Building Social Capital in Uganda: The Role of NGOs in Alleviating HIV/AIDS Challenges in Uganda

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Abstract

Social capital is one of the most widely discussed and contested concepts in the social sciences. It has received wide attention from development practitioners, policy makers, and academia. Despite its growing importance for analyzing and explaining social economic and political outcomes, there are few or limited studies that have addressed the issues of the process through social capital is built and its eventual outcomes. As such, there is limited empirical research concerning social capital building and its practice in improving people's health, especially in the context of developing countries. This paper discusses the role of NGOs in mobilising social capital and its effect on HIV/AIDS challenges. A major finding of the study is that the way individuals and groups are connected and interact with each other are important mechanisms for alleviating HIV/AIDS. In this regard, HIV/AIDS NGOs play a central role in the way individuals, groups and communities and state agencies interact is vital for people living with HIV/AIDS and especially for those who are HIV infected. Drawing lessons from Uganda the paper argues and concludes that social capital can be mobilised at different levels; the micro, meso and macro levels and that all these levels are significant in addressing a social phenomenon such as AIDS.

Key words: HIV/AIDS, Social Capital, NGOs, Synergy, Uganda

1.0 Introduction

The impact of Acquired Immunodeficiency Syndrome (AIDS) are well documented. It is registered as one of the major human catastrophes facing the world today,its consequences far reaching socially, economically and politically. The disease[1] is caused by the Human Immunodeficiency Virus (HIV). Different countries have responded differently; some with promising results of success. In Uganda and Thailand successful fight against HIV/AIDS is well recognised. The prevalence of HIV in Uganda, which stood at more than 20% of the adult population in 1991, had been reduced to about 5% by 2001 (Ministry of Health, 2003). In comparison, to southern African countries such as South Africa whose HIV/AIDS prevalence, was about 0.7% in the 1990s, and had increased to about 25% by 2001. This was in disregard of a well developed medical system with a doctor-patient ratio of 56 to 100,000 in South Africa (Parkhurst and Lush 2004: 1918), compared with less than 5 to 100,000 in Uganda (Ainsworth and Teokul 2000: 56), and the high South African per capita GDP of about US$ 2,941 in 2000, compared to Uganda's per capita GDP of about US$ 249 in 2001 (Parkhurst and Lush 2004)[2]. This success largely has depended on the social and interpersonal networks here referred as

[1] In practice AIDS is not a disease, but a condition. People who become infected with HIV lose their immunity and are susceptible to multiple infections. such as diarrhoea, malaria and tuberculosis, as well as non-infectious diseases.

[2] see also Barnett and Whiteside and 2002, Friedman 2000)[2]

social capital, which provide and avenue for information flow and acquisition of HIV/AIDS related knowledge.

Emerging literature such as Allen (2005) is critical of Uganda's success and argues that the success which Uganda claims may not be realistic. That the methods and approaches used in measuring success such as the sentinel surveillance reports are limited by the fact that there are few women who attend antenatal clinics. He also however also attributes the increase in HIV/AIDS infection to the relaxed use of condoms. One may not deny the fact that certain landmarks have been registered in the fight against HIV/AIDS. Uganda has provided main communication avenues through which knowledge about HIV/AIDS can reach people. The personal behavioural strategies, such as personal communication networks are quite significant. (Barnett and Whiteside, 2002). Uganda registered a decline in prevalence from about 30% and in 1990 to around 6.2 in 2000. Thus from Uganda's story there are several lessons to be learned; 1. findings in Uganda demystified the earlier contextual explanations such as witchcraft as the cause of the disease which had dominated community approaches to HIV:AIDS; 2 the findings in Uganda showed that fighting HIV/AIDS goes beyond the medical profession to include the social approaches. This approach is taken up by other countries such as South Africa(Parkhurst and Lush 2004). More over there are emerging theories explaining the new trend: there is relaxation of the use of condoms, the emergence of religious fundamentalists, use of ARVs as an emerging restoration of hope-living with HIV is possible.

This paper discusses the role of NGOs in mobilising social capital and its effect on HIV/AIDS challenges. A major finding of the study is that the way individuals and groups are connected and interact with each other are important mechanisms for alleviating HIV/AIDS. In this regard, HIV/AIDS NGOs play a central role in the way individuals, groups and communities and state agencies interact is vital for people living with HIV/AIDS and especially for those who are HIV infected. Drawing lessons from Uganda the paper argues and concludes that social capital can be mobilised at different levels; the micro, meso and macro levels and that all these levels are significant in addressing a social phenomenon such as AIDS.

2.0 Description of the Research and its Relevance to Social Capital

The paper is based on a study carried out between January and August 2004 on the workings of two non-governmental organizations (NGOs): The Aids Support Organization (TASO) and Post-Test Club/Philly Lutaaya Initiative (PTC/PLI), which are engaged in fighting HIV/AIDS in Uganda. The reason for choosing these two organizations is that they have successfully focused on building social capital by strengthening social relations among their members/clients, groups, the community, government institutions, the private sector and other NGOs.

This study was carried out in the Mbarara District[3] 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 time I collected my data (January to August 2004).

The study employed a variety of research techniques such as interviews, focus group discussions, observations and reviews of government and NGO documents. The respondents were beneficiaries (both HIV/AIDS infected and non-infected) of these NGOs, and government and NGO functionaries. 80 clients/members of TASO mainly infected with HIV/AIDS and 45 members of PTC/PLI-majority of whom were youths were interviewed. Other interviews were held with 10 government officials mainly from the directorate of Health at the Mbarara District.

In examining processes involved in generating and building social capital, I identified key variables important for understanding the level and influence of social capital in the context of my study. We thus, asked the respondents (both HIV/AIDS infected and non-infected) about the kind of people they most often spend time with, the extent to which they can trust members of their own and other organizations and the community, their level of integration in the community, their chief sources of information and their relationships with government officials, members of the community and neighbours. I also asked whether they considered life

[3] 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.

worth living and how confident they felt about living with HIV/AIDS. I also studied the synergy between NGOs, the government and other civil society actors. In the following, I discuss the process of building social capital and synergy between different actors that were crucial to the success Uganda has registered in fighting HIV/AIDS compared with other countries such as South Africa, which is also well endowed with NGOs[4]; But first it is important to understand the concept of social capital.

2.0 What is Social Capital?

Social capital can be understood as the number of social connections which an individual possesses and can be utilised for access to certain benefits. In recent years, the conceptualization and application of social capital have been at the centre of attention and dominated much of the scholarly work in a number of disciplines such as sociology, political science, economics, public health and, more recently, development studies. In the social sciences, the concept has gone through many transformations. From L.J Hanifan (1916), and other scholars such as Jane Jacobs (1965) and Loury (1977) who were among the first people to refer to the concept, to Bourdieu (1983), Coleman (1988) and Putnam 1993, and 2000 formerly opened up the usage of the concept into scholarly works, it is widely used in the social sciences. For some authors, such as Hooghe and Stolle (2003), there might be no need to define the concept social capital anymore in order to discuss it.

In spite of the wider discussions surrounding social capital as a concept, there is a need for every sc holar interested in applying the concept to develop her or his own understanding and boundary of the concept. This study borrows from Bourdieu (1983) conceptualisation of 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 2003: 15) and Putnam's view of social capital as networks and trust and associated norms of reciprocity. Social capital is, therefore, defined here as networks and associated norms of reciprocity and trustworthiness[5] which benefit individuals and communities affected by HIV/AIDS. Woolcock (1998) makes a distinction between three types of social capital – a) bonding, b) bridging, and c) linking social capital, and each type is

[4] See for example, http://www.tac.org.za/

[5] The main emphasis in this study is on interpersonal trust. This measures the extent to which people trust the people they interact with on a regular basis. It increases with face-to-face contacts, and it is important for this study because it facilitates information exchange and can be used as a basis for open discussions about HIV/AIDS in an environment where stigma and social exclusion are high. Therefore, an increasing level of trust is crucial if the impact of HIV/AIDS is to be mitigated.

associated with particular benefits. In my context, social capital is taken to include: a) micro-level relationships between family and kin indicated by regular face-to-face interaction, sharing of goods and services and collective responsibility for taking care of the sick and orphans and for working together with them; b) meso-level relationships between communities and local government officials; and c) macro-level relationships between NGOs, the government and the international community (bilateral and multilateral donors, international NGOs and so on).

This study systematizes social capital into public health research by explaining how different types of social networks affect people's health. By studying the process through which the NGOs of interest in this study generate social capital, the study generates knowledge about the practical value of social capital, the role of these organisations and the contextual aspect for the realisation of social capital benefits for addressing HIV/AIDS, a disease that spans the medical, public health and social environments. In the discussion, I argue that the context of social capital is significant for the understanding of the social capital outcomes. Social capital studies suffer from is the problem of aggregation (Sabatini 2005). The existing country-specific or cross-country studies on the political and economic outcomes of social capital for example, are mainly based on measures of social trust where data are primarily drawn from questionnaire surveys such as the *World Value Survey* or the General Social Survey (see, for example, Putnam 1995, 2000). Such data are mainly collected through surveys where people are asked, "Would you generally agree that most people can be trusted?" Responses to this single question are used to measure people's perception of trust, which is then aggregated to measure social or societal trust at a higher level. But such measurement says nothing about the social and political context in which the measurement was done and as such ignores the historical processes that have led to an increase or decrease in trust (Sabatini 2005). As Fine (2001: 105) argues, "If social capital is context-dependant- and context is highly variable by how, when and whom, then any conclusions are themselves illegitimate as the basis for generalisation to other circumstances". For this study therefore we analyse the circumstances that explain the social capital, the process of social capital building and its consequences in the context of fighting HIV/AIDS. To understand and analyze the processes of social capital building in a particular social context, a different method more appropriate for a particular context is required.

Scholars such as Stolle (2003), have argued that membership to organisations comes from already trusting individuals self selecting themselves to these organisations. The evidence I find runs counter to this argument. Social capital in Uganda has declined and where the

internal social cohesion and networks that used to hold society together, such as family ties, are now on the verge of collapse because of devastating epidemics like HIV/AIDS. The social relations and social support have declined considerably at the individual, family and community levels since the first diagnosis of HIV/AIDS. Because of experiences of stigma, social discrimination and lack of support from families, community and neighbours (Keough 2004; Monico, Tanga, and Nuwagaba 2001), people living with HIV/AIDS had developed distrust of others they come into contact with. What takes place in HIV/AIDS organizations is a process of initiation of members into becoming trusting individuals. These organizations foster trust relations by means of various activities including sensitization and teaching, group formation and community outreach programs.

Based on the above arguments, the functional role of civil society organizations in generating social capital then becomes important. I realise this importance by evaluating recruitment procedures as well as the social capital building process. My findings show that social capital generation involves a process of socialization through regular interactions among organization members. My research revealed that NGOs facilitate the development of relationships of trust between their members/clients, between members and other members of the community including family members, on the one hand, and between members/clients and officials of the organizations, on the other. B

3.0 General Impacts of HIV/AIDS

By the 1990s, HIV/AIDS had been registered as the first global epidemic since the influenza epidemic of 1918–1919 (Barnett and Whiteside 2002: 27). By the end of 2005, 63% of all infected persons were living in Sub-Saharan Africa, and higher figures still of HIV prevalence are recorded for Southern African countries. The years after 2005 however show increasing HIV infection in the countries of the former Soviet Union, particularly Russia, and in India and China (UNAIDS 2006). Mortality figures available for Uganda show that close to one million people had either died or were living with HIV/AIDS by the end of 2001 (UNAIDS 2002b).[6] 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,

[6] There are limited data available on HIV/AIDS trends in Uganda. The Ministry of Health, which is responsible for updating the statistics, still displays the AIDS surveillance report of 2003 on its website (seehttp://www.health.go.ug/hiv.htm).

> 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.[7]

The number of AIDS orphans is equally high, with more than one million orphans registered in Uganda. Apart from the mortality caused by HIV/AIDS, it has also had a serious socio-economic impact, leading to poverty, declining income levels, social exclusion and stigma and a threat to national security. These multiple effects have drawn the attention of many actors, both local and international and both private and public, to the need to fight HIV/AIDS.

NGOs and HIV/AIDS in Uganda

The involvement of NGOs in fighting HIV/AIDS is well recognized by both the government and the international donor community. Having initially encountered scepticism and ambivalence on the part of governments (Hashemi, 1993), NGOs are now increasingly recognized as partners of government in the provision of key services, such as education and health.

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)[8] 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,

> 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

[7] http://www.who.int/whr/2003/chapter3/en/index.html 03/08/06

> 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.

More than one thousand NGOs in Uganda are involved in HIV/AIDS-related activities. The purpose of my research was to map and analyze NGOs' roles in addressing HIV/AIDS challenges. The research maps the process through which NGOs addresses the challenges of HIV/AIDS. Apart from the medical clinics and psychosocial booths the NGOs realise that HIV/AIDS multifaceted impacts cannot be addressed through the application of science and medicine alone. They realise that the social relations- referred to in my research as social capital, is equally important. It is this social relational approach here in this paper referred to as a process of building social capital that I intended to examine, and its influence on HIV/AIDS impacts. The study of NGOs engaged in alleviating HIV/AIDS[9] in Uganda suggests that the building of social capital by NGOs in order to mitigate the impact of HIV/AIDS may shed new light on new approaches to dealing with a disease such as HIV/AIDS that has transcended the medical profession.

3.2 The Role of NGOs in Alleviating HIV/AIDS in Uganda

The interest of civil society organizations in fighting HIV/AIDS follows on from their long involvement in development and from the more recent recognition of their role by both governments and the international donor community. Over the years, NGOs have gone from strength to strength and are now frequently invited to participate in the policy-making process in various aspects of development including HIV/AIDS. The World Bank, for example, has recommended that countries wishing to access funding from the global fund to fight HIV/AIDS (as well as malaria and tuberculosis) should form Country Coordinated Mechanisms (CCM) in which NGOs would play a crucial part (Mohga 2002). Apart from NGOs' general interest in alleviating HIV/AIDS, their growing involvement in this issue, especially in developing countries, has grown out of several factors, including inadequate provision of health and related services by governments and a lack of social support from the community and family members for people with HIV/AIDS.

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

[9] AIDS - Acquired Immunodeficiency Syndrome, HIV - Human Immunodeficiency Virus.

NGOs have thus played an important role in fighting HIV/AIDS at the individual, family and community levels and have even influenced policy at the national level. The 2004 UNAIDS report in support of the role of civil society organizations points out that

> "civil society organizations often have innovative approaches to the epidemic, and can channel funds to communities, augment state service delivery, and monitor national government policies…at the community level, governments' administrative procedures must be flexible enough to include NGOs" (UNAIDS 2004a: 157-58).

AIDS is caused by HIV. However, its spread, especially in Sub-Saharan Africa, may be accounted for by the social, political and economic environments of the various communities and countries. The role of gender, the political situation in these countries and poverty are some of the explanatory variables for why HIV has spread so widely and why its impact has been so devastating (Barnett and Whiteside 2002).[10] These conditions have made the countries involved take similar approaches to combating the disease, with particular emphasis on prevention. But the results are quite distinct with regard to HIV prevalence in these countries. As earlier pointed out compared to South Africa, Uganda has been quite effective in controlling the spread of HIV. In both countries there is the existence of robust and dynamic civil society groups, such as Treatment Action Campaign (TAC) in South Africa, but their effect in alleviating HIV/AIDS are different. In the discussion that follow I discuss the way NGOs have facilitated the growth of social capital and how they have addressed the challenges of HIV/AIDS.

The process of building social capital involves multiple and multilevel synergies in which NGOs and state systems play a crucial role. Synergies at the micro-level take place between individuals, families, communities, groups and NGOs as well as between local government and other NGOs. At the meso level between district officials and NGOs, and at the macro level between state institutions, multilateral and bilateral donor organizations, international NGOs, pharmaceutical companies and think tanks. These synergies criss-cross organizational forms and geographical boundaries.

[10] Toney Barnet and Allan Whiteside's work is quite significant because it examines the social, economic and political reasons for the spread of HIV/AIDS in Sub-Saharan Africa. It drew our attention to the policy responses from a wide range of countries, including those outside Africa such as Singapore.

Strengthening Inter-personal Relations

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 1, below.

Table 1, 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 (a will be discussed in the next section), as well as serving to increase trust and access to knowledge regarding cause, transmission and mitigation of HIV/AIDS.

The above findings demonstrate that the two organisations TASO and PTC/PLI are 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).

The importance of communities and families as safety nets for people with HIV/AIDS is widely recognised[11]. 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 by HIV/AIDS need to be mended if HIV/AIDS intervention is to be successful. Building harmonious relations between community members and HIV/AIDS infected persons is the way forward for fighting HIV/AIDS. 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)

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 2 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 2, 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

[11] 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).

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.

Community level interventions

At the community level, NGOs have organized and mobilized those infected with HIV/AIDS, their families and the community in general. These organizations have made an enormous contribution to mitigating the impact of AIDS, for example, in counselling, education and sensitization, provision of quality health care and facilitation of regular interaction. These activities have all been significant in combating stigmatization and social exclusion. Moreover, by establishing forums for interaction, the NGOs have provided sources of social support and information for various groups of people.

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 3 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 3 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. Such relations constitute a positive impact that the NGOs have on HIV/AIDS. The personal relationships which developed among Ugandans, had significant effects on the HIV/AIDS prevalence. Through personal communication with friends and neighbour, knowledge about HIV/AIDS is acquired (Barnett 2002). It is thanks to the activities of organisations such as TASO that these relationships and modes of personal communication were established.

The role of state

One must bear in mind that NGOs are operating in an environment where external resources are necessary for success and where there are a large number and variety of actors. Families need support, they need incomes and medicine for the sick and they need information.

Therefore, their roles require external connections and linkages with other actors. Here the state has a particularly crucial role to play, not only in funding local community organizations but also in linking the civil society organizations to the international donor community. The state is a facilitator of community participation; it formulates laws and regulations that constrain and facilitate action. In a state of lawlessness, and in a situation where state structures have broken down, shared values and norms of reciprocity and trust may not develop. The likelihood of regular interaction among individuals and groups thus becomes limited. A state of uncertainty about the next course of action may limit interaction and the emergence of relationships of reciprocity and trust (Lister and Nyamugasira 2003). Therefore, the government and its institutions have been important in the way NGOs operate and the success registered in the fight against HIV/AIDS in Uganda.

Among other roles, the government has played an essential role on the international level; for example, in mobilizing funds to facilitate activities to combat and alleviate HIV/AIDS and in negotiating with drugs companies to reduce the prices of antiretroviral drugs. This complements the role NGOs play in their grass-roots activities.

In addition, 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), state health care system remain a major referral point for difficult cases and palliative care for HIV/AIDS patients. In an interview with HIV patients of TASO they said that

> TASO does not have an in-patient unit. We are referred to government hospital when we get seriously ill. 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. Their services reassures us of life. (Interview with respondents)

Apart from referring clients to government hospitals, NGOs work hand-in-hand with government in the delivery of services. 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. The involvement of 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. 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 different activities of the organisations of oitrstudy and the roles of government have had positive conseques on the effects of HIV/AIDS in Uganda. In the following discussion we present the consequences of social capital with regard to impacts of HIV/AIDS.

Outcomes of Social Capital

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 generally[12].

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

[12] see http://www.avert.org/aidsuganda.htm 15/12/05

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 District[13])

> 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.

As a result of the interactive meetings between members/clients of the organisations, they have learned to cope with HIV/AIDS. Through regular contacts and sharing their experiences with fellow members, and by handling issues related to stigma such as lack of social support due to nondisclosure of their HIV/AIDS status, members of TASO, for example, are now receiving more support from their neighbours, family members and the community. This is contrary to Muyinda et al (1997)'s past finding that there were high levels of stigma and discrimination.

In the study it was found that people who joined the Post Test Club, an NGO formed to cater for those who had undergone an HIV test were not required to share their HIV/AIDS status with others since this issue was considered a personal matter (AIC 2003a). However, it was found that 61% members of Post Test Club/Philly Lutaaya Initiative (PTC/PLI) had disclosed their sero-status to others (Muriisa 2007: 237). This indicates a high level of trust and improved relations between members who previously did not know each other or were not aware of each other's HIV/AIDS status.

[13] 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.

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.

Studies concerning HIV/AIDS interventions show that interactive discussions among people living with HIV/AIDS and role plays and are significant **(Kayaze)**. 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 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 fingure-pointed out as imoral beings and social

deviands[14], or being segregated and denied social support from their family members. 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 Surveilance 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 by 2003.

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. It has to be emphasised that the social, economic and political environment has serious implications for the spread of HIV and therefore needs to tackled for any effective HIV/AIDS mitigation. Thus beyond prevention, organisations involve their clients in other discussions. 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. 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.

[14] Religious fundumentarists for example have emphasised that the people infected with HIV/AIDS are immoral, and sinful.

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.

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).

7.0 Conclusions

This study aimed at analysing the way social capital is mobilised to alleviate a social phenomenon. The study discusses the methods of mobilising social capital in a context where emerging social phenomenon such as HIV/AIDS destroyed the existing social relations especially at the community level. The study explored the relationship between the context of HIV/AIDS: effects, pre-HIV/AIDS social setup, and the processes involved in alleviating this social phenomenon. The study finds that social capital can be mobilised at micro, meso and macro levels and all the levels are significant in addressing HIV/AIDS in Uganda. In considering the role of NGOs and state-society synergy in building social capital in Uganda, my investigation shows that the level of social capital in an environment depends on such processes. In Uganda, regular face-to-face interaction, various synergies between the state and society were found to be particularly important. The study finds that such interactions are important in addressing HIV/AIDS challenges.

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