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## Addressing HIV/AIDS challenges in Uganda: does social capital generation by NGOs matter?

Roberts Kabeba Muriisa, Ishtiaq Jamil

### Abstract

HIV/AIDS has had devastating impacts in many countries, Uganda in particular. However, Uganda is depicted as one of the most successful countries in fighting HIV/AIDS. Among others, Uganda's success story is attributed to the open general environment which allows open discussions surrounding HIV/AIDS when other countries such as South Africa and Kenya denied the existence of the disease in their countries. In addition, the success is attributed to the policy which allowed many actors to participate in the fight against the disease. The primary focus of this article is to map the process of social capital generation by NGOs and how social capital benefits enhance mitigation of HIV/AIDS challenges in Uganda. The key to social capital is nurturing relationships. In this regard, HIV/AIDS NGOs play a central role in the way individuals, groups and communities interact, and how various kinds of social relations are forged with people living with HIV/AIDS and especially for those who are HIV infected. NGOs' success in reducing the number of HIV/AIDS cases in Uganda is based on their abilities to generate social capital. This involves inclusion and building social networks and empowerment at the individual and community levels, and disseminating information to reduce social stigma as well as discrimination. We used a mixed-method strategy to collect data for this study. We used a structured questionnaire having quantitative and qualitative question sets which focused on different social capital measurement indicators. We used observations and in-depth face-to-face interviews. A major finding of the study is that the ways individuals and groups are connected and interact with each other are important mechanisms for alleviating HIV/AIDS challenges in Uganda.

**Keywords:** HIV/AIDS, social capital, NGOs, Uganda.

### Résumé

Le VIH/SIDA a eu des effets dévastateurs dans de nombreux pays et en Ouganda en particulier. L'Ouganda, cependant, est dépeint comme l'un des pays les plus performants en matière de lutte contre le VIH/SIDA. L'une des raisons de ce succès est attribuée à l'environnement ouvert dans le pays qui a permis des discussions avec un esprit ouvert sur la question du VIH/SIDA. Dans d'autres pays comme en Afrique du Sud et au Kenya, l'existence de cette maladie était au contraire niée. En outre, ce succès est attribué à la politique qui a favorisé la participation de plusieurs acteurs à la lutte contre la maladie. L'objectif principal de cet article est d'établir le processus de production de capital social par les ONG, et de montrer comment les bénéfices du capital social favorisent l'atténuation des problèmes liés au VIH/SIDA en Ouganda. La clé du capital social réside dans l'entretien des relations sociales. À cet égard, les ONG s'occupant de la question du VIH/SIDA jouent un rôle central dans la façon dont les individus, les groupes et les communautés interagissent, et dans la manière par laquelle les différents types de relations sociales se nouent pour les personnes qui côtoient le VIH/SIDA, et surtout pour celles qui sont infectées par le VIH. La réussite des ONG dans la réduction du nombre de cas de VIH/SIDA en Ouganda est basée sur leur capacité à générer du capital social. Cela implique l'inclusion et le renforcement des réseaux sociaux, l'autonomisation aux niveaux individuel et communautaire, et la diffusion de l'information pour réduire la stigmatisation sociale ainsi que la discrimination. Pour cette étude, nous avons utilisé comme stratégie une méthode mixte de collecte de données. Nous avons utilisé un questionnaire structuré ayant des séries de questions quantitatives et qualitatives qui ont été axés sur différents indicateurs de mesure du capital social. Nous avons utilisé des observations et des entretiens poussés en face-à-face. Une des principales conclusions de l'étude est que la façon dont les individus et les groupes sont liés et interagissent les uns avec les autres sont d'importants mécanismes pour atténuer les défis liés à la question du VIH/SIDA en Ouganda.

**Mots clés:** VIH/SIDA, capital social, ONGs, Ouganda.

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## Introduction

In Uganda the successful fight against HIV/AIDS is well recognised. The success in Uganda, among others, may be attributed to the engagement of community-based organisations and non-governmental organisations (NGOs) such as The AIDS Support Organisation (TASO) and the Post-Test Club/Philly Lutaaya Initiatives (PTC/PLI) in building networks in local communities to disseminate information to fight the disease (see for example Muriisa (2009)). The empirical evidence showing a process of network building, however, is lacking, although studies such as Low-Beer and Stoneburner (2004b) argue that Uganda's success in fighting HIV/AIDS was due to the social communication networks which were built in Uganda. We argue in this paper that an environment which allows communication was made possible because of the involvement of NGOs in creating social communication networks which for purposes of this paper we refer to as social capital.

HIV/AIDS is registered as one of the major human catastrophes facing the world today and its consequences are far-reaching, affecting nations socially, economically and politically. By the 1990s, HIV/AIDS had been registered as the first global epidemic since the influenza epidemic of 1918 - 1919 (Barnett & Whiteside, 2002). By the end of 2005, 63% of all infected persons were living in sub-Saharan Africa, and higher figures 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, 2006a). 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.*<sup>1</sup>

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).<sup>2</sup> The number of AIDS orphans is equally high, with more than 1 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. In order to address the menace of this deadly pandemic, it is now realised that the problem needs a multifaceted approach and cannot be addressed through the application of science and medicine alone. Different countries have responded differently to HIV/AIDS, some with promising results of success while in others its impacts and spread are still a challenge. Uganda's 'all-inclusive-open policy' to fight HIV/AIDS allows and recognises the functional role of NGOs. More than 1 000 NGOs in Uganda are involved in HIV/AIDS-related activities (Muriisa, 2009). But compared with other countries such as South Africa, which are also well-endowed with NGOs,<sup>3</sup> Uganda has been hailed as a rare success story in the fight against HIV and AIDS.

The paper maps the process through which NGOs address HIV/AIDS challenges. In particular, the paper discusses the process of generating social capital in Uganda, which is considered as one of the important factors that contributed to Uganda's success story (Low-Beer & Stoneburner, 2004b; Muriisa, 2009). Studies such as Barnett and Whiteside (2002) argue that the personal behavioural strategies, such as personal communication networks are quite significant for information sharing among friends and families. Pronyk (2002) suggests that strengthening the stock of social capital in South African communities could mitigate HIV transmission and impact. He argues that social networks may help to diffuse health-related information, to shape community norms and show-case positive role-modelling behaviours, and to provide members with material, emotional and social support to ensure a measure of stability and, therefore, mitigate high-risk behaviours. Creation of information diffusion avenues has been the critical role of civil society organisations such as NGOs to which we focus our paper.

The purpose of our research therefore, is to map and analyse NGOs' roles in addressing HIV/AIDS challenges through social capital building. Mapping social capital generation process, therefore, may shed new light on how social capital is applied when dealing with HIV/AIDS. The particular NGOs we investigated focus on building social relations and other forms of networks which we presume are beneficial for fighting HIV/AIDS. By studying the process through which TASO and the PTC/PLI create 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 certain phenomena such as HIV/AIDS, a disease that spans across the medical and public health professions, the social, economic and political spheres.

## Description of research methods

The paper is based on a study carried out between January and August 2004<sup>4</sup> on the workings of two NGOs: TASO and PTC/PLI, which are engaged in fighting HIV/AIDS in Uganda. The reason for choosing these two organisations is that they have successfully focused on building social relations among their members/clients, groups, the community, government institutions, the private sector and other NGOs, which in turn has led to the accumulation of social capital. The study was carried out in the district of Mbarara,<sup>5</sup> situated in 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 in keeping with the marked decline in the HIV/AIDS prevalence rate that was registered in Uganda where the HIV prevalence rate declined from about 18% in 1991 to about 6.2% at the end of 2001 (MoH, 2003: 9). The data regarding HIV/AIDS prevalence which we use in this study are from 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 when we collected data (January - August 2004).

## Data sources and data collection methods

We obtained secondary data from NGO reports, government documents and scholarly works such as textbooks and journals. Primary data were collected using mixed research methods. For this purpose, we administered the questionnaires to respondents

**Table 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
AIDS community workers	10	-			10
Members of communities visited by drama groups				6	6
Total	100	52	4	6	162

Source: Field notes.

who were purposively selected at the organisation service centres. The quantitative and qualitative data were gathered concurrently. We used a structured questionnaire having quantitative and qualitative question sets which were focusing on different social capital measurement indicators.<sup>6,7</sup> While most questions asked were structured, in order to gain a general understanding of the whole situation, some of the structured questions were followed-up with more probing questions. The probing questions allowed respondents to construct meaning from their own perspectives and experiences, thus making us gain a deeper understanding of the phenomenon. This generated more ideas and evidence about the social capital generation and how they benefit from it. We used qualitative observations to observe the different activities taking place in organisations. We used in-depth interviews to collect data from different groups of people. In-depth interviews were very helpful since they allowed people to tell their own story of how they benefited from the groups they belong to and different social relations they have. In-depth face-to-face interviews were conducted 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 was 162: TASO 80 clients/members 10 officials, 10 AIDS Community Workers (ACWs); PTC/PLI 45 members, 7 officials and AIDS Information Centre (AIC) workers; and 4 government officials. Tables 1 and 2 provide placement and profile of respondents for the study.

From Table 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 with 35% male (TASO 2003a). Likewise, at the Mbarara TASO 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.

**Table 2. Profile of respondents (beneficiaries) of HIV/AIDS organisations**

	Members/Clients of TASO (%)	Members of PTC/PLI (%)
Gender		
Male	30	36
Female	70	64
Age		
15 - 24	4	43
25 - 34	33	34
35 - 44	39	18
45 - 54	19	5
55 and above	5	-
HIV status		
Positive	90	11
Negative	4	82
Don't know	6	7
Total	N=80	N=44

Source: Field notes.

Another difference was that while 90% of TASO respondents were HIV/AIDS positive, only 11% of PTC/PLI respondents were. The respondents were beneficiaries (both HIV/AIDS-infected and non-infected) of these NGOs, and government and NGO functionaries involving 80 clients/members of TASO who were mainly infected with HIV/AIDS and 44 members of PTC/PLI of whom the majority were youths and HIV negative. Both HIV-positive and -negative members belonging to the two HIV/AIDS NGOs are likely to illustrate how NGOs build solidarity through social inclusion and network, and how these organisations impact on their members' lives through education and dissemination of information. In the following sections we conceptualise social capital followed by a discussion on the process of generating social capital and how it impacts on organisations' members' lives.

### Data analysis methods

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 data. To obtain a proper understanding of the way NGOs build social capital and its benefits in fighting HIV/AIDS, we 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 organisation 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 were analysed by linking them to the different social networks and relations built in each organisation, and then the two organisations were compared. This comparison of organisations widens the scope for making theoretical and empirical generalisations, which we make in this paper.

### What is social capital?

As one of the trendiest contemporary terms, the conceptualisation 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 (Farr, 2004). In the social sciences, the concept has gone through many transformations. Among the first to refer to the concept were Bourdieu (1983) and Coleman (1988), but it was Putnam (1993, 2000) who made the concept popular. After Putnam's use of the term to explain trust, functioning of democracy and civic associationism, it has now spread like a bushfire and is widely used in many contexts to such phenomena as economic development and efficiency (Fukuyama, 1995), co-operative behaviour (Askvik & Nelleke, 2005) and co-ordinated action (Adler & Kwon, 2002).

Whatever its use in different disciplines, and both as dependent and independent variables, the central thesis of social capital is 'relationships' (Field, 2003). Through common values, mutual reciprocity, a network of associations and trust, social capital binds people together to achieve goals which otherwise would have been difficult to achieve (Farr, 2004). Therefore relationships matter and work as an asset to easily resolve conflicts and overcome the problems of collective action (Hooghe & Stolle, 2003). The more the relationships people have and share common norms, values, and mindset, the greater is the degree of social capital.

In spite of the fact that we all seem to know the benefits of social capital in communities, such as enhancing democratic governance, participation and inclusion in policy making of those hitherto excluded, and acceptance and tolerance for others, how it is generated is an area where there is scant research (Hooghe & Stolle, 2003). We know little about how social capital is built, sustained and nurtured in societies, communities and groups. According to Putnam (1993), social capital follows a path dependency model, meaning that certain nations as a result of civic tradition have more stocks of social capital compared with others which are 'characterized by weak and bridging social interactions' (Hooghe & Stolle, 2003); (Bebbington & Perreault, 1999). For example, the Scandinavian countries score high on social trust as measured in the World Value Study and other similar surveys (Rothstein, 2004). In contrast, some African countries may be said to be low on social capital, given the dysfunctional nature of state and poor

performance of public institutions, making it difficult for them to achieve shared goals (Coullier & Gunning, 1999). This means that if social capital is path dependent, then those nations which score low on trust, norms of reciprocity and civic associationism may find it difficult to develop a network of relations to achieve co-ordinated action. This is sad news for a nation which has historically a low level of social capital. However, Krishna (2002) asserts that social capital can be generated and be made active through informal relations. In a similar fashion we argue in this paper that social capital can be generated, and in this regard we examine the process of generating social networks and their relative importance in mitigating HIV spread and impact.

This study borrows from Putnam's view of social capital as networks and associated norms and trust (Putnam, 2000). These networks and associated norms of reciprocity and trustworthiness benefit individuals and communities affected by HIV/AIDS. In the Ugandan context and with respect to HIV/AIDS, social capital focuses mainly on micro-level relationships between family and kin as indicated by regular face-to-face interaction, the sharing of goods and services and the collective responsibility for taking care of the sick and orphans and for working together with them.

With regard to social capital generation, NGOs as argued by scholars are seen as 'catalysts of social capital' (Barr, Fafchamps, & Owens, 2005). Lewis & Wallace (2000) argue that NGOs are regarded as important actors in generating social capital in addressing problems related to livelihoods and to the linking of policy responses at local, national and regional levels. This study applies social capital to public health by explaining how it affects people's health in general and mitigates HIV/AIDS menace in particular.

### The context of social capital

In our discussion we argue that the context within which social capital is generated is significant. For this study we therefore analyse the circumstances that explain the need of social capital, the process of social capital building and its subsequent benefits in fighting HIV/AIDS.

Social networks at community and family levels have long existed in Uganda and have played an important role in the way people live. Families, neighbours, friends and relatives provide material and moral support, which can be drawn upon when individuals are hit by crises (Woolcock, 2001). In Uganda this is particularly true, since families provide an important form of social security (Kayazze, 2002; Marshall & Keough, 2004; Tumwesigye, 2003). Marshall & Keough (2004) have argued that the deep-rooted kinship system that exists in Africa - the extended family networks of aunts and uncles, cousins and grandparents - 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.

The increasing number of people infected with HIV led to a decline of the social support existing in the family system. There was a disruption of social unity and of interpersonal relationships involving people infected with HIV/AIDS or suspected of being infected. The social relationships became characterised by discrimination. The number of orphans increased, while resources dwindled and could not be stretched to support any additional

member (Nyonyintono, Gilborn, Kabumbuli, & Jaqwe-Wadda, 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 & Whiteside, 2002). Further, because of experiences of stigma, social discrimination and lack of support from families, community and neighbours (Keough, 2004; Monico, Tanga, & Nuwagaba, 2001), people living with HIV/AIDS developed distrust of others they come into contact with.

Based on the above arguments, the functional role of civil society organisations in generating social capital then becomes important. We realise this importance by analysing the social capital building process. Our findings show that social capital generation involves a process of socialisation through regular interactions among organisation members. What takes place in HIV/AIDS organisations is a process of initiation of members into becoming trusting individuals. Our research reveals 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 organisations on the other.

### Social capital generation and the role of NGOs in alleviating HIV/AIDS in Uganda

This section discusses the findings regarding how social capital is generated by NGOs in their fight against HIV/AIDS in Uganda. Social capital is built by forming close relationships between clients/members of NGOs and those in the community who are either infected with HIV/AIDS or not. The purpose is to map the process through which networks are built, sustained and nurtured, which in turn would mitigate HIV/AIDS. In this regard, our focus was mainly on the following: a) NGOs' involvement in HIV/AIDS issues and how they address these issues through building synergies at the micro-level between individuals, families, groups and communities, and b) what are the benefits of social capital? In this regard, we focus on the extent to which social capital mitigates HIV/AIDS challenges.

Our findings are presented separately for TASO and PTC/PLI because of the differences in HIV status among the members of these organisations. The rationale behind this is that since the members of TASO are mostly HIV positive while most of the members of PTC/PLI are HIV negative, this status may influence the relationships between members of these organisations. TASO members are expected to be closer to each other than PTC/PLI members because HIV-positive members are likely to be more stigmatised, socially excluded and boycotted than HIV-negative members, hence more dependence of HIV-positive members on TASO for survival. Thus, TASO members are expected to have more bonding relationships compared with PTC/PLI members. In other words, the comparison may highlight whether perceptions of members toward HIV/AIDS organisations vary according to their HIV status.

### NGOs and HIV/AIDS: strengthening interpersonal relations among members

Relationships are the building block of social capital. Building interpersonal networks involves confidence building and this is done through regular face-to-face contact. According to Hall (1999) this promotes norms of reciprocity and trustworthiness of the individuals, and builds confidence. 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 the 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 differences 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.

We asked respondents about the frequency of their interactions with their organisations and participation in organisational decision-making and activities (formal meetings). Results are presented in Tables 3 and 4.

From Table 3 it is evident that over 90% of both TASO and PTC/PLI members perceive that their relationships with members and staff of their respective organisations are good. The extent of close relationship is an indication that both members and organisation staff have developed a close-knit network and relationships within the organisation. 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), we 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).

**Table 3. Relationships members have with other members and with the organisation's staff (frequency distribution)\***

	% who answered 'good' and 'very good relationship'	
	TASO	PTC/PLI
Relationships among members of the organisation	94	91
Relationship with staff of the organisation	95	93
	N=79	N=44

\*Respondents were asked about the nature of their relationship with members and staff of their organisations. The answer alternatives varied from 'very poor', 'poor', 'neither poor nor good', 'good' to 'very good'.

### Strengthening relations at community and family level

The importance of communities and families as safety nets for people with HIV/AIDS is widely recognised. 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.)*

We asked respondents how often they meet members of their organisations, family and friends and their neighbours. It was revealed that the meetings among these categories of people were frequent almost occurring weekly. Table 4 shows how often meetings between members of TASO and PTC/PLI with different people occur. Respondents were asked how often they meet members of their organisation, their family and neighbours.

From Table 4 it is evident that 88% of TASO members, compared with 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. It was also revealed that HIV/AIDS peer groups are already being formed in schools and members 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, as well as serving to increase trust and access to knowledge regarding cause, transmission and mitigation of HIV/AIDS. The meetings are inclusive and members of these organisations do not feel isolated but are 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. For people with HIV/AIDS interaction results in communication about HIV/AIDS (Low-Beer & Stoneburner, 2004a, 2004b; 2004c), and this builds their confidence in living with HIV/AIDS.

At 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 each other 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 and informal meetings at organisation centres and outreach programmes often lead to the development of close and friendly relationships among members. Table 5 presents correlations between the computed index for formal and informal meetings and time spent with other members, the number of close friends one has, participation in decision making, and participation in organisation activities.

The findings in Table 5 indicate a positive correlation between meetings of members with a number of other variables which also reveal positive impacts on variables such as getting friends and nurturing friendship, time they spend with other members of the organisations, and participating in the organisations' decision making and activities.

Given the above analysis, we wanted to find out the extent to which their relations with relatives and neighbours are influenced by their organisations through the above meetings. We present frequency distributions on variables which mapped this influence. Table 6 presents the findings. The question 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

**Table 4. 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

**Table 5. Correlations (Pearson's R) between the index of meeting (formal + informal) with time spent with other members, close friends one has, and participation in organisations' decision making and activities**

	<b>Index of meeting (formal + informal) Never - Every day</b>
Time spent with other members Never - Frequently	0.27**
Number of close friends one has None - More than two friends	0.15*
Participation in decision making Small - Large	0.23**
Participation in organisation activities Never - Several times a month	0.40**

\*\* Correlation is significant at the 0.01 level (2-tailed)  
\* Correlation is significant at the 0.05 level (2-tailed).

**Table 6. Organisation's influence on the relationships respondents have with relatives and neighbours (frequency distribution)**

<b>Type of persons</b>	<b>TASO large extent (% response)</b>	<b>PTC/PLI large extent (% response)</b>
Neighbours	88%	69%
Relatives	85%	76%
	N=78	N=43

with different people: neighbours, relatives, family members, members of the organisation to which you belong.

The findings reveal that memberships in organisations matter in nurturing relationships with neighbours, relatives and members of other organisations. TASO and PTC/PLI do play a major role in helping their members come in close contacts not only with the community but with persons who belong to different organisations.

In addition, we asked respondents whether their level of belonging to the local community has improved since TASO and PTC/PLI started operating. The answer alternatives varied on a 5-point scale from 'small extent' to 'large extent'. The findings revealed that 97% of TASO members and 98% of PTC/PLI members answered that their community belonging has improved to a large and very large extent after these organisations started operating in their communities.

### Confidence in NGOs

Social capital is built on the basis of trust and confidence people have in institutions. In this regard, it is vital that members trust their own organisation, take pride in it and perceive that its level of performance and honesty of its staff are high compared with other organisations working at the local level. We asked the respondents about confidence and trust they have in their own organisation. The results are given in Table 7.

**Table 7. Respondents' opinion about the pride they have in the organisation and their desire to continue as members (% distribution)**

	<b>% who answered 'Yes'</b>	
	<b>TASO</b>	<b>PTC/PLI</b>
Trust in one's own organisation	94	86
Trust in neighbourhood	50	48
	N=80	N=44

As evident in the findings in Table 7, members trust their organisations much more than their neighbourhood. We further asked respondents whether they would like to continue their membership with the organisation. 99% of TASO members and 100% of PTC/PLI members answered in the affirmative that they would like to continue their membership and take great pride in their membership of these organisations.

We asked respondents to evaluate the performance of these organisations and the trustworthiness of its staff compared with other institutions and actors operating at the local level (Table 8). The question that was asked: 'Using a 5-point scale, determine the level of efficiency of the institutions that are listed below'. The answer alternatives varied from 'very inefficient', 'inefficient', 'efficient', to 'very efficient'.

We collapsed the responses into two categories - efficient and inefficient - during data analysis. The respondents evaluated HIV/AIDS organisations to be very efficient compared with the traditional service delivery institutions at the local level such as the local government, police, judiciary and even government schools and hospitals. The majority members of TASO and PTC/PLI consider these traditional organisations operating at the local level to be largely inefficient. The members of PTC/PLI are generally more sceptical of these organisations compared with TASO members. We also asked the respondents how they perceive the trustworthiness of officials working in these organisations (Table 9). The question that was asked: 'In your organisation, how honest are the following agency officials. Please rate them on a scale from "very dishonest", "dishonest", "mostly honest", to "very honest"'. We collapsed these values into 'honest' and 'dishonest' during analysis of data.

Again we observe a very positive attitude among members to functionaries of HIV/AIDS organisations compared with other public officials operating at the local level. The members of PTC/PLI are more negative to these officials than TASO members. These findings do indicate the close relationship that NGOs have built with their members which are perceived to be more efficient and honest in the delivery of services compared with the public organisations which have failed to gain the same level of confidence of the local communities.

Having mapped the roles both TASO and PTC/PLI play in building social capital in local communities through inclusion, increased participation in organisation, decision making and activities, and strengthening members' networks with relatives and neighbours, we now analyse the benefits of social capital with regard to fighting HIV/AIDS.

**Table 8. Performance of different institutions operating at the local level (% distribution)**

	% response (efficient)		% response (inefficient)	
	TASO	PTC/PLI	TASO	PTC/PLI
Local government officials	38	26	62	74
Local council members	39	14	61	86
Government hospital officials	44	17	56	83
Government school officials	45	33	55	67
Police officials	35	21	65	79
Judiciary officials	33	22	67	78
Functionaries of NGOs dealing with HIV/AIDS	85	88	15	12
	N=80	N=43	N=80	N=43

**Table 9. Trustworthiness of officials working in institutions at the local level (% distribution)**

	% response honest		% response dishonest	
	TASO	PTC/PLI	TASO	PTC/PLI
Local government officials	44	20	56	80
Local council members	46	17	54	83
Government hospital officials	60	49	40	51
Government school officials	77	53	23	47
Police officials	46	18	54	82
Judiciary officials	33	30	67	70
Functionaries of NGOs dealing with HIV/AIDS	96	85	4	15
	N=80	N=43	N=80	N=43

## Benefits of social capital

### Knowledge sharing and dissemination about HIV/AIDS

In their interactions and in group meetings, members discuss various issues, including sex and sexuality, which were formally regarded as personal and could not be discussed in public (Putzel, 2003). Frank and honest discussions of sexual subjects that had previously been considered a taboo increased the high level of AIDS awareness among people generally.

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. 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 finger-pointed out as immoral and social deviants, or being segregated and denied social support by their family members.

The general lack of information about the transmission mechanisms increased levels of discrimination and stigmatisation of people infected or suspected to be HIV infected. For example, in 1997 Muyinda *et al.* (1997) found that people still feared that they could catch AIDS through normal social contact and that AIDS could be contracted through the sharing of utensils, clothes, meals and even through breathing the same air as those with the disease. This finding showed an information gap regarding HIV/AIDS and it is this gap that fuelled stigmatisation. The findings in this study reveal that the gap has been filled by the NGOs which have initiated open discussions about the disease. We investigated the extent to which HIV/AIDS-related issues with regard to cause/spread of HIV and coping strategies are discussed. Results are presented in Table 10. The following question was 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?' (The nature of the intervention was probed.) Respondents' answers were either 'always', 'often' or 'never'.

The results are overwhelming in the sense that almost all members in TASO and around two-thirds to three-quarters in PTC/PLI are of the opinion that they always discuss the causes of HIV/AIDS, how to prevent it, how to cope with it and how to live with other people. This means that both HIV-positive members in TASO and HIV-negative members in PTC/PLI frequently talk about these issues. The main purpose of such talks and open discussions is to bring changes in the lifestyle of the members and in the community that would prevent them from being infected by HIV/AIDS.

Through interaction, members and clients share personal experiences. Thus clients of TASO and PTC are well informed about the suffering HIV/AIDS inflicts on people. At the 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 wastage of time and 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, 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 HIV test results showing 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 in Mbarara, whom we 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.<sup>7</sup>)

*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.)

We asked members of both TASO and PTC/PLI how often group discussions tackled issues related to cause, mitigation and prevention of HIV/AIDS (Table 10). Such talks contribute to the awareness of how to manage the various impacts of the disease, such as stress, nutrition and HIV spread. As already mentioned, people with HIV/AIDS alleviate their stress by joining groups. With regard to nutrition, the respondents said that they had been taught that they should have a balanced diet, with a limited intake of rich food. In addition to paying attention to their nutrition, they said that they had been encouraged to work out frequently and get involved in some physical 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), whose finding was that there were high levels of stigma and discrimination and limited social support for people with HIV/AIDS.

In this study it was found that people who joined the PTC/PLI were not required to share their HIV/AIDS status with others since this issue was considered a personal matter (AIC, 2003). However, it was found that 61% members of PTC/PLI had disclosed their sero-status to others (Muriisa, 2009). 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.

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 or re-infection of individuals with HIV, and accelerated immunity loss by AIDS patients and eventual death. These findings agree with Asingwire *et al.* (2003), who point out that ‘today HIV/AIDS no longer carries the level of stigma and discrimination as in the past’.

### NGOs' influence in changing lifestyles of members

Increased knowledge about HIV/AIDS 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. Studies concerning HIV/AIDS interventions show that interactive discussions among people living with HIV/AIDS and role-plays are significant. 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 sensitise participants to personal risk. Often, HIV/AIDS organisations have video tapes about HIV/AIDS which members watch during their in-group sessions. These videos supplement the knowledge which individuals acquire through in-group interactions of people who have died of HIV/AIDS and/or those living with HIV/AIDS.

The knowledge that someone has HIV/AIDS or has recently died of it generates fear of contracting the disease. Low-Ber

**Table 10. Knowledge dissemination by HIV/AIDS organisations about the disease**

Organisations discuss the following topics	Response rate (% of clients/members)						Total %
	Always		Often		Never		
	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 cope with HIV/AIDS and to live with other people	99	79		21	1		100
	N=79	N=44	N=79	N=44	N=79	N=44	

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 with 68 - 71% in Kenya, Malawi and Zambia. The *Ministry of Health HIV/AIDS Surveillance Report 2003* found that 97% of married women in Uganda 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 confirming that behavioural change in Uganda had been achieved by 2003.

To further pursue to what extent NGOs are able to change the lifestyle patterns of their members and overcome problems associated with HIV/AIDS such as stigma, exclusion, wife sharing and widow inheritance, we asked the respondents about these issues. The findings are presented in Table 11. The questions that was asked: 'How would you rate the impact of NGOs (TASO or PTC/PLI) whichever is applicable, on the following behaviour from "strongly reduced", "reduced", "neither reduced nor increased", "less impact" to "no impact at all"?'

**Table 11. NGOs' influence in changing lifestyles of members (frequency distribution)**

Changes in lifestyles	% Response reduced	
	TASO	PTC/PLI
Influence on promiscuity	89	91
Influence on wife sharing	85	89
Influence on widow inheritance	86	79
	N=79	N=43

All the responses received indicated that no one had answered 'neither reduced nor increased'. During data analysis the above categories were collapsed into two categories, namely 'reduced' and 'no impact'. From the table, the findings clearly indicate a change in lifestyle of members caused by their respective organisations. This includes the drastic influence in reducing promiscuity, wife sharing and widow inheritance. The data presented in the above table show that the majority of the respondents were of the view that promiscuity, wife sharing and widow inheritance had reduced while the rest considered that there has been little impact. This also indicates NGOs' success in fighting the HIV/AIDS menace through changing members' lifestyles. In addition to the above questions, an additional question was asked for respondents to answer whether their lifestyle was changed by the organisation. In response, 99% of TASO and 95% of PTC/PLI members answered 'yes'. It indicates clearly that membership of these organisations really mattered in changing their lifestyles.

### Living positively with HIV/AIDS

Positive living connotes developing positive attitude in spite of the fear of being infected with HIV/AIDS. It involves self reassurance of increased life expectancy after HIV infection. It involves behavioural change and developing a positive attitude towards those infected with HIV/AIDS. The discussion presented earlier show that through regular interaction within NGOs, the clients build up their confidence in dealing with those adverse effects of HIV/AIDS such as stigma, social exclusion, and how to cope with

life. These relations are important sources of information and help to promote a positive attitude towards the HIV/AIDS infected. Correct information about how to live with HIV/AIDS serves to relieve some of the anxieties that weigh down both individuals and communities affected by HIV/AIDS.

Our 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, consequently, positive living. As Small (1997) argues, communication about HIV/AIDS has the effect of reducing stress and other pressures related to it.

We asked TASO members (90% of them are HIV positive compared with 11% in PTC/PLI) about the 'confidence in living with their HIV status'. The answer alternatives varied from 'much less' to 'much more' on a 5-point scale. Around 90% of the respondents from TASO answered that they have now much more confidence to live with their HIV status. Further, the more they interact with the staff of TASO, the more they become confident (Pearson's R of 0.42\*\* at the 0.01 significance level) in living with their HIV status.

### Conclusion

Our study aimed at mapping how NGOs build social capital, to what extent it is generated and how beneficial social capital is in fighting HIV/AIDS in Uganda. To achieve these objectives, we used mainly mixed research strategy. Our framework in analysing these objectives was straightforward. We argued that the meaning of social capital boils down to relationships and in this regard we focussed on two major actors in Uganda - TASO and PTC/PLI - who are increasingly involved in fighting the spread of HIV/AIDS.

The findings are overwhelming in the sense that both TASO and PTC/PLI members evaluate these organisations highly, irrespective of their positive or negative HIV status, along the variables that we identified as measures of social capital generation and benefits that accrue from such network building. According to members' perception, these organisations equally evaluated positively their relationships with members of these organisations and with staff. Participation in meetings was found to be positively correlated to their involvement in decision making, organisational activities and their chances of getting other close friends. This network building and close interface have helped them to live with the disease, talk openly about it, share their HIV status, and change their life pattern and behaviour. Overall, the presence, functions and operations of TASO and PTC/PLI have made a very serious impact on the members' attitudes to life as a whole and confidence in living with dignity in spite of their HIV-positive status. Stigma, social harassment and exclusion, which once haunted them regularly, have diminished through knowledge dissemination and interactions with the community. Disseminated at a low cost through social networks, this knowledge has helped to contain the spread of HIV. They now look forward to a life worth living. Social capital generation by these organisations, in a society where the deadly disease once severely devastated the social network,

has again brought hope for the HIV infected as well as for the community in general.

The benefits of social capital as found in this study in fighting HIV/AIDS challenges attest to the value of such an approach to address health-related issues. This is a valuable finding, especially where cure, prevention and care are long-term undertakings that require extraordinary measures such as network building and tight interactions among different stakeholders to include those who are socially boycotted and excluded. Bringing them back to the mainstream society to live a life worth living is what social capital generation by TASO and PTC/PLI has been concerned with, and has been crucial in mitigating the challenges of HIV/AIDS.

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## Footnotes

1. <http://www.who.int/whr/2003/chapter3/en/index.html> (accessed 2 October 2009).
2. 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 (see <http://www.health.go.ug/hiv.htm>).
3. See, for example, <http://www.tac.org.za/>
4. The research was done as part of the PhD training. The results were presented in a monograph which was successfully defended on 28 May 2007 for the award of Dr.Polit. degree of University of Bergen.
5. 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.
6. We borrowed from Szabo, S. 1999. *Social Intermediation Study: Field Research Guide: Exploring the Relationship Between Social Capital and Microfinance*. Quebec: Canadian International Development Agency and Aga Khan Foundation. This guide provides ways in which social capital should be investigated. We borrowed and modified some questions from this guide.
7. We also borrowed from Narayan, Grootaert, Nyhan and Woolcock (2003) *Integrated Questionnaire for the Measurement of Social Capital* <http://www.worldbank.org>, 2003 [cited 17/04/03 2003], to develop the questionnaire.