

# The Politics of HIV/AIDS in Uganda

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## Acronyms

<b>ABC</b>	abstinence, being faithful, condom use
<b>ACP</b>	AIDS Control Programme
<b>AIC</b>	AIDS Information Centre
<b>AIDS</b>	acquired immune deficiency syndrome
<b>AMREF</b>	African Medical and Research Foundation
<b>ARV</b>	antiretroviral
<b>CBO</b>	community-based organization
<b>DRC</b>	Democratic Republic of the Congo
<b>FBO</b>	faith-based organization
<b>GDP</b>	gross domestic product
<b>GTZ</b>	German Agency for Technical Cooperation (Deutsche Gesellschaft für Technische Zusammenarbeit)
<b>HIPC</b>	heavily indebted poor countries
<b>HIV</b>	human immunodeficiency virus
<b>ICASA</b>	International Conference on AIDS and STDs in Africa
<b>IMF</b>	International Monetary Fund
<b>IRIN</b>	Integrated Regional Information Networks
<b>JCRC</b>	Joint Clinical Research Centre
<b>MFPED</b>	Ministry of Finance, Planning and Economic Development
<b>NGO</b>	non-governmental organization
<b>NRM</b>	National Resistance Movement
<b>PLWHA</b>	People Living With HIV/AIDS
<b>STD</b>	sexually transmitted disease
<b>TASO</b>	The AIDS Support Organization
<b>THETA</b>	Traditional and Modern Health Practitioners Together Against AIDS
<b>UAC</b>	Uganda AIDS Commission
<b>UN</b>	United Nations
<b>UNAIDS</b>	Joint United Nations Programme on HIV/AIDS
<b>UNDP</b>	United Nations Development Programme
<b>UPDF</b>	Uganda People's Defence Force
<b>UWESO</b>	Uganda Women's Effort to Save Orphans
<b>WHO</b>	World Health Organization

## Summary/Résumé/Resumen

### *Summary*

This paper traces Uganda's experience of HIV/AIDS, and the reaction of the government, civil society and communities of Uganda to the epidemic.

The motives underlying the decision in 1986 of the National Resistance Movement (NRM) government to admit there was an HIV/AIDS epidemic in the country are examined. While the HIV prevalence rate was documented to have started dropping as of 1993, it was not until 2000 that President Yoweri Museveni began using the HIV/AIDS epidemic as a success story. The paper notes that from the mid-1990s, the earlier political and economic gains of President Museveni's government were being seriously eroded by rising economic mismanagement, high-level corruption, maintenance of a de facto one-party state, failure to pacify the northern half of the country, the fomenting of regional instability and attendant human rights violations. As a consequence, by 2000 there was a need to project positive achievements—such as the reduction in HIV prevalence—to galvanize support for the flagging fortunes of the NRM government, especially with regard to sustaining donor support. In doing this, the NRM government was helped by donor dynamics, as well as by politics in the United States where Right-wing Republicans used Uganda as an example to showcase the “human side” of President George W. Bush's administration.

This paper examines the roles of various players—donors, government, non-governmental organizations, faith- and community-based organizations, and families—in the struggle against HIV/AIDS. It argues that their contributions have been appropriated in a shameless piece of political gamesmanship. The paper also points to some of the critical actions necessary to respond to the HIV/AIDS epidemic, with specific reference to Uganda.

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### *Résumé*

Ce document retrace l'expérience ougandaise du VIH/Sida et la réaction du gouvernement, de la société civile et de la population ougandaise à l'épidémie.

L'auteur examine les motifs qui ont poussé le gouvernement du National Resistance Movement (NRM—Mouvement de résistance nationale) à admettre qu'il y avait une épidémie de VIH/Sida dans le pays. Si, selon les statistiques, le taux de prévalence du VIH a commencé à baisser dès 1993, ce n'est qu'à partir de 2000 que le Président Yoweri Museveni s'est mis à présenter l'histoire de l'épidémie de VIH/Sida comme celle d'une réussite. L'auteur note qu'à partir de 1995 environ, les avancées politiques et économiques antérieures du gouvernement du Président Museveni avaient été éclipsées par une mauvaise gestion économique en constante augmentation, la corruption, qui sévissait à un niveau élevé, le maintien de fait d'un Etat à parti unique et l'incapacité de pacifier la moitié Nord du pays, facteur d'instabilité pour la région et à l'origine de nombreuses violations des droits de l'homme. Il était donc temps en 2000 de présenter des réalisations positives—telles que la baisse de la prévalence du VIH—pour rallier des appuis au gouvernement du NRM, que la chance semblait boudier, et surtout s'assurer le soutien de donateurs fidèles. Ce faisant, le gouvernement du NRM a bénéficié d'un mouvement favorable de la part des donateurs, ainsi que du climat politique aux Etats-Unis, où les républicains de droite ont vu dans l'Ouganda un exemple propre à mettre en évidence le “côté humain” de l'administration du Président George W. Bush.

L'auteur examine ici le rôle de divers acteurs—donateurs, gouvernement, organisations non gouvernementales, organisations communautaires, organismes d'inspiration religieuse et familles—dans la lutte contre le VIH/Sida. Il montre que l'on s'est approprié leurs contributions

par un stratagème politique éhonté. Il évoque aussi quelques initiatives essentielles à prendre pour maîtriser l'épidémie de VIH/Sida, en se référant au contexte particulier de l'Ouganda.

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### **Resumen**

Este estudio describe la experiencia de Uganda con el VIH/SIDA, y la reacción del gobierno, la sociedad civil y las comunidades de dicho país ante esta epidemia.

Se estudian los motivos que inspiraron la decisión en 1986 del gobierno del Movimiento de Resistencia Nacional (NRM, por sus siglas en inglés) de admitir que había una epidemia del VIH/SIDA en el país. Aunque existen pruebas de que la tasa del VIH comenzó a bajar desde 1993, hasta el año 2000 el Presidente Yoweri Museveni no empezó a presentar la lucha contra el VIH/SIDA como un éxito. El documento señala que desde mediados de los años 90, los previos logros políticos y económicos del gobierno del Presidente Museveni estaban siendo gravemente erosionados por la creciente mala gestión, el alto nivel de corrupción, el mantenimiento de un Estado formado de facto por un solo partido, el fracaso en la pacificación de la mitad norte del país, el fomento de la inestabilidad regional y las consiguientes violaciones de derechos humanos. Como consecuencia de ello, en 2000 existía una necesidad de proyectar una imagen de éxito—como la reducción en la tasa del VIH—para galvanizar el apoyo a favor del futuro vacilante del gobierno NRM, particularmente en lo que concierne el mantenimiento de ayuda financiera. Mediante esta actuación, el gobierno NRM fue ayudado por la dinámica de los donantes y por la política de Estados Unidos ya que los republicanos de derecha usaron el ejemplo de Uganda para mostrar el lado más humano del gobierno del Presidente George W. Bush.

Este estudio examina el papel de distintos actores—donantes, gobiernos, organizaciones no gubernamentales, organizaciones basadas en grupos religiosos y comunidades, y familias—en la lucha contra el VIH/SIDA. Sostiene que sus contribuciones han sido apropiadas mediante una descarada maniobra de táctica política. El estudio también indica algunas de las medidas cruciales que han de tomarse para contrarrestar la epidemia del VIH/SIDA, centrándose particularmente en Uganda.

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# 1. Background

## *Introduction*

Since 2000, the global AIDS debate has been dominated by two major issues, namely the rising prevalence levels in Southern Africa, China, India and the Russian Federation on the one hand, and the claims of the Ugandan miracle, its possible causes and lessons on the other. As de Waal (2003) points out, the Ugandan HIV/AIDS “success story” has been so politically important for the government and the international HIV/AIDS “industry” that it has rarely been subjected to careful scrutiny.

In Uganda, AIDS was first identified in 1982 in a fishing village on the western shores of Lake Victoria. Since then, the epidemic has had a devastating effect on the demographic, economic and governance structures of the country. By the late 1980s, the country was experiencing a full-blown epidemic, the virulence of which was exacerbated by social dislocation and insecurity related to economic crisis and war (Putzel 2004). By 1997, the health system was strained to breaking point in a country where the per capita health expenditure at its best was under \$3<sup>1</sup> (McFarland 1997). Patients with HIV/AIDS-related illnesses occupied more than 55 per cent of the hospital beds (Kayita and Kyakulaga 1997), and by 2000 the occupancy rate had increased to 70 per cent (Ministry of Health 2001).

In 1998, an estimated 1.9 million people were living with HIV/AIDS (UNAIDS 1999). AIDS had overtaken malaria as a leading cause of death among people aged 12–49 years and was responsible for 12 per cent of all deaths. MacAdam (2003) reported that more than 800,000 people in Uganda had lost their lives to the HIV/AIDS epidemic, leaving behind an estimated two million orphans who had lost one or both parents. Extended family systems were hard pressed to care for this vast number of uprooted children.

As the epidemic continued to spread and intensify in Africa and other areas of the world in the early and mid-1990s, prevalence rates in Uganda were reported to be declining, especially starting around 1993. International and bilateral aid agencies that provide large sums of money for HIV prevention used Uganda as an example to argue that, with sufficient resources and appropriate prevention messages, HIV/AIDS could be controlled. The international community focused on two elements of Uganda’s strategy: (i) the important role of the political leadership in speaking publicly about the epidemic at an early stage; and (ii) the government’s assumed use of the approach of abstinence, being faithful and condom use (ABC) as a combination that reduced HIV prevalence. Once Uganda’s success story was told, along with those of Thailand and Senegal, the *raison d’être* for scaled-up global funding for HIV/AIDS programmes was set.

Uganda’s success in controlling the HIV/AIDS epidemic has important national and international implications. This paper examines the political dimensions associated with this success and explores how the HIV/AIDS epidemic affected the government’s ability to minimize global pressure to bring about full democratization, carry out military actions in the region and deal with criticisms of economic mismanagement at home, while maintaining the flow of donor support.

## *The era of positive political and economic developments*

Although the decline in HIV prevalence rates in Uganda began to be noticed in 1993, it was not until 2000 that the government, or to be precise, President Yoweri Museveni, highlighted the anti-AIDS success story. The timing of events is important in explaining the rationale that awakened President Museveni’s actions before and after 2000 regarding the Ugandan HIV/AIDS crisis.

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<sup>1</sup> All \$ figures refer to US dollars.

Prior to 1998, there were several positive political and economic developments taking place in the country. By 1994, Uganda had started to demobilize a large portion of its armed forces, estimated at around 100,000. This contrasted sharply with the dictatorship and turmoil that had preceded Museveni's National Resistance Movement (NRM) government. In addition to stabilizing the economy, the NRM government had politically stabilized most of southern Uganda. A new constitution, largely acceptable nationally, had been completed in 1995, and presidential, parliamentary and local government elections had been held relatively smoothly in 1996 and 1997.

Buoyed by increased coffee and fish exports, the country's economy was growing as was the gross domestic product (GDP). At the micro level, many households outside war-affected northern and eastern Uganda experienced improvements in their livelihoods. Macroeconomic and administrative reforms that further endeared the government to the donors and a large section of the local population included privatization of state enterprises and decentralization. In 1997, an ambitious universal primary education programme was started.

The "official" account of Museveni's political and economic achievements was, however, not entirely accurate. Uganda remained a de facto one-party state, since allowing a full-fledged multiparty democracy would have resulted in a direct political threat to the NRM. The NRM could not easily predict victory in a free and fair multiparty election, and the country's economic miracle was largely propped up by huge donor resources.

### ***The warning signs: Roots of HIV/AIDS as a governance tool***

Thus, riding a wave of domestic support and a largely forgiving donor community, Museveni's government was in no hurry to promote the success of the HIV/AIDS fight. To the contrary, as the discussion on the development of a national AIDS policy will show, between 1993 and 2000 the government actually maintained a lacklustre attitude to the anti-AIDS struggle. What, then, changed in the course of Uganda's development to make the HIV/AIDS struggle a showpiece of Museveni's achievements by 2000?

It is ironic that although Museveni's approval ratings were largely due to the political and economic progress of the early to mid-1990s, these areas became, by the end of the decade, his main challenge. As internal political and economic stability increased, Uganda's leadership sought a larger regional role, with the stated aim of contributing to much-needed political stability. In his 1996 election manifesto, Museveni declared that in his next term he would work to create a confederation of East and Central Africa (Museveni 1996). Possibly in line with this dream, the Uganda People's Defence Force (UPDF) invaded the Democratic Republic of the Congo (DRC) for the first time in 1997 to remove the regime of President Joseph Mobutu, who was accused of harbouring the 1994 Rwanda genocide perpetrators, or *interahamwe*. A year after the invasion, the relationship with Mobutu's successor, Laurent Kabila, soured. Rwanda and Uganda ignored Kabila's orders for their armies to leave the country. Instead, both governments increased their presence in 1998 and 1999. Soon, the UPDF became embroiled in local Congolese conflicts or offered support to rival local factions. These in turn destabilized the entire eastern region of the DRC, leading to the death of thousands of Congolese civilians (Amnesty International 2003a). Consequently, Uganda was brought before the United Nations (UN) Security Council (Amnesty International 2003b) and the International Court of Justice in The Hague. The worst moment for Museveni's DRC debacle occurred soon thereafter when the UPDF lost the trust of their erstwhile allies, the Rwandese Patriotic Front, and in 1999, lost to them three times in the fighting over control of the mineral-rich city of Kisangani.

A political analysis showed that Museveni's invasion of the DRC was largely motivated by economic gain for himself and his family. Analysts have pointed out that in the DRC, the UPDF was openly utilized as a tool for the financial benefit of military officers, together with the political elite, to operate hastily set-up business ventures for the sole purpose of ruthlessly exploiting the resources of the country. Dietrich (2000) noted that the UPDF was effectively

rendered a corporate-military business venture or mercenary force that was used primarily to grease the wheels of the patronage system.

These motives, and the cost of human and material resources, proved difficult to admit—much less justify—both at home and globally. The country's image had not been damaged like this since the Ugandan army, under President Idi Amin, invaded the United Republic of Tanzania 20 years earlier. It was comparable to the 1966 DRC crisis, when Colonel Idi Amin was accused of being involved in the plunder of gold and coffee in the country, fomenting a crisis in Parliament that contributed to the break-up of the first republican government and setting the stage for the 1971 military coup d'état. In the new DRC exploit, Museveni risked international alienation, and this necessitated the setting up of a propaganda machinery that included projecting an image of a successful battle against HIV/AIDS.

While peace was not forthcoming for Uganda and the DRC, the image of Museveni as the first of "a new breed of African leadership" was also becoming strained for other reasons. Official corruption was being publicly challenged, resulting in a parliamentary censure of two cabinet ministers. Close relatives and friends of the president increasingly featured in acts of financial impropriety, including shoddy military and civilian tendering processes; high-level cronyism and mismanagement in the divestiture and privatization of state property; questionable bank takeover bids; and the plunder of DRC resources (Clark 2002; Tangri and Mwenda 2001). In 1998, the global community started taking note of corruption in the country (Cooksey 2003). By 2000, the annual global Transparency International Corruption Perceptions Index rated Uganda the eleventh most corrupt country in the world, moving it to third position a year later. The role of the country's first family in its poor ratings was prominent, as different reports of the UN Commissions on the Congo (IRIN 2002; Amnesty International 2003b) and independent researchers (Prunier 1999; Cooksey 2003) increasingly laid most of the blame for the plunder of the DRC's resources on the president's brother, sister-in-law, and close political and military confidants.

Uganda's high military costs had begun to rise in the run-up to the DRC invasion. The portion of defence spending in the Ugandan national budget rose from 12.5 per cent in fiscal year 1997/98 to 19 per cent for 1998/99 (MFPED 1999). This official figure did not include significant off-budget costs or some of the classified expenditures of the UPDF and intelligence services. By 2003, the Ugandan military budget of about \$150 million was not only too high, but had been boosted by cuts of 23 per cent that had been made from the budgets of other ministries, with little to show for it in terms of increased security for the northern Ugandan population (IRIN 2004). A recent analysis of the budget showed that Uganda's military expenditure rose from \$110 million in 2000 to \$200 million in 2005 (Mwenda 2005a).

In addition, despite massive donor support, the economy was sliding due to poor investment in poverty eradication and the high costs of public administration. After the 1996 elections, Museveni ended the vestiges of broad-based leadership and free public support. He increasingly relied on political patronage through a shoddy privatization process and maintained a bloated public administration. As of March 2005, Uganda had 22 cabinet ministers, 43 ministers of state, over 70 presidential advisors, 304 members of Parliament, 116 resident district commissioners in 56 districts (implying 56 district chairpersons), twice as many district speakers and their deputies, more than 1,000 district councillors, five times as many paid political leaders at the subcounty level, and the NRM secretariat with structures running parallel to those of local councils. The government increased expenditure on public administration from under \$100 million to over \$200 million between 1998 and 2003 (Mwenda 2005a). According to a Private Sector Foundation Uganda budget analysis in May 2005, the annual public administration budget consumed 15 per cent of the national budget. It was second only to education in government annual expenditure and four times the budget for agriculture (*The Monitor* 2005). In a July 2005 bid for support in removing presidential term limits in the constitution, the government increased the number of districts from 56 to 76.

The economic warning signs had become evident by 1998. The coffee price boom of the early to mid-1990s had ended by 1997 and the proceeds of the coffee stabilization tax, which had been imposed during the price boom, had mysteriously vanished. Uganda's fish exports were banned for one year by the European Union, and the entire export economy faced a major challenge. Consequently, Uganda's overall exports declined from a peak of \$639 million in 1996 to \$463 million in 1999. The government recurrent account deficit rose every year between 1996 and 1999, from \$252 million in 1996 to \$477 million in 1999. The double-digit GDP growth of the mid-1990s proved a mirage, declining to 7.4 per cent and 5 per cent in the 1998/99 and 1999/2000 fiscal years, respectively. Thus, Uganda, the much-touted economic miracle of the 1990s, was identified in 2001 by the World Bank as one of the poorest countries in the world (World Bank 2001). Average per capita income in 2003 was estimated at \$259, life expectancy at birth dropped from 47 years in 1990 to 43 years in 2001, and the population with access to clean water remained a miserable 52 per cent in 2000.

At the regional level, Museveni's government continued to measure poorly in governance, especially by 2000. Elsewhere in sub-Saharan Africa, democratic change, encouraged by the change in leadership, had started taking root by 1990. Countries such as Kenya, Malawi, Mozambique, Rwanda, South Africa, the United Republic of Tanzania and Zambia as well as Ghana, Mali, Nigeria and Senegal were all consolidating democratic ideals. Young Kabila was steadily, and against overwhelming odds, stabilizing the DRC, except in the eastern part of the country where the armies of Rwanda and Uganda maintained either a direct or proxy presence. At the same time, in countries such as the DRC, Kenya, Malawi and Zambia, the era of strongmen who held on to their countries like personal estates was rapidly coming to an end, often ignominiously.

In comparison, the foundations of Uganda's NRM "no party democracy" – an all-inclusive, all-embracing movement – had long since been undermined through the political purge that included the "Movementists" who disagreed with the president. By 2002, after the rigged and violent presidential and parliamentary elections in 2001, the government was pushing for an early change in the constitution to allow the president to stay in power for life. The NRM military and political leaders, who wanted to do things differently – and who later united to oppose Museveni's bid for a life presidency, emphasizing the need for democratic reforms – were edged out of the mainstream and either forced into inactivity or broke ranks and launched rival bids.

### ***Courting donors for general budget support and HIV/AIDS programmes***

More than any other government in the country's history, the regime of Museveni has been heavily reliant on donor support. By mid-1987, the NRM was shedding its Marxist veil, with the government signing an agreement with the International Monetary Fund (IMF). This enabled Western donors to bankroll Uganda's rehabilitation programmes to the tune of \$2.017 billion; an average of \$600 million per year. This early assistance was essential for the government's delivery of basic social services, easing the acute scarcity of basic goods and paying the civil service (Mwenda 2005b), which bolstered the legitimacy of the NRM government. Since then, donors have provided nearly the entire development budget and the bulk of the recurrent expenditure budget support, as well as massive debt relief, making them the single most important political class in Uganda. The ideological shift, together with adherence to the World Bank and IMF conditions regarding economic liberalization, yielded dividends by exonerating Uganda from the pressure to embrace multiparty democracy.

Uganda was the first country to receive debt relief under both the first Heavily Indebted Poor Countries (HIPC) Debt Initiative and the HIPC Enhanced Initiative in April 1998 and April 2000, respectively. The speed with which Uganda received HIPC assistance without having to go through the standard six-year qualifying period was suspicious, but the donor industry and government were quick to point out that it was due to the country's exemplary record of macroeconomic reform and a proven commitment to poverty reduction. The question that was left unanswered was why the impressive policy reforms and sustained economic growth, given

as reasons for Uganda's HIPC fast-track qualifications, were not enabling Uganda to pay its debts.

While macroeconomic and political reforms, such as privatization and decentralization, had been largely implemented with success in Uganda, the commitment to poverty reduction was questionable, considering the fact that less investment has gone to the production sectors, particularly agriculture, from which the majority of the poor derive their livelihood. Since HIPC relief, inequalities between socioeconomic groups and regions have been widening and remain persistent. Moreover, while the population living below the poverty line was reported by the government to have fallen dramatically from 56 per cent in 1992 to 35 per cent in 2000, it rose to 38 per cent in 2002 (Kuteesa and Nabbumba 2004).

HIPC debt relief aside, the national debt burden kept rising as a result of increased military spending, unmitigated corruption, cronyism, inefficient revenue collection and the cost of public administration. Moreover, the country was not in a position to sustain the level of export earnings because of the years of inadequate support to the country's production sector.<sup>2</sup> Uganda's exports consist mainly of unprocessed or semi-processed agricultural products, which have continued to suffer due to bad weather and low international prices.

By the time Uganda qualified for HIPC assistance in 1998, the country's total debt stock was approximately \$3.2 billion. Under both the original and the enhanced HIPC programmes, Uganda received debt relief of about \$2 billion, meaning that nearly two-thirds of the country's debt was written off (Mwenda 2005a). Table 1 indicates the aid to Uganda before HIPC relief (1991-1997) and during the first six years of HIPC assistance (1997-2003).

**Table 1: Uganda foreign aid before and after HIPC assistance**

Before HIPC		After HIPC	
Fiscal year	Aid in million \$	Fiscal year	Aid in million \$
1991/92	509	1997/98	842
1992/93	596	1998/99	795
1993/94	508	1999/2000	700
1994/95	561	2000/01	666
1995/96	668	2001/02	849
1996/97	525	2002/03	847

Source: *The Monitor* 2005.

A comparison of the six years before and after HIPC relief shows that aid to Uganda increased by approximately one-third. Moreover, donors increasingly moved from loans to grants, so that by 2001, 60 per cent of total foreign aid was in the form of grants, and the remaining 40 per cent in highly concessionary loans from multilateral donors such as the World Bank (Mwenda 2005a).

Regarding the management of the HIV/AIDS epidemic, donor funding since 1987 has remained the single most consistent factor to both state and non-state actors. The bulk of donor funds, which are channelled to government programmes, come from the World Bank Multi-Country HIV/AIDS Program for Africa; The Global Fund to Fight AIDS, Tuberculosis and Malaria; the Great Lakes Initiative on AIDS; the US President's Emergency Plan for AIDS Relief; UN agencies; and bilateral resources. Other resources are given directly to international and local non-governmental organizations (NGOs), faith-based organizations (FBOs) and eminent individuals.

<sup>2</sup> The 2005 agricultural sector budget is \$57 million compared to the \$228 million estimated for public administration.

**Table 2: Funding of HIV/AIDS programmes (in dollars)<sup>a</sup>**

Programme/project	2000/2001 (\$)		Per cent	2001/2002 (\$)		Per cent
	Donors	Government	Donors	Donors	Government	Donors
Uganda AIDS Commission (UAC) Secretariat	NA	63,080	NA	NA	160,900	NA
Uganda UAC	NA	NA		6,114,900	459,700	93.0
AIDS Control Programme (ACP)-epidemiology/survey/research	1,380,800	NA	100.0	NA	NA	NA
HIV/AIDS and right to self-protection	1,480,200	NA	100.0	NA	119,480	NA
Strategies for HIV/AIDS and education for girls	NA	NA		NA	241,370	NA
Decentralized HIV Testing and Counselling Programme	1,767,400	305,200	85.3	3,275,800	NA	100.0
Sexually transmitted infections	NA	NA		4,695,400	574,700	89.1
AIDS Palliative Care Project	596,512	NA	100.0	43,600	NA	100.0
Support to The AIDS Support Organization (TASO)	961,000	NA	100.0	1,413,900	NA	100.0
<b>Total</b>	<b>6,185,912</b>	<b>368,280</b>	<b>94.4</b>	<b>15,543,600</b>	<b>1,556,150</b>	<b>90.9</b>

NA = not applicable. <sup>a</sup> The figures were originally in Ugandan shillings and were converted to dollars at the prevailing exchange rate at the start of each fiscal year. **Source:** Adapted from the Ministry of Finance, Planning and Economic Development (MFPED), Development and Expenditure, 2000/01 and 2001/02.

While not all donations may have been channelled to noble causes, it would have been difficult, without these funds, to contain HIV/AIDS in Uganda. Table 2 shows that as of fiscal year 2000/01, the government offered limited budgetary support only two of the of the nine HIV/AIDS aid recipient areas: the Uganda Aids Commission (UAC) Secretariat and the Decentralized HIV Testing and Counselling Programme. Overall, this amounted to 5.6 per cent of the total budget for HIV/AIDS; the rest was funded by donors. In fiscal year 2001/2002, donors provided nearly 91 per cent of the annual bill to fight HIV/AIDS in the country (World Bank 2001).

Thus, by 2000, an AIDS success story in Uganda was crucial to a wide spectrum of “stakeholders” who needed to justify further funding of their programmes. A mid-term review of the UAC found that many “stakeholders”, registered with the districts as having HIV/AIDS activities, had ceased to operate because donor funding had been exhausted (UAC 2004). For the government, failure to appease donors would lead to economic collapse and seriously roll back the national HIV/AIDS programme. There was little else to show for the huge donor resources poured into Uganda than an ill-planned and poorly executed Universal Primary Education Programme, which was also riddled with fraud at the school and district tendering levels. Thus, the government and local staff of donor institutions were under pressure to identify positive outcomes of the massive funds poured into Uganda.

## 2. The Uganda HIV/AIDS Success Story and Its Background

It is against the background of restoring the credibility of Museveni’s government in economic, governance and regional terms that the HIV/AIDS success story assumed monumental significance. At the 2000 African Development Forum in Addis Ababa, Museveni (2000:3) reported a dramatic decline in HIV/AIDS prevalence:

Uganda's estimated prevalence rate reduced from around 30 percent in the early 1990s to around 8 percent in the late 1990s; the age of first sex among girls increased from 14 to 16 years; and from 14 to 17 among boys between 1995 and 1998; sex with non-regular partners has also considerably reduced; and condom use increased from 57.6 percent in 1995 to 76 percent in 1998. Next year, we shall require 80 million condoms. Most important of all, the stigma attached to people living with HIV/AIDS has virtually evaporated.

This was soon followed at the 2002 Commonwealth Heads of Government Meeting in Coolumb, Australia, when Museveni was given a special award in recognition of his personal leadership and strong commitment to the crusade against HIV/AIDS. It was again reported that Uganda's HIV/AIDS rate had been reduced from 30 per cent to about 6.1 per cent. An impressive 24 per cent reduction in HIV prevalence within seven years, as announced by the president, was certainly dramatic—especially considering that HIV infection was soaring to even higher levels in Southern Africa and did not even register a 2 per cent decline in any other developing country.

Unfortunately, Museveni's statistics were misleading. Uganda's HIV prevalence rate had certainly been high in the mid-1990s, but had never reached 30 per cent. All of the epidemiological evidence from the survey indicated that Uganda's national HIV prevalence rate had remained below 15 per cent. There were only four antenatal sites, all in the capital Kampala and nearby Jinja, that had recorded prevalence rates above 20 per cent in the early 1990s, but the president was well aware that the urban population in Uganda constituted less than 15 per cent of the national population. Most people lived in rural areas, where the prevalence rates were under 5 per cent at the time.

While Museveni was receiving global accolades for fighting HIV/AIDS, the HIV/AIDS success story was being downplayed locally. Most Ugandans burying relatives who had died of AIDS did not easily accept the propaganda of the government's successful fight against the epidemic. Moreover, the Ugandan population was well aware of the role played by non-state actors in the struggle against HIV/AIDS, and knew well that this role far outshone the government's efforts.

At the opening of the Ninth International Conference on AIDS and STDs [sexually transmitted diseases] in Africa (ICASA) in Kampala in 1995, Director-General Hiroshi Nakajima of the World Health Organization (WHO) commended Museveni for his "openness and uncompromising stand against discrimination and stigmatisation" (Russell 1998). Globally, there has been an almost mythical interpretation to Uganda's open approach to HIV/AIDS at this very early stage.

### ***Background to Uganda's open approach to HIV/AIDS***

To its credit, in 1986, the new NRM government not only announced that there was HIV in the country and that it had killed people, but it also set up the national AIDS Control Programme (ACP) to establish the extent of the spread and mode of transmission of the disease and to strengthen the safety of the national blood bank. The ACP also started a mass education campaign about HIV/AIDS, and in 1988–1989 the president participated in the nationwide AIDS education effort.

Recognizing that HIV/AIDS had causes and consequences far beyond the health sector, the UAC was established in 1992 by a statute of Parliament and mandated to: (i) coordinate the development of policies and implementation of HIV/AIDS guidelines; (ii) forge the integration and harmonization of efforts to combat HIV/AIDS; and (iii) monitor HIV/AIDS activities in the country. By 1993, the UAC had prepared a strategy document, the Multisectoral Approach to the Control of AIDS, and in 1994 a National Operational Plan was circulated to provide guidance to implementers and other stakeholders. The UAC, from its beginning to date, depends almost entirely on donor support.

Since May 1986, when Uganda openly declared that it had an HIV/AIDS problem, many of the African governments, as well as the international community, were puzzled by the approach of

the then four-month-old government in combating an incurable disease that was also highly stigmatized. As Kaleeba et al. (2000) point out, the new NRM government opened the issue for public debate and tried to develop a broad-based consensus on how to proceed. The open approach fit in well with the so-called “correct line” of the NRM government. The slogan was used to distinctly contrast the new government’s approaches to problems with those of the governments that it had violently fought and eventually overthrown in the bloody war of 1981–1986. Still, could there have been other motives that directed the Ugandan approach to HIV/AIDS?

HIV/AIDS programmes in Uganda, like elsewhere, had a bumpy start. With donor support, the ACP started a mass education campaign about HIV/AIDS using scare messages on radio and television<sup>3</sup> that promoted abstinence and condom use. Until 1990, there was no condom distribution system and the influential church groups strongly criticized their use. Condom acceptance as of 1990 was rated at about 4 per cent (*The East African* 2003) and only increased to over 40 per cent after 1992.

Museveni’s personal contribution and that of his administration to the struggle against HIV/AIDS in Uganda needs to be put into political and social context. It is noteworthy that these laudable efforts against AIDS did not assume political significance during the 1990s, but they did become an important approval and marketing issue for the Kampala regime after 2000. The question remains whether the Ugandan government took credit for this or whether the global community gave undue credit to Museveni’s HIV/AIDS work, perhaps to serve its own agenda. What has been Museveni’s real motive in the fight against AIDS? What policies and strategies have been followed to attain the present status?

The initial government reaction to HIV/AIDS can be explained by four critical factors: (i) the approach of the new NRM government of 1986 to all issues that it did not perceive as threatening to its immediate hold on power; (ii) the potential threat that HIV/AIDS posed to the army; (iii) the location of the initial threat of the epidemic; and (iv) the winning of international acceptance. The next section sheds light on some of these issues.

### ***Potential threat to the army***

At the Ninth ICASA in 1995, Museveni gave a personal explanation for his reaction to the epidemic:

I was not then [1986] aware that the problem had become so serious but, by chance, I had sent some 60 military people to Cuba and at that time we did not carry out HIV tests because we thought that everybody was all right. When the 60 got there, the Cubans tested them...Out of the 60, 18 were found to be HIV positive. When I went to the Non-Aligned summit in Harare that year [Cuban President] Fidel Castro took me aside and said: “You know there is a big problem in your country,” and he told me the story. I had a meeting...in my office and I did not give them [doctors] kind words, but out of our quarrel we evolved a programme of talking openly about AIDS and educating people about its spread (Museveni 1995).

In view of the above, it would not be far-fetched to conclude that the potential threat that AIDS posed to the army, which was Museveni’s primary power base,<sup>4</sup> led to pragmatic steps such as the creation of the ACP and the openness of the government toward HIV/AIDS. In less than a month of receiving this information, the ACP was set up in October 1986.

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<sup>3</sup> Little did the programme implementers know that such messages were increasing stigma and discrimination against People Living With HIV/AIDS (PLWHA), and hence driving the epidemic underground.

<sup>4</sup> By 1986, President Museveni lacked a political base to govern Uganda. His own political party, the Uganda Patriotic Movement, had obtained only one seat in the 1980 elections. Aware of this fact, he formed a broad-based administration that included the leadership of the older parties. Later, when he gained his own political ground around 1992, he abandoned the broad-based approach in favour of a government that owed personal allegiance to him alone.



The strategic and political importance of HIV/AIDS was thus born. It was perhaps this threat to his power base, more than anything else, that provided the overwhelming motive for Museveni's personal effort. This was confirmed when Museveni also noted at the Ninth ICASA that: "Therefore, in the case of Africa, you cannot leave this kind of problem to the doctors who, in any case, are so few the political leadership must take the leading role in combating this disease" (Museveni 1995).

### ***Location of the epidemic***

The location of the main HIV/AIDS infection within Uganda was as important as the threat to the military. The intensity and magnitude of the epidemic in the clusters where it was first identified was such that it could not be masked in any way. Whole families were being wiped out in a short time, occasionally with several members of a family being buried on the same day. On the western shores of Lake Victoria and in Rwenshama on Lake Edward, AIDS killed scores of people and caused intense national panic. Many people fled the centres of outbreak for other parts of the country, spreading the infection more widely. The epidemic was soon identified within the populations occupying the major stopping centres for truck drivers along the trans-African highway.

One such stopping point, Lyantonde town, is home to many relatives of Museveni and to many of the most senior army officers. These populations had critical significance as the basis of the president's political and military power. As he later pointed out in a number of warning messages, they faced extinction by AIDS if they did not change their cultural practices, including sharing wives between the brothers and cousins of the husbands' family and friends, and the remarriage of widows to deceased husbands' brothers.<sup>5</sup> This was also an area that had the poorest medical and other social infrastructure. This situation, coupled with the death of senior UPDF commanders who also happened to come from the same area, caused real concern for Museveni. Against this background, Rushere Hospital was hastily built near the president's home and provided with HIV screening facilities long before most of the other hospitals in the country.

In sum, opening up the issue of HIV/AIDS for public debate was relevant to the specific political, military and economic power environment of Uganda in 1986. This included a regime whose legitimacy and hold on power consisted of its emergence as a dominant military force, without a substantial economic and political base to protect it. Some of Uganda's neighbouring countries with strong economic and sociopolitical constituencies were naturally hesitant, albeit fatally, to acknowledge that their populations were dying of the most highly stigmatized human disease in modern times. It is a logical explanation for the Ugandan government's openness about HIV/AIDS in all sectors and with the general population, with the exception of Museveni's real power base: the army. When it comes to the army, Uganda matches other countries in remaining vague about the extent of HIV/AIDS prevalence within its ranks because it is considered a strategic threat to Museveni's power.

### **3. Emergence of the ABC Debate**

With the end of the Cold War, Western donors set the democratization of politics, good governance and prudent management of the economy as standards for continued donor assistance to Africa. Against these measures, Uganda's ratings were poor as it remained a de facto single party state. The war in the north of the country continued and the Parliament and a section of the population revolted at the failure to curb official corruption. By 2000-2002, the Ugandan government needed new approaches to donors.

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<sup>5</sup> These remain common and persistent practices among Museveni's Bahima kinsmen.

While winning international acceptance was probably not one of the initial reasons for Uganda's open approach to HIV/AIDS, it eventually proved a winner for the NRM government. As a demonstration of how Uganda's AIDS programme was used to sustain the country's political approval, it is helpful to examine the manner in which the government rejected the multisectoral, multiplayer approach in favour of supporting pre-marital abstinence and marital fidelity as factors responsible for the reduction in HIV prevalence, while, at the same time, attacking condom use and remaining silent on other elements.

Uganda's management of HIV/AIDS had started with multiple elements: (i) love and care for affected people; (ii) promotion of fidelity, abstinence and voluntary HIV/AIDS counselling and testing; (iii) HIV/AIDS information and communication through FBOs, NGOs and traditional healers; (iv) support and care for orphans; (v) ensuring the safety of blood transfusion services; and (vi) condom use. Around 2002, the term ABC emerged as a dominant theme to represent the approaches that worked best in reducing the prevalence of HIV. In reality, only pre-marital abstinence was promoted, since advocating marital fidelity was more difficult in the patriarchal system that characterizes Uganda, and condom use soon became a target of attack by the president and his wife and the emerging Pentecostal church movement. Elements such as love and care for affected people, voluntary HIV/AIDS counselling and testing, support and care for orphans, and the work of NGOs engaged in various aspects of AIDS work and care-giving were ignored.

### ***The distortion of the Ugandan success story***

The question of which combination of intervention strategies have reduced or controlled HIV/AIDS in Uganda needs an explanation. The proponents of ABC have not provided convincing evidence as to which of the three assumed factors—abstinence, being faithful to one's partner or condom use—is responsible for the different levels of prevalence among different population subgroups.

In selling the success story, the Ugandan government exploited a ripe situation for which the donor agents on the ground were under pressure from Western capitals to demonstrate accountability for resource allocation to fight AIDS, a sizeable amount of which had been wasted on allowances to technical advisors, purchasing vehicles and endless seminars and workshops for the elite. Thus, a dramatic success story provided the necessary rationalization and justified increasing donor funding, not only to Uganda, but also to other countries, especially in Southern Africa where infection was rapidly rising.

To the conservative Right wing in the United States, with the support of the evangelical Christians,<sup>6</sup> the reported success in Uganda signalled an opportunity to show a human side of President George W. Bush's foreign policy—the commitment of \$15 billion over five years to fight AIDS worldwide. This was done without conceding that their stigmatization had been wrong and that it negated the Christian values they claimed they were upholding. Advocating Uganda's "success story" and the ABC campaign as the right model was acceptable and useful to the conservatives since it downplayed the use of condoms, placing it third in a strategy that emphasized abstinence and being faithful.

The US administration used the "success" of Uganda's HIV prevention programme to push the Right-wing Republican agenda against the liberal Democrats with regard to family and rights of individuals centred around sexuality. How was this done? On 11 June 2003, *The New York Times* reported that the White House used President Bush's June 2003 meeting with Museveni to showcase the \$15 billion global AIDS bill that Congress had approved a month earlier as a

<sup>6</sup> According to Epstein (2005), while Catholic and Protestant churches have been running AIDS programmes since the 1980s, few evangelical Christian groups did so, and many evangelical Christians were silent or worse. Evangelist Jerry Falwell claimed that AIDS was God's judgement on promiscuity, and former US Senator Jesse Helms, a long-time congressional ally of the evangelicals, told *The New York Times* on 5 July 1995 that AIDS funding should be reduced because homosexuals contract the disease through their "deliberate, disgusting, revolting conduct". When lawmakers moved to amend the Americans with Disabilities Act to protect people with HIV from discrimination, some evangelical Christians lobbied against them. In a 2001 poll, only 7 per cent of American evangelicals said that they would contribute to a Christian organization that helped AIDS orphans.

means to highlight the Bush administration's support of family values in foreign policy (Bumiller 2003). According to *The New York Times* report, this was politically palatable to Bush's conservative base because of its emphasis on sexual abstinence. Bush praised Museveni for his extraordinary leadership and demonstrated ability in turning around Uganda's HIV/AIDS epidemic. Bush noted that Uganda's success provided inspiration and persuaded him that HIV/AIDS money could be well spent in Africa. It was at this time that Uganda's ABC campaign was globally announced.

That was in public. In private, it was reported, Bush pressed Museveni to explain Uganda's role as a weapons supplier to militias in the then DRC's five-year-old war in which an estimated 2.5–3.3 million people had died. Bush and State Department officials also raised serious questions regarding Uganda's human rights record and urged Museveni to respect the constitutional term limit and provide for a smooth handover of power to a newly elected president in 2006.<sup>7</sup>

In 2003, during the congressional debates over the Bush administration's AIDS bill, the virtues of ABC were hotly debated and unfortunately distorted (Epstein 2005). Republicans argued in favour of earmarking funds for abstinence-only-until-marriage programmes, while Democrats tried to defend funding for condom programmes. In the midst of the proceedings, Uganda's first lady, Janet Museveni, flew to Washington, DC, and presented a formal letter to Republican lawmakers stating that abstinence was key to Uganda's success. Her "expert opinion" helped secure the \$1 billion funding earmarked for abstinence that appears in the final bill.

Janet Museveni's claim that abstinence had triumphed over AIDS in Uganda was incorrect. Although HIV rates in pregnant teenage Ugandan girls fell rapidly during the first half of the 1990s, between 1988 and 2001 the average age at which young Ugandan women started sexual activity increased by less than a year and Uganda's teenage pregnancy rates (a strong proxy indicator of their sexual behaviour) barely changed.<sup>8</sup> From 2004 Museveni and his wife, in line with their US Right-wing Republican friends, led a crusade against condom use at national and global levels. On 15 May 2004, in an address in Rakai during the installation of a hereditary chief, Museveni said:

I am going to review this issue. I will open war on condom sellers. Instead of saving life they are promoting promiscuity among young people. When I proposed the use and distribution of condoms, I wanted them to remain in town for the prostitutes to save their lives.<sup>9</sup>

According to *The New Vision* of 17 May 2004, Museveni's newly adopted stand was that the use of condoms is inappropriate for Uganda and Africa. He attributed the decline in infection rates to people's deliberate attempts to avoid sex, and yet they now seemed to be abandoning abstinence and using condoms instead. He also believed that the countries that emphasize use of condoms experience higher rates of HIV incidence. At the International AIDS Summit in Bangkok in July 2004, Museveni decried condoms as encouraging promiscuity and again lashed out at their inappropriateness for Ugandans (IRIN 2005). He termed condoms as an "improvisation and not a solution" and said he preferred "optimal relationships based on love and trust instead of institutionalized mistrust, which the condom is all about". In 2004, his wife led a march for virginity through the streets of Kampala.

<sup>7</sup> Article 105 (2) of the 1995 Constitution of Uganda stipulates a limit of two five-year terms for the president. Although Museveni has been in power since 1986 and by 2006 will have ruled Uganda for 20 years, the Cabinet has proposed to the Constitutional Review Commission that the term limit should be lifted to guarantee him or any other president a life term if they continued to win elections.

<sup>8</sup> Even today, adolescent pregnancy rates in Uganda are among the highest in the world. More than half of all Ugandan women have been pregnant by age 19. Based on research findings from Uganda and elsewhere, Human Rights Watch (2005), the Center for Health and Gender Equity, quoted in Epstein (2005) and Health and Development Networks (2004) concluded that every abstinence-only programme that has ever been evaluated has failed to reduce rates of teen pregnancy or STDs and accused the US government of violating the rights of young people to information about sexuality, condoms and other methods of contraception that could save their lives.

<sup>9</sup> *The New Vision*, 17 May 2004, p. 2.

A report of a panel study of 10,000 people aged 15–44 in 44 villages in the Rakai District found that the number of women infected with HIV dropped from 20 per cent in 1994 to 13 per cent in 2003. For men, the rate declined from 15 per cent to 9 per cent during the same period. However, there was no observed increase in abstinence or monogamy as the number of men reporting two or more sexual partners in the previous year rose from 28 per cent to 35 per cent, though condom use did increase in casual relationships. In addition, more HIV-positive people died per year than had their lives extended as a result of new sero-conversions (Wawer et al. 2005). The implications of this are that the promotion of pre-marital abstinence, which was adopted as the lead strategy by the Ugandan government and its backers, is not a feasible approach. Apparently, death (which the politicians cannot acknowledge as a victory) and condom use (which the Bush administration, the Republican Right and their emerging Pentecostal/evangelical churches in the United States and Uganda do not want to hear about) have been responsible for the Ugandan success story. Another element that the Ugandan president does not want to acknowledge is the fact that pre-marital abstinence, which used to be harshly enforced in pre-colonial days, no longer works since people are marrying later due to a better education and modern economic realities.

#### 4. Evidence of Uganda's Declining HIV/AIDS Prevalence

Benell (2003) notes that, despite the massive scale of the HIV/AIDS crisis, there is no country in Africa that has good quality data to accurately monitor the levels of, and thus the trends in, national HIV prevalence rates. Uganda used sentinel surveillance among antenatal mothers in selected clinics as the basis to claim a decrease in HIV prevalence. Figure 1 indicates a decline in HIV prevalence between 1993 and 1996 and a levelling-off in 1997. Assuming that it takes time for behavioural changes to have an impact, and that there is a time lag between infection and the detection of the virus, then it was likely that the decline in prevalence noticed in Uganda was a result of behavioural changes that occurred in the mid- to late 1980s.

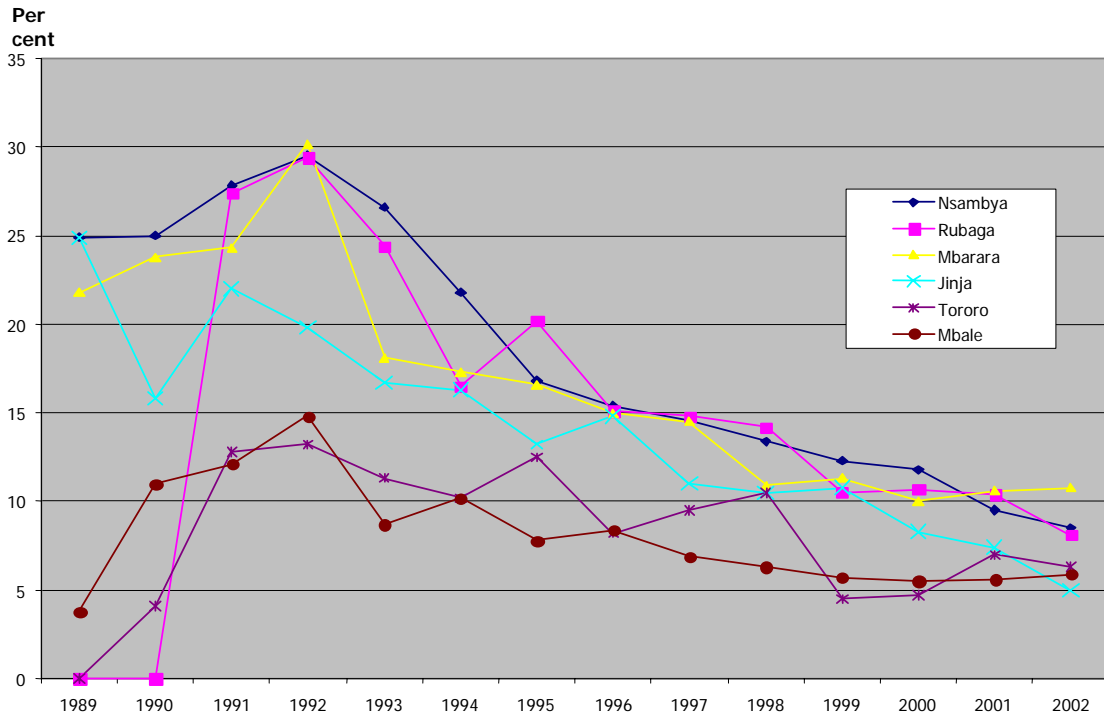
This period pre-dates the establishment of the UAC and its much-heralded official policies. Figure 2 shows the comparisons for 13 of 19 sentinel surveillance sites that had recorded data in 1998 and 2002. In 2002, HIV prevalence rates among antenatal attendees in 13 of the 19 sites averaged 6.2 per cent. In one site in Kampala,<sup>10</sup> the prevalence rate dropped from 29.4 per cent in 1992 to 14.2 per cent in 1998 to 8.1 per cent in 2002. Similar declining prevalence rates were recorded in other major towns.

Of the 13 sites, eight had more than a 1 per cent decline in the prevalence rate between 1998 and 2002. Four sites – Mbarara, Mbale, Hoima and Lacor – had less than a 1 per cent decrease. Moyo increased from 3.2 per cent to 4.3 per cent. Most of the centres with a significant decline in prevalence were in the capital Kampala and neighbouring Jinja. Three of the six centres had no clear pattern of decline and rates fluctuated from year to year. Tororo, for instance, decreased from a rate of 10.5 per cent in 1998 to 4.5 per cent in 1999 and then rose to 7 per cent during the following two years, finally decreasing to 6.3 per cent by 2002. In 1998, Mbarara had a prevalence rate of 10.9 per cent, rising to 11.3 per cent in 2000, then decreasing to 10.6 per cent over the next two years and again rising to 10.8 per cent by 2002. A similar erratic pattern was evident in Mbale. In short, it is rather misleading to talk of a general trend in the decline in HIV prevalence in Uganda based on sentinel surveys between 1998 and 2002.

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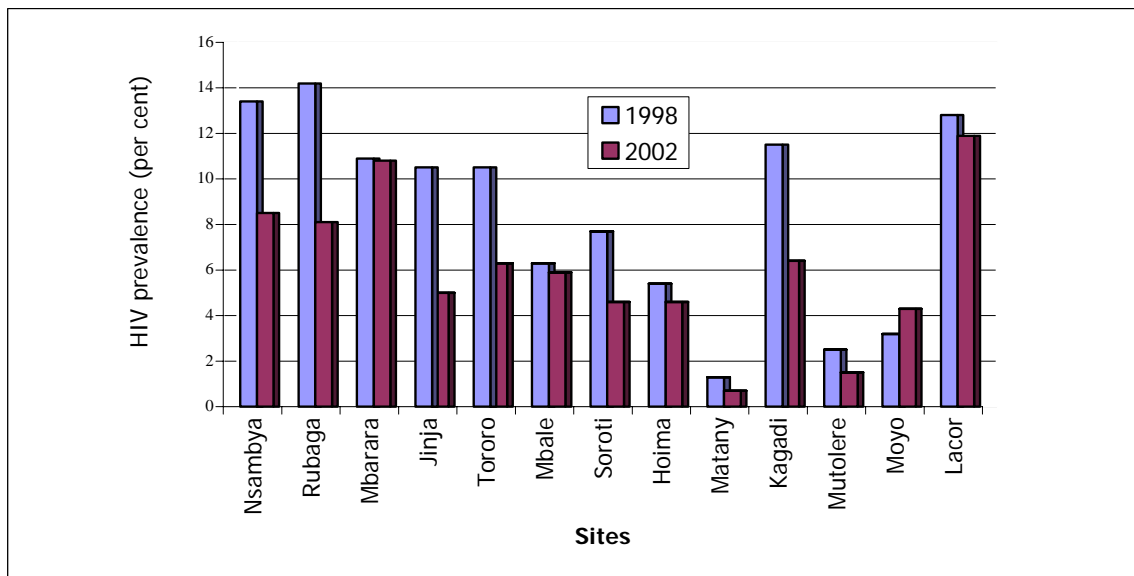
<sup>10</sup> Rubaga and Nsambya hospitals indicated in figure 2 are located in Kampala.

Figure 1: Antenatal sentinel sites HIV infection prevalence rates (per cent)



Source: Ministry of Health 2003.

Figure 2: Sero-prevalence rates among antenatal attendees in 1998 and 2002



Source: Ministry of Health 2003.

The 2002 surveillance report noted that 6.5 per cent of the women sampled at 20 antenatal clinics countrywide had HIV/AIDS, compared to 6.1 per cent in 2000. The AIDS Information Centre (AIC) reported that prevalence among young people remained at 10.1 per cent for both 2000 and 2001.

Based on these surveillance reports, the Ministry of Health declared that national adult prevalence was 4.2 per cent in rural areas and 8.8 per cent in urban centres (UNDP 2002). However, the same sources expressed caution due to underreporting, noting that only a small fraction of all new cases was known and/or reported to health facilities, and it was likely that the prevalence rates were higher than what has been presented (Ministry of Health 2003). The ACP also cast doubt on the reliability of sentinel surveillance data, while the UAC called for more representative studies to accurately measure the incidence of HIV/AIDS.

Parkhurst (2001) points out that sentinel surveillance data tell a complex story. He argues that there have been some impressive reductions, some less impressive declines and, in other locales, no decrease in HIV/AIDS rates at all. However, the Ugandan government has pilloried Parkhurst and those who have tried to question any emerging critique of the official line of “success” against HIV/AIDS. In August 2002, two cabinet ministers in a parliamentary debate attacked those questioning the president’s claims and declared that the success story was based on “scientific research”. The duo did not care to explain the science behind the president’s claims.

### ***Limited coverage***

In all of the sentinel surveillance sites only antenatal mothers were covered. In Uganda, females from 15 to 19 years old constitute one of the high-risk groups. A Deutsche Gesellschaft für Technische Zusammenarbeit (GTZ) sero-survey among 7,000 people in Kabarole indicated that in 1991 HIV infection rates were higher than 30 per cent among females aged 15–19 years (Kilian 2002). Many of these young women were not pregnant and hence not seeking antenatal services. Other high-risk groups that are omitted from the surveillance data include males from 15 to 24 years old, long-distance bus and truck drivers, residents of remote fishing villages, commercial sex workers, the many people within the smaller trading centres who rarely need or ever seek antenatal services in the designated health units, and the more than 1.5 million Ugandans living in internally displaced people camps where sentinel surveillance is not carried out. For example, HIV prevalence in war-affected areas of northern Uganda is nearly double the national average (Anderson et al. 2004). In addition, not a single surveillance site among those mentioned above is located within a medical facility of the armed forces.

Moreover, only public health units and relatively inexpensive mission hospitals are included in the antenatal sentinel surveillance sites of Uganda. The bulk of the affluent segments of the population rely on private providers. It is also important to note that this surveillance is only accessible to populations within easy reach of the sites. Most mothers in rural Uganda do not have access to antenatal services, including in the 29 health units where surveillance has been established. In effect, therefore, the claims of high HIV/AIDS prevalence of nearly 30 per cent in 1992 referred only to antenatal mothers that attended clinics in the largely urban areas where sentinel surveillance was established at that time, whereas many rural areas and those off the main trunk roads were estimated to have much lower rates. Controlled sample sero-surveys with national or subnational<sup>11</sup> coverage since 1988 have indicated that no more than 12 per cent of the population in Uganda outside urban areas had HIV/AIDS. A 1996 British Medical Research Council study in Rakai reported a prevalence rate of 12 per cent among young men five years before the sero-surveys (Mbulaiteye et al. 2002). Likewise, a community randomized controlled trial to investigate the impact of improved STD management and behavioural interventions on HIV incidence in rural Masaka indicated that HIV prevalence rates among 15,000 adults at the baseline in 18 rural communities in 1994 were no more than 10 per cent (Kamali et al. 2002). Similarly, the 1991 GTZ sero-survey in Kabarole revealed rural rates—rural and roadside combined—of little more than 10 per cent, though the report concluded that infection rates were much higher in the urban centres, most likely associated with better

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<sup>11</sup> All sero-surveys conducted at the subnational level and cited in this paper (Kabarole, Masaka and Rakai) have been carried out in areas with estimated higher prevalence rates than the rural average and yet none has revealed general population prevalence rates above 12 per cent.

educated people with greater mobility and more possibilities for “sexual networking” (Kilian 2002).

#### Rural-urban differences

Except for Rakai, where HIV first broke out, the prevalence rates were initially higher in Uganda’s urban areas and among selected groups. With time, rural prevalence rates have increased sharply due to the relatively lower levels of awareness about HIV/AIDS and condom use. Thus, it is misleading to rely on surveillance data that largely relate to attendees of urban-based health units where prevention interventions and access to health facilities are highest, while largely omitting the rural areas where a new wave of resurgence of HIV/AIDS has made inroads. Indeed, as Parkhurst (*The Monitor* 2002) noted, information from a small number of urban antenatal clinics, hardly indicative of rural Uganda where about 87 per cent of the population lived, appears to be the basis for HIV/AIDS statistics and is therefore not representative. Unfortunately, he added, these unfounded claims of the Ugandan success have persisted in international policy discourse.

#### ***Overall assessment of the evidence***

Although surveillance shows trends in the sentinel sites over time, especially where population mobility is limited, it will rarely accurately reveal the level of HIV/AIDS in the general population. In the case of Uganda’s urban areas, there was a significant decline in HIV/AIDS prevalence starting around 1993. However, most studies have revealed that sentinel surveillance data tend to inflate the level of prevalence in the general population. The reality is that the biases in sentinel surveillance data, especially with regard to the omission of several population subgroups such as males, most rural women with limited access to the sentinel surveillance sites and some of the high-risk groups, demand caution in our conclusions about its usage. Therefore, while HIV prevalence rates based on sentinel surveillance indicate a decline, this decline is not only uneven, its causes are also not known. Moreover, the recent national survey results appear to indicate that either HIV prevalence was slightly higher than earlier indicated or that the decline in its prevalence had levelled off, again for unknown reasons.

The reasons why the international community, which is often cautious in using data, seems to have been quick in accepting the Uganda claims without concrete proof, remain a subject of conjecture. Parkhurst (*The Monitor* 2002) noted that in claiming declining HIV/AIDS prevalence in Uganda that

the standards of proof for policy recommendations seem to have been lowered to provide the international community with the African success story it wanted, or even needs.

To Parkhurst, the pressure to produce results may have been due to “donor fatigue” and a notable lack of willingness to fund unsuccessful projects, combined with an overall reduction in funding available to Africa, as well as low morale among health workers, who needed a success story to boost them.

## **5. An Evaluation of Government Response in the HIV/AIDS Struggle**

Nearly every official government document concerning HIV/AIDS in Uganda describes the country as having adopted a policy of openness and political commitment to combating HIV/AIDS from the earliest days (UAC 2004, 2000). The government argues that it is basically these two elements in its policy that have contributed to increased levels of awareness among the population about the dangers of the epidemic and understanding of the means of prevention (UAC 2004) and, by implication, for the reduction in HIV/AIDS prevalence.

The government points to the personal efforts of Museveni in addressing the different facets of HIV/AIDS, the founding of the ACP in 1986 and the UAC in 1992, and the multisectoral approach, with the establishment of HIV/AIDS desks in different government ministries, as indicators of openness and commitment to the anti-HIV/AIDS struggle (UAC 2000). However, beyond these efforts, it is apparent that the government could have done more in policy development, resource inputs and coordination as a part of its political commitment in the fight against the epidemic.

Assuming that there has been a decline, or more accurately, a stabilization in HIV/AIDS in Uganda, the question is: Who has been responsible for this achievement? As indicated below, the role of Museveni and the government has been overplayed, both locally and globally, at the expense of other critical players in the struggle against HIV/AIDS.

### ***Mass media campaigns***

It would appear that the government's openness about the epidemic relates primarily to the mass media campaign on HIV/AIDS issues supported by the government and NGOs in the early and mid-1990s. Uganda enjoys a relatively free press, and the Ugandan population generally discusses issues freely. The liberalization of the mass media, particularly the commencement of private radio and television broadcasting in the mid-1990s, has expanded public awareness of issues related to HIV/AIDS. Many private operators launched AIDS programmes on their own initiative to inform the public about HIV/AIDS and to fight the associated stigma. At a time when HIV/AIDS victims were highly discriminated against in Uganda, the radio was used for education and sensitization on the transmission of AIDS and coexistence in society with PLWHA. Another important media outlet is *Straight Talk*, a small newsletter that delivers frank information about sex and relationships to 15,000 secondary and primary schools and 600 community groups.

However, freedom of the press in Uganda is relative and exists only as long as the press does not threaten Museveni's real power base, especially the army. For instance, when proceedings of the inquiry about military commanders who had for years siphoned off billions of Ugandan shillings by continuing to draw salaries, allowances, food supplies and military hardware on behalf of deserters and those killed in battle, or by illness such as AIDS (ghost soldiers), the press was gagged from publishing this information. In another example, in October 2002, the independent newspaper, *The Monitor*, was closed down for a week for allegedly publishing information about an army helicopter crash in northern Uganda where the then 16-year-old war continued to rage.

Therefore, a free debate about AIDS in the press and other media, especially regarding the civilian population, is allowed because, as with other non-military issues, it does not pose an immediate threat to Museveni's power. Open discussion allows Ugandans, especially the urban minority, to vent their anger and frustration without the state agreeing to any meaningful reforms. This explains why, during the late 1980s and early 1990s, HIV/AIDS prevention and anti-stigma messages featured frequently in the press and billboards of health, education and administrative units. Different government departments, such as the army, carried out targeted campaigns to promote and distribute condoms. Museveni emphasized:

Radio was also used to pass on the message, guaranteeing that almost everyone was reached. The language used and the timing is crucial. It must be in the vernacular, clearly expressed and at a time when people are listening (2000:3).

While information, education and communication as a strategy was common in the pre-1995 anti-AIDS struggle, thereafter the momentum began to slacken. The health messages on HIV/AIDS have been significantly reduced. Most public posters and anti-HIV/AIDS billboards have disappeared (Epstein 2005). Flyers, T-shirts and pamphlets on HIV/AIDS that used to be produced by NGOs and FBOs have vanished. By 2001, the bulk of donor funds for HIV/AIDS



was shifted from the UAC to the Ministry of Health. The newly appointed minister of health, a close relative of the president, had been censured for corruption by the sixth Parliament. Yet the minister and his personally appointed staff retained direct supervision of donor funds such as the \$290 million released between 2002 and 2005 under the Global Fund. According to a petition to Parliament by AIDS activist organizations in Uganda in May 2005, part of this money was being diverted to finance government political programmes (Nsangi and Nyanzi (2005); no independent audit of these funds had been carried out at the time of writing nearly three months later.

### ***Approach to stigma***

Fighting stigma was also one of the mandated tasks of the UAC. Museveni stated in 2000 that Uganda introduced a policy of non-discrimination against people with HIV/AIDS. Unfortunately, fighting the stigma is one area where the president and his government have done poorly. While, on the one hand, the president may have helped in giving the HIV/AIDS control campaign visibility, on the other hand, his personal approach to PLWHA is not above reproach. An example of stigmatization of PLWHA that has appeared in the Ugandan press since 2000 is the way HIV/AIDS has been handled in relation to the armed forces. The president stated, "There is no reason why People living with HIV/AIDS should be offered opportunity in the army. Because training officers who later die not from bullets in combat but from AIDS is so frustrating. It is like fetching water in a basket with holes" (*The Monitor* 2000:1-2).

At the 2000 African Development Forum the president stated that the army is not a hospital, implying that HIV-positive people had no place in the army. In a statement to Parliament, the minister of state for defence added, "With the advent of HIV, one of the factors considered when promoting individuals in the army is their HIV status. If your HIV status may not be conducive to your training...that would reflect against your chances of advancing further".<sup>12</sup>

In accordance with the above policy, recruits who test positive are dismissed, contrary to the spirit of the Constitution and prejudicial to the rights of PLWHA to employment and presumed dignity of person. Similarly, active discrimination of HIV-positive members of the UPDF through compulsory screening and dismissal of those who test positive from the carrier development programmes, promotion or deployment is unconstitutional, albeit practised.

In an interview with John Githongo of *Executive Magazine* in September 1993, Museveni said:

I am worried about other things. AIDS is not really such a big crisis. Voluntarily you go and look for it. What will happen is that many people will die and then others will begin to fear...The population of Uganda is now 17 million. Even if you assume that 2 million will die, you will still remain with 15 million which is higher than the population of 1956 (Tshihamba 2001).

Similarly, on several occasions the president has said that the infection is self-inflicted through "indisciplined" sex, comparing the process with sticking one's hand into in a hole with a snake in it. According to one senior army officer, such an attitude has been translated into the governments' reluctance to provide antiretroviral (ARV) drugs for people that need them or even facilitate the process for donors to do so.

The lowest moment occurred during the run-up to the March 2001 presidential elections when Museveni told a reporter from *Time* (2001) that his main challenger, Kizza Besigye, had AIDS. In a presidential election petition, Besigye declared that this was a false statement and made with the malicious intent to portray him as a person in poor health and therefore unfit to govern the country. Museveni also stated "A President should be someone fully in control of his mental and physical faculties. ... [T]here is no reason to wait for someone to get into office and get sick".<sup>13</sup>

<sup>12</sup> Statement of the minister of state for defence to Parliament. See *The New Vision*, 8 September 2000, p. 1.

<sup>13</sup> See *The Monitor*, 12 March 2001.

Also in March 2001, the female vice president of Uganda, a medical doctor, stated to Parliament, “people with HIV/AIDS should be told in the face since AIDS is like malaria”. The effect of this statement on the floor of Parliament from the second highest office in the executive implied that government wanted open disclosure of the HIV status of individuals, a practice that has attracted global condemnation as violating the human rights of individuals and is practised only in a handful of the most totalitarian states in the world.

Unfortunately for Uganda, although Parliament has rightly refused to adopt the open disclosure of HIV sero-status as policy, a number of practices against PLWHA in some sections of the private sector occur, such as mandatory testing for HIV before being hired, compulsory termination, lack of promotion (as in the army) and ostracism by other workers. This situation is setting the clock back and undoing the work of Ugandans in fighting the spread, stigmatization and denial of HIV/AIDS.

### ***Development of a national HIV/AIDS policy***

The need for a national policy on HIV/AIDS has long been recognized by the UAC, and to its credit, a spirited effort was made to write and adopt such a policy. In 1993, the UAC drafted guidelines for an HIV/AIDS policy. In 1996, the process of review of the 1993 policy guidelines was started. The completed draft was sent to the president’s office in 1999 for completion of the legislative process. Receiving no action from the relevant ministry, in 2002 the UAC, with funding and support from the United Nations Development Programme (UNDP) and the WHO, hired consultants to write yet another national AIDS policy. The consultancy was completed and the draft submitted once again to the office of the president in February 2004 for forwarding to the relevant legislative branches of government. As of mid-May 2004, no action on this draft document had been taken.

According to the draft policy document, the UAC has faced major constraints as a result of a lack of a national HIV/AIDS policy, including the failure to implement policy guidelines that have legal backing, and the inability to protect the rights of people at risk of infection, as well as those infected and affected, in the scale-up of activities in the anti-HIV/AIDS struggle. In addition, although Uganda is a signatory to many international conventions, agreements and commitments on HIV/AIDS, health, women, children and workers, the country has yet to ratify a number of these efforts for adoption and implementation. Without a national policy, administrative and operational policies of different sectors are at best fragmented and at worst illegal and unenforceable.

As a consequence, much of the policy guidance on HIV/AIDS is missing in areas such as: (i) departmental guidelines, implementation mechanisms and resource allocation to HIV/AIDS activities; (ii) protection of employee’s rights to HIV/AIDS treatment and respect, and community level protection; and (iii) social security for widows and orphans from property grabbers.

Apologists for the lack of an enabling policy on HIV/AIDS in Uganda may argue that although there is no official policy, there are several implicit and explicit ones that have been issued by different authorities regarding HIV/AIDS that could influence its management.<sup>14</sup> However, most of these policies are draft documents and many cannot be traced to the different departments, implying inadequate implementation. Others merely mention HIV/AIDS without outlining practical strategies or identifying resources for implementing the HIV/AIDS component.

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<sup>14</sup> In the course of research for this paper, government officials pointed out as examples of these authorities, the National Orphans and Other Vulnerable Children Policy, National Condom Policy and Strategy, National Policy on HIV/AIDS and the World of Work, Voluntary Counselling and Testing Policy, National Antiretroviral Treatment Policy for Uganda, Uganda’s Vision 2025, Poverty Eradication Action Plan, National Health Policy, Local Governments Act, Plan for the Modernization of Agriculture and universal primary education.

### ***State programmes and resources for HIV/AIDS***

While policy development may have been slow, any commitment on the part of the government ought to have been demonstrated in programmes and resources in the fight against HIV/AIDS and its impact. For instance, government commitment could be exhibited through the treatment of PLWHA at the national and local levels, as has been done in Botswana, or mitigating the impact of HIV/AIDS among their families. By mid-2004, the Ugandan government had yet to fund ARVs for the thousands of people in need of treatment, and was only paying lip service to supporting prevention, palliative care or impact mitigation. While for over five years the government had acknowledged the link between HIV/AIDS and poverty in the Poverty Eradication Action Plan, it had done little to proactively target AIDS-affected families with programmes for addressing poverty. Most of the current effort, such as prevention, behaviour change, treatment, psychosocial support, impact mitigation through economic protection and orphan care, reveals an absence of serious medium- or long-term planning by the state.

Even in institutions of critical importance to Museveni, such as the army, HIV/AIDS activities are either totally lacking or carried out on an ad hoc basis. Yet, it can be argued that the government has a number of medical facilities that can be used by members of the armed forces. At the Joint Clinical Research Centre (JCRC) some members of the UPDF receive full ARV treatment and others have been recommended for treatment abroad at the expense of the UPDF. However, it was reported by key informants that there is a lack of transparency regarding the criteria for determining who will receive treatment. One of the key informants interviewed for this paper summed up the situation:

If one sees the list of beneficiaries of Museveni's authorization for treatment, it becomes difficult to avoid accusing him of nepotism. The ordinary officer and man of UPDF cannot even access treatment [for] the ordinary conditions that require antibiotics or anti-fungal drugs. The policy of 'no treatment' coupled with discrimination and stigmatization has worked greatly against prevention and control measures within the UPDF.<sup>15</sup>

As indicated by a doctor at Mulago Hospital, what has been achieved in medical terms of HIV/AIDS patient management has been in spite of the inadequacies of the national health system. The doctor cited as an example that even at the National Referral Hospital patients must supply gloves, and at times syringes, for the doctors to use, and the idea of state-provided medical sundries is alien to most medical facilities in the country.<sup>16</sup>

### ***ARV therapy***

ARV therapy in Uganda dates back to the early 1990s when individuals with sufficient resources would go abroad for AIDS clinical treatment. The JCRC started administering ARVs around 1996, and the Ministry of Health and the Joint United Nations Programme on HIV/AIDS (UNAIDS) introduced the Drugs Access Initiative pilot project in 1998. As of December 2003, approximately 17,000 people had been treated at the JCRC, primarily at their own expense, although a few army officers who were personally selected by the state were treated at government expense. Those already on therapy were reportedly having difficulty covering the cost of their treatment and laboratory tests.<sup>17</sup>

An article in *The Lancet* of 16 December 2002 revealed that Uganda's Ministry of Finance, Planning and Economic Development (MFPED) had refused to lift the budgetary ceiling of the Ministry of Health from \$107 million for fiscal year 2002/03, despite an expected three-year grant of \$52 million from the Global Fund (Wendo 2002). The argument of the MFPED rested on the need to control expenditures in all government departments in order to stabilize the

<sup>15</sup> Personal communication with a medical doctor with extensive knowledge of working with a health unit handling military officers in Uganda, 14 July 2003.

<sup>16</sup> Personal communication with a senior consultant, Mulago Hospital, 10 August 2003.

<sup>17</sup> As of 1 December 2003, patients at the JCRC had to pay between \$28–\$60 per month for generic drugs and \$86–\$560 for brand name drugs; there was no government subsidy for ARVs.

national economy and reduce dependence on donors. The MFPED maintained that spending the \$52 million on importing ARVs and tuberculosis and malaria drugs would be tantamount to promoting “consumerism, making the country’s exports uncompetitive”<sup>18</sup> and lead to macroeconomic instability as the level of funding through the Global Fund was not sustainable.

Faced with political pressure, the Ministry of Finance agreed to a special window that would allow the Global Fund money to be spent. In 2004, that window was closed and the ceiling re-imposed. However, the Ministry of Health was incapable of spending more than a fraction of the funds largely because its human resources and other facilities were not yet prepared to handle the required massive scale-up. The question arises as to why, with so many people dying of AIDS and other preventable diseases in Uganda, the government has invested so poorly in the human and institutional resources of the health sector that the health ministry cannot spend the funds it has requested. Yet, in October 2002, the government had appropriated 23 per cent of all ministerial budgets and given the funds to the Ministry of Defence to continue fighting the then 16-year war in northern Uganda.<sup>19</sup>

According to the coordinator of the antiretroviral therapy programme in Uganda, the goal is to provide ARVs to some 100,000 patients by 2007, and to ultimately provide universal access. While the goal of expanding ARV therapy to all district and mission hospitals within one year is laudable, it will require resources, staff training and commitment of all agencies concerned. Many government facilities lack the logistic systems, infrastructure and training needed for delivery of ARVs. Interviews in Mulago in 2004 indicated that the hospital was not only understaffed, and overwhelmed by AIDS patients, but also did not have ARVs and other medical and laboratory supplies. The staff were not familiar with the policy guidelines on prevention and treatment of opportunistic infections. Many patients, unable to get prescribed drugs, were forced to purchase them in private pharmacies and clinics. In this regard, little has changed since the first cases of AIDS were reported in 1986.

Researchers who had just completed a study in hospitals in Mbale, Mbarara and Mulago and who were interviewed for this paper in February 2004, reported that supplies for opportunistic infections in all government health units were at best intermittent. This is in an environment where GDP per capita is less than \$350;<sup>20</sup> 82 per cent of the population lives on less than one dollar a day (UNDP 2002);<sup>21</sup> and only half of the population lives within five kilometres of a health facility. In district hospitals, even if ARV drugs were available at reasonable prices, the cost of transport, accommodation, meals and other treatment would be prohibitive for the majority of patients.

### ***Home-based care***

Unable to cope with the rising demands of care for PLWHA, the state has generally shifted the role of care for AIDS and tuberculosis patients from hospital to home-based care as a means of reducing the pressure on hospitals and health units. Accordingly, the bulk of care for AIDS patients and those affected by opportunistic infections such as tuberculosis is undertaken by relatives.

As in other fields without a policy or implementation guidelines, and with no established referral system across the continuum, NGOs and community groups mainly implement home-based care programmes in Uganda. In 2004, the Ministry of Health developed training tools

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<sup>18</sup> The stated reason was because of the higher value of the US dollar relative to the Ugandan shilling.

<sup>19</sup> There is information from some departments that as much as 63 per cent of their operational funds were diverted in the 2003/04 budget, a move that has literally crippled operations of these departments where only officials receive their salaries and for doing virtually no work. Some donor organizations threatened to reduce their commitments to Uganda because of this move. The World Bank, for instance, threatened to withhold approval of a budget support loan of \$150 million (285 billion shillings) for fiscal year 2003/04 under the Poverty Reduction Support Credit programme, with potential disastrous effects on the performance of the economy.

<sup>20</sup> See [www.iaea.org/inis/aws/eedrb/data/UG-gp.html](http://www.iaea.org/inis/aws/eedrb/data/UG-gp.html), accessed in June 2006.

<sup>21</sup> Only Nicaragua has a slightly higher percentage of people living on a dollar a day.

and, in collaboration with NGO partners, trained health workers in 11 districts to provide guidance on aspects of home-based care.

In sum, although the government recognizes that the critical caregivers in the management of HIV/AIDS and its resultant effects are the affected relatives and community members, it has—nearly two decades after the establishment of the ACP—yet to identify mechanisms and resources to assist caregivers or systems for sustainable livelihoods of AIDS-affected households.

## 6. Non-State Actors in the Fight Against HIV/AIDS

In addition to the government and donors, Uganda's struggle against AIDS, as in most of Africa, is dependent predominantly on non-state actors, including PLWHA, NGOs, community-based organizations (CBOs), FBOs, sensitized traditional healers, the mass media and private sector operators. Many of these effective facilitators and actors have never been recognized beyond the communities they serve. Some are not even conscious of the importance of the work they do, but only react out of a natural instinct to help those in need. This section briefly outlines some of these exemplary contributions.

A 2001 inventory of groups with HIV/AIDS activities and interventions in Uganda indicated that there were 717 agencies and organizations involved in such work,<sup>22</sup> from central and local governments, FBOs, CBOs, UN and other donor agencies, and private companies (AMREF-Uganda 2001). All of these stakeholders have transformed HIV/AIDS into one of the biggest industries in the country in terms of employment and financial resources.

### **PLWHA**

The pioneering work of PLWHA and their spirited fight, both against the stigma of HIV/AIDS and for the right to care and treatment, have shaped the Uganda HIV/AIDS agenda. By late 1986, the stigma of HIV/AIDS was rife and reportedly even higher among health care workers than the general public (Kaleeba et al. 2000). As a result, The AIDS Support Organization (TASO) was founded in 1987 by a group of 15 volunteer PLWHA and caregivers to expand services for psychosocial and medical support to help overcome the secrecy associated with HIV/AIDS. Despite initial setbacks, including the death of most of the founding members, 850 HIV/AIDS clients were registered during the first year of operation. Some of the people who had initially stigmatized PLWHA but later developed AIDS or lost close relatives to the disease also joined the pool of healthcare workers, becoming some of the best patient caregivers.

In addition to the pioneering work of TASO against stigma, top musician Philly Lutaaya, who in 1989 announced that he was HIV-positive, contributed to the effort. His song, *Alone and Frightened* (see box 1), became an anthem for PLWHA and volunteers in this field. Lutaaya's music cut across a wide spectrum of the Ugandan public, especially among the youth. Even as his health failed, he toured the country, performing his music and educating people about HIV/AIDS. Lutaaya's crusade for openness led to increased understanding of the disease and the treatment of PLWHA with respect and compassion. Other groups, such as the National Guidance and Empowerment Network of People Living with HIV/AIDS in Uganda and the National Community of Women Living with HIV/AIDS, followed the pioneering work of TASO and Lutaaya.

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<sup>22</sup> This is a conservative figure, as the umbrella Uganda National AIDS Service Organizations estimates that there are over 2,000 NGOs and CBOs working on HIV/AIDS in Uganda.

**Box 1: Extract from *Alone and Frightened* by Philly Lutaaya**

Today it's me  
Tomorrow someone else  
It's you and me  
We've got to stand up and fight  
We'll take a light in the fight against AIDS  
Let's come on out  
Let's stand together fight AIDS  
In times of joy, in times of sorrow  
Let's take a stand and fight on to the end  
With open hearts let's stand up and speak out to the world  
We'll save some lives, save the children of the world.

Not all of the efforts of the PLWHA resulted in the changes they sought, and their achievements were against overwhelming obstacles. The absence of national policies and laws promoting the protection of legal, ethical and social rights of PLWHA often limited their access to resources necessary for income generation and self-support. The lack or poor state of health facilities, inadequate supplies and resource allocation for services, care and support, lack of counselling and support staff in medical units with commitment and experience in handling PLWHA or their families, high levels of corruption as well as a stigmatizing leadership and society have all remained critical barriers to PLWHA. The struggle for ARV drug access has by-passed the poor PLWHA, while the multiple disadvantages and vulnerabilities of orphans and other vulnerable children, the elderly and widowed remain an unfilled gap.

Part of the challenge lies in the lack of effective strategies to include PLWHA in national poverty eradication programmes. The stigma, ambivalence and sluggish manner in which the legal protection of the rights of PLWHA has been treated is in direct conflict with the assertion that Uganda's pragmatic approach to the management of HIV/AIDS is exemplary. Furthermore, the government's neglect has not been effectively filled by NGOs, only a handful of which currently undertake the planning for economic and material assistance in order for PLWHA to earn a living. Those organizations that have attempted to do so, such as the Uganda Women's Efforts to Save Orphans (UWESO), are prohibited by law from mixing critically needed psychosocial support with microfinance operations. Despite the huge resource inflow from donors to government for HIV/AIDS activities, many of the concerned NGOs never access donor resources that could, in turn, be used to reach the millions of affected people. Other critical players such as faith-based actors, traditional leaders and women's groups are yet to be brought into the mainstream of planning and decision making when it comes to donor funding for HIV/AIDS work.

FBOs constitute 16 per cent of the total number of HIV/AIDS agencies. Given the poor coverage and quality of services in public health care, these organizations have stepped in with a chain of health units that provide relatively more comprehensive health care and palliative treatment to AIDS patients at a minimal fee. As the African Medical and Research Foundation (AMREF)-Uganda (2001) study noted, FBOs are the main providers of psychosocial support to PLWHA, especially in remote areas where services are more problematic.

### **NGOs**

The visible face of the anti-HIV/AIDS struggle in Uganda has been shaped by the work of NGOs and CBOs. Not only have these organizations increased HIV/AIDS awareness, but they have also provided PLWHA with counselling, food, shelter, clothing, school fees, basic training and income-generating schemes. TASO remains the lead agency in the country in providing post-test counselling and support. Since its beginning in 1987, TASO has grown into one of the largest national organizations, with eight branches nationwide and a registered clientele of

65,000. It works as the first referral point for the AIC and other HIV/AIDS testing and counselling services for HIV sero-positive people. Other services provided by TASO include medical care, social support, capacity building and training, AIDS education and sensitization and a resource centre. The organization has inspired many other groups in sub-Saharan Africa.

To address the needs of youth and children in school, the NGO Straight Talk Foundation was founded in 1993. The organization publishes two monthly newsletters, *Straight Talk* and *Young Talk*. Both newsletters seek to influence changes in sexual behaviour among youth by providing information about keeping adolescents safe from HIV/AIDS and STDs, and by communicating techniques that will promote better health. The *Straight Talk* newsletter has a monthly print run of 155,000 and is distributed through 15,000 primary and secondary schools, over 400 tertiary institutions and 600 community groups in Uganda. An estimated 400,000 young people read the publication regularly.

Launched in 1998, *Young Talk* has a monthly print run of 270,000. It targets adolescents (10–14 years old) and is sent to all 12,000 primary schools in Uganda; copies are also sent to teacher training colleges. *Young Talk* advocates sexual abstinence and provides information about condoms whenever requested by readers.

Regarding HIV/AIDS counselling and testing, AIC started operations in 1990, and by 2001 had a clientele of over 500,000. The AIC carries out voluntary counselling and testing of HIV and syphilis, and management of all STDs; provides family planning and tuberculosis services; sponsors a post-test club; trains volunteers in counselling and testing methods; and provides technical assistance. As of 2004, the centre had branches in 22 of Uganda's 56 districts.

UWESO is an indigenous organization founded in 1986 to help Uganda's war orphans. Initially, it provided relief supplies such as food, clothing, shelter and medical care. By the end of November 2001, UWESO members were caring for 120,271 orphans, over 80 per cent of whom were AIDS orphans. As of 2005, it had established a model for psychosocial support and income generation for orphan caregiver households. The organization has over 11,000 active members.

### ***CBOs and families***

The bulk of the work in the fight against HIV/AIDS in Uganda remains with the affected families and communities. Many communities have designed their own interventions with little assistance from the government or financially capable NGOs. Unfortunately, there is insufficient documentation on how households react and survive in the face of illness and death. What is known is that as first-line providers of care and support, families as well as informal community groups make a major difference by providing palliative care and material well-being. For example, at the peak of the AIDS epidemic in the Rakai district in 1993, an assessment of community responses found that many community assistance groups, consisting of five to 30 members, had been formed (Tumushabe et al. 1993). These groups were often the only mechanism for managing the challenges to their livelihood posed by the high morbidity and mortality of HIV/AIDS. Their activities included:

- growing fewer labour-demanding food crops, such as cassava, and focusing on more marketable crops and animals, such as vegetables and pigs;
- assisting needy orphans and widows to build and repair houses, providing food and assisting them with household chores;
- carrying out community health and HIV/AIDS education; and
- training girls who dropped out of school in income-generating activities, such as tailoring, making and marketing handicrafts, and improved farming.

In addition, nearly all of the communities in the survey (Tumushabe et al. 1993) had formed burial groups to organize funerals. Thousands of similar interventions have been formed with little or no external help or facilitation.

### ***Traditional therapies and healers***

An estimated 80 per cent of Ugandans use traditional health care, either fully or in part. Herbal medicines are used for treatment of opportunistic illnesses resulting from HIV, particularly among the poorer rural populations. Established in 1992, Traditional and Modern Health Practitioners Together Against AIDS (THETA) is the oldest collaborative project between traditional healers and biomedical workers in the AIDS field in Africa (Engle 1998). THETA's primary goal is to build a sustainable partnership between traditional and modern approaches to HIV prevention and HIV/AIDS treatment. The group meets for two or three days each month to share information, experience and materials on HIV/AIDS, STDs, counselling skills and educational strategies. The traditional healers receive practical training in areas such as HIV/AIDS counselling, use of condoms and community education. After a two-year follow-up in Kampala, THETA set up similar collaborative efforts in rural areas and is now working in seven districts across Uganda, involving about 30 traditional healers in each district.

Evaluation studies have revealed that THETA's use of herbs to fight opportunistic infections is encouraging, showing results from herbal therapies that are comparable to, and in some cases, better than biomedical drugs. Other achievements include:

- enabling traditional healers to organize their own education programmes that emphasize the importance of condom use, encourage young people to delay becoming sexually active and promote a reduction in the number of sexual partners;
- developing programmes for patient care, orphan fostering and education;
- fostering group formation and organization toward joint HIV/AIDS education programmes; and
- creating a Resource Centre for Traditional Medicine and HIV/AIDS in Kampala, which provides a forum for the exchange of ideas, experiences and a central information, documentation and training facility on traditional medicine and HIV/AIDS.

### ***The private sector***

The business community has generally not sought a leadership role in confronting the HIV/AIDS epidemic. The response has been slow and largely a defensive one, characterized by some companies making occasional philanthropic contributions to local AIDS organizations. In order to scale up initiatives, the Federation of Uganda Employers embarked on a mobilization drive among its members to establish HIV/AIDS policies and services in the workplace. In 2002, the Ugandan Business Council on AIDS was established, and more companies initiated workplace HIV/AIDS policies and services. The council has carried out an inventory of businesses that are providing workplace-based HIV/AIDS services with the aim of promoting interventions in the private sector.

## **7. Improving HIV/AIDS Responses in Uganda**

There is no doubt that the government of Uganda and its many partners have done some important work in their response to the HIV/AIDS threat since the mid-1980s. The relatively favourable donor resources, and the commitment and participation of many local and international groups and individuals, are noteworthy and deserve to be recognized. The political prominence given to HIV/AIDS, and the overall national response, have played important roles in encouraging open discussion about the epidemic and drawing international attention to the country's efforts.

Yet, Uganda's HIV/AIDS story has been distorted. Many of its key actors have gone unrecognized, while others have drawn inordinate attention. Especially noteworthy has been the gap in building upon the commitment, organization, resource generation and human



dedication shown by local communities. The numerous models of effective responses to the impact of the HIV/AIDS epidemic demonstrated by communities have received some rhetorical attention, but have not been backed with broad strategies or resources, or integrated into national poverty reduction plans.

Several actions, as described below, could contribute to a more balanced response to HIV/AIDS in Uganda, a response that more fully reflects the realities of all stakeholders in controlling the epidemic and its impact on society.

### ***HIV/AIDS as part of political discourse***

While it is important that the successes and failures in the struggle against the HIV/AIDS epidemic are regularly documented and disseminated among stakeholders, the manner in which the Uganda HIV/AIDS successes have been squandered in a shameless piece of political gamesmanship, without taking into account the impact that this action has on the very programmes that have brought about the recorded successes—such as the condom debate—is unfortunate and dangerous. In the case of Uganda, the positive political leadership regarding HIV/AIDS in the 1980s has translated into political capital for authoritarian rule in the twenty-first century. The Ugandan government is not using the success of the fight to ensure donor financial support as a weapon to emancipate Ugandans, but as a weapon for international deception and regime perpetuation.

This opportunistic leadership claim of success in fighting HIV/AIDS is risky, not only for the very programmes held up as major achievements, but also for the nation's people. For example, "success" in controlling HIV/AIDS may breed complacency among the actors and the population in general that the systems are in place to both prevent further infections and mitigate the impact of illnesses and deaths. This kind of success is likely to generate false hopes followed by huge disappointments. Moreover, the touted success of the country's HIV/AIDS programmes hides infrastructural weaknesses in service delivery and proper audit of activities. As elsewhere in Africa, Uganda's health care system is very fragile and its coverage uneven. The vast response at the community level has, in many cases, compensated for these weaknesses, but most communities are stretched to the limits of their capacity. The flaws in the assumptions about the strengths of communities are already widely evident. Finally, the rhetoric of success masks important work that remains to be done and hinders recognition of the need to scale up nearly all activities. The limited resource allocations to HIV/AIDS issues compared to so-called priority areas—notably defence, the state house, referendums to change the country's constitution and lift the term limit on the presidency and universal primary education—is a result of the perception of Uganda's success in fighting HIV/AIDS. When it comes to allocating budgets, HIV/AIDS is clearly not a priority. This inevitably perpetuates the country's dependence on external funding and resources to address HIV/AIDS.

### ***Utilization of non-state actors***

Most civil society organizations in Uganda have several years of experience in handling various specialized aspects of HIV/AIDS. Yet, funding for these organizations is fragmented and often too limited to expand effective programmes. The district local government structures, which have been the focus of donor funding in recent years, lack the capacity and experience to deliver quality HIV/AIDS services.

More focused and prioritized attention to key geographic areas and communities, based on appropriate surveys, can strengthen both national and local responses to the HIV/AIDS epidemic. Increased utilization of civil society organizations that have a proven track record for delivery of quality services in the implementation of state and donor-funded projects will go a long way in ensuring more effective management of the epidemic and appropriate use of resources. This can be done through a coordinated mechanism that ensures open competitive bidding in which civil society organizations would be invited to submit requests for resources,

rather than giving local government structures preferential treatment in the management of these resources.

***Development of the policy and legal framework***

Resolving this challenge calls for independent monitoring of the HIV/AIDS epidemic and assessment of success; optimum accountability and de-politicization of the budget; funding empowerment; and including multiple stakeholders in the decision-making process. An HIV/AIDS policy is needed to give guidance to appropriate responses and to provide a basis for generating legal safeguards for PLWHA and people affected by the epidemic. This policy would be a means to provide adequate laws and guidelines for the economic and material support to PLWHA, assure the legal rights and responsibilities of the infected individuals and protect spouses and children affected by HIV/AIDS. Such a policy would be critical to guide the mainstreaming of HIV/AIDS into different aspects of the development process of Uganda to ensure that its mitigation is founded on a rights-based approach and to expand planning in this era of AIDS to go beyond simplistic economic analysis.

A nationally acceptable HIV/AIDS policy can provide a means for successfully controlling the epidemic. Such a policy would expand the national response if it includes businesses, the armed forces, the teaching service, FBOs, NGOs and others that are a part of the national scene. The policy needs to be addressed in its own right and not as an appendage to other laws without operational modalities for implementation. The UAC and the president's office should push for a parliamentary debate of a national HIV/AIDS policy and ensure that there are legally binding instruments to assist programme development and implementation. These moves would be legitimate political actions toward success.

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