

# **BUILDING SOCIAL CAPITAL IN UGANDA: THE ROLE OF NGOs IN MITIGATING HIV/AIDS CHALLENGES**

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***Abstract:***

Social Capital is an important explanatory variable for performance of different nation states as well as improved livelihoods of people in different countries. The paper explores the process by which social capital is created and sustained to cope with HIV/AIDS challenges in Uganda. We argued that building social capital matters for the work against HIV/AIDS. Social capital makes a difference in lives of those living with HIV/AIDS. The paper focuses on the stock of cooperation (solidarity and social networks) among members, beneficiaries and or clients of NGOs and documents how cooperation is utilised to impact HIV/AIDS challenges; HIV transmission and spread, increased mortality and stress, social exclusion and stigma. We argue that, while a number of NGOs are engaged in HIV/AIDS related activities, only those that have focused on developing social relations among people living with HIV/AIDS have had greater impacts. We make an assertion that NGOs that have focused on empowering their members through bringing them into regular contacts have had an important contribution to their lives.

**Key Terms: Social Capital, Solidarity, Civil society, NGOs**

## 1.0. Introduction

The major purpose of the study is to analyse how building of social capital is mitigating HIV/AIDS challenges in Uganda. Since the 1980s, HIV/AIDS has become a global problem. In Uganda HIV/AIDS is considered as one of the major problems. Since its first identification in Uganda in 1982, it has had a devastating impact on the country's economy. It has greatly increased households' poverty, death toll, and social impacts such as stigma and social exclusion, has weakened social unity among different communities. The Uganda Aids Commission (UAC) notes that,

It is a severe health burden, a grave development problem and a potential security crisis (<http://www.aidsuganda.org>).

In spite of the above, Uganda is often cited as one of the most successful countries in controlling HIV/AIDS in the world. The prevalence rate has been declining from 18.5 % in 1995 to 6.1% in 2000 ([http://www.aidsuganda.org/analysis\\_2002.htm](http://www.aidsuganda.org/analysis_2002.htm)). By the year 2004, estimates were put to 5% (Monitor 15/04/04: 14). With these estimates, Uganda has registered a success story in HIV/AIDS prevention and control.

Fighting HIV/AIDS in Uganda involves the government, indigenous<sup>3</sup> and International nongovernmental organisations (NGOs) particularly established by people living with HIV/AIDS (PLWHAs). NGOs such as the AIDS Support Organisation (TASO) have focused on tackling HIV/AIDS from all fronts; social, economic, cultural and medical. Creating networks and linkages (social capital) takes precedence in NGO approaches to mitigate HIV/AIDS challenges. In the paper we discuss the process of building social capital and documents how it has utilised to mitigate HIV/AIDS challenges.

It should be noted that expenditure by government on the traditional care system such as hospitals and other health care systems, has not considered the impact social capital can create on people's lives. Emphasis is dedicated to ill-health interventions, which focuses on individuals with no regard to social dimensions of illness itself. Yet this has been found by studies such as, Campbell (2000), Kemenade(2002), Kawachi(1997), Putnam(2000), Putnam(2001), Veenstra(2001), Reuters(2004), to be an important variable for improved health. Lomas (1998: 1181) cited in (Campbell 2000) for example, notes that

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

The above arguments reveal that NGOs and civil society organisations matter but they matter as long as they facilitate networks and cooperation among individuals affected by HIV/AIDS. It is out of these networks that new alliances are borne, new knowledge and information acquired and platforms for discussion of HIV/AIDS related problems and their solutions created. At the same time, we contend that NGOs matter, but they matter as long as they are allowed or given a stable and peaceful political environment and perhaps synergic relations with the state rather than interference in their activities. Such environment may be provided by a responsive state. The state may be responsive in a number of ways: a) allowing different organisations to operate with relative autonomy and with limited control and interference, b) partnership and synergy between the state and NGOs in fighting HIV/AIDS, c) mobilising external support and, d) provision of infrastructure.

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<sup>3</sup> All NGOs including, regional and community based organisations with a Ugandan Origin.

Institutional set up of the state may facilitate growth and development of local organisations as well as trust relationships among different people. The role of civil society organisations in the solidarity initiative is to provide a better ground for cooperation and making society more civically engaged (Putnam, Leonardi et al. 1993; Putnam 1995; Putnam 2001). This is made possible if state institutions are responsive to people's needs.

With HIV/AIDS cure not forthcoming, the “multisectoral approach” has emphasised the role of civil society in controlling the spread, and mitigating associated effects. With limited state responses, formation of NGOs is one of the civil society approaches to dealing with social problems. In the case of HIV/AIDS, NGOs have modelled a number of approaches to mitigate the challenges which the disease has inflicted upon society. The modelled approaches involve care and support, education and sensitisation developed largely by PLWHAs. These approaches have focussed on the collective efforts of NGOs' members rather than individual initiatives. Emphasis is put on catering for the needs of PLWHAs through social support, empowerment, care and mobilisation of material (food aid, mattresses for needy families and scholastic materials for school going orphaned children) and financial support from different sources. These variables form important measures for social capital (Kemenade 2002).

Through solidarity mechanisms, namely a series of networks, groups and organisation formation, peoples' capacity is strengthening. Collective action has made many people infected and or affected by HIV/AIDS manage stigma, social exclusion and to address issues of prevention and control. The paper argues that NGOs possess institutional mechanisms that help to mobilise people into solidarity groups, which are capable of mitigating HIV/AIDS challenges.

We note however, that a number of NGOs that have focused on empowering individuals especially through counselling, have the capacity to empower individuals but may not contribute to reduction of social stigma and psychosocial problems resulting from HIV/AIDS. For example, although AIDS Information Centre (AIC) is the leading organisation in offering quality voluntary counselling and testing for HIV/AIDS, it does not empower individuals through social capital initiatives. More over, its emphasis on non-disclosure of ones sero<sup>4</sup>-status, parallels TASO's emphasis on opening-up to third party including family members. Therefore, TASO emphasises sharing of particular information regarding HIV/AIDS while AIC emphasises sharing general information regarding HIV/ADS. This situation limits AIC's clients ability to share their experience amongst themselves. Although AIC encourages its clients to join post test clubs<sup>5</sup>, the “non disclosure” close(AIC 2003), still binds them and still limits their sharing ability. Chapter 2, section 4(1) of the PTC charter stipulates that,

HIV status shall remain anonymous (AIC 2003: 9)

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<sup>4</sup> The word sero comes from laboratory terminology serology, that refer to the study of blood serum and its constituents, particularly their contribution to the protection of the body against disease. The tests that are carried in laboratories to look for antibodies in blood, which are generated by certain infections, either bacterial or viral are thus aimed at determining the blood status in that respect. The presence or absence of such antibodies implies that the person is either sero positive or sero negative in respect to the test carried. In this respect the sero status of an individual when referring to HIV virus implies the presence (sero positivity) or absence (sero negativity) of HIV virus in his /her blood.

<sup>5</sup> The post test club is an organisation formed as a follow-up measure of clients (especially the youth) who have gone through testing exercise irrespective of test results. Individuals who test have various challenges. On the one hand, those who test positive can drift into self-pity and self discrimination which has a devastating impact to their lives. On the other hand, those who test negative, have the challenge of drifting back to social life and become prone to infection if not followed and counselled on a continuous basis.

However, it should not be construed as a failing on the part of AIC. Rather, it should be understood in the light that every organisation has its focus and it strives to work towards that focus. The guiding principle of AIC in offering quality voluntary counselling and testing for HIV is protection of clients' HIV/AIDS status. Therefore, what we are conveying is that such organisations may not be good at mobilising social capital necessary for mitigating HIV/AIDS challenges.

Based on the above background our paper addresses the following questions:

1. What are the HIV/AIDS challenges?
2. What impact does solidarity and hence social capital have on the health of people living with HIV/AIDS?
3. How do NGOs facilitate social capital/solidarity formation?
4. How do solidarities work to create an impact on HIV/AIDS challenges?

## **2.0. Methods of Inquiry**

In order to map out the process of building social capital in Uganda, the district of Mbarara<sup>6</sup> was selected. The selection of this district was based on the prevalence of HIV/AIDS rate. The district is rated as the second in terms of high prevalence rates, with a prevalence rate of 10.6% compared to the national prevalence rate of 6.1% in 2001 (MDLG 2003). The analysis we present is based on the research carried out on one NGO, the AIDS Support Organisation (TASO)<sup>7</sup>.

TASO is the oldest organisation dealing with HIV/AIDS in Uganda. It has chartered the road map for most of the HIV/AIDS service NGOs and community based organisations (CBOs) and brought HIV/AIDS problem to the attention of government. The organisation offers a range of approaches to HIV/AIDS. In particular its focus on building social relations among people living with HIV/AIDS (PLWHAs) and communities in which they live makes it advantageous over other organisations in the same struggle. It is for the same reason that we selected this organisation as a case for our analysis. The analysis we present is based on 104 interviews; 80 beneficiaries of the organisation (90% living with HIV/AIDS), 4 government officials, 10 NGO officials and 10 AIDS community workers (ACWs) trained by the organisation.

Interviews were conducted at NGO's centres in a friendly environment; under a shade or inside a room with no major interruptions from external influences. People interviewed were selected from getting services at TASO counselling and day care centre or its outreaches. Those selected had been accessing services for a period not less than 6 months. Volunteers working with TASO helped to identify these respondents for us.

Interviews were conducted following a set of guiding structured and semi-structured questions. Questions were set based on a number of themes such as social support, empowerment, networking and sources of information. Interviews were face-to-face and lasted for about an hour. Face-to-face interviewing allowed respondents to account for their experiences through narrations.

## **3.0. Understanding Social Capital**

Social capital is a multidimensional concept and defined as a set of social norms, social networks, solidarity, and civic associationism that affect relations among people and are an asset for the individual and collective production of well-being (<http://w3.uniroma1.it/soccap/eng-index.htm>).

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<sup>6</sup> Located in southwestern Uganda, with a population of 1,093,388 (4.5% of national population) (National Population Census 2002), with a growth rate of 2.9%.

<sup>7</sup> TASO is the oldest NGO in the country dealing with HIV/AIDS. It was formed in 1987 by a group of people living with HIV.

Therefore, social capital can be understood as the benefit that would accrue to people as a result of investing in social networks and other forms of associations. Adler and Kwon(2002: 17), defines social capital as the

Goodwill that is engendered by the fabric of social relations and that can be mobilised to facilitate action

Social capital as a resource is embedded and can be produced through social relations and networks. Portes (1998: 7) observe that,

Where as economic capital is in people's bank accounts and human capital is inside their heads, social capital inheres in the structure of their relationships.

One of the major ingredients that sustain social capital is trust between and among people and groups facilitating cooperation and coordination for mutual benefit (Putnam 1995:67). These features of social capital are not only confined to within groups and only formal groups but include all forms of association and relationships (formal and informal) intended to benefit all those in association. Some forms of social capital such as parent-teacher association, labour union are highly formal. Others such as local sewing club or groups of people gathering after office hours for bowling, badminton or going to bar are highly informal. Yet another kind of almost invisible social capital is when people nod to one another in the street or in the supermarket or in the church (Putnam 2001: 42).

In recent years there has been an enormous interest in social capital following the seminal book by Putnam "Making Democracy Work: Civic Traditions in Modern Italy" published in 1993. A great explosion of research on social capital took place since then linking the importance of social capital to such areas as functioning of democracy, economic and civic equality, health and education of people, law and order situation, tolerance level, acts of philanthropy and generosity, etc. (Glaeser 2001: 34; Putnam 2001: 41-51). On most findings, higher social capital was positively related to the above variables.

Increased interest in social capital in explaining and understanding social phenomena has also led competing and contesting conceptualisations of social capital. In this regard, two schools of thought are discernible.

*a) Social capital as embedded in society:*

The most dominant idea is that social capital is embedded in society represented by mutual trust, solidarity, and participation in associations. The more the degree of social capital in the community the more healthier, safer, more employed, and hence more happier the community (Rooy 2001: 128). Social capital inheres in society and follows from history. In this regard, social capital is path-dependent. In *Making Democracy Work*, Putnam et al (1993) distinguished the Northern Italy from the Southern Italy in terms of *social capital* or *trust*. The central hypothesis of his book is: the more social capital a society possesses the better will a democratic government work. Widespread habits of civic co-operation or social capital are conducive to governance and effective performance of democratic institutions. Social capital is argued to be important for the quality of democracy.

Similarly, Fukuyama (1995), argues that the level of trust or social capital inherent in the society conditions a nation's well being, as well as its ability to compete. The ability of people to work together for common purposes in-groups and organizations depends on the degree to which communities share norms and values and are able to subordinate individual interests to those of larger groups. Out of such shared values comes trust and a high level of trust fosters solidarity, predictability, and spontaneous sociability. Trust thus reduces the cost of transaction and risk in

organizing social and economic activities. One of the consequences of a culture with a high degree of trust is the ability to form large corporations. High trust societies like Japan, Germany, and the United States were able to create large-scale enterprises for economic growth. Low trust societies like China, Taiwan, and Hong Kong as well as Italy and France are largely dependent on small-scale family businesses because trust is confined mostly to families and do not allow initiatives to form large organizations. Large enterprises in these countries are few and formed with either active support of the state or foreign investments.

In this school of thought the nature of social capital embedded in community determines the nature and type of institutions from being democratic to being non-democratic and unresponsive. Institutional or and social outcome is a result of social capital (see Putnam (1993).

*b) Social capital as an investment of (welfare) institutions:*

The second school of thought has its foundation in studies concerned with Scandinavian welfare institutions. It argues that social capital in the Scandinavian countries can be explained by the way their welfare policies are formulated and implemented (Rothstein and Kumlin 2003). In this regard, state institutions matter for the generation of social capital. In the Scandinavian countries, people are protected from “cradle to grave” by state institutions. Welfare states are usually large because of their interventionist nature in involving itself in providing public services. While in many cases, large states suffer from legitimacy because of high levels of corruption, lack of accountability, and unresponsive to citizen’s demands and aspiration, the welfare states in Scandinavia, in contrast, have managed to demonstrate the opposite that “big governments” are not “bad governments”. Rather, according to a report on Human Development by the United Nations Development Program, the Scandinavian countries are the least corrupt, have highest concern for universal human rights, and a high respect for rule of law (UNDP 2002: 149).

This school, which may be termed structuralist, focuses on the role of formal institutions, namely the institutions of the state in mobilising social capital. These states are concerned with good governance practices. The concern is to fit welfare state institutions to the needs and aspirations of the people. The more the fit is, the more the legitimacy of the state and hence the more trustworthiness. Trust within society and in government is therefore a function of the state and its institutions. Therefore, Scandinavian welfare state programs and institutions can be seen as investments in social capital (Rothstein and Kumlin 2003: 5).

However, these two competing conceptualisations of social capital - social capital as embedded in society and social capital as investments of welfare state institutions - may not reflect the social situations in Uganda in respect to HIV/AIDS. Studies such as Kayazze (2002), Tumwesigye (2003) show that Uganda is rich in social capital embedded in society. However, UNAIDS (2001), Orla (2004), have shown that with the advent of HIV/AIDS, social unity as well as social support became eroded. Like wise, in Uganda, there is inadequate capacity of state institutions to provide extensive welfare services. According to the UNDP report, Uganda is at the lower rank of human development index (UNDP 2002: 151) and is high on corruption scale (MFPED 2002; Price 2004). The state may not have the capacity to provide medical treatment and care needed to PLWHAs and to include them in the mainstream society. Given these facts, they feel unworthy of living, dejected, and frustrated with little hope to get the required help and social care either from society or state.

Given the above argument, the basis of building social capital is to put into consideration both situations. The argument we propose is the synergy approach. Therefore, we launch a third approach, which is concerned with synergy between state and societal approaches to *building social*

*capital.* We argue that social capital building through solidarity, network, and strengthening civil society may facilitate social inclusion of those people living with HIV/AIDS. At the same time, the state must come forward to facilitate and encourage those non-governmental institutions involved in building social capital. Given the devastating impacts, and the nature of social tragedies caused by HIV/AIDS, the role of the state in this regard may be inadequate. Therefore, the state may need to encourage other actors in this process of building social capital. Without state involvement, the fight against HIV/AIDS may not produce desired results. The situation may require some social mechanisms to help those who are already infected by HIV/AIDS as well as to warn those not infected. The preventive and curative efforts require more than technical and medical help. It calls for a more social approach to building solidarity, mutual help, information campaign, trust, and in removing social stigmas by means of social inclusion. In this regard, social capital building may become a useful tool in fighting against HIV/AIDS. We assume that building social capital is a necessary measure to fight challenges of HIV/AIDS. Therefore, it is pertinent to ask: What are the challenges of HIV/AIDS that require social capital to mitigate? Who are the actors involved in the process of building social capital? What are the mechanisms involved in this process? In the next section we present HIV/AIDS challenges that require mitigation. The rest of the paper tells the story of social capital building in Uganda.

#### **4.0. HIV/AIDS Challenges**

The challenges of HIV/AIDS go beyond the framing of this fatal disease in terms of medical science. While AIDS as a medical problem entails searching for the causative agents of the disease, the social challenges of HIV/AIDS require a social approach (Jönsson and Söderholm 1995: 461-466) and this approach calls for education, behaviour change, and social inclusion policies to go along with medical as well as biological approaches MOH(2000)

#### **4.1. Demographic challenge:**

The biggest challenge AIDS has posed to the economy is its demographic impact and the depletion of the human resource. At the end of 2001, 600,000 cases (individuals, adults and children) were reported living with HIV/AIDS while 84,000 AIDS deaths occurred in the same period (UNAIDS 2002). These figures testify for themselves that HIV/AIDS is a problem needing serious attention. The disease has spread widely. There is hardly any part of the country unaffected.

Although the national prevalence rate has continuously declined, there are still indications that HIV/AIDS is still spreading. Both Uganda AIDS commission (UAC) and agencies like The AIDS Support Organisation (TASO) continue to register increasing numbers of new clients country wide (table 1 and 2)



**Table 1 Cumulative reported AIDS cases (sentinel surveillance) in Uganda by year (1983 - 2002)**

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

**Sources:** 1. Different figures are got from different report; Uganda AIDS Commission, [http://www.aidsuganda.org/analysis\\_2002.htm](http://www.aidsuganda.org/analysis_2002.htm), 2. Uganda Epidemiological facts sheets on HIV/AIDS and Sexually transmitted infections, 2002 Updates

UNAIDS [http://www.unaids.org/hiv/aidsinfo/statics/facts\\_sheets/pdfs/Uganda\\_en.pdf](http://www.unaids.org/hiv/aidsinfo/statics/facts_sheets/pdfs/Uganda_en.pdf) MOH (2003: 23) etc

From table 1, the following trend can be observed. It can be noted that HIV/AIDS in Uganda has taken 3 basic phases: phase 1 rapid increase in number of cases (1983 to 1991 with a record of 10,235 cases reported in a single year (1991). Phase 2 characterised by rapid declining rates, follows from 1992 to 1999. From 2000 (phase 3), cases begin to in rise again although at a rate slower than in phase 1. The same trend is also observed in the figures reported by TASO (see table 2 below)

**Table 2: TASO Client Load**

Year	1997	1998	1999	2000	2001	2002
New clients	4787	7445	7018	6634	8700	13807
Total clients served	11033	15779	16707	12734	21738	28776

Source: TASO information Booklet 2003:3

Other reports also show that HIV/AIDS has been increasing especially in rural areas. Many urban areas are hard hit and for some rural area, numbers seem to be increasing or levelling off instead of reducing. Ssessanga (2003) reports that in Rakai district, HIV/AIDS infection rates are unchanging. Quoting the district health educator, he notes that

Rakai district has registered a stable HIV/AIDS prevalence of 12%-15% for the last two years. HIV/AIDS prevalence, which was at one time 35%, has been continuously coming down to 12% in 2001. The situation has not changed according to the preliminary findings in 2002 (<http://www.newvision.co.ug>)

UNDP (2002) notes that there is a change in the trend of HIV/AIDS infection rates; with faster declining rates in urban centres and increasing rates in rural areas.

Deaths resulting from HIV/AIDS and related causes have left many orphaned children. The Uganda AIDS Commission (UAC) notes that, Uganda has the highest number of orphans in the sub-Saharan Africa. An estimated 1.1 million children below the age of 15 years have lost a mother or both

parents to AIDS. Some of these orphans are being taken care of by relatives (some of whom might be sick themselves) and by organizations, while others are lacking basic necessities of life having lost both parents and having no relatives to take care of them. The capacity of the traditional family system to cope with this increasing rate is being over stretched (<http://www.aidsuganda.org>, Poverty Status Report 1999).

#### **4.2 Socio-economic Challenges:**

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

The amount of time spent on funerals and mourning have a devastating impact on production and output. Studies in Tanzania show that the financial burden of death can be far greater than that of illness. Households have reported spending up to 50% more on funerals than on medical care (UNAIDS 2002). In Uganda, some traditions require that the dead be buried at a specific place (usually the ancestral grounds) irrespective of where one dies. A minimum of 4 days are spent on mourning and if the deceased is the head of the family it takes 7 days. The impact on food security and possible wide spread of hunger is eminent. In general, the impact on work and output is high since majority of the affected adults are the work force. The impact is observed in reduced output, deepening poverty, increased economic dependence and food insecurity.

Of the 80 beneficiaries of TASO interviewed (90% living with HIV/AIDS), only 7% were employed in private sector, NGOs and government institutions. The rest were unemployed (17%), volunteering in NGOs (7%) or self-employed in agriculture and the informal sector (69%). They all reported putting less effort to work as one way of prolonging their life. Reduced effort into work affects output and leads to low incomes, and hence poverty.

In Uganda, the poverty status report 1999 states that HIV/AIDS poses the most serious challenge to the future success in reducing poverty in the country. The report further notes that, AIDS is estimated to annually reduce Gross Domestic Product (GDP) by up to 2% in severely affected countries like Uganda. Observing that in Uganda there is a shift from high to low labour intensive farming systems and a decline in the production of cash crops, the report continues to note that Agricultural production<sup>8</sup> has been shown to decrease by 37-61 % in such countries.

UNAIDS observes that HIV/AIDS is one of the major causes of poverty in Africa and notes thus;

HIV/AIDS cannot be described simply as a disease of poverty, it affects both rich and poor...AIDS creates poverty, AIDS deepens poverty, and AIDS makes poverty harder to escape from (UNAIDS 2001).

UNDP (2002: 21), reports that HIV/AIDS has contributed to low level of survival in Uganda The report notes that the national human poverty index (HPI) reduced from 39% in 1996 to 34% in 1998. But between 1998 and 2000, it registered an increase from 34% to 37.5%. This increase in the proportion of the deprived is due to the increase in the percentage of the population not expected to survive to age 40. This is directly linked to life expectancy and mortality levels in the

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<sup>8</sup> Agriculture forms the biggest part of the production sector. In Uganda, Agriculture contributes about 80% of GDP and about, 59% of total export earnings Muriisa, R. (2001). NGOs and Rural Development in Uganda. Public Administration And Organisation Theory. Bergen, University of Bergen.

population. Respondents of our study considered poverty as the biggest challenge faced by people including PLWHAS. 83% of the respondents ranked it as number one problem against 3% and 13% who ranked it as second and third respectively.

### **4.3. Social Exclusion and Stigma<sup>9</sup>:**

Although social exclusion and stigma appear to be declining, they still stand as major challenges to PLWHAS and as such pose a threat to social unity. In many Ugandan societies PLWHAS are regarded as social deviants because cause and transmission is mistakenly associated with promiscuity, which is regarded as a shameful act (Monico, Tanga et al. 2001). As such, stigmatisation, denial, suspicion, and isolation of persons with HIV/AIDS are common practices.

Given this background NGOs have put much emphasis on building solidarity networks that can facilitate the sensitisation of the public on the issue of HIV/AIDS while helping to socialise their members themselves. Most people who were interviewed noted that stigma and social exclusion were no longer big problems faced by people living with HIV/AIDS, especially those who have joined associations and other network groups. Respondents were asked to rank the problems (poverty, self exclusion/stigma, social exclusion and harassment) faced by people living with HIV/AIDS. Only 6% ranked stigma as number one problem against 24% and 34% who ranked it as taking second and third position respectively. Only 9% ranked social exclusion as number one problem against 49% and 19% who ranked it as second and third respectively.

From the above analysis, it can be argued that, the NGOs, particularly HIV/AIDS organisations have played a vital role in minimising stigma and discrimination levels.

## **5.0. Building Social Capital: Mitigating the Challenges of HIV/AIDS**

In order to understand the process of building social capital to mitigate HIV/AIDS challenges, it is important first and foremost that one understands the emergence of NGOs and their growing interest in HIV/AIDS. Uganda is a country fluid with NGOs, but in recent times, the number of those NGOs interested in HIV/AIDS has tremendously grown. In the next section, we trace the emergence of these NGOs.

### **5.1 Growth of HIV/AIDS NGOs**

The number of NGOs dealing with HIV/AIDS in Uganda is not clear. UNDP (2002) reports that as of 1997, the Uganda AIDS commission (UAC) had registered more than 1,020 agencies, mostly NGOs working in various aspects of HIV/AIDS. UNAIDS (2000: 10) reported that 1,050 NGOs and community based organisations were working in the AIDS field. Oketcho (2001: 10) identified 546 NGOs, including; a) 156 community based organisations (CBOs); b) 9 UN agencies; c) 86 International NGOs; d) 115 Faith Based Organisations; e) 123 National NGOs; f) 57 National NGOs<sup>10</sup> participating in HIV/AIDS related activities. Coutinho (2003) cited in Garbus (2003) noted that there are about 2,500 NGOs involved in HIV/AIDS in Uganda.

The growth of the HIV/AIDS organisations can be explained by several factors. First, civil society gained prominence in the late 1980s with the realisation that HIV/AIDS was no longer just a medical (health) problem but also a social problem. The care and support required by those

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<sup>9</sup> Stigma is defined as a significant discrediting attribute possessed by a person with an undesired difference (Goffman (1963). *Stigma*. New Jersey, Prentice-hall.

<sup>10</sup> Organisations formed locally; may be operating at district or regional level and may be receiving funding from government but they are autonomous.

infected with HIV/AIDS led to the realization that HIV/AIDS has multiple faces with the sociological face requiring an immediate attention as was medical or biological (Small 1997; MOH(a) 2000).

With increased rate of infections and little state response in terms of getting more involved and devising solutions to problems inflicted by HIV/AIDS, NGOs developed to fill the gap. Stimulated by social exclusion<sup>11</sup>, increased spread, neglected public responsibility and threatened employment status, HIV/AIDS organisations were born in early 1990s, by a group of people who faced such challenges. The initial focus of these organisations was to meet the challenge of exclusion and members' livelihood. Today, their initiative has gone beyond looking at themselves (PLWHAS), to teach the whole world about the need to come together to fight the dangerous disease.

In the USA, the Gay men's health crisis (GMHC) was the first response to the needs of those infected with HIV. Small (1997: 19) notes that specialized organizations have developed in order to respond to the needs of women with HIV/AIDS. Katz and Eugene(1976)<sup>12</sup> cited in Putnam (2000: 151) argue for the emergence of self-help groups, that they are seen as vehicles through which outcast persons can claim and grow towards new identities, redefining themselves and society. Self-help groups are a means through which the socially excluded can overcome solitariness. Through identification with a reference group, sometimes they can work towards social ends or social change. Putnam (2000: 152) argues that the rising of self-help groups (*as in the case of HIV/AIDS*)<sup>13</sup> reflects the application of social capital remedies to a set of previously neglected problems; that they bring what were thought to be private problems into the public realm.

In Uganda as elsewhere in Africa e.g. Tanzania and South Africa, HIV/AIDS NGOs developed as a result of a need to form self-help programs to provide for the HIV/AIDS affected persons. For example, The AIDS Support Organisation (TASO), developed to support the socially excluded, provide care and counselling services, and community outreach programmes. This organisation formed in 1987, has grown to be one of the biggest NGOs providing HIV/AIDS related services in Uganda.

Secondly, with failing states' responsibility towards HIV/AIDS, NGOs gained prominence and recognition by the international donor community, which sought to channel development aid through them. The World Bank's Multi-Country AIDS Programme for Africa explicitly aims to use non-governmental organisations (NGOs) as implementing partners for approximately 50% for the funding provided (UNAIDS 2002). The recent established Global Fund to Fight AIDS, Tuberculosis, and Malaria requires country proposals to pass through 'Country Coordination Mechanisms (CCMs), which should involve civil society. In his paper, Mohga (2002) recommended that NGOs should contribute to the global decision making process on AIDS. He also recommended that the CCMs should give a strong voice to NGOs, in decision-making programming, implementation, monitoring, and evaluation.

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<sup>11</sup> Social exclusion is a short hand label for what can happen when individuals or areas suffer from a combination of linked problems, such as unemployment, poor skills, low incomes, poor housing, high crime environments, bad health, and family break down Munn, P. (2000). Social capital, Schools and exclusion. Social Capital. S. Baron, Field and T. Schuller. New York., Oxford University Press.

<sup>12</sup> Alfred H Katz and Eugene Bender (eds.) (1976) , The strength in us: Self help groups in the modern world, New York, Franklin .

<sup>13</sup> Emphasis added

The recent support from World Bank for community HIV/AIDS initiative (CHAI) requires that money be channelled through NGOs and Community based organisations (CBOs) involved in HIV/AIDS related activities; participatory approaches involving people living with HIV/AIDS, community based information, education and communication (IEC) initiatives, poor orphaned children's education etc (Mbarara DHS records). This requirement has led to the further growth of HIV/AIDS organisations. Our study found out that in Mbarara district over 50 NGOs and CBOs have been formed to respond to this fund.

Thirdly, as market forces makes the state to relinquish the few responsibilities it held in public spending, more attention is being put on the role of civil society. It is important to note that the days when health depended on public spending may be coming to an end. Today, most countries, including the traditional welfare countries are looking at the complementary role of the private sector in providing health care. In developing countries, with state pull-back and the market taking the lead in providing health care, the poor are left out with barely any services. Given this situation, in developing countries, under the market system, the poor and other disadvantaged groups such as PLWHAS will find it difficult to survive individually.

Threatened by the disease, most families in Uganda, including poverty stricken rural households, have used a big portion of their incomes and resources in responding to the challenges of HIV/AIDS. The fact that medical treatment in Uganda is not fully provided worsens the situation.

Given this background, NGOs like TASO have come up to fill this gap and provide for the poor. TASO has an outpatient clinic, which provides medical services to the sick, employs community nurses to care for the sick in the community. In 2002, a total number of 26,065 individuals turned up at the seven TASO clinics (TASO 2002: 7). In 2003, a total number of 17,311 individual clients received medical services at Mbarara TASO clinic (TASO records)

## **5.2 Mitigating the Challenges:**

In this section we argue that mitigating the challenges is not a single body's task, but rather it requires a concerted effort from both the state and civil society. Both these bodies have what they can contribute. Therefore, Synergy between the two has a more profound impact than instead of single-handedly initiative. However, we argue that impacting the challenges will be realised if social capital approaches such as networks are utilised. Below we examine such processes.

### **5. 2.1.The Role of the State and State Leaders**

States in Africa have offered limited effort to fighting HIV/AIDS yet, as Voelker (2003: 20) notes, strong government commitment is needed in countries with scant resources(Voelker 2003: 20). In Brazil, the country that has made success in fighting HIV/AIDS in Latin America, success is attributed to "strong government's commitment to addressing the problem" (ibid 23). Most African leaders have shown little response to HIV/AIDS and instead deny that HIV/AIDS is a problem. Thambo Mbeki while opening the international conference on AIDS in 2000, had this to say,

We cannot blame everything on a single virus. Poverty is the underlying cause of reduced life expectancy, handicap, disability, starvation, mental illness, stress, suicide, family disintegration and substance abuse. ([http:// www.aegis.com/news/irin/2000/1R000703.html](http://www.aegis.com/news/irin/2000/1R000703.html))

On the contrary the World Bank notes that in South Africa, where the government has been slow to react to HIV, there is eminent economic collapse within the three generations unless elected leaders take more forceful action (Voelker 2003: 22).

However, the government of Uganda has made a positive response in the HIV/AIDS initiative. There is a strong political leadership led by the president. Museveni has stressed on many occasions that AIDS has become an 'African' disease, and that as African leaders, they must take the lead in finding resources and negotiating with drug companies to lower prices. For this leadership he is popularly praised for his fight against HIV/AIDS both at home and abroad. For example president Bush of the United States praised Museveni on several occasions for his fight against the epidemic (Lobb 2002).

On leadership, Museveni himself notes that

Where AIDS is a big problem, it is mainly due to leadership. I call on African leaders to rise up to the occasion and save the people (Lobb 2002).

In October 2001, Museveni became one of the 12 winners of the commonwealth awards for action on HIV/AIDS. The award was given in recognition of his personal commitment, to and leadership in addressing the HIV/AIDS epidemic which has shown that the spread of HIV/AIDS is not inevitable and as such made Uganda a symbol of hope in the developing world (<http://www.para55.org>).

Different political leaders who recognise that HIV/AIDS is a threat to social-economic progress of the country support the HIV/AIDS spearheaded by the president. In his address to the population of Mbarara at the international Labour Day celebrations, the Local council five (LCV) chairman strengthened the call to fight HIV/AIDS adding that it is the biggest challenge that threatens the labour force of the country.

People living with HIV/AIDS acknowledge that strong political leadership is a necessity in the fight against HIV/AIDS. Most people who responded to the question, "*Do you know of any government programme to fight HIV/AIDS?*" mentioned the role of the President in making HIV/AIDS public as one of the reasons why there has been marked decline in social exclusion and stigma in Uganda.

However, in spite of the strong commitment of the presidency, a lot more needs to be done at local level in terms of political commitment. The political commitment seems to end at the top level and there is little follow up at the lower level. For example, although there is an indication that a programme runs from the Uganda AIDS commission to the local level, there is little to show for this. Most respondents showed that there is no known government programme in their communities although they were aware of the president's commitment. The district health personnel noted that they are poorly funded and have not put in place any direct programme to benefit the communities, hastily saying "with the global funding and bush funding, the response to HIV/AIDS is coming in full swing" The personnel of the organisation who were interviewed were positive on the government's response to HIV/AIDS at the national level. But they decried lack of response by local political who at times fail to welcome them in the communities they lead. They also sighted some utterances by leaders that incite discrimination and promote stigma to people living with HIV/AIDS. Citing one case, a TASO official noted that on the International AIDS day celebrations, the master of ceremonies, invited TASO drama group to present some songs by saying "*Aba silimu mwije aha*" meaning that those with HIV/AIDS should come here and present to the congregation. The TASO official noted that such references, stigmatises those with HIV/AIDS and may even incite discriminative attitudes from the public towards PLWHAS.

However, we noted that a responsive state towards civil society, allows them to exercise their potential. The government has welcomed the contribution of NGOs in the fight against HIV/AIDS and has provided infrastructure to allow them function. For example, most TASO and the AIDS Information Centres are established in government hospitals and health centres. Employees of NGOs work hand in hand with government health officials who handle referrals from NGOs. Both NGO and government officials acknowledged that they need each other for their effectiveness. They noted that they have had representatives from NGOs on various meetings to deal with HIV/AIDS.

In addition to allowing civil society organisations to participate in the HIV/AIDS activities, the government has a positive attitude on HIV/AIDS. This is supported by a number of government programmes aimed at fighting HIV/AIDS. For example, the district directorate of health (Mbarara) indicated that there is a programme running in all schools. School authorities are by law required to hold HIV/AIDS talks with school children every fortnight and to include HIV/AIDS on all health educational talks every week.

In spite of the above response, more effort is still needed for successful fight against HIV/AIDS. For example, the government is supposed to have programmes at grassroots, which have remained “paper” programmes. Interviews with officials at the district directorate of health services indicated that there is no government response at grassroots. These officials noted that much of responses at the local level are contributed by NGOs. Commenting on the role of NGOs a government official said that though NGOs are small, they are more effective than government. He argued that the government has a problem of setting up grand programmes which it fails to execute.

### **5.2.2 The role of Government in building social capital**

The institutional perspective recognises that social capital inheres in areas where there are competent and responsive institutions. Where there is equal treatment of citizens in terms of welfare benefits and protection of the law (Rothstein 2001; Rothstein and Stolle 2001; Stolle 2001; Szreter 2002; Rothstein and Kumlin 2003; Stolle 2003; Rothstein 2004; Stolle 2004).

Although the government of Uganda fails to meet the criterion (trust and responsiveness) used by the structural perspective, it has nevertheless played a vital role in social capital mobilisation. There are a number of indicators for this: First, as already indicated, the multisectoral approach that has been pursued by the government allows participation of different organisations including NGOs and other civil society organisations. Second, political leadership creates assurance of government support to the people living with HIV/AIDS. This gives them a sense of trust into government although they hold low trust of state institutions such as the police and legal officials. Note that the government of Uganda ranks high on corruption scale (see Garbus and Marseille (2003: 33); MFPED (2002: 55)). Third, government initiatives to mobilise resources to fund institutions that are engaged in the fight against HIV/AIDS has led to formation of grassroots organisations to fight HIV/AIDS. The government has mobilised funding to carry out HIV/AIDS activities through Community HIV/AIDS Initiative (CHAI). Records at the district directorate of health services (DDHS) Mbarara, indicate that groups to qualify for this funding include a) community based organisation for people living with HIV/AIDS, and b) community based information education and communication (IEC) initiatives to reduce HIV/AIDS.

These groups have to possess a number of qualities including a) practical participation of beneficiaries in identifying their HIV/AIDS problems, solutions and management of action plan, b) HIV/AIDS activities identified and directly carried out by the community and or contracted out by

the community to civil society organisations at a cost not more than 5% of the total cost of the subproject, c) community contribution of 10% towards the project sustainability, and d) elect a community project committee that is gender sensitive composed of at least 44% female.

The above requirements and qualifications have a number of effects on social capital formation. First, they empower communities to mobilise funding to supplement governments funding. Second, they encourage collective action through group formation aimed at fighting HIV/AIDS. Third, they inculcate into beneficiaries (communities) democratic capabilities through participatory election of their leaders, hence developing leadership skills. Finally, all these requirements focus on fighting HIV/AIDS and have empowered people especially those living with HIV/AIDS, to fend for themselves.

Given the above government initiatives and roles in mobilising social capital, we note that the government remains an important element in mobilising social capital even when the citizens do not trust a number of government institutions. Intuitively however, we recognize the government recognition of the contribution of civil society and communities in this initiative. This emphasizes that neither government nor civil society organizations alone can do it.

### **5.2.3. The role of NGOs**

As earlier discussed, the challenges posed by HIV/AIDS are enormous. These challenges transcend individuals and cut across social as well as economic boundaries. The poor as well as economically well-to-do persons are affected by the impacts of HIV/AIDS.

These challenges have attracted different development practitioners, including NGOs. NGOs have come to be dominant players in the fight against HIV/AIDS in Uganda. They are currently involved in the control, care and sensitisation programmes related to HIV/AIDS. In Uganda almost all NGOs have included fighting HIV/AIDS on the list of their activities. As such, Community HIV/AIDS Initiative (CHAI) programme, has gained ground on NGOs agenda. Because of the initiative a number of NGOs and CBOs have been formed strategically to address the challenges of HIV/AIDS.

### **5.3. NGOs, Solidarity and HIV/AIDS challenges**

As indicated in our opening remarks, the intention of the paper is to understand how NGOs mitigate HIV/AIDS challenges using solidarity mechanisms. At the very onset, HIV/AIDS had a divisive power by means of social exclusion, stigmatisation, self-denial and self-exclusion. These became the initial challenges facing people living with HIV/AIDS. Ironically, these challenges became the unifying forces that created identity among PLWHAs. For these people, societal attitudes (stigmatisation and discrimination) towards them became the driving force in unifying into forming solidarity groups. Some of these groups have grown into big HIV/AIDS organisations dealing with different HIV/AIDS related issues like care, support, counselling, sensitisation, advocacy, and resource mobilisation. Since the late 1980s these have remained cornerstones in the fight against HIV/AIDS. They have become important channels through which people living with HIV/AIDS participate in development, share experience, and access information as well as resources (financial and material).

#### **5.3.1 Information access and coping with stress**

It is important to note that the more the people are connected, the more they are able to access information, resources, and develop appropriate behaviour towards one another as well. NGOs have played a role of bringing people together through constant interactions and hence building



solidarity relationships that have made members to develop trust relationships, which eased information dissemination. Solidarity confers upon members norms of trust that facilitate participation for common benefit. Members of organisations disseminate information to one another and to those members of the communities affected by HIV/AIDS. 86% (69 respondents) of the people interviewed mentioned that they trusted members of the organisation in which they belong. Such trust relationship is important in making these people exchange views and other useful information for their survival. This reduces transaction costs that would be involved in disseminating information.

Information access and sharing experiences are starting points for reducing stress and other related problems. A counsellor at TASO centre (Mbarara) whom we interviewed about the benefits clients get by sharing their experience succinctly put it in the following way,

*“A problem shared is a problem halved.”*

In his research to determine the impact of emotional disclosure on the health of people with HIV/AIDS, Dr Kevin J Petrie concluded that

Patients with HIV infection, who don't get to discuss their feelings have a faster decline in their health (Reuters 2004: 21).

The staff of the organisation contented that TASO clients are well connected to one another and are involved in sharing experience whenever they meet. One counsellor said that their clients identify themselves as belonging to the 'family'. Another one noted that

The HIV/AIDS persons had certain solidarity that is lacking among many people. For example during home visit, one client may inform us of another client in the neighbourhood needing our services. They know each other and always bother to find out what is happening to their colleagues (interview with counsellor).

TASO clients interviewed about the benefits they get from relating with others contended that they were able to access resources, gain knowledge about medicine, and how to cope with stress. This confirms Putnam's assertion that,

Controlling for blood chemistry, age, gender, whether or not you jog and for all other risk factors, your chance of dying over the course of next year are cut in half by joining one group, and cut to a quarter by joining two (Putnam 2001), <http://www.isuma.net>).

A respondent who is a member of TASO drama group was interviewed about how she benefits by belonging to the group. She said that by joining the group like drama, they all become happy and relaxed especially after singing. Responding in the local language she had this to say,

Omuntu yabugana abandi akeshongora nabo nananuka. Kandi nitwegyeramo bingi, nokumanyisibwa ebirikugyenda omumaisho.

The meaning of the above is that if a person meets others and sings with them he/she gets relaxed. And we learn new things, and get information of what is taking place. Another respondent said that groups help reduce stress,

When I am in a group, I only think of what we are doing at the time.

The above is in line with findings by scholars such as that individuals use social resources to deal with psychologically stressful events and situations regarding social support. Their investigations resulted in the conclusion that social resources are important for dealing with life's problems. Sandefur and Laumann (2000) argue that

In addition to providing social support conducive to maintaining health or coping with crises, relationships with trusted others free an individual to use her energies more efficiently and effectively to attain desired goals.

Putnam (2000) and (Putnam 2001) argues that social relations (*Social capital*)<sup>14</sup> determine the well being of the people. The more integrated people are with their communities, the less likely they experience colds, heart attacks, strokes, cancer, depression, and premature deaths of all sorts. He argues that loneliness appears to decrease immune response and increases blood pressure.

Therefore through providing avenues for constant interaction between its members TASO has managed to make people avoid loneliness. At TASO Mbarara, a day-care centre was set up as a meeting place for its clients. Clients/members meet others on any day depending on their schedules. In addition, the branch sets two days in a week for clients to come to the centre for medical consultations and counselling services. In addition to the daily meetings, members can meet others on these designated days. Through these constant meetings clients discuss issues related to their health and develop further solidarities and relationships, which are important to their health.

### **5.3.2 Bridging the gap between people with HIV/AIDS and the community**

By initiating dialogue about their conditions and comprehensive self-responsibility, self-determination to live and public participation, the organisations have developed and successfully promoted perspectives that go beyond self to civic responsibilities. The organisations included in this category include the service organisations like The AIDS Support Organisation (TASO), The Philly Lutaaya Initiative (PLI) and various clubs formed by different organisations. For example drama clubs under TASO (TASO Drama), The post test club (PTC)<sup>15</sup> under AIDS Information centre (AIC) and the Youth Challenge club under TASO. All these organisations are engaged in different activities aimed at enhancing HIV/AIDS awareness in the country. TASO drama Mbarara branch, for example has an average of four presentations to different communities in a month (interview with drama group members). TASO Quarterly Report from January to March 2003 reported that the drama group had made 162 performances as follows; Mulago 27, Entebbe 21, Masaka 25, Mbarara 23, Jinja 27, Tororo 20 and Mbare 19. The presentations had reached 30,212 audiences. Philly Lutaaya Initiative (PLI) brings together people living with HIV/AIDS who have voluntarily accepted to go public and talk about their personal experiences of living with HIV/AIDS.

The Post-Test Club (PTC) brings together members who have gone through HIV screening exercise irrespective of their sero status (negative or positive). At Mbarara AIC branch, the group meets twice a week to discuss wider issues relating to their activities. This group also has a drama group that takes performances to communities. The coming together of members with different sero status is significant to the extent that it communicates to the members of the community that people living with HIV/AIDS and those not yet infected can live in harmony.

The initiatives above (drama, PLI, the PTC) demonstrate how people living with HIV/AIDS can combat HIV/AIDS related stigma, discrimination and denial and also extend the boundaries of openness about how to respond to the HIV epidemic. The presentations and testimonies by people living with HIV/AIDS are concluded by a question/answer session in which spectators allowed to ask questions which are answered by the leader or any other person in group depending on the

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<sup>14</sup> Social capital refers to Networks, Linkages and trust that result there of among persons, organisations i.e. interpersonal linkages and trust, intra and interorganisational linkages and how these networks facilitate development Coleman Coleman, J. S. (1990). *Foundations of social theory*. Cambridge, Mass., Harvard University Press.

argues that social capital inheres in the structure of relations between actors and among actors. And that it is embodied in the relations among persons.

<sup>15</sup> Because of the time constraint and the on going data collection from PTC and PLI findings are not presented our paper.

nature of the question (observation made during field study). However, in all the communities we visited to attend the presentations, we made an observation that other than drama, which was presented in the local language most songs were presented in English. At Rwobuyenje for example, six songs were presented, all in English. Indeed when asked to comment on the presentations, spectators made an indication that the drama was more effective than the songs because it was presented in a language which they understood. In spite of this shortcoming we cannot deny that these programmes have created an impact on local communities and Ugandans in general. By following these programmes many Ugandans have gained a deeper understanding of the AIDS epidemic and made personal commitment to positive action in response to the many new challenges the epidemic poses for society. Such an atmosphere creates a culture of mutual respect, tolerance and cooperation with people living with HIV/AIDS. In addition it has been a step towards creation of cross cutting ties with people living with HIV/AIDS and the general community since by getting informed about HIV/AIDS people gain knowledge and understanding of the disease and how to cope with it.

Other than bridging the gap between people living with HIV/AIDS and the community, drama presentations have contributed significantly in reducing HIV spread. Songs presented at performances, which we attended during our study, had a message about how HIV spreads, and how it can be prevented. Testimonies made by people living with HIV/AIDS have a significant impact. At Rwobuyenje church of Uganda in Mbarara, we had an interaction with community members to get their views about the presentation. Members echoed the need for these performances in their community and indicated that such performances are educative. An old lady who is taking care of AIDS orphans left by her son said,

The youths are leaving us. The disease is lobbying us of our children. We like these performances. They educate us, this is the third time these people have visited our church. We wish they could keep on coming. Our children could survive AIDS (field notes).

Driven by the quest for developing approaches, which are necessary to mitigate the challenges of HIV/AIDS), the organisations are committed to develop opportunities for public participation into HIV/AIDS related activities. NGOs organise public debates on HIV/AIDS, like radio and Television talk shows, where society participates in a question and answer programme about HIV/AIDS related issues, causes, challenges, and approaches to its containment. In 2003, 115, talk shows were conducted in radio by TASO Mbarara. Also seminars and workshops about the HIV/AIDS have been organised. In 2003, TASO Mbarara organized a seminar that benefited 27 members belonging to a high-risk group. In the same period, 2 workshops benefiting 43 apprentices were organised (TASO-Mbarara records). Seminars and workshops have brought the organisation and HIV/AIDS before policy makers and the international donor community. The organisations have intensified their efforts in facilitating community participation for the control of HIV/AIDS. These organisations share a common perspective on the challenges of HIV/AIDS and envision greater opportunities to establish a comprehensive civil society participation in the HIV/AIDS activities.

### ***5.3.3 Solidarity and poverty alleviation in the era of HIV/AIDS the case of TASO***

NGOs have developed initiatives that involve people to finance their activities to eradicate poverty. Solidarity mechanisms are used to mobilise resources and funding access by different groups of people involved in activities aimed at mitigating HIV/AIDS challenges. Through a system of co-guaranteeing and group lending, individuals gain support of their *solidarity* group and are able to obtain short-term interest free loans to finance their own activities. Although the loan is given to an individual, he/she obtains the loan by getting the support of the group to which she/he belongs.

Individuals are required to form groups of five. Groups are formed on the basis of mutual trust among members. An individual must be credible, and trust worthy to join such groups.

Before the loan is given out, clients are trained in various skills such as; project identification, project management and record keeping. The individual who applies for a loan is co-guaranteed by his/her group members by indicating that the member is in position to repay the loan and that they will pay the loan in case their member defaults. The member who receives a loan signs a binding agreement to repay the loan and the group members support him/her by signing another agreement, which binds them into repaying the loan in case of loan default by a member they support. Group members hold each other accountable for regular loan repayment. An interview with a counsellor about the need for membership to a group as a requirement for accessing a loan said that,

By signing this agreement each member becomes responsible for his/her friend and this makes recovery and monitoring of the loan easy.

Records at TASO-Mbarara indicate that a number of clients have already obtained loans through group support. The money given to each individual ranges between Uganda Shillings 100,000 (\$ 53) and Uganda Shillings 150,000 (\$79) and is supposed to be repaid within 16 weeks divided in 4 instalments. Up to 2.79 Million (\$1468.4) Uganda Shillings has already been loaned to 6 groups. Those who access loans are given a grace period of one month after which they begin to repay. So far Uganda Shillings 1,245,660 (\$655.6), i.e. 45% has been recovered. The recovery rate is below average. UNAIDS (2002) has a similar finding and notes that loan recovery from HIV/AIDS patients was a problem due to increased pressures of illness and disease. It reports 57% difficulty in loan repayment for an observed period. In addition to low rate of recovery, the loan approach has had negative implications for client access to medical and other TASO services. In an interview with the counsellor in charge of day care centre, it was revealed that some clients who accessed the loan facility stopped attending the health clinic because of the fear of being embarrassed for failing to pay back. She noted that

If a person fails to pay, it is not possible to chase this person, because, our objective is to provide care and support. Some people may use this as a weapon to tarnish our name. We cannot use the same means as the bank uses.

The official noted that TASO is in the process of phasing out the programme (see TASO (2002)).

In spite of the shortcomings of the programme, some clients who obtained loans were grateful that the loan has facilitated their wellbeing. The facility has instilled into them a culture of saving. This is emphasised by the organisation. Every member who accesses a loan is supposed to make a mandatory saving of at least Uganda shillings 1000 (\$0.53) each time a payment is made. So far the six groups together managed to accumulate a saving of Uganda Shillings 227,275 (\$119.6).

However, clients noted that the time is still too short to determine the success of the project. They argued that they are mostly handicapped by disease constraint since they are “patients”; a condition that is likely to make them fail to pay back in the long run. This confirms fears of organisation officials.

#### ***5.3.4 Solidarity and resource mobilisation***

As noted earlier, NGOs have used solidarity mechanisms such as group formation, in order to access loans and mobilise funding. A number of NGOs and community based organisations have accessed Community HIV/AIDS initiative funds. Funding to these groups ranges between Uganda Shillings 1.7 million (\$894.7) to Uganda Shillings 5.2 million (\$2736.8) (Mbarara District records). These funds are to implement certain programmes like paying school fees for orphans, drama activities and providing basic necessities such as mattresses to the needy HIV/AIDS patients.

## **6.0 Institutional competences of NGOs**

In the introduction to this paper we did indicate that NGOs possess institutional competences to mitigate the challenges of HIV/AIDS. In this section we present these competences possessed by NGOs. In particular we focus on the following;

- Capacity building
- Participatory management
- Policy making
- Resource mobilisation
- Capacity to create Identity to fight a common cause.

### **6.1. Capacity building:**

TASO has set up a number of strategies to build capacity of both staff and clients. For the staff the organisation conducts special refresher courses to equip them with skills to take care of the increasing challenges of AIDS. A number of counsellors have trained in these skills.

To take care of the increasing number of the clients, the organisation has trained the AIDS Community Workers (ACWs). These perform a number of Tasks; counselling, home care and sensitisation. At the end of 2000, 7,936 clients received counselling from the ACWs, they made 723 home care visits. Counselling empowers individuals to overcome stigma and helps individuals to reveal their sero-status. The ACWs have formed themselves into Drama groups to re-enforce the training and dissemination of information. Ten ACWs interviewed from two TASO supported communities indicated that they make three drama performances in a week.

The organisation has managed to make communities form committees. There is the Parish AIDS committee (PAC), composed of 30 ACWS, 10 of whom are leaders trained in project identification, and implementation. They coordinate AIDS activities in the parish.

The day care centre allows clients to fellowship. This is aimed at making clients share experience and cope with the disease. In addition, clients are always encouraged to form themselves into groups so as to access resources. A number of groups have been formed. These include the National community organisation of women living with HIV/AIDS (NACWOLA), the PTC and PLI.

### **6.2. Participatory management.**

Management at TASO is participatory involving both staff and clients. The clients participate in management of the organisation through the clients' council, headed by the chairman who is democratically elected by clients. A committee, composed of people living with HIV/AIDS, assists the chairman. The clients have a representative at the centre advisory committee and board of trustees; the overall body that manages the organisation. From the above, we note that clients are involved at different levels of decision making in the organisation. Clients were asked to rate the level of involvement in the decision of the organisation. More than half (44(55%) of the respondents indicated that they contributed to a greater extent.

Like clients, employees of the organisation are consulted whenever important decisions are to be made. When asked the extent to which clients and staff of the organisation are involved in making decisions for the organisation, such as how budgeting and work plans for the branch are made, the manager said that clients and staff are consulted in order to map their preferences. In addition, departmental meetings are held where members of staff make their contribution. These contributions are presented to the general staff meeting held monthly at the centre. Interviewed staff members agreed that they fully participate in decision making through monthly management

meetings held at the branch and organisational retreats. In addition they indicated that other than routine meetings, there is a weekly assembly addressed by the manager. At this assembly certain issues are clarified; the past week programmes are reviewed, the programme for the week presented and any other question may be clarified during this meeting.

### **6.3 NGOs and policy-making**

The organisation works hand in hand with government through district AIDS committee where they are represented. Through this committee the organisation manages to take part when important decisions are being made. All members of staff of government directorate of health services at the district who we interviewed said that NGOs are involved at different levels of policy making in relation to HIV/AIDS. TASO and other NGOs have been involved in different meetings with the district officials to decide on certain issues. For example, they participated in a meeting that decided on the venue for the international AIDS day celebrations. TASO was also represented in a meeting to decide on how CHAI funding should be utilised. TASO management as well as district officials confirmed that government has honours TASO's input. This is further confirmed by our finding that most of CBOs which received CHAI funding had been recommended to government by TASO.

### **6.4. Resource mobilisation.**

One of the reasons why TASO has succeeded in its programmes is its ability to mobilise resources through linkages and networks. TASO has a number of linkages and networks with international organisations; USAID, DANIDA, EU; SIDA. These provide funding for its programmes. The organisation has a lot of collaboration and networking with the government. The organisation does what is in line with the national strategic plan. At the district level the organisation links up with the directorate of health services. Such linkages with government bodies have helped the organisation to gain government support.

### **6.5 Identity Creation**

We noted earlier that any solidarity begins with identity formation. Further, we noted that creation of common identities enable people to share certain characteristic and thereby form solidarities. We also indicated that most clients of TASO easily identify with one another and prefer to be referred to as a family (interview with the both counsellors and clients). In this section we map the means TASO has employed to create such identity. First, the organisation managed to unite people living with HIV/AIDS by making them realize their plight. As mentioned earlier, faced with social exclusion TASO was formed to bring together these people and make them united against such social forces like discrimination. Other organizations have continued to be formed under the encouragement of TASO.

Second, TASO has made it possible for clients to have constant contact with one another. In the discussions above we did indicate that there is a day care centre where clients meet to discuss issues that affect them. The centre has proved to be an important meeting place that has made clients easily identify with one another. We asked the chairman clients' council, counsellors and the manager TASO to compare the day-care centre with government hospitals' out-patient clinic where the sick also meet in an open space to wait for treatment. All responses indicated that the difference lies in the fact that at TASO, only people with similar problem (HIV/AIDS) meet, this allows interaction among the attendants, while at the outpatient clinics in government hospitals, people have different medical problems. They neither share their problems nor do the same people meet regularly. Therefore it is impossible to identify with one another.

Other than the day care centre, the organisation often holds a pre-medical open education talk show. Clients (mostly HIV/AIDS patients) are brought together and are addressed by the chairman clients' council or any other client volunteer. The programme involves talk on health and hygiene, how to access treatment and a call to all to share experience. This programme brings together clients and allows them an opportunity to identify themselves as one.

## **6.6 Expertise of NGOs**

NGOs are an epistemic community, i.e. knowledge based community. The development of knowledge and use of such knowledge in combating AIDS and its related problems grows within these organisations and via collaboration with other organisations. The fact that NGOs (particularly HIV/AIDS organisations) are developed by people, who are affected by the disease, makes them specialised in this area and thus develop knowledge abilities that can be used to develop strategies to cope with the challenges. According to World Bank,

NGOs' work is based on a commitment to community participation and pluralism rather than dependence on the government. They are closer to the clients and know more about their needs...they can tailor services to niches...they pilot new technologies (WorldBank 1993: 127).

In addition NGOs emphasise experiential learning - learning by doing. NGOs' employees often learn from the field-from people they work with. NGOs have a belief that people (beneficiaries) know better what affects them. Holloway (1989) observes that,

Only the poor can change their own lives given resources necessary (Holloway 1989) cited in Muriisa (2001).

They therefore allow people to define their own needs thus generating more knowledge about a particular problem. It is this belief and orientation that has made NGOs experts in such fields as HIV/AIDS.

It should however be noted that knowledge does not only mean knowledge about AIDS but also whom they know, who can help them to solve the problem. Through the long history of their participation in this challenging area, they have come to develop linkages with different international and local bodies that can help them.

## **6.7. Informal approach by NGOs**

NGOs have informal approaches to management. An interview with organisation's employees revealed that one does not need to wait for a meeting with the manager to bring an important matter to her. It was indicated that the manager can be reached any time and is always available to listen. By granting autonomy to different heads of sections, decision-making takes place at different levels and decisions may be reached through informal discussions. In addition, through recognition of the contribution of beneficiaries (clients) to the wellbeing of the organisation, it allows them to contribute towards the formulation of policies that affect them. Solutions are determined not by those at the top but by those affected in cooperation with experts. It was indicated that clients have a mandate to recommend the dismissal of any staff members who does not treat them well. Such approaches to decision-making reduce hierarchy and centralization of authority and encourage more participation and access to decision making.

## **6.8. Inter organisational Linkages**

Through linkages and connections made by the NGOs, they have formed partnership with one another and built synergic relations with government. This has led to better coordination of activities and programmes and between NGO functionaries and AIDS infected people. In the fight against HIV/AIDS, organisations are linked together by an organised referral system where one

organisation refers its clients to other organisations for cases it cannot handle. For example, TASO has made a number of references to HOSPICE Mbarara for cases of cancer, while they keep on receiving clients referred to them by AIDS information centre. At AIC Mbarara, records indicated that, 496 referrals were made to TASO in the third quarter -July to September 2003(AIC 2003).

Partnership between organisations is not only observed through the above referral system but also through, implementation of joint HIV/AIDS programmes. In this respect, one organisation may contract another to help implement its programmes. For example, in the year 2003, Population service international (PSI) an organisation involved in commercial services, contracted TASO's drama group to sensitise the public on its behalf. PSI does not have such a group. TASO, records indicated that, 8 drama presentations were made to different communities in which, PSI operates. Due to good performance, the organisation was again contracted to perform more eight shows in the year 2004 and the staging of these performance was slated to start in June 2004.

Synergy, with government is observed in a number of ways:

1. Government and NGOs plan together for some HIV/AIDS programmes. For example to commemorate the international AIDS day 2003, a number of NGOs (TASO, AIC, West Ankole Diocese) were invited to participate in planning for the occasion. In addition the NGOs involved in HIV/AIDS activities, are represented at each district Aids (DAC) committee of government.
2. By having joint programmes. NGOs are considered by government as partners in the fight against HIV/AIDS. It is for this reason that, most TASO activities like outreaches and satellite sites take place in government health facilities. An interview with TASO coordinator of counselling services at Mbarara, found out that among the requirements for the organisation to have its services in any locality, is the presence of government health facility where programmes can be implemented and in particular it is necessary for medical referrals. Also, interviews with the ACWS found that, most of their counselling activities take place in the health units and are assisted by the health nurse stationed at the health units.
3. Local community leaders mobilising local population to attend the organisation programmes. ACWS and workers of the organisation indicated that some local leaders have been involved in mobilisation work although they expressed concern that the local leadership was still lax in this regard.

#### **6.9 Government and NGO relations: Costs and advantages:**

In the sections above we did indicate that NGOs have synergic relations with government. However, NGOs stand advantageous over government in dealing with social problems like HIV/AIDS. NGOs are known for having an advantage of flexibility and easily adapt to change compared to large bureaucracies of government (Muriisa 2001). The fact that there is autonomy of departments and sections in taking decisions means that rule following typical of bureaucratic organisations is relaxed. This makes it possible to respond to situations as need arises. In NGOs, decisions are taken after few consultations compared to government in which a long process takes place before a decision is reached. An interview with health officers at the directorate of health found out that NGOs are flexible, they take a small programme and implement and complete it in time before they can embark on another programme. Government on the other hand, take up too many programmes and fail to complete them. They are more democratic and result oriented (Jamil 1998) compared to government bureaucracies, which are process oriented.



## 6.10. NGOs' challenges

In spite of the above competences, NGOs and TASO in particular were found to be limited in a number of ways. In the first place, NGOs are said to be mainly limited to locality usually the urban centres with limited rural reach, TASO Mbarara was found to be operating in a radius of 75 km from TASO centre located in town. Even then, the community outreach within this radius is rotational and each selected area of operation is visited twice a month (at the beginning and end of the month). Considering the fact that HIV/AIDS patients need constant monitoring, this is far from adequate. The organisation benefits more to those who reside in town with close proximity to the centre than the rural population. The rural population often fail to meet the cost of transport to and from the centre.

During our study we also noticed that the organisation benefits a few individuals. For example, with about 10% of all children in Uganda being orphans<sup>16</sup> (most of them needy orphans) (WorldBank 1993: 185), the organisation benefits only about 0.02 %. At Mbarara branch only 35-orphaned children benefit from the school skills program annually. This number is too small for the organisation to claim too much credit. However, it should be noted that in spite of this shortfall, NGOs are praised for their "do small but better" approach to programmes.

The organisation is also heavily reliant on external funding with no income generating projects to sustain their programmes. Because of this they always wait for handouts and sometimes their programmes are not accomplished. An example of such programme is the food aid to HIV/AIDS needy patients that stalled for some time when world food programme ceased its support until Agricultural Cooperation Development International Volunteers Overseas Cooperative Assistance (ACD/VOCA) stepped in to fund the programme.

## 7.0. Conclusion

The purpose of the paper was to map the role of NGOs in mitigating HIV/AIDS challenges through building social capital and forming solidarities among people living with HIV/AIDS (PLWHAS). The challenges of HIV/AIDS are many and cannot be addressed alone by technical and formal institutional mechanisms. The situation needed a more social approach by which non-governmental organizations by creating solidarities and identities among people affected by HIV/AIDS have managed to overcome social stigma, exclusion, spread and cure of the disease. The smooth functioning of NGOs was facilitated by an enabling state encouraging NGO involvement.

It is argued in the paper that solidarity is an important mechanism for resource mobilisation, information exchange and knowledge acquisition. We discussed how NGOs, particularly TASO has utilised solidarity to mobilise resources, to make its clients, mostly people living with HIV/AIDS identify with one another for easy access to resources and psychosocial support.

The paper presented a number of institutional competences, which the organisation possesses and how these competences have been used to make its programmes succeed.

We make a conclusion that, in spite of the increasing challenges of HIV/AIDS, which are a developmental threat, building social capital is a necessary mechanism for limiting the impacts of

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<sup>16</sup> An orphan in Uganda is that child aged 0-18 years who has lost one or both parents. And a needy orphan is one 'who lacks basic necessities, lives with elderly grand parents who cannot support them, lives with large foster families which lack proper care and or child headed households' (UWESO constitution, cited in Muriisa Muriisa, R. (2001). NGOs and Rural Development in Uganda. Public Administration And Organisation Theory. Bergen, University of Bergen.

**HIV/AIDS.** Well developed social capital leads to social inclusion, it helps in information flow, reduces stress. All these can lead to sustained livelihoods for people living with HIV/AIDS.

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