisations therefore, has made it possible for the needy especially the PWHA to have access to these services (see discussion in 5.6.1 and 6.2.6).

8.2 The Impact of HIV/AIDS on the Social Values, Norms and Customs of Mbarara

In chapter 4, the relationship between cultural practices and HIV/AIDS transmission was discussed; for instance, gender-related issues, have their foundations in the social and cultural practices of specific communities. This has been a contributing factor to the spread of HIV. It is for this reason that TASO and PTC/PLI have “waged war” on such cultural values, as a means of controlling the rate of transmission of HIV and alleviating the related consequences of AIDS. In this chapter I argue that rather than focusing on the education for behaviour change alone, integration of this education with education that targets the social, economic and political environment should be the core focus for the successful fight against HIV/AIDS. I argue that both TASO and PTC/PLI have taken this focus as their main mechanism of fighting HIV/AIDS.

The focus of these NGOs has been on educating people regarding the dangers of such cultural practices. Education and dissemination of HIV/AIDS-related knowledge takes place in what may be called social capital infrastructures, such as informal and formal group meetings. Group meetings and interaction between individuals facilitate discussions about the roles of such cultural practices in increasing HIV transmission and how these practices and their impact may be alleviated. These discussions have a profound impact on changing social

¹⁶⁷ In an interview, the director of counselling services at TASO Mbarara revealed that the idea of a community nurse came from Zimbabwe following an exchange visit between TASO staff and representatives of Zimbabwean NGOs to study HIV/AIDS management technology.

values. Asingwire, et al (2003a) found that such cultural practices are now on the decline. The discussions that follow will examine the process leading to this decline.

Through group discussions and through informal and formal interaction, knowledge is acquired and disseminated. The main focuses of HIV/AIDS education have been: a) the cause and transmission of HIV/AIDS, b) the various impacts of HIV/AIDS, and c) the ways to deal with these impacts. Acquisition of such knowledge is important for behavioural change, particularly for developing people's assertiveness, for example women, who are disadvantaged by existing socio-cultural practices (see gender relations in chapter 4).

This study found that because of increased knowledge about HIV/AIDS, women are beginning to be assertive in their relationships with their husbands. They are demanding safer sex if they suspect their husbands of being HIV positive or of being promiscuous. Women demand not only safer sex, but also influence their partners' decisions to take the HIV test. This assertiveness is based on their knowledge of the impact of the disease and their fear of dying from HIV/AIDS-related illnesses. Such knowledge is acquired from NGOs' HIV/AIDS-related activities, such as education and sensitisation. This finding is reflected in the following narrative taken from an interview with a PTC/PLI member. According to my respondent:

After listening to a radio programmes and attending meetings of the organisation, I decided to take the HIV/AIDS test. I was informed about the dangers and modes of HIV/AIDS transmission. The results of the test were negative. After finding that I was HIV/AIDS negative, I wanted to start practicing safe sex with my husband, who comes to visit occasionally from the urban centre where he lives with his other wife. However, my husband didn't know how to use a condom. He demanded that I have unprotected sex with him. I refused to give in and demanded that he should first find out his HIV/AIDS status. So today he came to take the test although reluctantly; but he could not force his way to make me give in. I now know what to do to save my life from this deadly disease.

During the whole process of pre-test counselling, the husband was grumbling and muttering. I asked him his opinion on this issue and he replied that;

Women these days have been given freedom and independence to demand what they want. She could not allow me to have my conjugal rights because I have not taken a HIV test. She thought I would be reluctant to come. She is my wife, but I could not force her to do anything

against her wish. I am here to take the test. She is satisfied and our marriage is hopefully going to work again. (Interview with a respondent at AIC)

Women's assertiveness is still limited because of the existing laws, especially the law regulating property ownership. However, an increasing number of NGOs are providing legal counselling regarding the limits of these laws and how such laws can be used to women's advantage, which is facilitating assertiveness. The emergence of groups such as the National Community of Women Living with AIDS (NACWOLA) has helped to address issues related to the family pressures put on widows, particularly regarding the matter of inheriting them as well as their property. Indeed Asingwire et al (2003b: 35) conclude that;

A number of networks of PHAs namely National Community of Women Living with HIV/AIDS (NACWOLA), Philly Lutaaya Initiative (PLI),...have made a significant contribution in the fight against HIV/AIDS. The participation of PHAs in prevention activities is one of the unique best practices in Uganda's response, changing the paradigm of HIV/AIDS, and setting a new regime for combating HIV/AIDS.

Through women's groups of this nature, widows acquire essential knowledge, specifically related to their rights to self and property. Thus, they can protest against male pressure to inherit them when their spouses die.

These groups supplement the efforts of TASO and PTC/PLI. In TASO and PTC, I asked respondents about the type of information they obtain at the organisation meetings, and how this information helps to alleviate HIV/AIDS. In this regard, I asked them to comment on the impact made by HIV/AIDS NGOs on behaviours, for instance promiscuity, widow inheritance and wife sharing. These findings are presented in table 8.1 below

Table 8. 1 The Impact of Organisations (TASO and PTC/PLI) on Cultural Practices in Mbarara District

Cultural Practice	Reduction in practice	
	TASO	PTC/PLI
Promiscuity	95%	93%
Wife Sharing	92%	93%
Widow Inheritance	95%	97%
	N=79	N=43

Note: The question I asked was: *How would you rate the impact of the NGO you belong to (TASO or PTC/PLI) on the following behaviours: Promiscuity, Wife sharing, and Widow Inheritance?*

Respondents were required to select one answer from the options: Strongly reduced, Reduced, Little impact, No impact at all. These categories were collapsed into the two categories; reduced and little impact during data analysis.

The majority of respondents in both organisations acknowledged that these organisations had an impact on such practices. The data presented in the table indicates that habits such as promiscuity, the cultural values of wife sharing and widow inheritance, had reduced. This finding is confirmed by other studies carried out elsewhere in the country. In their study in Eastern Uganda, Asingwire et al (2003a: 72) found that cultural practices such as widow inheritance have been reduced due to the involvement of civil society organisations.

However, it is important to bear in mind that such practices have not been eradicated completely. They still exist in some areas, especially where the NGOs have not ventured deep enough to make people aware of the diverse effects of such practices. An interview with another TASO client revealed that widow inheritance is still practiced by some men as the case of her brother in-law. According to the client, “Although I continually reminded him of the death of his brother and the cause of death, he continued to follow me about, insisting on taking me as his wife. I could not stand it; I came back to my father’s home, leaving behind my children” (interview with a client at Buteraniro).

Like widow inheritance, promiscuity has not been eradicated completely, especially among men. According to the client in Kigarama,

Men do not listen. They keep on coming to me, trying to seduce me for sex. I keep on explaining to them that I am sick, but they insist on having sex with me. They argue that a man does not live to be the age of a tree to be harvested for timber. If it was not for the teachings of TASO, maybe I would give in to some of them and they would follow in my footsteps with HIV too. But I thank TASO for its teachings. Its clients (she generalises) do not simply give in to sex pressure because we are taught not to spread HIV apart from getting a new HIV infection.

We are taught that getting HIV does not mean that you are going to die tomorrow or the next day. Therefore, each day you live you should guard against new HIV infections. It is better that you deal with the HIV that is in your own body, instead of getting new infections through unprotected sex. Every person has a unique virus in terms of its composition. That is what they teach us. Each time you have sex with another person with HIV, you get a different type

of HIV. When it combines with your own, a different type is formed. This accelerates your body deterioration and you die in a short time.

The examples above are an indication of the extent to which organisations can limit HIV/AIDS transmission. As the examples illustrate, people who are members of HIV/AIDS organisations are better able to control their sexual behaviour. This minimises the spread of HIV/AIDS.

8.3 Alleviating Stigmatisation and Social Exclusion

Stigmatisation has been demonstrated to have a negative impact on social interaction, employment opportunities, emotional well-being and self-perception, resulting in withdrawal from social interaction, and undermining prevention, care and treatment (see, chapter 4). In addition, as mentioned in 7.4.1, a focus on the individual such as the work of religious fundamentalists, increases stigma. As a result, HIV/AIDS organisations have focused on groups and social relations as avenues for reducing stigmatisation and social exclusion. The role of drama (which will be discussed later in the chapter) and other activities have contributed significantly to increasing interaction and minimising stigmatisation. The discussion will show that stigmatisation and discrimination which faced people with HIV/AIDS earlier due to the fear of the transmission of disease (Monico, Tanga, and Nuwagaba 2001; Muyinda et al. 1997), have been addressed.

As the discussion in chapter 4 demonstrates, levels of stigmatisation are indicated by the degree of integration of individuals in the communities to which they belong. Their integration is measured in terms of the perceived amount of support which they receive from various people and the extent of their participation in various community activities¹⁶⁸.

Table 8.2 below summarises the responses of TASO and PTC/PLI members regarding their level of community belongingness.

Table 8. 2 Sense of Community Belongingness Reported by TASO and PTC/PLI Members

State of community belongingness	TASO members	PTC/PLI members
Improved	98%	98%
Unchanged	2%	2%
	N = 80	N = 45

Note: The question asked was: *There are often problems of associating with people with HIV/AIDS, even for people living in the same community, or attending the same church or mosque or any other*

¹⁶⁸ See Chapter 2 (2.6)

prayer group. To what extent would you say that your sense of belonging to your local community has improved since the organisation(s) started operating?

Table 8.2 reveals that most of the respondents considered that their sense of belonging had improved since joining the organisations. Members of both PTC/PLI and TASO responded that their sense of belonging to the community was higher, with a response rate of 98% for both. Rather than focusing on individual clients, the organisations focus on discussing HIV/AIDS-related issues in groups. Through such discussions individuals are able to gain the necessary knowledge and skills to deal with various HIV/AIDS-related problems. Since HIV/AIDS also has personal impacts, one-to-one counselling is provided regarding such matters, including medical counselling.

To find out more about their level of integration with their fellow members, I asked members of PTC/PLI¹⁶⁹ the following question:

Do you notice any differences when you are interacting with fellow members of the organisation?

The following are some of the responses from different respondents related to the integration function of PLI /PTC:

- (a) There are no noticeable differences between members of PLI and other PTC members;
- (b) We are well integrated;
- (c) We are united, we are one;
- (d) There are no differences we are all friends;
- (e) No differences; for example PLI members teach us; they counsel us; we learn from them.

The above responses indicate how members of the organisation who are different in terms of their HIV/AIDS status are integrated. For example, response (e) above reveals that members extract meaning from these interactions. Respondents are of the opinion that they learn from those who are HIV/AIDS positive. These explanations emphasise the role of TASO and PTC/PLI in fighting HIV/AIDS by bringing together different groups of people. The above findings reveal that in spite of differences in HIV/AIDS status, PTC/PLI members are well integrated.

¹⁶⁹ PTC/PLI is composed of members who are HIV positive and those who are HIV negative. The HIV/AIDS status of PLI members is not known to anyone apart from fellow members (at least in theory; this is a central principle of the organisation, but often members know each other's status through interaction).

In chapter 6, it was stressed that NGOs play an important role in facilitating relationships between members of organisations and their families and relatives, their neighbours and other people in the community. A comparison of the NGOs' approach and that of religious fundamentalists in addressing the problem of HIV/AIDS (chapter 7) is insightful. The latter have chosen the "abstain from sex and be faithful to your partner" (AB) strategy, which individualises HIV/AIDS. This creates a sense of blame and to some extent stigmatises individuals, who feel criminalised by the institution for their 'negligence and abandoning God's ways'. It was argued that whereas this approach is used in fighting the spread of HIV/AIDS, it actually causes other AIDS-related problems such as stigmatisation and decline in condom use. The latter is likely to lead to increased HIV spread¹⁷⁰. For this reason, TASO and PTC/PLI focus on group strategies rather than individual approaches to address the problem of HIV/AIDS.

The group discussions which are a central strategy in these particular NGOs help to provide individuals with knowledge about the transmission of HIV and how to avoid infection and re-infection. Discussions focus on correcting misconceptions about how HIV/AIDS is transmitted and on informing people about transmission mechanisms. Misconceptions regarding these matters (see chapter 4) were the root cause of social disintegration and the withdrawal of social support from AIDS patients and those suspected of being HIV positive, including orphans and widows.

In the interactions and groups, members discuss various issues, including sex and sexuality which were formally regarded as personal and private. In this way, the stigma is broken by increased discussion and interaction. It is argued that the reduction in the HIV prevalence rate in Uganda is partly explained by the open discussions about issues which were not discussed or secretly discussed previously:

There was considerable effort made towards breaking down the stigma associated with AIDS. Frank and honest discussion of sexual subjects that had previously been taboo was encouraged. There is a high level of AIDS-awareness amongst people generally¹⁷¹.

¹⁷⁰ See for example, http://www.healthgap.org/press_releases/05/091905_Uganda_condoms_press_clippings.doc 11/08/06

¹⁷¹ see <http://www.avert.org/aidsuganda.htm> 15/12/05

The discussions of the causes of HIV addressed issues such as sex and sexuality, which were earlier considered taboo and could not be discussed in public (Putzel 2003). These were made part of core issues discussed in group discussions arranged by TASO and PTC/PLI. In order to alleviate the problem of stigma, both TASO and PTC/PLI focus on increasing the level of HIV/AIDS-related knowledge through interactions within the organisations. Through interaction, members and clients shared personal experiences. Thus clients of TASO and PTC are well informed about the sufferings HIV/AIDS inflicts on people. At AIDS Information Centre, the counsellor in charge of PTC/PLI activities noted that:

Learning is a bit wide. They keep learning from each other through sharing experiences, helping each other sometimes without our efforts. Moreover, they are the real victims; they know what it means to be HIV positive. When they meet, there is no wasting of time, they share a lot with regard to HIV/AIDS. The information they get here is later shared with their families and other members of the community. This is how we manage to defeat HIV/AIDS. (Interview with counsellor in charge of PTC/PLI activities)

In an interview with a new TASO client at Katungu (Bushenyi district) outreach, it was stressed that social interaction is more important as a means to manage HIV/AIDS than isolation. During the interview the client said; “The fear that engulfed me when I received the results that I am HIV positive is now giving way. I am still afraid, but I will join others, I see they interact freely and I hope to learn from them how they have managed”. A counsellor at TASO Mbarara, whom I interviewed about how clients benefit by sharing their experiences, put this succinctly: “a problem shared is a problem half solved”.

When asked whether they considered group discussions to have been beneficial to them, the following responses were forthcoming from members/clients of TASO:

Issues discussed in a group help you to learn more and to share this with others, and you don't consider yourself as an isolated human being but as someone with others like you, and others around you, who can give you love and support. Group discussions help us not to view ourselves as criminals for being HIV/AIDS positive. (Respondent from Makenke Mbarara district)

Others perceive groups as leisure clubs where lessons can be learnt by sharing personal experiences with others:

Joining these groups is part of leisure time. We grow happy and relaxed, especially when we meet and sing together. When we meet others, we learn new things and get information. (Respondent from Kasese District¹⁷²)

We learn how to keep close relations with others, while avoiding any encounter that may become stressful. We eventually learn how to cope and get along with others in the community. (Respondent from Katungu, Bushenyi District)

I asked members of both TASO and PTC/PLI how often group discussions tackled issues related to cause, mitigation and prevention of HIV/AIDS. Such talks contribute to the awareness of how to manage the various impacts of the disease, such as stress, nutrition and HIV spread. As mentioned, PWHA alleviate stress by joining groups. With regard to nutrition, the respondents said that they had been taught that they should have a balanced diet, with limited fatty foods. In addition to nutrition, they said that they had been encouraged to exercise frequently and get involved in some activities that would give them some exercise.

Other benefits include the wider knowledge gained about the dynamics of the disease. This knowledge may lead to a reduction in risky behaviour which might in turn lead to infection/re-infection of individuals with HIV, and accelerated immune loss by AIDS patients and eventual death. Kelly(1995) argues that, to enhance the salience of risk and participants' readiness for change, interventions have often included in-session discussions involving group members and persons who have AIDS, video tapes of persons with AIDS talking about their disease, or similar activities to sensitize participants to personal risk.

All of these activities are central to the in-group discussions that take place in TASO and PTC/PLI. Both organisations focus on what causes the spread of HIV, preventive strategies, HIV/AIDS-related problems and ways of addressing these problems. In addition, people who have HIV/AIDS share their experiences with other members. These strategies are important because of the general lack of information about HIV/AIDS. For example, in 1997 Muyinda, et al (1997: 145) found that people still feared that they could catch AIDS through normal social contact and that AIDS could be contracted through sharing of utensils, clothes, meals and even through breathing the same air as those with the disease. It is for these reasons that

¹⁷² TASO does not have a centre in Kasese district (about 140 km from the TASO-Mbarara centre), although it is affiliated to the Kilembe Mines Hospital. Some clients travel this distance at least once a month to get medical and other benefits which the organisation provides.

strategies were designed to facilitate the dissemination of knowledge regarding HIV/AIDS. As pointed out, one of these strategies was to encourage interaction between AIDS patients with other people (as is the case of PTC/PLI) so as to facilitate discussions and the sharing of experiences.

The knowledge that someone has HIV/AIDS or has recently died of it generates fear of contracting the disease. Low-Beer and Stone Burner(2004a) argue that Uganda's successful HIV/AIDS intervention depended largely on the communication and knowledge about people with or who had died of HIV/AIDS. They claim that, in 1995, 91.5% of all men and 86.4% of women in Uganda knew someone with AIDS, compared to 68-71% in Kenya, Malawi, and Zambia (Low-Beer and Stoneburner 2004a: 6). It has to be stressed that the levels of stigma can be said to be reduced if more people can talk about HIV/AIDS openly, if they can share their experiences without fear of being figure-pointed out as imoral beings and social deviands (see religious fundamentalism), or being segregated and denied social support from their family members (see 4.5.2). In addition to reducing stigma, communication about HIV/AIDS has the effect of reducing stress and other pressures related to it (Small 1997).

It has to be stressed further that, increased knowledge about HIV/AIDS, which is acquired through group discussions and interactions between individuals and groups, contributes significantly to behavioural change. Behavioural change in this context ranges from having protected sex, for instance using condoms, to reducing the number of sexual partners one has. The *Ministry of Health HIV/AIDS Surveillance Report 2003* found that 97% of married women had no sexual partners other than their spouses, while 12% of married men had one or more partners besides their spouses. This was a significant finding that behavioural change in Uganda had been achieved.

Table 8.3 indicates some of the various topics covered in the formal group discussions which are arranged by TASO and PTC/PLI for their clients/members.

Table 8. 3 Topics Covered in Group Discussions (TASO and PTC/PLI)

Types of Topics covered in Group discussions	Response rate (% of clients/members)						
	Always		Often		Never		Total %
	TASO	PTC/PLI	TASO	PTC/PLI	TASO	PTC/PLI	
Causes of AIDS and spread of HIV	98	68	1	30	1	2	100
Preventive mechanisms	98	73	1	25	1	2	100
How to live with other people	99	79		21	1		100
Others issues such as Income generating activities ¹⁷³	97	80		8	3	12	100
	N= 80	N=45	N=80	N=45	N=80	N=45	

Note: The following questions were asked: *How often are the following topics discussed in the meetings: a) causes such as promiscuity, b) coping mechanisms, c) how to live with other people and, d) other issues- (I probed for the nature of the intervention).*

The above table indicates that discussions are not limited to the causes of AIDS and spread of HIV, but also address preventive mechanisms and how to live with other people. While recognising that causes and prevention of HIV/AIDS should be the primary goal, these NGOs also considers that the integration of people, especially those with HIV/AIDS, should be their targets. As discussed above, lack of integration limits participation and interaction. For this reason, issues related to how members of TASO and PTC/PLI should live with other people are included in the group discussions. From these discussions members learn how to associate with their fellow members and to live with people in their communities. As the discussion in 8.6 will show, this contributes significantly to the extent people feel confident to live with HIV/AIDS.

In addition to the causes of AIDS and the spread of HIV, prevention of HIV and integration, TASO and PTC/PLI recognise that the social-economic environment propels HIV transmission. Therefore, other issues related to the social and economic implications of HIV/AIDS are discussed. As pointed out earlier, emphasising prevention without addressing social and economic conditions of people will not produce the desired results (White 2002). During interviews, respondents were asked to describe some of the other issues discussed in their groups. Income generating activities (IGA) were cited as an important intervention mechanism to reduce poverty. Measures included sharing project experiences, and engagement in income generating and productive activities. According to one PTC/PLI member, the members educated each other as to which projects were more productive and easy to sustain. For example, one member explained how a goat project can be productive.

¹⁷³ Respondents were asked to mention what other issues other than the ones mentioned

He stressed that the goats' productivity depends on feeding and taught the other members how to feed goats so that they will multiply quickly. Other income generating activities which were discussed include engaging in small businesses requiring little space, as a shady place in front of ones home. Members of PTC/PLI stressed that increased engagement and interaction in the groups was important to keep them busy. Idleness would lead them into unproductive activities, including high-risk activities such as promiscuity.

Often, HIV/AIDS organisations have video tapes about HIV/AIDS, which members watch during their in-group sessions. These supplement discussions held in the groups, and sometimes a video may trigger further discussions about HIV/AIDS. On the whole, it was found that in one way or another, members benefit from these interactions and group discussions by learning to deal with different HIV/AIDS impacts which they face.

The above discussions have revealed that stigma is mitigated in many ways, including interaction and discussions within formal groups. These findings agree with Asingwire, et al (2003a: 41) who point out that "today HIV/AIDS no longer carries the level of stigma and discrimination as in the past". The next point to consider is how the information and knowledge acquired from interactions has an impact on stigmatisation.

8.3.1 Information Access and its Impact on Stigma

It is important to note that the more people are connected, the better their ability to access information and resources and to develop appropriate behaviour that would reduce their susceptibility to HIV infection. Increased sensitisation through counselling and participation in different activities, such as drama and other social events, facilitates information and knowledge transfer. This information and knowledge has an impact on stigma. In order to increase such interaction, NGOs are emphasising the building of solidarity networks that can increase levels of socialisation. At TASO Mbarara, a day centre has been set up as a meeting place for clients, who are free to meet there any day, depending on their schedules. In addition, there are two days a week when clients can come to the centre for medical consultations and counselling services, as well as to meet others. PTC/PLI has a recreation centre where members meet twice a week.

Through regular interaction, the clients build up their confidence in dealing with the other and trust relationships may develop. In chapter 6 – 6.2.1, it was stressed that TASO and PTC/PLI members also have friends who are non members of these organisations. Personal connections

with friends and members of TASO and PTC/PLI are important sources of information, not only about HIV/AIDS but also about their world; for example, about jobs, new products etc. Through the interactions between members of TASO and PTC/PLI with non-members, HIV/AIDS-related knowledge especially regarding prevention, management and the impact of HIV/AIDS is disseminated to family and other community members. This helps to create harmony among these groups of people and to promote a positive attitude towards the HIV/AIDS infected. Consequently, people with HIV/AIDS live positively (see discussion in 8.6).

8.4 Alleviating Poverty

As discussed in chapter 4, poverty, especially among women, drives them to engage in risky sexual behaviour. They depend on men for their survival and may not be able to negotiate safer sex. They are victims of sexual abuse and harassment. During my field research, I held focus group discussions in Makenke community. Respondents identified poverty as the major contributing factor to the spread of HIV/AIDS in their community. They argued that, in spite of adequate knowledge about the causes of HIV and modes of its transmission, poverty had forced them (especially the women) to continue engaging in unprotected sex. The women claimed that when men approached them wanting unprotected sex, they agreed because they have no other source of income. They added that they cannot afford to buy condoms. Moreover, they stressed that the men sometimes wanted unprotected sex, and they could not refuse because they needed money for survival¹⁷⁴. They pointed out that, if people were not poor, many HIV/AIDS-related problems could be controlled. One of the respondents stressed that “many rich people are living longer despite being HIV positive because they can afford medicine and good food”.

In a separate interview with one woman from the group, she claimed that she had had three separate attacks by herpes Zoster (a viral infection) that might be associated with HIV/AIDS, but she still practices unprotected sex even when she knows that she risks re-infection with HIV. She attributed this behaviour to poverty.

¹⁷⁴They were responding to the following questions: *Do you think HIV/AIDS is a problem for/in this community? If so, how is it a problem?*

In order to address poverty, TASO and PTC/PLI developed initiatives targeting income-generating activities for their clients/members. The organisations have also tried to put in place a micro-credit scheme for their members/clients in order to finance these activities. Through a system of co-guaranteeing and group lending, individuals, with the support of their group members are able to obtain short-term interest-free loans to finance their own activities.

To obtain loans in this system, individuals must belong to a group. The member of the group who receives the loan signs a binding agreement to repay the loan, and group members support him/her by signing another agreement, which binds them into repayment of the loan in case of loan default. Selection of members with whom to associate is up to the individual member. Individuals who are not considered trustworthy will not find anyone to act as co-guarantor for the loan, since in the case of default other members will have to pay the loan. “By signing the binding agreement, each member becomes responsible for loan payment and this makes loan recovery and monitoring easy” (interview with the TASO officer in charge of social services).

Records at TASO-Mbarara indicated that between March and December 2003, a number of clients had obtained loans through group support. The money given to each individual ranged between Uganda Shillings 100.000 (\$ 53) and 150.000 (\$79) and was supposed to be repaid in 4 instalments within 16 weeks. Up to 2.79 Million (\$1468.4) Uganda Shillings had been lent to 6 groups. Only Uganda Shillings 1,245,660 (\$655.6), i.e. 45% had been recovered, the rest was still held by borrowers although the repayment date was passed.

It has to be stressed that the approach to directly alleviate poverty has not been successful. The recovery rate of the loans is below average. In addition, the micro-credit scheme has had negative implications for clients’ access to medical and other TASO services. In an interview with the counsellor in charge of the TASO day centre, it was revealed that some clients who took up a loan stopped attending the medical clinic for fear of being embarrassed for failing to pay it back. She commented that;

If a person fails to pay, it is not possible to employ “harsh” means such as confiscation of his/her assets. We cannot use the same means as banks use. Some people may use this as a weapon to tarnish our name. This goal conflicts with and undermines our main objective of providing care and support. Therefore, we are slowly phasing out the programmes. We may

revive the programmes after carefully studying the appropriate recovery options. (interview with counsellor in charge of TASO day-centre).

At PTC/PLI, the project has not taken off. The organisation is still negotiating the modalities of lending to youths who complete school. Considering the fact that most members of the club are still attending school and are not involved in income-generating activities (IGA), the club has not emphasised micro-finance as a poverty alleviation strategy.

In spite of the above short comings in the poverty eradication strategy, the contribution made by group formation to promote cooperative behaviour is evident. Interpersonal networks are also important to gain access to Community HIV/AIDS Initiative (CHAI) funding. For example, a number of NGOs and community-based organisations have accessed Community HIV/AIDS Initiative (CHAI) funds, the amount ranging from Uganda Shillings 1.7 million (\$895) to Uganda Shillings 5.2 million (\$2737) (Mbarara District records). These funds are donated to facilitate the implementation of specific programmes; for example, programmes to pay school fees for orphans, carry out drama activities, and provide basic necessities such as mattresses to needy HIV/AIDS patients. Those affected directly or indirectly by HIV/AIDS are unable to meet these basic needs without such assistance because of the expenditures on care and medical which takes large part of people's incomes (see chapter 4 – 4.5.3).

Nevertheless, this approach has several limitations. As already mentioned (see 7.9 for a critique of CHAI project), CHAI funding is donor based, which raises the question of sustainability. Moreover, the money is spent on consumables rather than on investment. Nor are there any poverty eradication or income-generating activities mentioned in the criteria for approving applications eligible for funding.

In general, the initiatives that are intended to directly alleviate poverty have failed. The income-generating project started by TASO was abandoned because of loan recovery problems. At PTC/PLI, the proposals for how income-generating activities for youths can be developed are not yet in place. The project to make youths self-sufficient by working as tailors is still progressing. In both organisations, there is no project that is in place that provides sustainable food security. The food project run by TASO is 100% donor funded. Although the apprenticeship programmes (see discussion in next section) is meant to reduce

the burden of orphans on households, the programmes absorbs too small a number of orphans to have a significant effect on poverty.

Nevertheless, it should be stressed that these organisations provide services such as care and counselling, medical treatment free of charge to members/clients. Since purchase of these services consumes most of the income of people with HIV/AIDS, their provision free of charge at the organisations' clinics releases this money to be spent elsewhere. Thus, their poverty is being indirectly addressed. To illustrate this point, the way in which these organisations address the problem of orphans will be discussed in some detail.

8.5 Addressing the Problem of AIDS Orphans

The increasing number of AIDS orphans has led TASO and PTC/PLI to focus on mobilising resources that can be used to take care of these children. The number of orphans in Uganda is in the range of 1-2.5 million (see chapter 4), and the majority of these have no family able to take care of them.

Various NGOs have taken the responsibility of providing "homes" for orphans who have no one to take care of them. The Masulita Children's Home, for example, was established by Uganda Women's Effort to Save Orphans (UWESO). This programme is unique in that it institutionalises orphan children in an alternative family system. Stress is placed on the importance of building relations among children who come from different environments, and they are joined together as members of a "family" under the care of a "mother". In this family system, the children grow and become attached to one another as brothers and sisters, so this project has been considered a success (Muriisa 2001). However, such structures are limited and cannot accommodate a large number of orphans; for example, the Masulita children's village currently caters for only about 54 children¹⁷⁵, and as mentioned, the Friends Orphanages School, caters for only 72 orphans. As stressed in chapter 4, given the number of orphans in the country, this is just a fragment.

8.5.1 Supporting Orphans' Education

In addition to providing homes for AIDS orphans, as described above, NGOs support some programmes targeting orphans within their home or foster-home environments. For example, the provision of formal education for AIDS-orphans is one such programme. The role of

organisations is to mobilise funding to run the programmes; for example, TASO receives funds from Celtel (U) Ltd. to support AIDS orphans in school (see 6.6.1). Some orphans are placed in various schools for formal education, while others are placed in apprenticeship programmes to learn practical skills.

Since formal education is a long-term project and may not be sustainable in the long run, both TASO and PTC/PLI run various apprenticeship programmes for orphan children. TASO sponsors at least 50 children of both sexes annually to attend such programmes; for example, in hair dressing, tailoring, carpentry and joinery, construction and concrete work, motorcycle and vehicle mechanics, and welding and metal fabrication. Those selected are placed in workshops to learn these skills from practicing artisans. Courses normally last between 9 months and 1 year. Those who complete the programmes are given a starter kit which contains the tools required to start-up their own business. Between 2001 and 2003, about 150 students graduated with different skills and were given starter kits. I traced three of these graduates who are now self-employed. They all agreed that the skills they had acquired were helpful. One of them had this to say;

After the death of my parents, we were left under the care of my aunt. Because my parents were clients of TASO, my aunt sought support from TASO, and I was selected to undergo training in carpentry and joinery. Not only did I get skills, TASO, gave me the equipment to start with in my own business. Presently, I am self employed and employ those you see around. I am now supporting my aunt and my sisters and brothers who are in school. Thanks to TASO for the support. (Interview with a beneficiary of apprenticeship programmes)

The PTC/PLI training programmes for tailors is organised differently. The programme was primarily set up to generate income for the club, although it allows members to recommend people such as orphans who are in need of training. The cost of training is Uganda Shillings - UX10.000 (US\$6) per month and the course lasts between 6 and 9 months. Unlike TASO, the students in PTC/PLI meet all the costs of the programmes. This is a limitation since many orphans cannot afford the fees.

¹⁷⁵ http://www.uweso.org/programme_masulita.php

8.6 Living with HIV/AIDS Infection: Coping With Life

The impact of HIV/AIDS and the community perception of individuals infected with HIV/AIDS create an environment which threatens the wellbeing of those bearing this stigma. Although there are few studies relating HIV/AIDS to a number of suicides in Africa (Meel and Leenaars 2005) and particularly in Uganda, it was not uncommon in the early days to hear about people committing suicide because they suspected that they had contracted HIV. The fear of being shunned by society, the guilt and shame associated with the disease, the prospect of prolonged suffering and the hopelessness knowledge that there is no cure for the disease made those infected by HIV/AIDS desperate enough to commit suicide. Referring to the USA, Kausch (2004) claims that patients who suspect that they are infected with HIV/AIDS often develop feelings of shame and guilt, which lead them to an irrational decision: to commit or attempt to commit suicide. Others with HIV/AIDS have committed suicide because of the sufferings caused by the disease, considering their lives to be worthless. Suicide stories are less common today, however, because people have come to terms with living with HIV/AIDS. As mentioned, proper information for those infected on how to manage HIV to lead a better life is the prerequisite for positive living (see 8.3.1).

At present, there is no cure for HIV/AIDS and people are still going to be infected with it for some years to come. Likewise, the impacts of HIV/AIDS, such as orphans, may not be fully mitigated in the short term. Efforts are being made to discover a vaccine for HIV/AIDS, but even when this has been discovered, it will be impossible to save the lives of those already infected. In Uganda, there are over 1 million people infected with HIV/AIDS. However, as discussed in 4.4.1, the exact figure is not known since surveillance reports have largely depended on hospitalised cases and as such the figures obtained through this means may not be realistic (Allen 2005; MoH 2003; Ouma 2004)¹⁷⁶. Efforts should therefore, be made to make people already infected with HIV/AIDS to come to terms with living with HIV/AIDS.

Given the above situation, it is imperative to stress the importance of correct information about how to live with HIV/AIDS; it serves to relieve some of the anxieties that weigh down both individuals and communities affected by HIV/AIDS. NGOs are putting in place mechanisms to provide the life sustenance especially of AIDS patients. In a study of 44 women with HIV/AIDS carried out in Zimbabwe, it was found that information received from

¹⁷⁶See 4.4.1

counselling sessions was important for maintaining optimal health. In addition, the study revealed that, because most women did not inform their relatives about their HIV/AIDS status, support groups were important for overcoming isolation and sharing feelings and experiences (Krabbendam et al. 1998).

The present study found that, through interactive meetings, people infected with HIV/AIDS are able to participate in HIV prevention and AIDS care activities. They share their experiences and acquire the necessary skills to promote positive choices and preventive practices. Such interaction promotes self-esteem, self-confidence and a sense of belonging. By joining hands and standing together, their quality of life is improved (Sekirevu 2002).

Furthermore, the present study found that organisation members who join drama and singing groups are able to deal with stress which threatens their life. A member of the TASO drama group was interviewed about the benefits she gained from belonging to the group. She said that when she is with the drama and singing group she is able to let her mind relax. Responding in the local language, she stated: *“Omuntu yabugana abandi akeshongora nabo nanaanuka kandi nitwegyeramu bingyi, nokumanyisibwa ebirikugyenda omumaisho”* (If a person meets others and sings with them he/she gets relaxed. In addition we learn new things and get information about what is taking place).

Another respondent said that when she is with the group, she gets counselling from other members of the group. This places HIV/AIDS in the wider context of disease and, to some extent, it may pass as any other disease. She had the following to say:

Malaria has been around for many years. The only difference is that I am more likely to get malaria than a person who does not have HIV. This I know, therefore, I take precautions. To gain this perspective on HIV/AIDS, you must have the support of others who share the same view. Such a perspective can only be obtained by interacting with others like yourself and sharing the experiences you have with the disease, your perceptions of it and ways of living with HIV. (Interview with an HIV positive person)

From the interviews with the staff of TASO, I learned that clients of TASO are closely connected to one another and are involved in sharing experiences whenever they meet. One counsellor said that clients identify themselves as belonging to the “family”. He noted that,

Our clients have a certain solidarity that is lacking among many people. For example, during our home-based care visit, one client may inform us of another client in the neighbourhood needing our services. They know each other and they always try to find out what is happening to their colleagues. (Interview with counsellor)

Given the above discussion, it is important to understand how clients/members of TASO and PTC/PLI perceive of their ability to live with HIV/AIDS.

Respondents were asked about the extent to which they perceived that they can live with HIV/AIDS. More specifically, they were asked about their perception of how worthwhile life is, their attitudes towards the services they obtain from organisations, their perception of the organisations' contribution to preparing them to live with HIV/AIDS, and their willingness to disclose their HIV status to others (for example their relatives). Responses of interviewees from TASO and PTC/PLI on these variables are tabulated below.

Table 8. 4 Perceptions of the Extent to Which People Can Live with HIV/AIDS

Extent to which people can live with HIV/AIDS	Response Rate (%)	
	TASO	PTC/PLI
Perception that NGOs contribute greatly in preparing people to live with HIV/AIDS	99	98
Perception that life is worth living	99	96
Disclosure of one's sero status and sharing experiences with his/her colleagues	88	61
Confident that one can live with HIV/AIDS	90	93
Can publicly disclose one's sero-status	85	94
	N=80	N=45

Note: I asked the following questions: *1. Generally speaking, would you say that you are happy with the organisation's activities*

2. Since you joined the organisation, would you say that your health has improved or not improved; do you feel that life is worth living?

3. Using a 5-point Scale from 1-5 (where 1 is very low, 5 is very high) how would you rate the contribution of NGOs in preparing people to live with HIV/AIDS? How would you rate your confidence to live with HIV/AIDS?

The questions were aimed at understanding the attitudes of individuals who were members or were receiving services from TASO and PTC/PLI to living with HIV/AIDS. The findings in table 8.4 reveal that organisation members perceive that they are able to live with HIV/AIDS. Over 90% of the respondents in TASO and PTC/PLI were happy with the services they were getting from the organisation to which they belonged. They expressed confidence that they could live with HIV/AIDS. This is represented by 90% and 93% for TASO and PTC/PLI

respectively. They also said that they disclose their sero status and share their HIV experiences with their colleagues (88% for TASO and 61% for PTC/PLI members). Apart from sharing their sero status to their colleagues, majority of the respondents in the two organisations were of the view that they could publicly disclose¹⁷⁷ their sero-status (89% and 94% of the respondents from TASO and PTC/PLI respectively).

From the findings above, it can be stressed that the members of these two organisations had a better self-rated health and a positive attitude towards living with HIV/AIDS. An assertion therefore, is made that TASO and PTC/PLI have been successful in instilling into their members confidence in handling HIV/AIDS.

The above findings are supported by other findings concerning for example, community belongingness which indicated that respondents were integrated in their communities (see discussion in 8.3). Such integration has serious implications for individuals who contract HIV/AIDS. As discussed, integration means that they are less stigmatised and less isolated, and that they participate in community activities. Therefore, HIV/AIDS associated shame and guilt that would place a strain on HIV patients is minimised, thereby increasing their ability to live with HIV/AIDS. It should be noted that the finding that in both organisations majority of respondents expressed that they could live with HIV/AIDS is an indicator that networks are important for people's well being. It was stated that people in the same organisation necessarily have a bonding relationship because they share the same interests – interests of the organisation (6.1). However, it is important not to ignore the fact that members/clients of these organisations differ markedly; TASO clients are largely people with HIV/AIDS, while PTC/PLI members/clients are both PWHA and the non-infected (5.4.1). Based on this idea, I stated that TASO may be regarded as a bonding organisation while PTC/PLI may be regarded as a bridging organisation. The finding presented in table 8.4 therefore, indicate that both forms of associational relationships have similar impact on HIV/AIDS status. This effect however, largely depends on the approaches used by these organisations to address HIV/AIDS related problems.

As discussed in 6.2 - 6.2.4, the social interaction and interconnection between people with HIV/AIDS and others (family members, relatives and neighbours) relieves them of stress.

¹⁷⁷ Whereas an individual may disclose his or her sero-status to people close to him- friends, members of the family it may not follow that such individual may make this disclosure to the general public.

Increased counselling for community, families and clients gives them confidence. The group discussions about how to manage the disease and how to live with other people, and the experiences shared, all contribute to improving their health.

In addition, the leaders in these organisations set a good example of how to manage the disease, which often gives the others courage and hope. In an interview with the chairman of the TASO's Clients' Council and his vice-chairperson, they both revealed that they had been living with HIV/AIDS for about 15 years. This revelation is often made to clients on counselling days and also in their speeches at the outreach clinics. Figure 5.1 b, shows the chairman addressing clients, and it is on such occasions that he makes his testimony about how he has managed to live with HIV/AIDS for that long. It is such messages that give the clients courage and confidence that they can live with HIV/AIDS.

In their Zimbabwe study, Krabbendam, et al (1998) found that newly diagnosed women were inspired by the revelations of HIV-positive group leaders who were living a satisfying life. This is also true for clients of TASO when they are addressed by a long-time sufferer of HIV/AIDS such as the chairman of the Clients' Council.

Furthermore, the medical clinics provided by organisations for their clients also boost their health and also a positive living (see discussion in 8.1). All the above factors boost the individuals' ability to manage and live with HIV/AIDS.

8.7 Bridging the Gap between People with HIV/AIDS and the Community

The increasing impact of HIV/AIDS has constrained the social fabric of Uganda. As discussed in chapter 4, HIV/AIDS-related social discrimination and stigmatisation are causing the breakdown of social unity. This decline is translated into a decrease in social support for people with HIV/AIDS and orphans (see for example 4.2.2). Similarly, increased stigmatisation and discrimination limits medical care and support from would-be providers (family, relatives, friends and members of the community). In the discussion that follows I will examine the extent to which TASO and PTC/PLI are managing to solve the problems of HIV/AIDS by bridging the gap between people with HIV/AIDS and other community members.

8.7.1 The Role of Music and Drama in Addressing Stigma and Social Discrimination

HIV/AIDS NGOs are engaged in various activities, such as drama and other community outreach programmes, aimed at increasing HIV/AIDS awareness in the country. The drama group at TASO Mbarara has an average of four presentations in different communities each month (interview with drama group members). Elsewhere in the country where TASO has branches, drama is also used to deliver HIV/AIDS-related messages. The *TASO Quarterly Report January to March 2003* reveals that the drama groups for each branch had held the following performances: Mulago 27, Entebbe 21, Masaka 25, Mbarara 23, Jinja 27, Tororo 20 and Mbale 19. All together a total of 162 performances were made. These performances were watched by 30,212 people (TASO Quarterly Report January to March 2003).

PTC/PLI uses the same approach to communicate HIV/AIDS-related messages to the communities. By the end of 2003, PTC/PLI- Mbarara, had held 50 presentations of songs and HIV/AIDS-related plays in various communities reaching, a combined audience of 14,260 people (AIC Mbarara- PTC/PLI core activities).

Drama is a mechanism for information transmission to communities. For example, HIV/AIDS-related plays are a means of communicating to people the realities of the disease. After the play, the audience usually has the opportunity to participate in a question-answer session with the actors, where they can ask questions about HIV transmission, cause and impact. In their discussion of the contribution made by people with HIV to the fight against HIV/AIDS, Muyinda, et al(1997: 147) argue that “involvement of people with AIDS in education campaigns may be an effective strategy in making AIDS a reality to the general population. This helps people to identify with those with AIDS and to see them as part of society”. As mentioned, Asingwire et al (2003b) reach a similar conclusion and argue that involving PWHA in fighting HIV/AIDS is the reason why Uganda has succeeded in this fight. Drama sessions in the community therefore, have created social unity in various ways.

First, they bridge the gap between people with HIV/AIDS and the community because community members are informed of basic facts about HIV/AIDS. This may increase the feeling of community belongingness of those with HIV, as discussed in 8.3.

Second, by talking to people, a positive response may be generated towards treatment and disclosure, and prevention measures and care proposals on the part of those who have not yet

been exposed to such issues or who were still in doubt. Disclosing one's status results into the sharing of personal experiences with other people, who seek advice about how those who are infected are coping with the disease and accessing medical treatment.

The drama activities of NGOs' demonstrate how people living with HIV/AIDS can combat HIV/AIDS-related stigmatisation, discrimination and denial, and how to extend the openness about how to respond to the HIV epidemic. In addition, this is a step towards the creation of cross-cutting ties linking people with HIV/AIDS and the general community; once people are informed about HIV/AIDS, they gain knowledge and understanding of the disease and how to manage it in terms of prevention and mitigation.

In addition to bridging the gap between members of the community and people with HIV/AIDS, drama is also an educative and mobilisation programme. In the first instance, role playing by drama group members makes them able to resist certain temptations such as promiscuity. The youth always act role plays showing how they are lured into temptations to have sex with their fellows and they play the ways of resisting such temptations. This has the effect of reducing the possibility of HIV infection. The interventions which have been shown to be effective in producing behaviour change have all focused on skills training and practice, and behaviour change rehearsal exercises (Kayazze 2002; Kelly 1995). According to Kayazze (2002), "...programmes which focus on helping teenagers to change their behaviour using role-playing and games have shown signs of success".

At a presentation by the Post Test Club drama group in Kashari, a member of the community said that, "our children are taking the messages about AIDS seriously. I wish such groups could keep coming to our community so that our children could maintain the change in their behaviour" (Member of the community Kashari-Rutoma).

At Rwobuyenje Church of Uganda in Kakiika-Mbarara, I talked to community members to get their views about the play presented by TASO drama group. The members of the community whom I interviewed confirmed the need for these performances in their community, and stressed that they are educative. An old lady who is taking care of her son's AIDS-orphaned children said that, "the youths are leaving us. The disease is robbing us of our children. We like these performances. They educate us. This is the third time these people

have visited our church. We hope they will keep on coming so that our children will survive the menace of AIDS” (interview with member of community in Rwobuyenje).

For the communities, drama is a source of information about HIV/AIDS transmission and mitigating impacts. It serves to mobilise some people to visit the testing and counselling centres to determine their HIV status, and others to seek medical help and assistance. Mungherere¹⁷⁸ notes that: “we made the government realise that to do community mobilisation around treatment, you need us, people with AIDS, to talk to people, to help them with disclosure and treatment compliance”¹⁷⁹.

8.7.2 Community Training and Participation in HIV/AIDS Activities

To address the impact of HIV/AIDS, TASO and PTC/PLI are committed to developing opportunities for public participation in HIV/AIDS-related activities. They seek to identify approaches that are geared towards controlling the spread of HIV in general, and to bridging the gap between people infected with HIV/AIDS and other people, in particular.

Discrimination affects people infected or suspected to be infected with HIV/AIDS (UNAIDS and WHO 2003: 31). To deal with this impact of HIV/AIDS, TASO and PTC/PLI have built networks that bridge the gaps existing between HIV positive and negative people. For example, AIDS community workers, who are engaged to provide care and support, in addition to doing community counselling, are a means of bridging this gap. It is a way of helping people with HIV/AIDS to be more integrated in their communities.

In order to take care of the increasing number of clients, TASO encourages people to participate in HIV/AIDS activities through community initiatives, such as home-based counselling, community outreaches and sensitisation programmes. Community participation involves not only those with HIV/AIDS, but also other volunteers from the community. A large portion of TASO's HIV/AIDS community activities, including counselling, training and mobilisation, is implemented by AIDS Community Workers (ACWs) who may not be infected with HIV/AIDS. The involvement of these people has the impact of filling the

¹⁷⁸ A representative of the National Forum of Networks of People Living with HIV/AIDS in Uganda.

¹⁷⁹ <http://www.plusnews.org/webspecials/ARV/ugaPlw.asp> 17/04/06

gaps¹⁸⁰ left by lack of technical personnel to deal with HIV/AIDS. Moreover, the available number of personnel cannot match the extent of HIV/AIDS infection.

In an interview with ACW members, it emerged that there are ACWs who have not taken the HIV test. The involvement of people who are not or may not be infected with HIV/AIDS in activities of an organisation, in association with people who are infected, is one way of increasing community participation and hence bridging the gap between these people and consequently HIV/AIDS problems such as stigmatisation and isolation are addressed.

The TASO Aided Communities

There are 12 semi-autonomous communities under the supervision of TASO-Mbarara branch. Three others had been phased out due to lack of commitment on the part of the AIDS Community Workers (ACWs). Since TASO's role is strictly supervisory, the communities are responsible for programme design and implementation. The latter is the work of ACWs, with the collaboration of other organisations, such as local religious bodies and local government officials.

The communities are self sustaining, according to the counsellors in charge of them (interview). They develop their own programmes, which are in line with organisation's activities; for example, awareness creation, condom distribution and social support (see figure 8.1). Where possible, the organisation may facilitate these programmes; for example, by providing free condoms.

The ACWs work as volunteers. They are provided with material support to facilitate their work, such as bicycles, torches, umbrellas and gumboots; they may have to work at night and in bad weather conditions (interview with ACW in Nyarubungo community). The ACWs are trained in counselling, management of income-generating activities, and most importantly, in collaboration, networking and outreach skills (Asingwire et al. 2003a: 26). The aim is to help these people link up with other stake holders, such as political and religious leaders, who are crucial for community mobilisation. They are also trained to keep a record of their activities, track their progress and make appropriate progress reports (interview with ACW in Nyakayojo community).

¹⁸⁰ See the role of ACWs in the discussion below.

The ACWs perform a number of tasks. They are programme implementers. They carry out community sensitisation, counselling family members and AIDS patients in order to encourage positive attitudes to HIV/AIDS. In addition, they visit the homes of AIDS patients to provide care and support. At the end of 2000, 7,936 clients had received counselling from the ACWs, who had made 723 home care visits (TASO records). The ACWs refer patients to the TASO-medical department if they cannot handle the case. According to records at Mbarara, in the months of January to April 2004, ACWs had made 1,833 such referrals; the target for 2004 had been 1000.

In addition to these activities, the ACWs have also formed drama groups to re-enforce the training and dissemination of HIV/AIDS-related information by TASO. The ten ACWs interviewed from two TASO-supported communities indicated that each ACW drama group holds three drama performances each week.

For the purposes of monitoring, accountability and feedback from the community, the ACWs submit monthly records of their activities to TASO branch office. TASO staff provide support supervision in these communities, but are not directly involved. Support supervision involves guiding the ACWs on matters such as: how to run and implement programmes, write accountability reports, and design programmes. While the supervisors do not influence the programme design, the programmes should be in line with TASO objectives. Each community is under the supervision of a TASO counsellor, who visits it once a month to provide guidance and ascertain that the programmes are being implemented according to TASO's overall goals of care and support. From January to April 2004, 44 support supervision visits had been made out of the set target of 132 for the year.

In order to make participation effective, various committees¹⁸¹ have been formed (TASO records). These include the Parish AIDS Committee (PAC), composed of 30 ACWs, 10 (PAC leaders) of whom hold leadership positions. By April 2004, there were 321 ACWs and 120 PAC leaders in place providing services in various communities. PAC members are trained in different skills, such as managerial, community mobilisation, collaboration and networking, resource mobilisation, team building and creation of relationships. The formation of such committees is intended to replace or fill the gap left at parish and local levels by

¹⁸¹ The committees differ from the proposed UAC coordination committees at various levels (see 7.2b), which are non-functional at the parish and community levels due to poor funding. (interview with the DDHS- Mbarara)

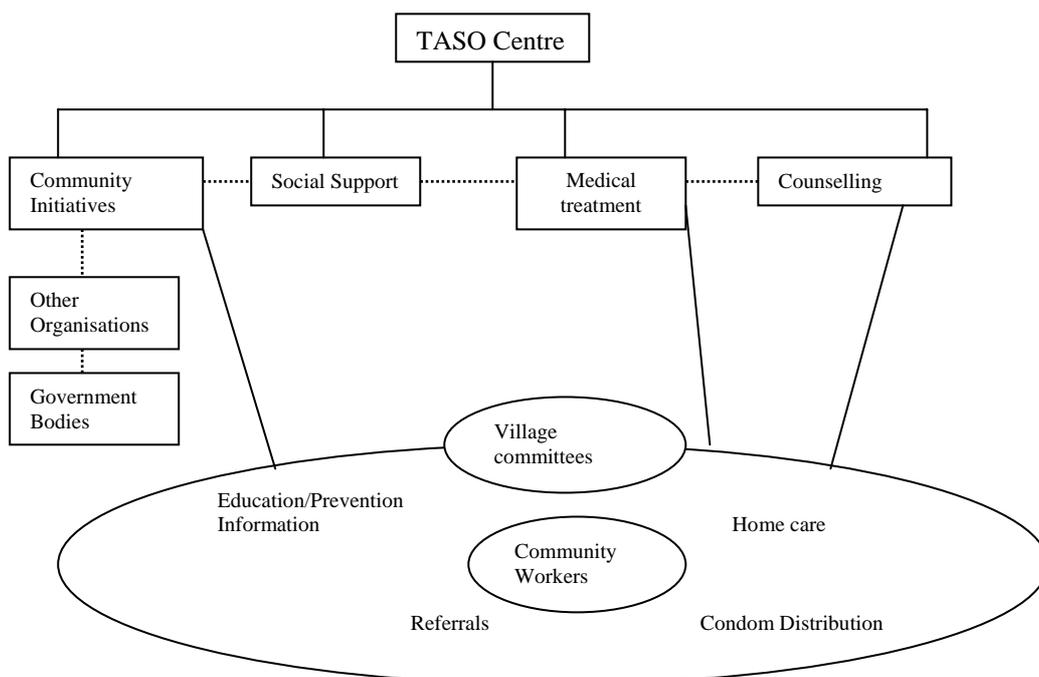
failure of the District AIDS Coordination Committee (DACC) to take off because of funding problems (see discussion in 7.4.2).

In an interview, the head of the Department of Counselling at TASO Mbarara stressed the importance of ACWs:

I am happy for the work of ACWs considering that they volunteer their service. They have sustained HIV/AIDS-related programmes in their own communities without our direct involvement. They have committed themselves to fighting HIV/AIDS. This is evident in the drop out rate for ACWs, which is about 10%. Even this is attributed to death, migration in search of employment and, to a lesser extent, low motivation. (Interview with head of counselling)

The above view is supported by UNAIDS, which applauds the work of NGOs in recruiting community volunteers to participate in tackling HIV/AIDS problem. Thus, UNAIDS (2000: 11) asserts that; “NGOs are the pioneers of home based care for people with HIV/AIDS, which has recruited thousands of community-level volunteers and trained them to deliver a variety of services from basic preventive health care and first aid to practical advice and emotional support”.

Figure 8. 1 TASO Initiated Community Participation in HIV/AIDS Activities



Adapted from: TASO (1995: 77).

Figure 8.1 above illustrates the relationship between the organisation and community involvement in HIV/AIDS activities. It indicates that TASO branches have four departments: community initiatives, social support, medical treatment and counselling. The communities are directly under the department of community initiatives, but they are also linked to the medical treatment and counselling departments. These departments provide services to patients who are referred to them from the communities.

The figure also indicates the range of activities which communities are engaged in. These activities include: education and prevention of HIV, home care and support for AIDS patients, and condom distribution. It is the community volunteers (ACW) that carry out these activities.

The PTC/PLI Satellite Sites

Like TASO, PTC/PLI has satellite centres which operate independently of the main branch. The phase out plan of PTC/PLI (discussed in 6.2.5), encourages the formation of autonomous PTC/PLI centres. Rushere, Ruhoko and Ndeija PTC/PLI centres were formed under this programme. Like TASO, AIC provides periodic training and refresher courses for PLI members, for example, in public speech and communication skills. This group forms the core of PTC/PLI activities in the community since members of PLI are the ones who speak publicly about their HIV/AIDS status during community outreach programmes. Between July and September 2003, 30 members received such training (AIC records).

In March 2004, I met 20 PLI members from Masaka and Mbarara districts who were attending a two-weeks training session. In a focus group discussion with these trainees, it was revealed that these trainees were equipped with various skills; for instance, they learned about different approaches to counselling and disclosure of HIV status to others, and how to manage various community responses to people with HIV/AIDS, including harassment and finger-pointing. PLI members who receive such training meet regularly for on-going counselling, peer support, sharing of experiences and recreation activities. All these strengthen the capacity of those affected by HIV/AIDS to manage the impacts of HIV/AIDS. For example, the increased communication and care given to people through such activities partly explain the steady decline in HIV/AIDS prevalence in Uganda (Low-Beer and Stoneburner 2004a; 2004b; 2004c).

PTC/PLI also provides training to members of the general public. In 2002, the supervisor of Mbarara was involved in training of community leaders in Lyantonde in HIV/AIDS management skills (AIC records).

8.7.3 Capacity Building at the Family Level

In order to bridge the gap between people with HIV/AIDS and their family members, TASO embarked on a programme to strengthen the capacity of family members to take care of the sick. This is done through home care visits, which involve offering treatment, counselling and services to clients, and counselling and sensitisation of family members on how to deal with various HIV/AIDS-related problems. The counselling and care sessions focus on orienting family members towards non-discriminatory care of AIDS patient and quick response to opportunistic infections such as colds, fevers and diarrhoea.

TASO counsellors provide home care counselling, health care and other support services to HIV/AIDS patients in the presence of family members. Counselling and hands-on training of family members facilitate the transfer of knowledge and enable them to fill any counselling gaps which exist at the family and community levels. As a result of hands-on training, family members continue to provide such services in the absence of the TASO counsellor. In addition to improving the health of the patient, such services minimise the costs that would be incurred if patients were maintained in institutionalised settings, for example, in hospitals.

It should be noted that this approach has created unity at both family and community levels (see discussions in 6.2 and 8.3). As Côté (2001) observes, by bringing services nearer to people, especially those at risk like the elderly, and letting those infected stay closer to their families and communities, social ties are sustained and their health improved.

By April 2004, 163 family members and 435 clients had been counselled in such sessions (TASO records). Counselling makes it possible for individuals to overcome the stigma associated with this disease and to reveal their sero-status to their spouses and care givers, and also inculcates positive attitudes towards the sick in caregivers. As mentioned, the government is planning to follow NGOs' strategy of home-based care and service provision

as a means of controlling further spread of HIV¹⁸² which has been indicated to be on the increase again (Allen 2005; UNAIDS 2006).

8.7.4 Public Debates and Radio Talk Shows

NGOs organise public debates such as radio and television talk shows on HIV/AIDS. People participate in question and answer programme about HIV/AIDS-related issues, causes, impacts, and approaches to its containment. In 2003, 115 radio talk shows were conducted by TASO Mbarara. Although participation in these talk shows is limited because of low income of most people, they act as important sources of information for people who, for various reasons, are not able to join organisations such as TASO and PTC/PLI. In addition to talk shows, TASO and PTC/PLI often organise seminars and workshops about HIV/AIDS. These seminars target specific groups which are considered to be vulnerable and susceptible to HIV infection. In 2003, TASO Mbarara organized a seminar that benefited 27 members who belonged to a high-risk group. In the same period, 2 workshops benefiting 43 apprentices were also organised (TASO records Mbarara).

In addition to providing information about HIV/AIDS, talk shows and seminars serve as a means of dealing with HIV/AIDS myths and realities. The gaps created by such myths are thereby narrowed.

8.8 Increasing the Social Support and Care provided to PWHAs by Family and Community Members

As has been stressed, social support becomes evident when people are able to obtain assistance from neighbours, family members, relatives and the community at large (see chapter 2 – 2.6). The provision of support by these sources reflects the integration of organisation members in social networks, which enables them to live happy lives. The capacity of the traditional family care system to take care of AIDS patients is overstretched due to the lack of resources. As discussed earlier, the onset of HIV/AIDS lead to the depletion of resources. Through the activities of TASO and PTC/PLI, HIV/AIDS patients obtain social support in the form of services, material assistance, and psychological and emotional counselling. This has been made possible through the increasing participation of community members, and the counselling of clients/members and their families.

¹⁸² see <http://www.newvision.co.ug/D/8/13/533674/AIDS>

The sources of social support include family members, members of the community, friends and relatives. The amount of social support received depends on the value which respondents attached to this support, which is largely in the form of companionship and emotional support. This support carries with it expressions of love and compassion, which are particularly important for people with HIV/AIDS as an avenue for sharing problems and public disclosure of one's status.

In the 1990s, there was little or no social support available to AIDS patients, since community and family members feared that they would be infected with HIV if they provided assistance, such as bathing patients or sharing utensils with them (Monico, Tanga, and Nuwagaba 2001; Muyinda et al. 1997). Other studies also reveal that the economic and social pressures on the family limited the kind of support they could provide for people living with HIV/AIDS and AIDS orphans (Barnett and Whiteside 2002; Marshall and Keough 2004; Orla 2004). However, with the initiation of activities which focus on HIV/AIDS education and strengthening social relations in the communities by TASO and PTC/PLI, people are getting support from different people.

In the present study, respondents indicated that they were receiving various kinds of social support from the community, relatives and friends Table 8.5 below indicates the percentage response by interviewed members/clients of TASO and PTC/PLI in relation to the amount of support obtained from these sources.

Table 8. 5 Perceived amount of Support to members of HIV/AIDS NGOs from different sources

Source of Support	A lot of support	
	Members of TASO	Members of PTC/PLI
Family	51%	69%
Relatives	36%	53%
Friends	60%	72%
Community	40%	46%
	N= 80	N= 36

The question which was asked: *On a scale of 1to5 (where 1 is Very little support and 5 a lot of support), determine the amount of support obtained from the following sources: Family Members, Friends, Relatives, and Community.*

From the above table, it is evident that the majority of TASO respondents were getting a significant amount of support from family members (51%) and friends (60%), compared to the support being obtained from relatives (36%) and the community (40%). Similarly,

PTC/PLI members responded that they were receiving a lot of support from family (69%), relatives (53%) and friends (72%), compared to the support they received from the community (46%). As already pointed out, the family has always been a source of support when members encounter problems. The table indicates that, in TASO and PTC/PLI, clients/ members obtain a substantial amount of support from their families and friends.

Note that PTC/PLI members receive more support from relatives and families compared to TASO members. This is because, majority of PTC/PLI members are mostly still single and dependant on their families while TASO members are caretakers of their families and for the case of widows and widowers, they are sole providers.

The nature of the support obtained from various sources varied according to the following combinations: a) emotional, companionship, services; b) financial, c) other types of support.

Table 8. 6 Type of Support Received from Different Sources by Members of TASO and PTC/PLI

Nature of Support	Sources of Support (Response rate- %)							
	Family		Friends		Relatives		Community	
	TASO	PTC/PLI	TASO	PTC/PLI	TASO	PTC/PLI	TASO	PTC/PLI
Emotional, Companionship, Services such as washing and assistance on farms	84	62	86	75	78	78	79	64
Financial	12	24	10	11	9	10	14	17
Other	4	14	4	14	13	12	7	9
	N=80	N=36	N= 80	N= 36	N=80	N=36	N=80	N=36

Note: The question which, I asked was: *Describe the nature of the support obtained from the following groups I am going to read: Family Members; Friends; Relatives; Community. Select from the following Choices (a) Emotional, Companionship, Services, and Financial (b) Services only (c) Financial only (d) No support at all.*

From table 8.6, it is evident that families, friends, relatives and communities all provide support in the form of emotional, companionship and services to people who depend on them. This finding is in conformity with other findings earlier presented. For example, it was earlier presented that the two organisations’ activities have led to the creation of a bridge between PWHA and their families, relatives and communities (see discussion in 8.7). The number of respondents obtaining financial support from various sources, however, was higher for PTC/PLI members than TASO members. This is because the majority (73%) of PTC/PLI members were in the 15-34 age bracket (see table 3.2), and as mentioned above were still

dependant on their parents for education and other people for different forms of support. This is in contrast with TASO members, majority of whom are sole providers of their families.

8.9 Discordant Couples

The term “discordant couples” is used when one of the partners is infected with HIV while the other partner remains HIV negative despite being exposed to the HIV virus¹⁸³. There is little data available about the number and behaviour of discordant couples in Uganda. However, TASO (2002a: 34) mentions that the statistics indicate that there are increasing numbers of discordant couples registered under TASO.¹⁸⁴ It is for this reason that TASO embarked on designing approaches to tackle this problem, relying on joint-partner counselling. This type of counselling requires specialised training and attention. Since government institutions, such as hospitals and health centres, have no permanent counselling positions, this activity has been left to NGOs like TASO. One of the focuses of joint-partner counselling is on the regeneration of deteriorating sexual relations between partners, due to the fear of catching HIV on the part of the partner who is HIV negative.

TASO’s objective is that couples maintain their relationship with one another and with their families while ensuring that the HIV negative person does not become infected (interview with a TASO counsellor). Couples are taught how to use the condoms which are provided free of charge (see discussion in 8.2).

Another issue which is addressed is the importance of avoiding alcohol. Alcohol reduces people’s ability to pass judgement that is necessary for the prevention of HIV/AIDS. Through the joint-couple counselling approach, couples are living with HIV/AIDS positively.

An interview with a TASO client at Katungu outreach in Bushenyi district revealed that he was HIV/AIDS positive while his wife was not; he said that joint-partner counselling and training had helped to sustain his marriage, which had been about to break down due to his HIV status. He stressed that he was happy with his wife and children.

8.10 Complementary Roles of the State in Addressing HIV/AIDS-related Problems

In chapters 1 and 2, the concept of synergy was suggested as an important analytical tool in places where social capital cannot be developed from either societal or state sources alone. It

¹⁸³ <http://www.aidsmap.com/en/docs/FCB146AC-C838-4D32-8BD3-8B62560DF0FD.asp> 11/08/06

¹⁸⁴ Also see, <http://www.newvision.co.ug/D/8/17/517067/discordant%20couples>

was also stressed that synergy was important in dealing with a phenomena such as HIV/AIDS which has widespread impact. It was argued that, both state and society have a role to play and may compliment each other. As a basis of analysis, chapter 2 explored why the state and NGOs may complement each other in alleviation of HIV/AIDS related problems. In this section, the focus is on the extent to which the state complements the activities of TASO and PTC/PLI in tackling HIV/AIDS-related problems.

In chapters 5 and 7, it was indicated that the state plays a minimal role in directly intervening in HIV/AIDS activities due to the international requirement that neoliberal policies be introduced, rolling back its welfare services. However, as indicated in chapter 7, the state is engaged in activities that not only facilitate social relations and interaction between individuals, groups and organisations, but also are addressing HIV/AIDS-related problems.

Although the discussion in chapter 7 focused on the aspects of synergy between government and society in generating social capital, it was imperative to mention some of the government activities for combating HIV/AIDS. In the discussion I emphasised that state activities such as multisectoral approach, political leadership and mobilisation of funding, have contributed significantly to the success of HIV/AIDS policy. The discussion that follows will highlight a few more significant fields in which the government complements the activities of other actors and the impact of such activities on HIV/AIDS related problems.

Government HIV/AIDS Prevention Programmes

Like NGOs, the government is initiating preventive approaches through the media and other forms of advertisement. The HIV/AIDS messages, which emphasis positive living, have had a positive impact on stigmatisation¹⁸⁵.

At the height of HIV/AIDS controversy in the 1990s, when most African countries were denying the existence of HIV/AIDS, the government established a preventive policy (see chapter 4). One feature of this policy was the provision of Nevirapine for pregnant women who were infected with HIV/AIDS, so as to prevent mother-to-child transmission of HIV (PMTCTH). It is a policy that every woman attending the antenatal clinic be tested for HIV. Even when ARVs were introduced in the country and their provision to AIDS patients was left to private organisations and pharmaceutical companies, the government retained the PMTCTH programme. This programme complements other preventive approaches, therefore,

which are employed by other actors engaged in HIV prevention. By 2001, 30 out of 56 districts in Uganda had established counselling sections that targeted mothers, to facilitate the early detection of HIV (Okware et al. 2001). This programme has contributed to the decline in the HIV/AIDS prevalence. Moreover, as the discussion in chapter 4 shows, the HIV/AIDS prevalence and incidence figures upon which Uganda's success have been rated are got from these counselling sites.

Similarly, the government provides information through the media, schools and other institutions. For example, school authorities talk about HIV/AIDS at the general assemblies at least twice a week. The government also provides HIV/AIDS health education materials to active NGOs such as TASO and PTC/PLI. These organisations distribute the materials and leaflets to their clients or display them (in the case of large posters) at their centres for their clients to view. Travelling throughout Uganda, along main roads and highways, one cannot miss the large billboards set up by the Ministry of Health with messages about HIV/AIDS prevention. In addition, apart from funding provided to a few groups and organisations, the government is involved in procurement of condoms and medicines at low costs. These are distributed to NGOs which in turn give them to their clients. All these approaches had the effect of reversing the trend of HIV infection in Uganda.

Government and Poverty Alleviation

The implications of poverty for HIV/AIDS transmission was discussed in chapter 4. In particular, it was stressed that poverty aggravates HIV transmission. For this reason, the government has developed a comprehensive approach to address poverty. Because of the multidimensional impact of HIV/AIDS, the government has focused on an integrated approach. The multisectoral approach discussed in 7.4 is intended to mainstream HIV/AIDS into different government ministries. This approach is progressively mainstreaming HIV/AIDS in the Poverty Eradication Action Plan (PEAP). The PEAP is a comprehensive and integrated programme which provides support for universal primary education, primary health care, road maintenance, and poverty alleviation. The plan makes funds available in the form of conditional grants directly to the districts and local levels for specified activities to mitigate poverty (Okware et al. 2001).

¹⁸⁵ <http://news.bbc.co.uk/2/hi/africa/3250021.stm> 11/08/06

In addition to this programme, the government is funding individuals who are able to establish income-generating activities. Recently, the government appointed a minister to be responsible for micro-finance (Bona Bagagawale¹⁸⁶), to facilitate transfer of funds to the local communities and educate people on how to increase their savings through engaging in such activities. This approach supplements the TASO and PTC/PLI poverty alleviation programme. Since it was extensively discussed that HIV infection rates tend to increase with increased levels of poverty, I therefore, argue that the establishment of poverty alleviation strategies is likely not only to reverse the HIV infection rates but also, the impacts of HIV/AIDS which were discussed in chapter 4.

Table 8.7 below provides a summary of the discussion presented in the chapter. The table indicates the activities involved in by these organisations and the impact of these activities on HIV/AIDS challenges.

¹⁸⁶ All should become rich

Table 8. 7 Alleviating Impacts of HIV/AIDS

Organisations	Activity	Impact on HIV/AIDS Challenges
TASO and PTC/PLI	-Formal and informal group meetings and interaction between individuals -Group Discussions about HIV/AIDS-related issues	- Information is accessed, resulting in changed behaviour and societal values. - Increased assertiveness of women - More positive attitude towards living with HIV/AIDS - Reduction in levels of stigma - Increased knowledge about HIV/AIDS - Improved levels of communication about HIV/AIDS - Emotional support is obtained
	Medical care and Counselling	- Health of PWHA has been improved - Psychological and emotional support - PWHA who are needy have access to free medical and counselling services
	- Orphan education (TASO) <ul style="list-style-type: none"> • Apprentice programme • Formal education support • Tailoring project (PTC/PLI) 	- Improved living standards of orphans - Skills acquisition by orphans - Families relieved of the burden of maintaining AIDS orphans - Emotional and Psychological support
TASO	-Drama	- Increased HIV/AIDS awareness - Psychological support for PWHA - improved communication between members of organisations and the community
	- Community training for self-sustenance <ul style="list-style-type: none"> • Training of ACWs • Training of local leaders 	- Integration of PWHA with other people alleviates stigmatisation - Increased social cohesion - Closes the human resource and information gaps
	-Group formation	- Group-specific HIV/AIDS issues have been addressed - Integration of PWHA with other people - alleviates stigmatisation - Promotes social cohesion, and social and psychological support
	-Family Support and Care giving	- Skills acquisition in counselling and HIV/AIDS care - Relieves families of costs of maintaining patients in institutional settings of travelling to get medical care and counselling services - Provides emotional and psychological support - HIV/AIDS awareness is increased
PTC/PLI	-Recreation and Sports Activities	- Provides physical, psychological and emotional support - Information sharing and improved social relations - Minimises stigma
	-Drama	- Information sharing - Increased HIV/AIDS awareness - Reduces HIV/AIDS vulnerability of members, especially the youth
	-Community training	- Information sharing and increased HIV/AIDS awareness - Involvement of community leaders in HIV/AIDS activities
	-Group formation	- Increased HIV/AIDS awareness - Increased participation in HIV/AIDS activities by community members - Increases social cohesion and integration
GOVERNMENT	- Prevention campaign - Poverty alleviation programme.	- Reverses the trend of HIV infection - May result in the economic empowerment of disadvantaged groups.

8.11 Conclusion

The purpose of this chapter was to explore the extent to which TASO and PTC/PLI alleviate the impacts of HIV/AIDS. Various activities initiated by these NGOs to alleviate the different impacts of HIV/AIDS were considered. It was indicated that NGOs focus on breaking down factors such as cultural practices, poverty, gender etc, which facilitate HIV transmission and aggravate the impact of AIDS. The fact that the levels of stigmatisation have been addressed and the levels of social unity increased at both the community and organisational levels, is a clear indication of success.

It may be concluded that, even with limited direct government involvement, TASO and PTC/PLI have facilitated the transfer of HIV/AIDS-related knowledge from their members/clients to people in the communities. Through various activities, they have succeeded in instilling a positive attitude about living with HIV/AIDS in people. In addition they have carried the services nearer to those who actually need them. TASO has minimised the expenses that would be incurred for maintaining the terminally ill in the institutions such as hospitals by introducing home care visits.

In all, the conclusions to be drawn from this chapter are that the activities of HIV/AIDS organisations have minimised the impacts of HIV/AIDS, such as HIV spread and poverty, by reducing some of the expenses that would be incurred by people taking care of HIV/AIDS patients. In addition, since a cure for HIV/AIDS is not forthcoming, the creation of self-sustaining communities and mobilisation of volunteers helps to minimise the impact of HIV/AIDS. The discussions in this chapter have indicated that the success which TASO and PTC/PLI have registered is largely dependent on their focus on groups and individual interactions rather than isolated individuals. Thus, I conclude that these organisations have succeeded due to their focus on social capital. It is also possible to conclude, therefore, that unless social capital is developed at individual, social and community levels, chances are that the success of these organisations would be limited.

With regard to the role of the government, it has been stressed that state interventions complement NGOs activities. In addition to creating an environment that facilitates the active participation of various actors, it may be concluded that the government involvement in activities such as PMTCTH has contributed to the decline of the spread of HIV/AIDS among the newly born children.

PART THREE

CONCLUSIONS

CHAPTER 9

Conclusions: Social Capital and the Role of NGOs in Alleviating the Impacts of HIV/AIDS in Uganda

9.0 Introduction

More than two decades after the identification of HIV, there is still neither a vaccine for HIV nor a cure for AIDS. The virus is transmitted through transfusions of infected blood, sexual contact with infected persons and transmission from HIV-positive mothers to their unborn or breast-feeding children. Since there is no cure, HIV/AIDS infection often leads to death, although victims can live between 5 to 15 years after contracting the virus. In addition to these untimely deaths, HIV/AIDS has had other devastating impacts (see chapters 1 and 4).

HIV/AIDS has personal, social and political consequences. On the personal level, the immediate health consequences for People with HIV/AIDS (PWHAs) include the weakening of the immune system and subsequent increase in susceptibility to opportunistic infections such as malaria, diarrhoea and tuberculosis. Failure to guard against such infections may shorten the lifespan of PWhA. In addition, HIV/AIDS often results in personal poverty for two reasons: PWHAs' ability to participate in productive work is reduced, and thereby their ability to generate income; and their prolonged suffering and expenditure on medical care is a drain on their resources and incomes (O'Manique 2004). Socially, HIV/AIDS divides society through stigmatisation, discrimination and denial. Moreover, it increases the social burden on families and communities in caring for and supporting dependents, both AIDS orphans and PWhA themselves (Barnett and Whiteside 2002; Kayazze 2002; Marshall and Keough 2004). Politically, HIV/AIDS exerts an enormous pressure on the government budget, depletes the human resources and poses a threat to national security. As stressed in chapter 4, all these problems need to be addressed.

Given this situation, the purpose of this study was to investigate the extent to which HIV/AIDS NGOs alleviate the impacts of HIV/AIDS in Uganda. With more than 1,000 Non-governmental organisations (NGOs) and an ever growing number of community initiatives working in the HIV/AIDS sector, these organisations play a central role in fighting HIV/AIDS. NGOs are engaged in various activities, and the study has focused on those that facilitate regular interaction between individuals, groups and organisations. Such interaction ultimately leads to a strengthening of social relations among those involved. The study has argued that such social relations are embedded with resources which can be utilised to deal

with various HIV/AIDS challenges. Thus, social relations and associated resources were conceived as social capital, and the study has argued that the extent to which the selected NGOs will succeed in alleviating HIV/AIDS-related problems depends on the generation or revival of social capital (see chapter 2).

The study was carried out in Mbarara district of western Uganda and focused on two NGOs: The AIDS Support Organisation (TASO) and Post Test Club/Philly Lutaaya Initiative (PTC/PLI). Using a variety of qualitative and quantitative methods such as interviews, focus group discussions, observations and secondary sources (chapter 3), data were collected from NGO members and managers, government officials employed in the District Health Directorate, and people from the communities served by the two organisations.

The study has addressed the following questions:

- a) *What role do HIV/AIDS NGOs play in alleviating the impacts of HIV/AIDS in Uganda?*
- b) *What factors influence the performance of NGOs in alleviating the impacts of HIV/AIDS in Uganda? How do NGOs feature in government programmes? Does the government play a role in facilitating social capital formation, and consequently in NGO performance in addressing HIV/AIDS' challenges?*
- c) *To what extent are TASO and PTC/PLI successful in alleviating the impacts of HIV/AIDS?*

Having introduced the research problem, the methodology and the cases selected for study, the next question is the extent to which social capital is relevant in addressing the challenges of HIV/AIDS in Uganda.

9.1 What is the Relevance of Social Capital in Alleviating the Impacts of HIV/AIDS?

The study has argued that, in addition to medical interventions, social interventions play an important role in addressing the problems of HIV/AIDS. In particular, interventions building social capital were considered to have great potential.

The study argues that, because publicly-financed social welfare programmes are not well-developed in Uganda, people have always relied on social support networks of family, friends, relatives and neighbours (Kayazze 2002; Keough 2004; Marshall and Keough 2004; Tumwesigye 2003). However, with the advent of HIV/AIDS and its impacts, this support system started to crumble and to give way to individualised support and survival strategies (chapter 5). In this context, the study argues that it is necessary to revive this support system

by increasing the depleted social capital, in order to address the impacts of HIV/AIDS. The study hypothesised, therefore, that the success of NGOs in alleviating HIV/AIDS depends on the extent to which they can revive these social relations.

Furthermore, the alleviation of HIV/AIDS problems requires correct information and knowledge about transmission, prevention and management of HIV/AIDS. This is facilitated by the involvement of many actors. These actors must be supported by favourable policies for their successful functioning, and must work together in a mutually reinforcing manner rather than in isolation. Such relationships may falter if they are not based on trust and if there are no established norms to guide their action; for example, the norms of reciprocity, of mutual respect for others' work and engagement. In addition, a well-organised medical infrastructure and personnel is required for successful anti HIV/AIDS interventions. However, the degree of success achieved depends on how much people trust the personnel and the medical system as a whole; for example, between individuals/groups and the medical professionals, and between citizens and government officials. Such trust not only makes coordination of different actors possible, but also facilitates the transfer of resources and information, and effective communication regarding HIV/AIDS.

This study revealed that the transfer of the HIV/AIDS-related knowledge, and of the means of alleviating the impacts of the disease, was facilitated by the creation of social networks at different levels, including community, family and individual levels. Increased discussion of the problem in different forums took this "secret" disease into the open where other actors could play a part. The study has confirmed that interaction in NGO networks opens channels through which information can be processed for dissemination to people who are not members of these groups. For example, network members' discuss and share their experiences related to HIV/AIDS, and this knowledge proved to be effective in mitigating stigma, reducing social exclusion and, above all, bridging the gap between PWHA and other members of the community. This illustrates the way in which such networks have a positive social function.

The importance of such social capital for alleviating the impacts of HIV/AIDS has been illustrated in the study by a comparison of the approaches used by TASO and PTC/PLI

(chapter 6), on the one hand; and by the FBOs and religious fundamentalists, on the other¹⁸⁷ (chapter 7). The latter portray the PWHA as irresponsible, as having brought this illness on themselves, and as adulterous (unfaithful to their marriage partners) or promiscuous (not abstaining from pre-marital sex). The study found that such a narrow focus increased stigmatisation, withdrawal and denial; discouraged the disclosure of HIV/AIDS status, thereby facilitating the further spread of HIV/AIDS; and had such dire consequences as suicide in some cases. In contrast, TASO and PTC/PLI focus on integrating PWHA into networks, as well as on strengthening their ability to live positively with HIV (chapter 8). Moreover, since HIV is spread in a variety of ways, the emphasis of the FBOs on HIV as simply a sexually transmitted disease is incorrect (see 7.1).

The study revealed that, NGOs which focused on group or social network created an environment in which disclosure of HIV/AIDS status, as well as open communication and discussion of the disease, was possible. It was also evident that individual and group interaction was important for addressing such HIV/AIDS impacts as social discrimination and self denial. Thus, on the basis of this comparison it may be concluded that a focus on groups and social relations facilitated identity creation and social cohesion, and limited social exclusion and self-denial. It was revealed that discussions of the individual HIV/AIDS problems enabled PWHA to identify grounds for mutual social support. Through open discussions about HIV/AIDS, it was possible to deal with the secrecy and stigma associated with the disease.

The findings of this study also support the assertion that the concept of social capital may be effectively applied in countries where, historically, the responsibility for the provision of welfare and social support services has fallen on community and family networks. This is also true for countries where resources are limited and the infrastructure to provide basic needs such as effective medical treatment is not available (see chapter 5). Moreover, social networks are not just sources of social and psychological support, but also of HIV/AIDS-related knowledge. This knowledge can change public attitudes regarding what are effective preventive measures, thereby reducing its spread; it can change attitudes to the victims of HIV/AIDS, thereby reducing stigma and facilitating positive living (chapter 8).

¹⁸⁷ Religious fundamentalism in this case was taken to refer to those religious groups with a strong moral tone in their religious teachings. For example, they were identified with strong criticism of people who contract HIV/AIDS regarding them as immoral and deserving punishment from God. This was different from other mainstream religious teachings as in the Anglican sect which although not approval of contracting HIV/AIDS, but they talk about it with little criminalising the victims.

The spread of HIV/AIDS across Africa is discussed in this study (chapter 4), and it is stressed that more or less similar conditions facilitated this process. These conditions included: vulnerable economies characterised by poverty, and cultural factors that promote stigma, gender imbalance and the marginalisation of women. All these factors prevailed in many African countries, although the degree and form varied; together they created societies vulnerable to attack by disease and other external forces. These findings are confirmed by existing studies, which conclude that the spread of HIV was due to the vulnerability of societies in countries such as Uganda, South Africa and Tanzania (see, for example, Barnett and Whiteside (2002), O'Manique (2004) and White (2002)). Not only are the contributing factors common, but also the policy responses. These involved following WHO and World Bank recommendations; for example, education and sensitisation, prevention, the use of condoms and state roll-back. In spite of these similarities, however, there were marked differences in the HIV prevalence rates and impacts in African countries.

In Uganda, the HIV prevalence rate has declined steadily since the 1990s, while in some countries in southern Africa, the rates have continued to rise. This study attributes the decline in Uganda primarily to the existence of synergistic relations between government and civil society organisations. In chapter 2, it is suggested that this synergy, particularly between NGOs and government, is the most effective weapon in the battle against HIV/AIDS. Based upon the findings of this study, certain conclusions can be drawn regarding the need for synergy in the battle against HIV/AIDS.

9.1.1 A Synergistic Model for Addressing the Problem of HIV/AIDS

Based on the theoretical discussions in chapter 2-2.4.1 and 2.6.1, the empirical analysis in the thesis demonstrates that both the NGOs and the government have a role to play in fighting HIV/AIDS (chapters 6 and 7). The analysis reveals that each has certain advantages, so it is essential that the two reinforce one another if HIV/AIDS initiatives are to be successful.

NGOs have worked closely with communities and have been successful in addressing many development challenges, particularly in the fields of rural development, advocacy and human rights, and grassroots mobilisation. With respect to HIV/AIDS, NGOs have made an enormous contribution in the areas they have prioritised; for example, counselling, education and sensitisation, provision of quality health care and facilitation of regular interaction. These activities have all been significant in combating stigmatisation and social exclusion.

Moreover, by establishing forums for interaction, the NGOs have provided sources of social support and information for various groups of people. In fact, according to government health workers, NGOs were more efficient than the government because they streamlined their programmes to meet the needs of their local target population. However, this finding may be countered by the claim that only a few of those who really need the HIV/AIDS-related services benefit from NGOs' activities (chapter 6 – 6.4).

I have argued therefore, that the government is in a position to provide large-scale services – including programmes ensuring food, security and poverty reduction. However, this is only possible with proper utilisation of the already established physical infrastructure¹⁸⁸ and health care services. This is particularly important since, as discussed in 6.4, NGO s' ability to increase the scale of their operations is limited. They are heavily dependent on funding from abroad for most of their budget, and on the government for the necessary infrastructure. Moreover, the HIV/AIDS NGOs' area of operation is often limited to urban centres and their suburbs. Thus, the study has concluded that NGOs alone cannot successfully alleviate the HIV/AIDS problem, and that there is a need for synergy between the government and the NGOs. The government has played an essential role on the international level; for example, in mobilising funds to facilitate HIV/AIDS activities and negotiating with drug companies to reduce the prices of antiretroviral drugs. This complements the role the NGOs play with their grass-roots activities.

I have also argued that the effectiveness of prevention in Uganda can be attributed to a combination of factors, of which social capital is the most important. For example, most countries have tried to popularize the use of condoms through preventive messages. This approach has not been successful, however, and the study attributes this to the lack of interpersonal communication and the poor relationship between state and society. In this context, a comparison of Uganda and South Africa has revealed that the latter's AIDS policy has not been as effective in achieving the desired results. One of the reasons for this is the failure of the government to forge a partnership with civil society organisations. Several examples are provided to illustrate the open conflict that exists between the government and civil society organisations in South Africa. Thus, the study concludes that a lack of synergy

¹⁸⁸ Although this infrastructure needs rehabilitating and restocking in terms of physical and human resources, success is possible if this is done. The government is making some progress in this direction.

between government and society may explain why the performance rate with regards to HIV/AIDS prevention is poor in countries such as South Africa (chapter 7 – 7. 8).

In contrast, the study reveals that the effectiveness of Uganda can be attributed to the cooperative relationship between the government and other actors, particularly NGOs. This facilitated the processing of knowledge about the disease, encouraged the involvement of people through civil society organisations and increased HIV/AIDS awareness. Several important mechanisms generating social capital and the success of HIV/AIDS NGOs have been identified: the mobilisation of funding by the government, the involvement of political leaders including the president, and the creation of an enabling environment for the operation of NGOs. The study also revealed that the government has been instrumental in forging partnerships with other governments, donors, and NGOs, and that these partnerships have led to increased donor support. Thus, it is evident that for the optimal performance of NGOs, government support is critical.

On the basis of findings such as these, the study concluded that synergy between state and civil society has facilitated the success of these two organisations in alleviating HIV/AIDS impacts. This synergy also included business organisations, the private sector and care-giving organisations such as hospice. A related conclusion was that HIV/AIDS NGOs need to work with government agencies if they are to increase the scale of their activities. Thus, synergy with the government as well as individual effort is essential, both in the generation of social capital and in its effective use in fighting HIV/AIDS.

From the preceding analysis and the overall argument developed in this thesis, I have concluded that social capital is important in addressing complex social, physiological, psychological and catastrophic phenomena such as HIV/AIDS. These phenomena are rooted in the social and economic circumstances of the communities and people affected. The most effective strategies for reducing the various impacts of HIV/AIDS, therefore, operated on two levels: the improvement of relations between different actors and the government (the meso level), and the establishment of partnerships with families and communities (micro level) in the provision of care and support for PWHA.

The study has emphasised the importance of social capital in addressing the challenges of HIV/AIDS. Evidence has been provided in the case studies that demonstrates how social

capital functions. In addition, by relating Uganda's success and South Africa's failure to differences in their approaches, the study has demonstrated the importance of social capital in fighting HIV/AIDS. This is the lesson that can be drawn from the Ugandan experience by other countries addressing the HIV/AIDS problem. Having established the relevance of social capital, the question of how it is built needs to be addressed.

9.2 Building Social Capital

In chapter 4, it was argued that the social capital which had existed in Ugandan communities prior to the discovery of HIV/AIDS had declined, due to the increased social and economic pressures associated with HIV/AIDS. Given the effectiveness of social approaches in alleviating HIV/AIDS impacts and the limitations of the social welfare services provided by the government, the study has argued that it is essential to revive the social support networks of community, family, friends and relatives. The study also contends that, with government support, HIV/AIDS NGOs have successfully built up the social capital. The following conclusions have been drawn with respect to the role of HIV/AIDS organisations and the government in building up social capital in Uganda.

9.2.1 The Role of HIV/AIDS NGOs in Building the Social Capital for HIV/AIDS Intervention.

The study has stressed that, in order to alleviate the impacts of HIV/AIDS, the local social, economic and political milieus should be addressed and utilised to develop grass-roots institutions. In addition, the creation of an environment that can successfully combat HIV/AIDS depends upon different levels of engagement: at the micro level, the family functions as caregivers of the sick, the needy and the destitute; the community provides support and education; and at the meso level, there is a favourable political environment and infrastructure for interaction – the role of political leadership and the relationship between local governments and the HIV/AIDS NGOs are good examples of this environment. Unfortunately, these social networks at the local, community and intermediate levels have been seriously damaged by the disease itself, as well as by forces of globalisation. In addition, state involvement in HIV/AIDS-related activities has been limited to a supervisory role and distribution of educational materials. This is due to various political crises and international pressure on the state to roll back its activities (see chapter 4 – 4.3). It has been argued that the HIV/AIDS organisations, therefore, have successfully mobilised families, communities and individuals to participate in HIV/AIDS activities. Thus, the study argues

that these organisations pioneered the revival of social capital at community and individual levels.

Various approaches were employed by NGOs to strengthen social networks at all levels. These approaches included many types of activities: interaction between members/clients at regular meetings, family support and sensitisation, inter-organisational network-building, and community mobilisation and training. Another important feature was the development of flexible management approaches which encouraged the participation of clients/members and organisation staff. The study reveals that these approaches not only strengthened the capacity of the staff, but also facilitated interaction between staff and members/clients. In addition, it is argued that both TASO and PTC/PLI are engaged in activities intended to strengthen the ability of family members, local leaders and people such as AIDS community workers (ACW) to cope. These approaches were found to be effective in improving the management of HIV/AIDS problems. In addition, the study argues that such approaches have enabled TASO and PTC/PLI to develop trust-based relations at individual, community and organisational levels (chapter 6). These relations have facilitated further interaction and communication addressing issues of HIV/AIDS spread, stigma and social exclusion (chapter 8).

TASO and PTC/PLI have employed different strategies to build social capital. On the one hand, TASO has focused on strengthening the relationships linking HIV/AIDS sufferers. On the other hand, PTC/PLI has focused on bringing people together, irrespective of their HIV/AIDS status. Interestingly, the outcomes of these approaches have been the same: both organisations have strengthened social relations and generated trust among their members; both have made a positive contribution to mitigating the stigmatisation and social exclusion of PWHA, and to promoting interpersonal communication about HIV/AIDS; and both have facilitated the social integration of their members into their communities.

Furthermore, the study reveals that these organisations have also created an inter-organisational network that gives their members access to HIV/AIDS-related services which they do not provide themselves, such as palliative care for the terminally ill and legal services for the widows. Through such partnership arrangements, NGOs relations are strengthened.

9.2.2 The Role of Government in Building Social Capital

In spite of international pressure on the Ugandan government to reduce its direct involvement in HIV/AIDS activities (O'Manique 2004), it has played an important role in mobilising social capital in various ways. The study reveals that government support, through local councils' involvement, the local government officials and above all the role of top political officials such as the president, has created an environment which facilitates the participation of different actors. This environment encouraged not only the mobilisation of the HIV/AIDS NGOs, but also facilitated their success in involving families and communities in HIV/AIDS-related activities.

The study argues that political support from the president and other top political leaders is a source of encouragement for people infected with HIV. For example, the district leaders talk about HIV/AIDS during political rallies marking major national events. The local council chiefs and personnel were also involved in mobilising the local population to participate in HIV/AIDS-related activities. As a result, PWHA are less ostracised, which instils in them a sense of belonging and confidence when dealing with their fellow citizens. In addition, state involvement and support legitimises the call for action and encourages other actors to get involved. As discussed in chapters 1, 6 and 8, trust between different groups, individuals and organisations increased interaction, as well as encouraging people to talk openly about HIV/AIDS and share their experiences during formal and informal gatherings.

In addition to creating an enabling environment which encourages social capital generation, the government has also initiated programmes that directly facilitate its formation. For example, the multi-sectoral approach allows inter-ministerial and inter-organisational collaboration, thereby facilitating network formation and collaboration between actors. This interaction is made possible through the Uganda AIDS Commission's (UAC), the partnership forums and the partnership committees (chapter 7). This approach is particularly effective in mobilizing finances; for example, in securing a grant from the Global Fund to Fight HIV/AIDS, TB and Malaria, and in forging partnerships with other donors such as the United States Agency for International Development (USAID).

The projects funded by these international donors are implemented by various actors, including the private sector and the NGOs. The implementation of projects through community initiatives (see 7.5.1) was revealed to have a number of implications for social

capital formation: (a) it encouraged the formation of solidarity groups among people with HIV/AIDS; (b) it encouraged the formation of groups other than those for PWHA; and (c) it encouraged the development of governance structures at the community level. Thus, the development of such groups widens the scope for involving a variety of people in HIV/AIDS activities. The more community groups there are addressing the impacts of HIV/AIDS, the greater their impact will be on HIV/AIDS (Barnett and Whiteside 2002).

This discussion has established that a social capital base is a precondition for the successful fight against HIV/AIDS. The next question raised concerns the effectiveness of different types of networks in addressing HIV/AIDS-related problems.

9.2.3 Is Success in Addressing HIV/AIDS Problems related to the Type of Network?

In chapter two, three types of networks are identified: bonding, bridging and linking networks (see 2.3). The perceived contribution of each to development is discussed, as well as their structural differences (see table 2.1). In chapter 4, the many impacts of HIV/AIDS were discussed. These cut across the categories of gender, race and community; and they may take different forms, social, economic and political. It was emphasised that to address these impacts fully a multi-dimensional approach is required. In chapter 6 these two discussions were integrated in a consideration of how the various types of networks can address HIV/AIDS problems.

The study argues that the alleviation of each impact requires a specific type of network. For example, the mitigation of stigma requires bridging networks that link community members and PWHA. In contrast, bonding networks are more effective in addressing problems which are exclusive to AIDS patients, such as pain and other illness-related ailments. Bonding networks provide a forum in which PWHA can share their experiences. Finally, linking networks involving interaction between state and civil society facilitate the flow of financial and technical resources. These relations between network type and HIV/AIDS impacts will be considered in greater detail, supporting the conclusions drawn in this study.

I have stressed that the analysis of social capital should consider both the structure of the relations and the nature of resources and benefits accessed through these relations. The study reveals that different networks are embedded with different resources that people require, and concludes that the different network types are mutually supportive and play different roles, all

of which are important in the fight against HIV/AIDS. Chapter 6 explored how HIV/AIDS NGOs have participated in building various social networks and how these have contributed to mitigating HIV/AIDS-related problems. Chapter 7 examined the role of the state in facilitating the building of various kinds of social relations. On the basis of the analysis provided in these chapters, a number of conclusions were drawn regarding the usefulness of networks in addressing impacts of HIV/AIDS. The various networks discussed in this study were evaluated in chapter 8 with regard to how PWHA felt that each type had benefited them. The findings indicated that bonding networks helped PWHA to obtain services from support groups such as families; bridging networks helped them to deal with stigmatisation; and linking networks helped them to access resources such as finances and technical advice regarding HIV/AIDS.

The study reveals that increased interaction between members of the organisations provided them with more psychological and emotional support. In addition, face-to-face interaction facilitated communication and discussions about different issues related to HIV/AIDS. Such discussions served to establish the relationship between HIV spread and cultural practices, and to provide information about the spread mechanisms and preventive measures. This knowledge, in turn, was found to reduce the spread of HIV, a finding which is supported by other studies, such as Asingwire et al (2003a).

In the specific cases of TASO and PTC/PLI, drama and role-plays by members/clients were found to encourage increased interaction and support, as well as being sources of information and psychosocial healing. In this way, bridging relationships between community and members of the organisation addressed issues of stigmatisation and bridged the information gap regarding HIV/AIDS. On a different level, the vertical relationships between the government and the international donor community generate the funding necessary for the implementation of various HIV/AIDS programmes.

In these discussions, it became evident that different types of social networks (bonding, bridging and linking) play different roles; and that they are all necessary to address HIV/AIDS-related challenges. To support this conclusion, the discussions of table 8.4 sum up the key findings regarding TASO and PTC/PLI. It was stressed that, in spite of differences in membership base, the majority of respondents in both organisations believed that it was possible to live positively with HIV/AIDS. This supports the conclusion that it is not one

particular type of network that is responsible for these NGOs success, but rather a combination of network types. Moreover, it is argued that every network benefits people and communities affected by HIV/AIDS (chapter 6).

9.3 To What Extent Have TASO and PTC/PLI Addressed the Impacts HIV/AIDS?

As mentioned, the purpose of this study was to evaluate the effectiveness of HIV/AIDS organisations in addressing the challenges of HIV/AIDS (chapter 1). It was argued that this could be achieved by building social relations at individual and societal levels. In order to investigate this hypothesis, two HIV/AIDS organisations (TASO and PTC/PLI) were selected as cases studies. In the course of this thesis, therefore, the activities that these organisations have initiated to alleviate HIV/AIDS problems have been examined. These organisations were found to have made a significant contribution to the alleviation of HIV/AIDS impacts in a variety of ways (chapter 8). For example, since the spread of HIV/AIDS is associated with the prevailing social, political and economic conditions (chapter 4), both TASO and PTC/PLI were involved in various activities that combated the cultural practices which contributed to the spread of HIV/AIDS, such as widow inheritance.

I found that where these NGOs were active, women have become more assertive in defending themselves against HIV/AIDS infection, for example by refusing to have unprotected sex. In addition, these organisations have increased HIV/AIDS awareness through group interaction, drama, community training and family care services. It was also found that behavioural change approaches had been integrated with approaches which target the social values and economic conditions of the people. In this regard the two NGOs in this study were found to have made a substantial contribution to the decline of social values such as widow inheritance and wife sharing. Thus, I have concluded that these NGOs have helped to control the spread of HIV/AIDS by developing increased general awareness of HIV/AIDS and women's assertiveness, and by eliminating features in the social cultural environment that have facilitated the spread of HIV/AIDS. The study found that this new awareness and assertiveness is the result of regular meetings that strengthen social relations and knowledge transfer, especially through group discussions. Participants may have the same or different HIV/AIDS status, and may be members of the same or different organisations. In any case, relationships within the group can be categorised as bonding and those with outsiders as bridging. These relationships were found to be of great significance in addressing stigma and social exclusion, and above all, in increasing the confidence of the organisation members,

particularly those with HIV/AIDS, regarding living with HIV/AIDS. It is here the greatest strength of TASO and PTC/PLI lies.

Furthermore, these interactions have affected people's perception of themselves and of the disease. Sharing experiences related to HIV/AIDS is partly responsible for the decline in stigmatisation and psychological stress, and the increase in social cohesion and the ability to live with HIV/AIDS. Other factors include the group discussions and interaction, the counselling and medical care, and the support provided for members and clients of these organisations. Thus, the NGOs had managed to convey the message that HIV/AIDS infection is not a "death sentence", and that many people are coping with the disease and living positively with the disease.

Programmes focusing on the community and family – for example, family outreaches, training of AIDS Community Workers (ACWs) and drama activities – have resulted in increased social support for PWHA and social cohesion at both individual and community levels. The study found that these programmes helped family members who were caring for HIV/AIDS patients to acquire skills in HIV/AIDS counselling; and to provide better care and more psychological, emotional and social support. This meant that the families were relieved of the burden of having to take care of HIV/AIDS patients in institutionalised settings such as hospitals, since more care could be provided at home. It also meant that PWHA no longer had to travel long distances to centres for counselling, care and support. It was evident that the social integration of PWHA into their families and communities was facilitated by offering these services to their families. Finally, all of these initiatives have addressed the problems of stigmatisation and social discrimination, since most PWHA indicated that they were more integrated.

With regards to HIV/AIDS treatment, it must be emphasised that, although ARVs were in use, only a few people could afford them, for example, the business and elite classes. The government of Uganda has been involved in negotiating for the reduction in the ARV prices and success has been achieved in this direction. However, the study found that in spite of the reduction in ARV prices, still there are very few people who were accessing them. For example the study found that, there about 70000 people needing ARVs , but only 35000 were on these drugs.

In addition, the study found that the programme to introduce free ARVs in the country through TASO was not yet in place although plans were underway. Therefore, a large number of TASO clients could only avail themselves of the social and counselling services provided by the medical personnel and fellow clients. The study concluded, therefore, that the success of TASO and PTC/PLI in helping PWHA to develop a positive perception of life with HIV/AIDS was not due to their provision of ARVs, but to their focus on communication, interaction and open discussion of HIV/AIDS.

The study found that TASO patients accessed specialised care and support services through inter-organisational networks. Thus, TASO's relationships with other organisations provided a channel through which patients gained access, for example, to information about cancer from hospice Uganda, and to legal counselling from FIDA. Without these networks, patients would not have been able to obtain these services. Furthermore, it was evident that inter-organisational networks played a role in mobilising resources such as funding; for example, TASO received some funds for the AIDS orphans educational programmes from Celtel (U) Ltd. It may be concluded, therefore, that inter-organisational networks are an important factor contributing to the effectiveness of NGOs. A review of the role of private organisations and care givers revealed that these organisations have also contributed significantly to the fight against HIV/AIDS in Uganda. For example, business organisations have played a role in supporting the activities of other organisations and plan to bring the fight against HIV/AIDS to the work place; and the hospices provide palliative care for terminally ill AIDS patients, and strengthened the care capacity of the families. These activities complement the work of TASO and PTC/PLI.

The study found that the involvement of PWHA with other people and groups such as NACWOLA, TASO and PTC/PLI, addressed issues related to the cultural values which facilitate the spread of HIV/AIDS, for example wife sharing and widow inheritance. In addition, such groups facilitate learning and knowledge acquisition regarding HIV spread and control, and how to minimise the suffering inflicted by HIV/AIDS.

The success of these NGOs in combating HIV/AIDS-related problems is still growing. Although women have become more assertive, this is still on a limited scale since the extent to which they can negotiate for safer sex is linked to economic empowerment. The NGOs have already implemented their poverty reduction strategies, for example by funding programmes to reduce the number of dependants. However, all those who need support are

not yet reaping the benefits of these programmes. In addition, these programmes rely heavily on external donations such as USAID and ACD/VOCA for food aid; hence, the withdrawal of such donations can have serious consequences, as the collapse of Global Funding illustrated. The study concludes that, to effectively fight HIV/AIDS, the programmes must be sustainable and less dependent on external support.

It was found that one of the challenges related to HIV/AIDS is the issue of discordant couples, which has threatened stable marriage relationships. The question is whether marital relationships should continue if one of the spouses is found to be HIV/AIDS positive. The study found that the partner counselling programme provided by TASO for its members/clients has saved marital relationships between discordant couples.

Yet another significant impact of HIV/AIDS is the numbers of children orphaned and in need of support. It was argued that these children lack basic necessities, including access to formal education system (chapter 4). The study revealed that the orphans' education programmes initiated by the NGOs indirectly addresses the problem of poverty, although only a small number of the many needy orphans have benefited. TASO and PTC/PLI have focused on the education of AIDS orphans, assisting the orphans by paying their government school fees. They have also established apprenticeship programmes where they can learn practical skills from carpenters, metal workers and tailors. This has reduced the burden HIV/AIDS has placed on the households that are taking care of these children.

Unfortunately, most of the HIV/AIDS programmes are dependent on international donors for funding. The dependence of the government on foreign funding to run HIV/AIDS programmes has been a source of frustration for the beneficiaries of these programmes, since funding may be suspended by the donors. For example, the suspension of funding to Uganda by the Global Fund to Fight HIV/AIDS, Malaria and TB in August 2005 meant that many patients who were already on antiretroviral drugs (ARVs) with the support of the GFFAMTB, were now without medication, which placed them in jeopardy (chapter 7 – 7.9). Another example of this dependence is in the matter of secure food supplies; the NGOs were 100% dependent on USAID and ACD/VOCA donations. Thus, the food rations clients received from TASOs' food project are dependent on external goodwill, which can easily be withdrawn. The vulnerability of HIV/AIDS programmes operating under these conditions is clear.

In spite of the few shortcomings discussed above such as the dependence on external support for certain programmes, the findings indicate that TASO and PTC/PLI have succeeded in addressing the central challenges of HIV/AIDS in Uganda. The study has revealed that there are a variety of factors which have facilitated the success of TASO and PTC/PLI in fighting HIV/AIDS. In particular, the study has demonstrated that their success can be attributed to their ability to mobilise networks of different sorts and establish collaborative linkages with the government.

The study has argued that government involvement has been essential in the mobilisation of funding and in the negotiations with major drug companies; this resulted in a reduction in drug prices that has enabled PWHA to access medicine. In addition, the study has argued that the complementary role of the government, for example in the creation of an enabling environment, has facilitated not only the functioning of NGOs and other private sector initiatives, but also the interaction of individuals, particularly PWHA. Thus, the final conclusion to be drawn is that TASO and PTC/PLI have significantly alleviated the impacts of HIV/AIDS, and that this success can be attributed to their skill in facilitating social relations between individuals, groups and organisations. Social capital, therefore, is important for the successful alleviation of the impacts of HIV/AIDS, as the case of Uganda demonstrates. Table 9.1 provides a summary of various conclusions from the study.

Table 9. 1 Social Capital and the Performance of TASO and PTC/PLI in the Alleviation of the Impacts of HIV/AIDS

Actors	Generating Social Capital	Alleviation of HIV/AIDS Impacts
<p>The Role of HIV/AIDS NGOS -TASO and PTC/PLI - in building social capital for HIV/AIDS intervention</p>	<p>Networks and Trust Building</p> <ul style="list-style-type: none"> • Interpersonal networks • Networks at family and community levels • Formal and Informal interactions • Trust building 	<ul style="list-style-type: none"> - Information is accessed; results in behaviour change and decline in counter-productive societal values; - Increased HIV/AIDS awareness of HIV/AIDS - Increased assertiveness of women led to the prevention of the spread of HIV - Increased social integration and communication of PWHA,
	<ul style="list-style-type: none"> - Medical clinics run by the organisations • Interaction and group counselling during clinic visits 	<ul style="list-style-type: none"> - Access to medical services by members of the two organisations, resulted in improved health of those with HIV/AIDS and other members - Through shared experiences, emotional support is obtained
	<ul style="list-style-type: none"> - Organisational development: • Capacity building and participatory management • Community development and training • -Participatory management - Structures that facilitate interaction: • PTC/PLI Recreation centres • TASO Day centre • TASO and PTC/PLI Drama performances 	<ul style="list-style-type: none"> - Interaction closes the gap between PWHA and other members of the community, hence stigmatisation, social exclusion and discrimination have been alleviated - Community leaders are now involved in HIV/AIDS activities - Increased participation in HIV/AIDS activities by community members has been achieved - Establishment of educational programmes for orphans has led to: improved living standards and integration of orphans with other children and people; skills acquisition by orphans; reduced burden on the families maintaining AIDS orphans - Group formation has led to a focus on group-specific HIV/AIDS issues such as of widow inheritance and property rights.
	<ul style="list-style-type: none"> -Training of families and care givers 	<ul style="list-style-type: none"> - Acquisition of HIV/AIDS-related skills; counselling and care - -Relieves families of costs of maintaining patients in institutional settings - Integration and social unity at community and family levels have been promoted - Physical, psychological and emotional support is provided
	<ul style="list-style-type: none"> - Intra- and inter-organisational networks • Referral system • Partner and joint programmes 	<ul style="list-style-type: none"> - Improved interorganisational relations and information sharing - Increased resource access - PWHA have access to specialised service organisations - Role playing reduces HIV/AIDS vulnerability of organisation members, especially the youth
<p>Synergy Between Government and the NGOs</p>	<ul style="list-style-type: none"> - The multisectoral approach and involvement of various actors in HIV/AIDS programmes - State-NGO relations: • Complementarity and Embeddedness - Creation of a favourable environment that favours NGOs' autonomy-complementarity • Political leadership • Integration of NGOs into government programmes - Joint planning of activities - Institutions that facilitate interaction such as the UAC - Mobilisation of funding and negotiation of reduced drug prices. 	<ul style="list-style-type: none"> - Involvement of different actors has made it possible to fight HIV/AIDS on different fronts, including political, social and economic; and the involvement of religious and traditional healers and medicine men - - Preventive approaches such as the use of condoms are not so vehemently opposed by religious groups. - Political leadership has led to improved state-society relations - Participation of PWHA - Reduced prices has led to increased number of people accessing ARVS

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APPENDIXES

Appendix 1: Introduction and Question guides

Introduction to interview questions:

My Name(s) is Roberts Muriisa. I am a Ugandan. I also work as a lecturer at the faculty of development studies Mbarara University of Science and Technology. Currently, I am a student at the University of Bergen Norway. This study is conducted as part of a Ph.D. programme at the department of Administration and organisation theory, University of Bergen.

This study maps the role of Nongovernmental Organisations (NGOs) in dealing with HIV/AIDS challenges. We focus on the impact that can be created when relationships between individuals and groups as well as organisations are facilitated.

This study is carried out with an academic interest. Your responses to the questions set are guaranteed full anonymity. And the answers shall be processed in a manner that no respondent can be individually identified and the conclusions from this study will reflect the general situation than individual situation.

I, Mr. Muriisa and no one else shall access data collected in its detailed and original format. Confidentiality in regard to your responses is guaranteed.

Your responses are of high value.

Thank you very much.

Roberts Muriisa

QUESTIONNAIRE

Questions to be answered by Staff of Organisations

A. Back ground information?

1. What is the name of the organisation..... (Branch)
2. What is your Position in the organisation? Are you volunteering or you are employed by the organisation?
3. How many people does the organisation employ?
4. Are there volunteers who work for the organisation?
*If any, how many?
6. How old is the organisation, (Branch)? Probe for the formation period if the informant knows when exactly?
7. What segment (age and gender) of the population does your organisation focus on? (probe for reasons for this selection).
8. What percentage of the population (HIV/AIDS) in this community does the organisation benefit?
9. What is the percentage of
 - (a) Women
 - (b) Men
 - (c) Youth
 - (d) Children
10. In which area does your organisation operate in the district? (Probe for reasons for the selection).
*On what Basis does the organisation decide on the area in which to operate?
11. What is the nature of your clients?
 - *Paid up members
 - *Any one with HIV/AIDS
 - *Any community member who registers with us
 - *Volunteers
 - *Any other.
12. What are the activities of the organisation?
13. What is the organisation's capacity to
 - (a) carry out specialised tasks for its beneficiaries (such as credit, training in specific fields etc), community mobilisation?
 - (b) Resolve conflicts and problems with other organisations?
 - (c) Resolve problems among clients?
14. How does the organisation identify the common needs and priorities of its clients (members)?
15. In what way has the organisation addressed such demands?
16. What are roles of the Organisation's staff working in the field?
*Do you have any client/member of the organisation working in the field?
17. How is the organisation funded?
18. How are the activities selected?

Counsellors and field staff

1. How do you get clients (members) or how do clients know that the organisation exists?
* Approximate the number of your Clients (Probe for records).
2. Since the organisation started operating in these areas, has the number of members/ clients been increasing or decreasing (probe for records).
3. What are the activities of the organisation?
4. Do clients participate in the decision making such as selection of the activities and projects of the organisation?
5. Are there some clients involved in leadership positions in the organisation? (probe).
6. Describe how clients participate in the organisation's activities and programmes?
E.g. Membership contributions
Drama and other performances.
7. How do you enhance client's participation in programmes?
8. How would you describe the relationship of your organisation and other organisations or programmes dealing with HIV/AIDS?
Do you think those organisations have something they are contributing that your organisation can learn from?
9. In your own opinion do you think clients are positive about the organisations' activities?

C. Activities of the Organisation (both management and field staff)

1. In your own opinion what are the main challenges facing HIV/AIDS infected persons?
2. How does the organisation address such challenges?
*For example other than counselling, do you have any other activity to address such challenges?

3. HIV/AIDS divides society. How does your organisation address this problem?
4. Considering your activities and your operations what is the most important contribution to communities in which you operate?
5. Do you think the organisation try to change the social cultures and values, such as wife sharing, widow inheritance? Do you think the organisation has had an impact? How?

- 6 Do you think the community attitude towards people with HIV/AIDS has changed?
*What is your contribution of your organisation to this change of attitude, if any?

D. Net working

Interpersonal linkages.

1. How often do you organise meetings for clients (members)?
2. How do (members)clients respond to these meetings (like turn up rate)? And how do they participate? (ie. Are they information meetings, debates and discussions, teaching –probe for what is done at these meetings.
3. Do you think the knowledge and skills clients (members) gain from these meetings has an impact on their lives and health? How?
*Do you think by making clients meet each other has a contribution to their lives? How
4. How would you describe the relationship?
Among your clients
Clients and Staff
Clients and the organisation in general
5. Are there times when you visit your clients outside the designated time for work?
6. Would you say you are confident to discuss HIV/AIDS outside your work and clients (probe)?

Organisation's relationship with the community

1. Do you organise meetings for the communities outside your clients?
2. How do they respond?
*Do you get a big turn up?
*Do you have records? Of this?
3. What issues do you discuss in these meetings?
4. Are there times when you arrange meetings for clients (HIV+) and those from the communities?
*In your opinion do you think clients would wish to have such meetings where they interact with members of the community?

*If not, what strategy does the organisation use to see that the community and the HIV/AIDS persons live in harmony?

5. How would you describe the relationship between your clients and other members of the community?

Relationship with other organisations (for management and counsellors)

1. Before you started operating in these communities were there other organisations operating in the communities? If any probe for some and their activities.
2. Do you think these organisations have contributed to the understanding of HIV/AIDS and addressing problems associated with it?
How do you perceive these other organisations
There are rumours that some organisations, are formed for the purpose of exploiting the infected and access donor funds. Do you have any idea about such organisations
3. Are there situations when your organisation interact with these other organisations?
If yes which organisations (CBOs, Faith organisations, Other HIV Organisations, Hospitals)
What is the nature of the relationship?
4. At what level of your operations does this interaction take place?
Eg. Community activities, implementation of the programmes
5. Do you think these organisations influence the way you select and implement your programmes? How?
6. In your own opinion, do you think these other organisations can be trusted or one has to be careful when dealing with them?
7. Do you have joint activities with these other organisations? If yes what are these activities?
8. Do you hold any meetings with these other organisations (probe for interval)? If yes, what is the purpose of these meetings? Who decides on the agenda and how does it come up? How do you think these meetings have benefited people with HIV/AIDS, the community and the organisation?
9. Describe how other organisations dealing with HIV consider your Organisation.

Relationship with International organisation (for management)

1. Do you have any collaboration with International NGOs? If yes examples?
What is the nature of collaboration (e.g. Programmes design, funding etc.)
2. Do these organisations influence decisions, programmes and activity selection in the organisation? How
3. Are there some int. organisations involved in the activities similar to the ones you are doing?

4. What is the nature of your relationship?

E. NGO-Government relationship (For both management and field staff)

1. Do you normally interact with government officials?

2. At what level do you normally interact with government officials in your operations?

3. Changing customs and community life may require the government to step in, do you think the government (LC, Police, Courts etc, contribute (Both positive and negative).

4. Do you think the government has a role it can play in influencing community responses to your programmes like voluntary testing for HIV and voluntary declaration of ones HIV/AIDS status? Or even through government's initiated programmes?

*Do you think the government plays this role?

5. How would you describe the relationship between the organisation and government?

*How does Government feature in your programmes and Activities?

6. Do you receive any support (material, financial political etc) from the government for your activities?

7. Is there any government programme you know dealing with HIV/AIDS.

8. How does your organisation's programmes feature in government HIV/Aids programmes?

9. How do you compare the effectiveness of government HIV/AIDS programmes/activities to your own?

10. What are your general experiences in dealing with government officials? (Probe for type)

11. Do you think the government is an important element for the success of your organisation's programmes?

*How

F. Participation.

1. How many people voluntarily tested for HIV and are accessing your services in the last 6 months? (Management)

2. How many people voluntarily testified for being HIV+ in the last 6 months? (Management)

3 How are decisions of the organisation taken?

*Voting,

*Lot

*Deliberation and discussions

*Directives from above

4. How often are clients involved in the decision making process?

*Probe for any meetings on an important issue?

5. What is the nature of staff-client relationship?

6. How often do you hold meetings with the field staff?

7. How often do you hold general meetings?

Preparing people to Live with HIV/AIDS

1. Do you often talk about HIV/AIDS to clients as a group or each is handled secretly?

2. Do you think group discussions are important for people living with HIV/AIDS?

*HOW?

3. Many PLWHA are faced with the problem of poverty, self-exclusion, social exclusion, stigmatisation, how does your organisation fix these problems?

G. Trust

1. How do you consider client's response when they are discussing their problems with you?

2. Are there times when client share with you their problems, which are not related to HIV/AIDS? What is the nature of these problems?

3. How do Clients perceive the way your activities are organised for example rule following, bureaucracy and the way you arrange and select programmes?

Questions for Clients and Members of Organisations

A. Homogeneity

1. Gender

Male	
Female	

2. What is your age?

15-20	
21-25	
26-30	
31-35	
36-40	
41-45	
46-50	
Above 50	

3. About how many close friends do you have these days? These are people you feel at ease with, can talk to about private matters, or call on for help (Adopted from World Bank 2003, See Narayan et al)

5. Are these friends of the same;

Organisation as you belong

Ethnic background

Have the same HIV/AIDS status (only for HIV/AIDS positive respondents)

Gender

Employment

Family and kin

All categories

6. Of these friends estimate, how far from where you live to where your friends live.

(1) 1- 2 Kms; (2) 3 –10 Kms); 3. Above 10 Kms

B. Net working

1. Which organisation(s) do you know dealing with HIV/AIDS?

2. How long have you known the organisation? (TASO or AIC (PTC/PLI) or any other, whichever is applicable)

3. How did you know the existence of the Organisation (TASO or AIC (PTC/PLI), or any other organisation in which a member belongs, whichever is applicable?)

4. Are you a member of the organisation you have mentioned or both?

5. What is the nature of your membership?

Paid up member

Client

Volunteer

Any other (mention).

6. How would you define your relationship with other members of the organisation?

Very Poor	Poor	Neither poor	Good, nor	Good	Very good
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*How would you define your relationship with staff of the organisation?

Very Poor	Poor	Neither poor	Good, nor	Good	Very good
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7. To what extent do you participate in the organisation's decision making such as participating in meetings of the organisation?

To a very small extent

To a small extent

Neither Small or Large extent

To a large extent

To a very large extent

8. How often do you meet with a member or members of the organisation?

1. Every day; 2. Several times a week; 3. Every week; 4. Once or twice a month; 5. Never

9. How often do you meet with a member or members of the organisation outside these scheduled meetings by the organisation?

1. Every day 2. Several times a week; 3. Every week, 4. Once or twice a month; 5. Never

Have you attended or been represented to a meeting dealing with HIV/AIDS at national or international level

10. What are the main issues discussed in these meetings?

11. Does the organisation arrange for meetings with members of the public to discuss HIV/AIDS related? 1. Yes 2 no 3 I am not sure

12. On average how often do you participate in the organisation's activities in a month?

1. Several times a month 2. Once a month 3. Twice a month 4. Never

13. How often do you participate in the following activities?

	Each week	Once a month	Twice a month	Never
	1	2	3	4
Spending time with close family or other relatives				
Spending time with friends and neighbours				
Spending time with co workers and professional colleagues				
Members of your organisation				
Persons met in other organisations or Volunteer or service organisations				

14. How would you define your relationship with the persons and groups mentioned in the preceding question?

	Very poor	Poor	Good	Very good	Excellent
Close family or other relatives					
Friends and neighbours					
Co workers and professional colleagues					
Members of your organisation					
Persons met in other organisations or Volunteer or service organisations					

15. Using a 5-point scale from 1 to 5, where 1 represents to a very small extent and five represents to very large extent, determine the extent to which belonging to the PTC/PLI or TASO has contributed to your relationship with different people, neighbours, relatives, family members, members of the organisation in which you belong and the community.

	Very small	small	1/2, 1/2	Large	Very large
Close family or other relatives					
Friends and neighbours					
Co workers and professional colleagues					
Members of your organisation					
Persons met in other organisations or Volunteer or service organisations					

C. Causes, prevention and cure

I am going to ask you questions related with AIDS causes, cure, prevention and mitigation. Your answers are a secret between you and I. You are free to answer but in case you are not comfortable with the question you may not.

1. What is your HIV/AIDS status?

- (a) Positive
- (b) Negative
- (c) Don't know
- (d) Refuse to answer.

2. In your opinion how does your HIV status affect your working ability?

3. Does the organisation talk or discuss issues related with HIV/AIDS openly with its clients or members as a group? YES/NO

4. How often are the following topics discussed in these meetings (For responses (1 and 2) probe for nature of intervention)?

	Always	Often	Never
Causes			
Coping mechanisms			
How to live with people with aids			
Others			

5. In your opinion how are these discussions important in increasing your knowledge of HIV/AIDS?

6. How would you rate the impact of NGO you belong (TASO or AIC (PTC/PLI) which ever is applicable) on the following behaviours? For members who belong to both repeat the question for the other organisation.

	Strongly reduced them	Reduced	½, ½,	Less impact	No impact at all	I do not know
Promiscuity						
Wife sharing						
Widow inheritance						

7. I am going to name organisations that are involved in HIV/AIDS activities, please mention in order (1, 2, 3) of their contribution to the knowledge you have acquired.

Government programmes

Media (News papers, Radio and Television)

NGOs

8 To what extent has your neighbourhood / community benefited from the activities of organisations dealing with HIV/AIDS e.g. TASO, AIC (PTC/PLI)

(a) To a very small extent

(b) To a small extent

(c) Neither Small nor Large extent

(d) To a large extent

(e) To a very large extent

9. Using a 5-point scale, how would you rate the contribution of NGOs in preparing people to Live with HIV/AIDS?

1 Very low 2 Low 3 So-So 4 High 5 Very high

*Probe for the choice of response

10. How often does the organisation (AIC, TASO) encourage you to form your own groups?

D. Self-confidence and contentment

1. Generally speaking, would you say you are happy, with the organisation's activities in handling HIV/AIDS (Probe)?

*Are you proud to be a member of the organisation?

*Would you continue to be a member of the organisation?

2. Since you joined the Organisation would you say that your health has improved or not improved?

After becoming a member of the organisation, do you feel that life is worth living?

Does the NGO change your lifestyle and living conditions?

3 How has belonging to TASO or PTC/PLI (whichever is applicable) helped you? Probe

-Have discussed your sero status with any one in the group you belong?

-How many people in the group have you discussed your status?

-Do you notice any differences when PLI are associating with other PTC members?

4. Do you know the existence of the Government's HIV/AIDS programmes? Yes or no

5. If yes how would you describe the programmes compared to the NGOs programmes?

6. Do you think you can do the following?

	YES	NO
Go public and tell people about HIV/AIDS including your status?		
Go Public but not tell my status.		
Can not go public and cannot tell my status		
I am not sure		

7. Using a 5-point scale, how confident would you say that you are more prepared to live with HIV compared to years ago?
 1 Much less confident 2 Less confident 3 Same 4 More confident 5 Much more confident

E. Social support and social exclusion or inclusion

1. On a scale of 1 to 5 where 1 is very little support and 5 is a lot of support, how would you rate the support you are getting from

	Very little support	Little support	So-so	Some support	A lot of support
Family members,					
Friends					
Relatives,					
Community and neighbours.					

2. What is the nature of support do you get from

	Emotional Companionship Services	Financial	Other
Family members,			
Friends			
Relatives,			
Community and neighbours.			

F. Social inclusion and exclusion

1. There are often problems with associating with people living with HIV/AIDS even with people living in the same community, or attending the same church or mosque or any other prayer group. To what extent would you say that your sense of belonging to your local community has improved since the organisation started operating?

- To a very small extent
- To a small extent
- So- So
- To a great extent
- To a very great extent.

Which of the following (name them) has greater impact in minimising these differences (probe for reasons for the selection).

- (a)NGOs
- (b)Church or any other faith based organisation
- (c)Government
- (d)Family
- (e)Community

3. List in order of magnitude (1,2,3...) the biggest problems facing people living with HIV/AIDS?

	1	2	3	4
Poverty				
Social exclusion				
Self exclusion/Stigma				
Harassment				

4. Do you think the government can play a role in fixing these problems? (Yes /No).

*How?

*Do you think the government has taken any steps in fixing some of these problems?

5. How have NGOs helped to fix these problems?

G. Trust in people and institutions of government

In all communities, people get along with others, trust or not trust each other or government. Answer the questions below.

1. Many people would wish to share their problem with some one else that they trust. If (when) you found that you had HIV/AIDS, whom (did) would you tell about it first?

Member of my family 2. A friend 3 Spouse 4. none

2. Would you agree to the following statements? (Adopted and modified from Narayaan (2003))

	Yes	No
A. Most people in my village/neighbourhood are willing to help if you need it.		
B. Most people in the organisation I belong are willing to offer help if I need it		
C. Most people in my neighbourhood can be trusted		
D. In the organisation I belong most people can be trusted		

3. Using a 5-point scale determine the level of competence or efficiency of the institutions I am going to name.

	Very inefficient	Inefficient	Average	Efficient	Very efficient
Local Government/ Municipality Officials					
LC Officials					
Tax Officials					
Government Hospitals					
Government Schools					
Police					
Judiciary (Court)					
Other NGOs dealing with HIV/AIDS					

4. In your opinion, how honest are the officials and staff of the following agencies? Please rate them on a 1 to 5 scale, where 1 is very dishonest and 5 is very honest (This question is adopted from World Bank and modified Narayan et al(2003))

	Very honest	Mostly honest	Neither honest nor dishonest	Mostly dishonest	Very dishonest
A. Local council (LC) officials					
B. Local government officials					
C. Doctors and nurses in health clinic and hospitals					
D. Teachers and school officials					
E. Police					
F. Magistrates, Judges and staff of courts					
G. Staff of NGOs					

5. If you had HIV/AIDS how much confidence do you have that government authority, like courts of law and police can protect you and people like you from harassment, exclusion and or unlawful dismissal from your employment if you have one?

- (1) Not confident at all
- (2) Not confident
- (3) So-so
- (4) Somewhat confident
- (5) Very confident

6. Would you say that the government is an important element in the protection of people with HIV/AIDS?

7. In the last six-month have you or any one you know with HIV/AIDS been a victim of violence (probe)?

8. Other than HIV/AIDS related issues, would you trust a NGO official with some other information e.g. family problem, financial difficulties, any other? YES/NO

9. Would you do the same with the government official? Yes or no?

*Probe for any differences in responses to question 8 and 9.

J. Current issues and sources of information.

Today there are many programmes on radio like, 'Tusheshure' on radio west and others, in newspapers or Local meetings by other organisations answer the following?

1. How often do you listen to such programmes?

*Do you think such programmes are Beneficial to the community and people in general?

2. How often do you do the following?

	Never	Rarely	Often	Very often
Read newspaper				
Listen to news and Radio programmes				
Watch News on TV				
Local meetings by other organisations				

Questions for Government Officials

1. What is your position in the government?
2. Do you think HIV/AIDS is a problem to this country?
 - *How
3. Do you have or know any government-aided programmes dealing with HIV/AIDS problem?
 - *What is the nature of the programmes?
 - *Probe for programmes in the press (Radio, TV Newspapers)
 - *Probe for the existence of the government aided community programmes.
 - *Probe for group discussions with clients
 - *Probe for HIV policy.
4. To what extent have the programmes benefited the communities and people in general?
 - *Probe for any voluntary testimonies.
 - *Probe for Communities visited and impact
 - *Programmes Implementation at Community Level
5. There are often problems, which are faced by people living with HIV/AIDS, apart from the general sickness, in your opinion what are the BIGGEST problems facing these people?
6. Do you think the government have tried to fix these problems?
 - *How?
7. If you had HIV/AIDS how much confidence do you have that government authority, like courts of law and police can protect you and people like you from harassment, exclusion and or unlawful dismissal from your employment if you have one?
8. Would you say that the government is an important element in the protection of people with HIV/AIDS?
 - *How

GOVERNMENT, NGO relationship

1. Do you know any NGOs dealing with HIV/AIDS?
2. How do you perceive NGOs?
3. How do you perceive their activities in respect to handling HIV/AIDS problems?
4. Do you have any activities done by NGOs supported (funded by the government).
 - *Do you have any support you offer to NGOs fighting HIV/AIDS?
 - *Do you have any joint activities in the above area?
5. How would you compare the effectiveness of NGOs programmes to that of NGOs in dealing with HIV/AIDS, like reaching the people, influencing voluntary testimonies etc?
 - *How do you perceive NGOs dealing with HIV/AIDS?

Government and other agencies

How are your programmes funded?

Do you receive funding from international agencies?

How are decisions about programmes taken?

Who decides on the programmes to be taken

What is the level of involvement of the people living with HIV/AIDS in the decision making?

Focus group Discussions Guiding Questions

1. Do you think HIV/AIDS is a problem do this country/ community

How?

2. What are the main problems faced by HIV/AIDS infected persons in your community?

How does your community help solve these problems?

3. Have you known any agencies; government, Church, NGOs, dealing with HIV/AIDS in this community? Probe for agencies.

4. Since the organisation started operating in this community, have you noticed any changes in the way people with HIV/AIDS are perceived by the community?

5. Since the organisation started operating in this community, have you noticed any change in the behaviour of the people; in terms of promiscuity, cultures of wife sharing and widow inheritance?

6. Do you think these changes (if any) are attributable to the work of NGOs?

7. Do you know of any government activity dealing with HIV/AIDS? (Probe for activity)

8. In your opinion how have these programmes facilitated your understanding of HIV/AIDS?

9. How would you compare the effectiveness of the NGOs like TASO, NACWOLA to that of government?

10. Considering the NGOs dealing with HIV/AIDS in your community, in your opinion what is their most important contribution to the community?

11. Have you assisted any one with HIV/AIDS in the last one month? What kind of assistance if any have you given?

12. Have you observed any HIV/persons being excluded from participating in certain activities?

*If yes why?

*What kind of activity

13. In the last 6 months have you participated in resolving some family conflicts resulting from HIV/AIDS problems (status etc)?

14. Do you think the government is an important element in solving some community problems like those related with HIV/AIDS?

15. Do you think the government has done any thing to solve some of he problems you have mentioned?

Appendix 2: Applications and Approvals for Carrying out Research in Uganda

A: Applications

Appendix 2A-I Application form to be filled by researchers intending to do research in Uganda

UNCTST/RC1

THE REPUBLIC OF UGANDA
UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY
APPLICATION FOR PERMISSION TO CONDUCT RESEARCH
(N.B. Read instructions and guide in annexes I and II before completing this form)

FOR OFFICIAL USE
APPLICATION No.....
FIELD OF RESEARCH PROJECT No.....
.....
.....

SECTION A: PARTICULARS OF APPLICANT

1. Full Names.....;(underline surname)
2. Male() Female() (Please tick)
3. Date and Place of Birth.....;
4. Marital status
5. Nationality
6. Permanent address
Fax.....;Tel
E-mail
Address of institution of affiliation in Uganda
Fax.....Tel.....
E-Mail.....
7. Current emigration status* (if already in Uganda)
*foreign applicants
8. Present Occupation Status.....
Institution.....;
If on contract date of Expiration.....
9. Education
(i)University Qualification.....
Qualification.....Class.....Year.....
Field of Speciality.....
(ii) post graduate research experience, with lists of publications if any (use additional paper if necessary)
.....
.....
(iii) Names, qualifications and status of personnel involved in the research;
name.....:Qualification,.....Status(with regard to the project).....

Section B MAIN FEATURES OF RESEARCH PROJECT

- 10 Title of research project.....
- 11 Main objectives of research.....
- 12 Brief outline of research methodology.....
- 13 Research type (please tick) () Degree award () none degree award
(If degree award, state type of degree e.g. BA, MSc, PhD etc and the institution awarding the degree).....
- 14 Districts of Uganda in which research will be carried out.....
- 15 Estimated cost of research.....;
Sources of funds.....
Duration of ;.....

Breakdown of expenditure (This table must be filled by all applicants)

Item

Year 1
(US\$)

Year 2
(US\$)

Year 3
(US\$)

Total (US\$)

Personal Travel*.....Material and Supplies.....Administration.....
Result Dissemination.....Other.....; Contingency.....

*both local and Foreign

Section C

17 Names and Address of two referees

.....
.....

18(a) I undertake to submit

- (i) Six Monthly progress reports of my project
- (ii) Final Results on completion of the project
- (iii) Copies of any published paper/ article arising from the project

(b) I hereby certify that to the best of my knowledge and belief, the particulars given in this form are true and complete in all respects

Date.....; Sign of Applicant.....

Section D

TO BE FILLED IN BY THE HEAD OF DEPARTMENT? INSTITUTION AND /OR SUPERVISOR

19 comments by head of institution/Department.....
.....

Name.....

Signature.....Date.....

21 Ethical Clearance (especially for health research involving human subjects)

.....

Chairman Ethical Committee (Name, Signature and stamp

Date.....

Appendix 2A- ii Application form to be filled when applying to use government documents to collect data

R6

PRESIDENT'S OFFICE
RESEARCH SECRETARIAT,
P.O. BOX 7168,
KAMPALA, UGANDA

APPLICATION FORM FOR RESEARCHERS WISHING TO CARRY OUT RESEARCH IN UGANDA AND TO USE GOVERNMENT ARCHIVES

(Please complete three (3) copies of this form and attach four (4) recent passport-size photographs)

SECTION A

1. Surname.....
2. Other Names.....
3. Date and Place of Birth.....
4. Nationality.....
5. Passport No, Date and Place of Issue.....
6. Permanent Address.....
.....
7. Address of Institution/Organisation of Association or Affiliation.....
.....
8. Have you been sentenced or bound over by a civil court, or has a charge against you been dismissed by a civil court? If so give dates and circumstances.....
.....
9. Marital Status
 - (a) Married or Single.....
 - (b) If Married, name of husband or wife at birth.....
 - (c) Number and ages of Children.....
10. Details of Farther
 - (d) Name and Nationality
 - (e) Present Nationality
11. Details of Mother;
 - (f) Name and Nationality
 - (g) Present Nationality

SECTION B

Details of Education Standard;

- (a) Name of Schools and colleges attended with dates.....
.....
- (b) Names of Universities Attended, Qualification obtained with dates.....
.....
- (c) Post Graduate course taken.....
.....
- (d) What language do you speak.....

SECTION C

13. Employment Since leaving school.....
.....
14. Countries you have visited.....
.....
15. Title of research project.....
.....
16. Brief description including methodology of project.....
.....
17. Areas of Uganda in which the research will be carried.....
.....
18. Name of the organization recommending the candidate.....
.....

19. Project Duration.....

Signature of the researcherDate.....

FOR OFFICIAL USE ONLY

PRESIDENT'S OFFICE
RESEARCH SECRETARIAT,
P.O. BOX 7168,
KAMPALA, UGANDA

PERMISSION TO USE GOVERNMENT ARCHIVES

Surname.....
Other Names.....
Nationality.....
Present Address.....

.....
Title of Research Assignment.....
.....
.....
Sponsors.....

You are permitted/not permitted to use government Archives

Secretary for Research

Date.....

Note: Only files and documents that are older than fifty years are available for researchers. More recent files and classified documents require fresh application to the Secretary for research.

Appendix 2 B: APPROVALS

Appendix 2 B-(i) Approval of application to do research in Uganda by UNCST

 **Uganda National Council For Science and Technology**
(Established by Act of Parliament of the Republic of Uganda)

Your Ref:.....
Our Ref:..... **SS 1503** Date:.....**15-Dec-03**.....

Mr. Muriisa Roberts
C/O Mbarara University of Science and Technology
P.O Box 1410
MBARARA

Dear Mr. Muriisa,

RE: RESEARCH PROJECT, "PRACTICING SOCIAL CAPITAL: THE ROLE OF NGOS IN MITIGATING HIV/AIDS CHALLENGES IN UGANDA "

This is to inform you that the Uganda National Council for Science and Technology (UNCST) approved the above research proposal on **December 2, 2003**. The approval will expire on **December 2, 2004**. If it is necessary to continue with the research beyond the expiry date, a request for continuation should be made in writing to the Executive Secretary, UNCST.

Any problems of a serious nature related to the execution of your research project should be brought to the attention of the UNCST, and any changes to the research protocol should not be implemented without UNCST's approval except when necessary to eliminate apparent immediate hazards to the research participants(s).

This letter also serves as proof of UNCST approval and as a reminder for you to submit to UNCST timely progress reports and a final report on completion of the research project.

Yours sincerely,


Julius Ecuru
for: Executive Secretary
UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

LOCATION/CORRESPONDENCE
PLOT 10, KAMPALA ROAD
UGANDA HOUSE, 11TH FLOOR
P. O. BOX 6884
KAMPALA, UGANDA.

COMMUNICATION
TEL: (256) 41-250499
FAX: (256) 41-234579
E-MAIL: uncst@starcom.co.ug
WEBSITE: <http://www.uncst.go.ug>



Uganda National Council For Science and Technology
(Established by Act of Parliament of the Republic of Uganda)

Your Ref:.....

Our Ref: **SS 1503**

Date: **15-Dec-03**

The Resident District Commissioner
Mbarara District
MBARARA



Dear Sir/Madam,

RE: RESEARCH CLEARANCE

We wish to introduce you to **Mr. Muriisa Roberts** who would like to carry out a research project entitled, **"Practicing social capital: The role of NGOs in mitigating HIV/AIDS challenges in Uganda"** between December 2, 2003 and December 2, 2004 in your district. The Uganda National Council for Science and Technology has approved the research project.

This letter is to request you to give the researchers the necessary assistance to facilitate the accomplishment of the research project.

Your cooperation in this regard is highly appreciated.

Yours Faithfully,


Leah Nawegulo
for: Executive Secretary

UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

cc Mr. Muriisa Roberts
C/O Mbarara University of Science and Technology
P.O Box 1410
MBARARA

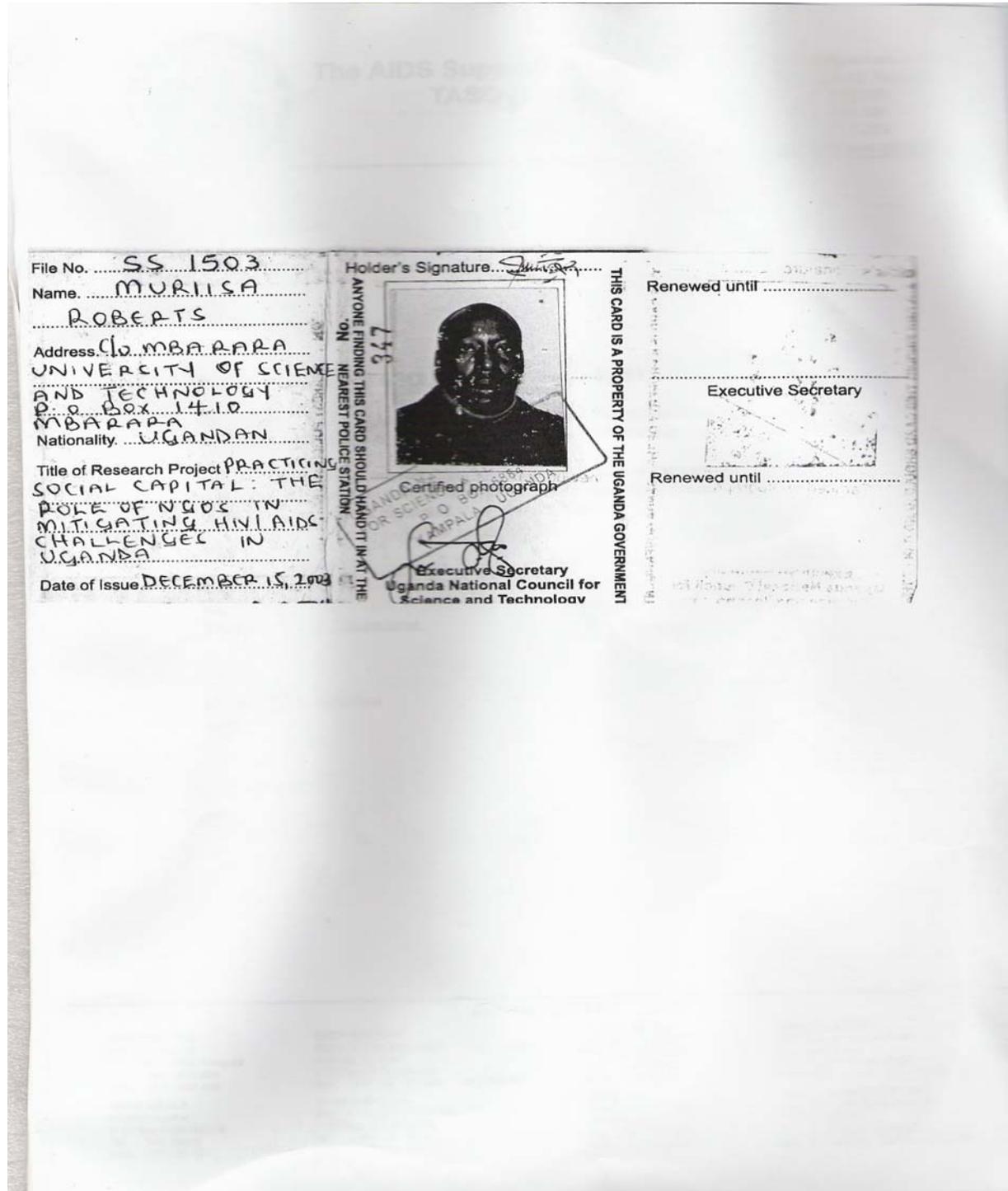
LOCATION/CORRESPONDENCE

PLOT 10, KAMPALA ROAD
UGANDA HOUSE, 11TH FLOOR
P. O. BOX 6884
KAMPALA, UGANDA.

COMMUNICATION

TEL: (256) 41-258499
FAX: (256) 41-234579
E-MAIL: uncst@starcom.co.ug
WEBSITE: <http://www.uncst.ro.ug>

Appendix 2 B-iii Researcher's identity card issued by UNCST



Appendix 2 B-iv Letter to Manager TASO Mbarara Branch to allow me collect data from the organisation



**The AIDS Support Organisation
TASO (U) Ltd.**

TASO Headquarters, Mulago
P. O. Box 10443, Kampala
Tel: 041 532 580
041 532 581
Fax: 041 541 288
Email: mail@tasouganda.org

January 28, 2004

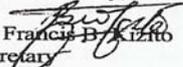
The Manager
TASO Mbarara

Ref: Research at TASO Mbarara Centre by Mr. Robert Muriisa.

On behalf of TASO Research Committee, I would like to introduce to you Mr. Robert Muriisa a student who is pursuing a Ph D degree course at the University of Bergen.

The purpose of this letter is to request you to allow him at the center in order to conduct the research as described in the protocol. He should present to you all the protocol documents as requested by the committee.

Yours sincerely,


Dr. Francis B. Kizito
Secretary
TASO Research Committee.

cc. Mr. Robert Muriisa

SERVICE CENTRES

TASO MULAGO
Mulago Hospital
P. O. Box 11485, Kampala
Tel: 041 530 034
Mob: 077 430 468

TASO MBALE
Mbale Hospital
P. O. Box 2250, Mbale
Tel: 045 33507
Mob: 077 440 829

TASO MASAKA
Plot 1-19 Kigamba Road
Masaka Hospital
P. O. Box 1679, Masaka
Tel: 0481 20527 Mob: 077 499 988

TASO ENTEBBE
Plot 15-17 Lugard Avenue
P. O. Box 235, Entebbe
Tel: 042 320 030
Mob: 077 617 126

TASO TORORO
Plot 30 Cox Road
P. O. Box 777, Tororo
Tel: 045 45009
Mob: 077 461 207

TASO JINJA
Plot 2-48 Baxi Road
Jinja Hospital
Tel: 043 120 382
Mob: 077 359 942

TASO MBARARA
Off Mbarara-Kabale Road
Mulindwa Road
P. O. Box 1010, Mbarara
Tel: 0485 21323 Mob: 075 693 475

TASO TRAINING CENTRE
Kanyanya, Off Gayaza Road
After Mpererwe
P. O. Box 10443, Kampala
Tel: 041 567 637 Mob: 077 767 637

Appendix 2 B-v Approval of a proposal to collect data from TASO



**The AIDS Support Organisation
TASO (U) Ltd.**

TASO Headquarters, Mulago
P. O. Box 10443, Kampala
Tel: 041 532 580
041 532 581
Fax: 041 541 288
Email: mail@tasouganda.org

January 28, 2004

Dear Robert,

Ref: Research at TASO Mbarara center.

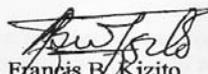
Thank you for taking interest in conducting your Ph D research at TASO Mbarara. You will be required to submit a copy of your final report to TASO before your findings are published.

You will notice that the workload at the center is enormous, and therefore the Research Committee would appreciate if you scheduled your time at the center accordingly.

Please provide a photocopy of the research protocol and the relevant documents to the Manager before you embark on your research work.

Good luck

Yours sincerely


Dr. Francis B. Kizito
Secretary
TASO Research Committee

Cc: Manager
TASO Mbarara

SERVICE CENTRES

TASO MULAGO
Mulago Hospital
P. O. Box 11485, Kampala
Tel: 041 530 034
Mob: 077 430 468

TASO MBALE
Mbale Hospital
P. O. Box 2250, Mbale
Tel: 045 33507
Mob: 077 440 829

TASO MASAKA
Plot 1-19 Kigamba Road
Masaka Hospital
P. O. Box 1679, Masaka
Tel: 0481 20527 Mob: 077 499 988

TASO ENTEBBE
Plot 15-17 Lugard Avenue
P. O. Box 235, Entebbe
Tel: 042 320 030
Mob: 077 617 126

TASO TORORO
Plot 30 Cox Road
P. O. Box 777, Tororo
Tel: 045 45009
Mob: 077 461 207

TASO JINJA
Plot 2-48 Baxi Road
Jinja Hospital
Tel: 043 120 382
Mob: 077 359 942

TASO MBARARA
Off Mbarara-Kabale Road
Mulindwa Road
P. O. Box 1010, Mbarara
Tel: 0485 21323 Mob: 075 693 475

TASO TRAINING CENTRE
Kanyanya, Off Gayaza Road
After Mpererwe
P. O. Box 10443, Kampala
Tel: 041 567 637 Mob: 077 767 637