

## **Institutionalising an Emergency Response: HIV/AIDS and Governance in Uganda and Senegal<sup>1</sup>**

A report submitted to the Department for International Development  
May 2003

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## **Executive Summary**

### **1. Introduction**

By the end of 2002 some 42 million people were living with HIV/AIDS, 70% of whom were in Sub-Saharan Africa, where average life expectancy averaged 47 years when it would have been 62 years without AIDS. While the implications of the AIDS crisis are devastating, some countries in Africa have made progress fighting the pandemic. This report examines how governance in Uganda and Senegal may have contributed to that progress.

- 1.1 Five reasons are identified explaining why the international community was so late in responding to the crisis.
- 1.2 The battle against HIV/AIDS lies squarely at the intersection between 'emergency response' and 'development intervention' making it one of the most difficult policy and programme issues facing national and local governments and the international development community. Work on governance and the political dimensions of HIV/AIDS has so far been more on the impact of the epidemic on governance and has tended to be apocalyptic in tone, while this study examines the impact of governance on controlling HIV/AIDS.

### **2. HIV/AIDS in Uganda and Senegal**

The epidemiological and social factors that drive the epidemic have shaped the requirements for government action to bring it under control. The achievement of government in Uganda was to bring a full-blown epidemic under control, while in Senegal government action contributed to arresting HIV/AIDS before it reached epidemic proportions.

- 2.1 HIV in Africa is spread mainly through unsafe sex between men and women and since no cure is available efforts to control the virus require a change in sexual behaviour among high-risk groups and the population at large. For both social and physiological reasons women are even more vulnerable to infection than men. In Uganda, political instability and war, and the widespread presence of sexually transmitted infections contributed to an explosive HIV/AIDS epidemic while Senegal's political stability, early legalisation of commercial sex and treatment of STIs coupled with the presence of the less virulent HIV-2 virus provided the basis for positive government action to avoid a full blown crisis.
- 2.2 Based on these patterns four types of intervention to counter HIV/AIDS have been identified involving epidemiological surveillance, prevention, care and treatment and addressing the long term causes and impact of the virus. Most interventions require action of *both* a 'medical/technical' and 'social, economic and political' character as demonstrated in Figure 1 in this section.
- 2.3 In Uganda national prevalence peaked at about 15% in 1991 with action by the National Resistance Movement government contributing to bringing down prevalence to between 6.1 and 6.5% by 2002. In Senegal, early action by the Parti Socialist government helped to keep prevalence below 2%. While both countries have made significant progress in the first two types of intervention focusing on transforming individual behaviour, much remains to be done in providing care and

treatment and very little has yet been done to address the behaviour of groups and long-term causes and impact.

### 3. National and Central Leadership

Most discussions of HIV/AIDS policy have focused on the need for 'political commitment' at the highest levels of government, but this tells us little about why and how such commitment emerged. A detailed analysis of what led Presidents Museveni and Diouf to engage with HIV/AIDS is presented and four central aspects of leadership are identified: (a) an incentive structure emerged in which leaders had little to lose and everything to gain from engaging the fight with HIV/AIDS; (b) leaders came to act on the basis of medical and scientific evidence; (c) it became illegitimate for anyone to occupy a position of government without fully committing to the fight against AIDS; and (d) central leaders were pivotal to the mobilisation of social organisations. Political organisation was determinant for all four factors, but political outcomes were also influenced by the action of the donor community.

### 4. Multi-Sectoral Approaches and 'mainstreaming' HIV/AIDS

Mainstreaming HIV/AIDS across government and developing a cooperative effort between government and non-government sectors can only be achieved through *political* action. The organisational template being imposed by UNAIDS, the World Bank and the Global Fund is not necessarily conducive to developing an effective battle against the epidemic.

- 4.1 The national commissions called for by the Bank and the Global Fund have tended to weaken government and overly marginalise the health sector and medical profession and this model needs to be much more cautiously applied.
- 4.2 Religious organisations, when influential in society as in Uganda and Senegal, can greatly increase the reach of campaigns against HIV/AIDS and contribute positively to both care and treatment and the plurality of messages required to influence behavioural change, though this is best achieved under secular state leadership.
- 4.3 Non-governmental actors including NGOs, other associations and the private sector were initially mobilised *by the government* and while they need to be fully involved in both planning and implementing work on HIV/AIDS this can best be achieved under strong state leadership.
- 4.4 Private sector actors need to contribute to developing prevention, care and treatment and to invest in all three aspects directly.

### 5. HIV/AIDS and the governance agenda

Success or failure in the fight against HIV/AIDS is determined significantly within the realm of politics. Nine dimensions of the battle against the pandemic are identified as central to the governance agenda.

- 5.1 There is a tension between the principles of democracy and the respect for individual rights on the one hand and the imperatives of securing public health on the other and polities need to be open to considering more compulsory measures where conditions warrant and capacity exists to engage in this constructively.
- 5.2 Decentralisation of health services may be inappropriate where capacity is lacking and, when coupled with 'donor zoning', may not deliver resources based

on need and epidemiological evidence. Privatisation may run counter to the need for a strong public health sector to wage a sustainable campaign over time against HIV/AIDS, as is required by institutionalising an emergency response.

- 5.3 Investing resources in treating STIs and legalising the commercial sex industry appear to be two key areas for government action to stem the virus.
- 5.4 There is a need to target high-risk groups addressing the particular needs of women and children. Men who have sex with men and injecting drug users get scant attention in most African countries including Uganda and Senegal.
- 5.5 Special efforts must be made to alter sexual practices of military forces. While AIDS has clearly contributed to social and political breakdown, the campaign against it could also form part of peace processes, although there is little evidence of this happening to date.
- 5.6 The transformation of economic activity in many developing countries has brought with it displacement, labour migration and long-distance trading, all factors which, while possibly contributing to economic growth, may in fact be contributing to the spread of HIV. The AIDS crisis necessitates rethinking strategies of economic change, though there is little evidence that this has seriously begun.
- 5.7 Antiretroviral therapies are becoming accessible to many developing countries, but give rise to new problems related to the allocation of resources, to the impact on political incentives to fight AIDS and in relation to the biological processes of the virus itself.
- 5.8 International funding has been and will continue to be central to the fight against AIDS, but new issues of taxation are posed by the challenge of the epidemic.
- 5.9 There is a pressing need to devote attention to the ethics of medical practice and of research related to HIV/AIDS.

## **6. Conclusions and Recommendations**

HIV/AIDS is a crisis of monumental proportions for the international community, which is undermining hard-won gains in the developing world. The tensions involved in responding to the AIDS crisis - between emergency and developmental action, centralised and decentralised organisation, control and participation, the public good and individual rights - mean that we must look at governance analytically and politically, not merely as a checklist of functions and best practices. Emergency action is called for, but the nature of this emergency is long-term, so we must consider how to institutionalise an emergency response.

The key findings of the report are summarised along with central recommendations for new research.

## **Acronyms**

ACTafrica	AIDS Campaign Team for Africa (World Bank)
AIC	AIDS Information Center
AIDS	acquired immunodeficiency syndrome
ANCS	Alliance Nationale Contre le Sida
ANRC	AIDS related national crises
ART	Anti-retroviral Therapy
ARVs	antiretroviral
CBOs	community based organisations
CNLS	Conseil National de Lutte Contre le SIDA
CNPS	Comité National Pluridisciplinaire de Prévention du VIH/SIDA - Multi-disciplinary National Committee for the Prevention of HIV/AIDS
CSW	commercial sex workers
DFID	Department for International Development
ENDA	Environnement et Développement en Afrique
HIV	human immunodeficiency virus
ICASO	International Council of AIDS Service Organizations
MAP	Multi-country AIDS Programme of the World Bank
MSM	men who have sex with men
NCPA	National Committee for the Prevention of AIDS
NGO	non-governmental organisation
PLWH	People Living with HIV/AIDS
PNLS	Programme National de Lutte contre le VIH/SIDA - National Programme of Struggle Against HIV/AIDS –
PPAP	Participatory Poverty Assessment Process
STIs	sexually transmitted infections
SWAA	Society for Women and Aids in Africa
TASO	The AIDS Support Organisation
UAC	Uganda AIDS Commission
UBTS	Uganda Blood Transfusion Services
UNAIDS	United Nations Programme on HIV/AIDS
USAID	United States Agency for International Development
UNASO	Ugandan Network of AIDS Service Organizations
WB	World Bank

## 1. Introduction

By the end of 2002, some 42 million people world-wide were living with HIV/AIDS with an estimated 5 million people newly infected during the course of the year. Over the year an estimated 3.1 million people died from AIDS. Of these 29.4 million, or 70% of those living with HIV/AIDS, were in Sub-Saharan Africa, which accounted for 70% of new infections and some 77% of all those who died due to the virus.<sup>2</sup> At the end of last year, UNAIDS reported that the worst of the epidemic in Africa has not yet passed, as the numbers who have acquired the virus over the past several years mean the death toll on the continent will not peak until the end of this decade. In some countries, UNAIDS reports, 'HIV prevalence has risen higher than thought possible, exceeding 30%: Botswana (38.8%), Lesotho (31%), Swaziland (33.4%) and Zimbabwe (33.7%)'.<sup>3</sup> The demographic impact of the virus is shocking. By 2002, life-expectancy in Sub-Saharan Africa averaged 47 years, when it would have averaged 62 years without AIDS, destroying the hard won gains in prolonging life that figure so centrally in our notion of human development.<sup>4</sup>

While the implications of the AIDS crisis are devastating, some countries in Africa have made progress fighting the pandemic. This report examines how governance in Uganda and Senegal may have contributed to progress in fighting HIV/AIDS. I suggest that the role of central government has been crucial to successes achieved thus far in the fight against HIV/AIDS. Most controversially, I make a distinction between the development of a multisectoral approach to the epidemic as a key to success, and the template of multisectoral organisation that has been promoted by UNAIDS, the Global Fund and the World Bank, which I argue is extremely problematic. I also suggest that the successful move away from purely biomedical approaches to disease that has been so important in the international HIV/AIDS campaign, risks going too far toward the opposite extreme, losing sight of the crucial role that the medical profession and the health sector must play. I present a typology of the main activities that governments need to engage in to confront the epidemic, demonstrating that most involve *both* 'bio-medical/technical' and 'social, economic and political' dimensions. Hopefully, this report can also serve to educate governance experts about HIV/AIDS connecting the physiological and epidemiological features of the crisis with the political and social concerns of those who work in the governance field.

In this section I begin with an explanation of why the international community took such a long time to respond to the crisis. I then briefly justify the focus on governance dimensions of HIV/AIDS. Finally, I conclude with an outline of the report.

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<sup>2</sup> UNAIDS, *AIDS Epidemic Update*, December 2002, UNAIDS/02.46E . The rising number of people living with HIV in Asia (which experienced an estimated 10% increase in new infections during 2002), especially 3.87 million people in India at the end of 2001, and another 1 million in China (according to official estimates) by mid-2002, are only small indications of the devastating impact the virus, which appeared nearly a decade later than in Africa, will have in the Asian region over the next ten years. Similar early signs of a spiralling epidemic in the Russian Federation and CIS indicate we are very much at the beginning of this crisis.

<sup>3</sup> UNAIDS, *AIDS Epidemic Update*, December 2002, p.71.

<sup>4</sup> UNAIDS, *Report on the Global AIDS Epidemic 2002*, p.44.

## 1.1 Why was the international community late?

The international community was very slow to take up the fight against the HIV/AIDS pandemic and, indeed, even today there are many governments that have hardly begun to take the kind of measures necessary to prevent the further spread of the virus or address its long-term social, political and economic impact. In an extraordinary admission, when looking at the AIDS crisis in Africa in 1999, the World Bank commented, 'We in the Bank have not done our full part.... we have failed to bring to bear the full weight of our collective instruments, intellect and influence. As Africa is the hardest hit, we in this Region bear the primary responsibility to lead'.<sup>5</sup> There are at least five reasons that may explain why the most devastating epidemic to have hit the developing world in modern times has not received the attention or central position it should occupy for national and international political authorities and officials, or indeed the academic community involved in studying development.

First, attitudes about the virus were heavily determined by its initial association with minority groups in the western countries - men who have sex with men (MSM) and injecting drug users. These origins continue to affect the way the epidemic is dealt with and thought about.

Second, once it became a recognised fact that the virus in the developing world was embedded in general population groups and transmitted primarily through heterosexual activities, it nonetheless required the need to discuss sexual practices and sexuality. Public officials appear to have difficulty addressing these issues, in part for fear of eliciting opposition from powerful religious interest groups and in part because sex and sexuality are often seen as matters of individual behaviour and not the object of public pronouncement and action.

Third, the early literature about HIV/AIDS produced by the economics profession, which gained a hegemonic position in most international agencies and in the thinking of liberalising and reforming national administrations by the early 1980s, may have led some to believe the epidemic would have a marginal, or in the more extreme accounts, positive impact on the macroeconomic patterns of development. René Bonnel, of the World Bank's ACT in a paper on the impact of the virus on economic growth wrote, 'The conclusion that lower population growth could increase income per capita underlied [sic] the early economic analysis of HIV/AIDS'. He reported, 'In some cases such as Botswana, per capita income was projected to increase as a result of HIV/AIDS...'.<sup>6</sup> One can imagine that such thinking had an impact on attitudes within Botswana, which now has among the highest rates of prevalence in Africa. Of course,

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<sup>5</sup> 'A wildfire is raging across Africa', Memo (signed Callisto & Jean-Louis) issued on June 2, 1999 to World Bank staff and supporters announcing the new AIDS in Africa initiative and the AIDS Campaign Team (ACT) for Africa. <http://www.worldbank.org/aids-econ/africa/fire.htm>

<sup>6</sup> René Bonnel, 'HIV/AIDS: Does it Increase or Decrease Growth in Africa?', ACTAfrica, World Bank (6 November 2000). His full explanation of Botswana was as follows: 'In some cases such as Botswana, per capita income was projected to increase as a result of HIV/AIDS mainly because AIDS was projected to affect labor force growth more than national saving, but Botswana's situation is clearly unusual... Most of Botswana's income comes from diamonds exports which are unlikely to be adversely affected by HIV/AIDS. In addition, due to Botswana's excellent international credit rating, any shortfall in domestic saving could easily be offset by borrowing from abroad with the result that the stock of capital would not fall'.



there were other economists projecting a more severe negative impact of the epidemic.<sup>7</sup> Nevertheless economists Bloom and Mahal could write, as late as 1997, that 'there is more flash than substance to the claim that AIDS impedes national economic growth'.<sup>8</sup>

Fourth, HIV/AIDS was seen as a 'medical issue' best left to the medical profession. Despite the accumulated knowledge within social studies and the policy community concerning the social basis of epidemics in the history of today's developed countries, one of the prices of the quick advance of medical science in the 20<sup>th</sup> century seems to have been the evolution of a strong belief in the ability of the scientific community to 'find a cure', or a vaccine, and eventually overcome any health problem. HIV/AIDS defies this reduction of health to the domain of the technical expert, but this type of thinking no doubt had an effect on the response to the epidemic.

Finally, and perhaps most importantly, the sheer complexity of the epidemic – involving physiological, epidemiological, social, economic and political dimensions – no doubt led many to resist 'looking into the problem', as it very quickly became clear that HIV/AIDS was putting into question, or undermining, much of what had been accomplished in the developing world since the end of the Second World War. Both governments and donors have been wedded to policies that produce quick solutions, with measurable positive results and the epidemic threatened this approach and reinforced what might be a natural impulse towards 'denial' in the face of the array of complex and highly negative factors associated with the crisis.

## 1.2 Why look at governance?

The battle against HIV/AIDS lies squarely at the intersection between 'emergency response' and 'development intervention' and it is this fact that has placed it among the most difficult policy and programme issues facing national and local governments and the international development community. Confronting the pandemic requires dealing with a set of severe tensions between:

- fast emergency response and sustainable development intervention;
- centralised and decentralised organisation and resource mobilisation;
- authoritarian and coercive measures of control and participatory involvement of grassroots organisations;
- the imperative of public health (the good of the community) and respect for individual rights; and
- pressures to allocate resources to immediate killer diseases and the imperative to head off an epidemic whose deadliness is not immediately evident.

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<sup>7</sup> See in particular, Mead Over, 'The Macroeconomic Impact of AIDS in Sub-Saharan Africa' Population and Human Resources Department, World Bank (June 1992).

<sup>8</sup> David Bloom and Ajay Mahal, 'Does the AIDS epidemic threaten economic growth?' *Journal of Econometrics*, 77 (1997), pp.105-124. Despite the fact that Bloom and Mahal acknowledge the wholly inadequate data on prevalence and incidence of HIV/AIDS in Africa, they nonetheless constructed complex econometric models using this data to reach their conclusions. Not only was this work based on very incomplete epidemiological data, but it also vastly underestimated or ignored the complex array of costs of care and treatment, the drain on public resources, the demolition of human capital and the widespread destabilising impact of the virus over the long-term.

This tension-ridden character of the fight against the pandemic places it squarely in the domain of governance, which is all about reconciling tensions and making choices. It also requires the application of the 'art of governance', since the fight against HIV/AIDS defies easy resolution through the development of universally applicable 'templates' for organisational and programmatic responses. It is an emergency response that needs to be dealt with over decades – sustaining an emergency character, but forcing international and local actors to examine the developmental consequences of intervention. How can governments institutionalise an emergency response? This is part of the problem.

Confronting the pandemic requires a willingness to question some of the received wisdoms about the organisation of public services and the tool kits to deliver health programmes. It also requires openness to discussion and debate about sexuality and traditional and religious beliefs - transgressing the boundaries between what has generally been considered the divide between the private and the public.

While social scientists, especially in the French language, have been carrying out significant work on HIV/AIDS,<sup>9</sup> there has been very little research on HIV/AIDS and governance and political scientists have hardly begun to touch the issue.<sup>10</sup> What exists so far has focused on the impact of the epidemic in terms of greater demands placed on government services and the erosion of government capability through AIDS-related deaths.<sup>11</sup> More work must be done in this area both to enable leaders to plan for these impacts and to convince political authorities of the urgency to act *before* the full impact hits.

Alex deWaal has written more than anyone else about the need to develop a new model of governance to deal with the complex challenges posed by HIV/AIDS.<sup>12</sup> He argues that existing public bureaucracies and the security forces depend on long trajectory career paths that are thrown into question by early deaths from AIDS – thus, the kinds of challenges that are raised are not only the already difficult ones of replacing lost human resources, but of rethinking the way public agencies are organised. He raises the need for early warning systems that will indicate the onset of 'AIDS related national crises (ANRC)'. De Waal's contribution is important as he suggests we need to look at the basic characteristics of state formation (although one might dispute the particular basics he suggests) and evaluate how the HIV/AIDS

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<sup>9</sup> The most important collection is Charles Becker, Jean-Pierre Dozon, Christine Obbo and Moriba Touré, ed.s, *Vivre et penser le sida en Afrique (Experiencing and understanding AIDS in Africa)* (Dakar: Codeseria and Éditions Karthala, 1999).

<sup>10</sup> Noteworthy here is the important article by Catherine Boone and Jake Batsell laying out the unmet challenge HIV/AIDS poses to political science, 'Politics and AIDS in Africa: Research Agendas in Political Science and International Relations', *Africa Today* Volume 48, Number 2 (Summer 2001), pp.3-33.

<sup>11</sup> Two of the more important contributions in this vein are Barnett and Whiteside (2003), chapter 12 and Alex de Waal, 'How Will HIV/AIDS Transform African Governance?', *African Affairs* (2003), 102, pp.1-23.

<sup>12</sup> In addition to de Waal (2003), see: Alex de Waal, 'AIDS-Related National Crises: An Agenda for Governance, Early-Warning and Development Partnership' (September 2001); Alex de Waal, 'Modeling the Governance Implications of the HIV/AIDS Pandemic in Africa: First Thoughts', (June 2002); and Alex deWaal, Review of, Jeffrey Sachs and others, 'Macroeconomics and Health: Investing in Health for Economic Development,' Report of the Commission on Macroeconomics and Health to the Director-General of the World Health Organization, 20 December 2001 (provided by the author).

pandemic affects these basic functions.<sup>13</sup> This gets beyond seeing 'governance' as a check-list of policies and recognises that any programmes or assessments of governance in the developing world need to take account of political processes of on-going 'state formation'.<sup>14</sup>

However, de Waal paints an almost apocalyptic account of the potential impact of HIV/AIDS on governance. His worse-case scenario posits a reverse model of demographic transition where women are reduced to a status of virtual slavery and there is a reversal of the Weberian model of bureaucratic transition, where authority becomes less and less rational. With low or no life expectancy, soldiers will go on the rampage and government officials will engage in the worst forms of corruption. Property will become more unequally concentrated; the state will lose its monopoly over the legitimate means of violence; the tax base will shrink and public services will collapse. The state, likely to lose all legitimacy, will no longer be able to protect citizens from demographic crises, and, where the state collapses into civil war, combatants with AIDS will engage in unrestrained acts of violence. He concludes, 'Those who are certain that they are going to die may be so desperate and reckless that they are not amenable to pressure or rational argument'.

De Waal is no doubt writing in part to shock governments into action. A number of the negative pressures on governments and governance, which he describes, are already very real and present dangers, some of which I discuss below. However, the same pressures may have effects entirely opposite to the ones he predicts.

Historically, those who occupy positions of authority within states have undertaken their most radical reforms in the face of threats to their power or to the existence of the state.<sup>15</sup> This has been clearly part of the story in Uganda. The fiscal situation in most developing countries, where processes of state formation are still underway is appallingly weak and just as states historically have created a fiscal capacity in situations of crisis and fights for survival, the AIDS crisis, even in the face of its negative impact on the economy, could serve as incentive for fiscal construction.

We have long known that cooperative forms of organisation have their greatest success when communities are under siege,<sup>16</sup> and there is some evidence of this in Uganda and Senegal where the struggle to cope with HIV/AIDS has served as the basis for community organisation. Finally, the epidemic may well serve as the basis for governments to increase their legitimacy (de Waal recognises this), as has undoubtedly been the case for Museveni in Uganda and even for Abdoulaye Wade,

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<sup>13</sup> The basic parameters of state formation he identifies are: (1) the emergence of a property owning middle class; (2) the rise of a governing elite that recruits people into its ranks to ensure stability and incremental change; (3) the consolidation of a state monopoly of legitimate use of force; (4) the establishment of revenue, expenditure and financial systems; (5) provision of public goods including health, education, law and order and justice; (6) a promise to eliminate of demographic catastrophes through state protection.

<sup>14</sup> See Tom Caruthers, 'The End of the Transition Paradigm' *Journal of Democracy* 13:1 (2002), pp.5-21 and my essay, 'Thinking about civil society and political parties: Challenges for development assistance' [http://www.simians.co.uk/drc/working/SeminarJP161002\(revised\).pdf](http://www.simians.co.uk/drc/working/SeminarJP161002(revised).pdf)

<sup>15</sup> I develop this theme in relation to radical land reform in *A Captive Land: The Politics of Agrarian Reform in the Philippines* (1992) and again in relation to an explanation of developmental achievements in East and Southeast Asia in, 'Developmental States and Crony Capitalists' in P. Massina, ed., *Rethinking Development in East Asia: From Illusory Miracle to Economic Crisis* (Curzon 2002).

<sup>16</sup> See my discussions of this in *Gaining Ground* and in *Captive Land*.

who boosted the legitimacy of his new government in Senegal by maintaining the campaign on HIV/AIDS.

In this report I focus less on how HIV/AIDS will affect governance than on *how governance can have an impact on the epidemic*. Much of the discussion about government action to date has been limited to descriptive accounts of measures taken and progress made to achieve targets in surveillance, prevention (especially individual behaviour change) and care and treatment.<sup>17</sup> I briefly review government action in these terms in the two countries studied, but do so within a political analytical framework in order to understand:

- What permitted government action?
- What choices made a difference to outcomes?
- How important was the shift to a 'multisectoral approach' and what is the appropriate role of scientific, medical and technical action within a multisectoral approach?

I examine the more controversial aspects of the template for intervention advocated by international organisations working on HIV/AIDS, and the key issues that governments need to confront beyond the tasks as they are currently perceived.

### 1.3 Outline of the study

Uganda and Senegal have been chosen as case studies based on the widely recognised success they have achieved so far in confronting the HIV/AIDS epidemic. Uganda, one of the earliest and hardest hit by the virus appears to have brought it under control. Senegal is one of the few countries in Africa where HIV prevalence has been maintained at below 2%. In this report I examine what contribution different approaches to governance in these two countries may have made to the fight against very different experiences of the epidemic. If similar governance initiatives contributed to progress in two different experiences of the epidemic, we can identify some meaningful lessons.

The study is based on two brief field visits to Kampala and Dakar, meetings and interviews conducted with over 50 people working in government, NGOs, the

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<sup>17</sup> The prime examples related to our two case studies are Janice A. Hogle, ed., *What Happened in Uganda? Declining HIV Prevalence, Behaviour Change and National Response*, Projects, Lessons Learned Case Study (USAID, September 2002 and UNAIDS, *Lutte Contre le SIDA: Meilleures Pratiques, l'expérience sénégalaise* (UNAIDS, June 2001). Much of what is published by other agencies on these governance dimensions remains of a prescriptive and non-analytical character, for instance, UNDP, 'Global Crisis, Global Action' (June 2001), or the widely cited but terribly shallow, Lee-Nah Hsu, 'Governance and HIV/AIDS: South-East Asia HIV and Development Project', UNDP (March 2000). Other work on governance focuses on HIV/AIDS and local government, for instance, Nomtuse Mbere, "Local Governance and HIV/AIDS" prepared for "Local Governance for Poverty Reduction in Africa" Maputo, Mozambique 23-25 May 2002, Issue Paper No. 4, which I deal with below, or discussions of how one might measure better governance as it relates to HIV/AIDS, such as, 'Political Commitment, Governance and AIDS: A discussion paper', written by David Patterson for Intragency Coalition on AIDS and Development, Ottawa, (1 December 2000). See also Dennis Altman, 'A Framework for Conceptualizing the International Response to HIV/AIDS', ICASO Update (1999) 16.

academy and international agencies in the two countries, and documentation collected in country and from my base in the UK.

The next section of the report outlines the pattern of the epidemic as it has developed in Uganda and Senegal, a typology of action that emerges in relation to the basic characteristics of the epidemic and a brief review of what has been achieved through action in the two countries. Section 3 considers the role of central leadership in the HIV/AIDS campaigns in both countries and offers both an explanation of the conditions which gave rise to successful leadership and a suggestion of what lessons may be most relevant for other countries. Section 4 provides an analysis of the multisectoral approach pursued in both countries, suggesting that the model or organisational template for multisectoral action promoted by the leading international agencies may be problematic. It goes on to consider the role of religious, non-governmental and private organisations in the multisectoral approaches taken in the two countries. Section 5 looks at nine dimensions of the battle against HIV/AIDS identified as central to the governance agenda in developing countries. The final Section sums up the main findings and recommendations and suggests lines for further research.

## **2. HIV/AIDS in Uganda and Senegal**

In order to understand the terrain for government action in relation to HIV/AIDS, it is essential to take note of the epidemiological and social factors that drive the epidemic in each country. In this section I first look at the pattern of the epidemic, beginning with its basic biological and epidemiological characteristics and how these led to different experiences of the virus in Uganda and Senegal. I then outline a typology of the different types of action required to deal with the epidemic. Finally, I briefly review the principal achievements in each of the two countries.

### **2.1 Pattern of the epidemic**

Like all viruses, the human immunodeficiency virus (HIV) is a submicroscopic parasite that survives and reproduces inside the cells of a host organism.<sup>18</sup> But it is a particular type of retrovirus, known as a lentivirus. While most viruses are attacked by the immune system leaving lifelong immunity, a lentivirus is slow-acting and never wholly eliminated from the body. HIV infects CD4+ cells which are part of the immune system. It is the loss of CD4+ cells that devastate the immune system, making it vulnerable to all sorts of opportunistic infections. HIV functions solely to reproduce itself and it has a long latency period – that is, it takes considerable time before the body's immune system no longer generates the immune response required to suppress HIV leading to an intensified replication of the virus. It is the loss of CD4+ cells and the rapid rise of the amount of HIV circulating in the bloodstream (the viral load) that indicates full-blown acquired immunodeficiency syndrome (AIDS).

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<sup>18</sup> This description is paraphrased from Raymond A. Smith, ed., *Encyclopaedia of AIDS: A Social, Political, Cultural and Scientific Record of the HIV Epidemic* (Penguin, 2001), pp.327-28

So far, there are two distinct HIV viruses – HIV-1 and HIV-2, with many sub-variants. They have distinct genetic compositions, whereby they encode and share different genes. HIV-2 seems to have been most prominent in West Africa (though incidence is increasing elsewhere perhaps spread through migration), while HIV-1 is firmly established worldwide. The two differ in their 'pathogenic potential', or ability to cause disease, whereby HIV-2 has been shown to be either less pathogenic or to have a longer latency period.

Transmission of HIV happens when contaminated body fluids, including blood, semen and vaginal secretions, pass from a carrier of the virus to another person.<sup>19</sup> For infection to occur the virus needs to enter a body in sufficient quantities passing through an entry point in the skin or mucous membranes into the bloodstream. The most common forms of transmission (as distinct from the highest probabilities of transmission) in Africa are generally accepted to have been in order of importance:

- unsafe sex
- transmission from infected mother to child
- use of infected blood and blood products
- intravenous drug use with contaminated needles
- other blood related modes of transmission (eg, bleeding wounds)<sup>20</sup>

I look at each of these in turn.

### Transmission through unsafe sex

In developing countries in Africa, evidence so far suggests that the epidemic has been most widely spread through heterosexual intercourse.<sup>21</sup> Particular problems related to this include the greater vulnerability of women than men, the likely connection between sexually transmitted infections (STIs) and HIV, and the role of other sex-specific cultural practices that affect transmission like female circumcision that likely increases vulnerability and male circumcision which may reduce risk.

*Greater vulnerability of women:* The probability of infection is higher from men to women for both social and physiological reasons. Worldwide and in Africa the rate of infection in women is higher than in men. Women have less say in initiating sexual intercourse than men, less say in determining who they will marry, and their social and economic disadvantages make them more dependent on sexual activities for survival. This vulnerability is accentuated by situations of economic crisis and even more so by situations of warfare, where both violence against, and particularly rape of, women is more pronounced, and women even more vulnerable to providing sex in exchange for food or access to shelter for themselves and their families.

Physiologically, the greater concentration of HIV in semen than vaginal secretions, the penetrability of the female genital tract, and for young women the particularly vulnerable character of the cellular structure of the uterine cervix, all mean that transmission is more likely from an infected man to a woman than vice versa. The likelihood of transmission between an infected male to another male or female

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<sup>19</sup> From Barnett and Whiteside, and from World Bank 1997

<sup>20</sup> Whiteside and Barnett follow the World Bank (1997) in arriving at this order of importance in transmission. The Bank (1997, chapters 1 and 2) based its assertions on work published in 1992.

<sup>21</sup> A foundational study of sexual behaviour and HIV/AIDS is John Cleland and Benoit Ferry, ed.s, *Sexual Behaviour and AIDS in the Developing World* (London: Taylor and Francis for the World Health Organisation, 1995).

through anal intercourse is even higher because the membrane lining the rectum is less able to resist absorption of HIV into the bloodstream. In Africa it is estimated that less than 1% of infections have occurred through men who have sex with men (MSM).<sup>22</sup>

*Sexually transmitted infections (STIs) and HIV:* There is considerable evidence that the prevalence of STIs in a population will make the transmission of HIV more likely. While it has been hard to disentangle the extent to which both STIs and HIV may be correlated to risky sexual behaviour, there are physiological reasons to believe that untreated STIs, which are widespread in many parts of the developing world and particularly in Africa, have hastened the transmission of the virus.<sup>23</sup> STIs such as herpes, syphilis, and chancroid cause lesions through which the HIV virus can much more readily enter the bloodstream. There is less evidence that non-ulcerative STDs like gonorrhea, chlamydia, or trichomoniasis contribute to transmission rates of HIV. However, the World Bank reported a study in Malawi that demonstrated a much greater concentration of HIV in the semen of men with urethritis, which increased the risk of transmission of the virus.

*Male circumcision and Female genital mutilation:* While again it is difficult to disentangle the extent to which male circumcision is coterminous with particular religious factors that may have affected transmission patterns, there are physiological reasons to suspect that circumcised males are less likely to transmit the virus.<sup>24</sup> The sheath of the circumcised penis is more protected and the uncircumcised more susceptible to chancroid and other sores related to poor genital hygiene, and the cellular composition of the underside of the foreskin more vulnerable to HIV transmission. Female genital mutilation, sometimes also referred to as female circumcision, may make women *more* vulnerable to infection, both through the risk of blood borne infection when it is carried out and through the higher incidence of abrasions and wounds during vaginal intercourse or the greater resort to anal intercourse.<sup>25</sup>

### Transmission from mother to child

There is a high rate of transmission of HIV from infected pregnant mothers to their children, particularly in the uterus when the child is in contact with the mother's blood and in nursing after birth. The World Bank (1997) reports that in Sub-Saharan Africa this could be the cause of 15 to 20% of infections. While this is a major source of new infections it is unlikely to have contributed to the overall rate of the epidemic's development since these children seldom survive to the age of sexual activity. The Bank, citing UNAIDS, suggested that two-thirds of all instances of mother-to-child transmission occur in Sub-Saharan Africa.

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<sup>22</sup> Due to taboos against MSM, this is probably an underestimation – see last section.

<sup>23</sup> World Bank (1997, chapter 2).

<sup>24</sup> Anne Buvé, Kizito Bishikwabo-Nsarhaza, Gladys Mutangadura, 'The spread and effect of HIV-1 infection in sub-Saharan Africa', *The Lancet*, vol 359 (June 8, 2002), pp. 2011-17.

<sup>25</sup> 'Female Genital Mutilation', report of a WHO Technical Working Group Geneva, 17-19 July 1995.

### Transmission through injecting drug use

In 1997, the World Bank reported that worldwide, the second most important mode of transmission was through sharing unsterile needles by injecting drug users. It has been the most important route of transmission in Southeast Asia outside of Thailand, in China and has become increasingly important in Eastern Europe and the Russian Federation. The probability of infection appears high and the spread within a community of drug users can be extremely rapid.

### Transmission through contaminated blood supplies

In the early years of the appearance of HIV, transmission through infected blood supplies was significant, since the probability of transmission is between 90 and 100% if a person receives a transfusion from contaminated blood. This was no doubt worsened in situations of warfare and state collapse in the early 1980s. However, most blood is now screened for HIV, though this remains a problem in some parts of the developing world. The World Bank asserted that even in the developing world contaminated blood supplies never were responsible for more than 10% of infections.

### Transmission through faulty medical practices

There is a possibility that some transmission of HIV has occurred through contaminated injections used in medical practice. As with the use of contaminated needles among injecting drug users, the probability of transmission if contaminated needles are used in the administration of medication is very high. The World Bank, however, suggests that this mode of transmission has never accounted for more than 5% of infections, arguing that the age distribution of infection does not support the idea that this could have been a major route of transmission.<sup>26</sup> A recent series of articles argues that this route of transmission may in fact have been much more important than is recognised.<sup>27</sup> Given the widespread practice of injecting medicine in developing countries and the general evidence of dirty needles employed, the role this played in early transmission of HIV warrants further research.<sup>28</sup> However, even if the use of dirty needles did contribute to the earlier spread of HIV, this in no way puts into question the conclusive evidence that, once the virus is established in the general population, sexual intercourse becomes the major mode of further transmission. At the same time, with consciousness of HIV, there may well have been improvement in the use of sterile needles in medical practice and this may have contributed to progress in fighting the epidemic. We simply do not know, but there is a logical case for devoting more resources to cleaning up parenteral practices.

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<sup>26</sup> World Bank, 1997, chapters 1 and 2.

<sup>27</sup> See the work of David Gisselquist et al, published in the *International Journal of STD & AIDS* (2003), 14. For UNAIDS, WHO reply: UNAIDS, 'Expert Group Stresses that Unsafe Sex is Primary Mode of HIV Transmission in Africa', press release (Geneva, 14 March 2003) [http://www.unaids.org/whatsnew/press/eng/HIVinjections140303\\_en.html](http://www.unaids.org/whatsnew/press/eng/HIVinjections140303_en.html)

<sup>28</sup> On the prevalence of dirty needles in medical practice in the developing world see, L. Simenson et al, 'Unsafe injections in the developing world and transmission of bloodborne pathogens: a review', *Bulletin of the World Health Organisation*, v.77, n.10, pp.789-800 (1999). See also, Ernest Drucker, et al, 'The Injection Century: Massive Unsterile Injections and the Emergence of Human Pathogens', *Lancet* (12 August 2001) v.358, no.9297, pp.1989-1992



*The spread of the epidemic in Uganda*

In Uganda the first cases of HIV appeared among people from the southwestern region of Rakai and it is believed that the virus established itself among high risk groups there and in Kampala by the late 1970s.<sup>29</sup> Economic collapse and social dislocation, and new economic activities including the proliferation of the smuggling trade, contributed to the spread of the virus. Young women turned to the sex trade and the spread of the virus seems to have followed the trade and communications routes from the African east coast to the centre of the continent. Long haul truckers removed from home, with plenty of money to spend, gave rise to the expansion of bars and brothels along their routes as people sought income generating activities. The increased sexual activities of men in this industry with commercial sex workers (CSW) whose trade was entirely unregulated and with multiple partners along their routes likely accelerated the spread of the virus. STIs were widespread and mostly untreated throughout these communities.

The southwestern region also experienced the movement of armies, when Ugandan rebel forces and invading Tanzanian forces overthrew the government of Idi Amin in 1979. Warfare and the movement of soldiers contributed to the spread of the virus through an increase in violence against women and trading sex for survival, as well as casual sex among multiple partners. The combined effects of social, political and economic disruption and war created conditions for the virus to pass from high risk groups – truckers, soldiers and commercial sex workers – into the general population. The highest levels of infection were reported in urban areas, in rural areas along trade routes, and in districts beset by conflict and war.<sup>30</sup>

The decade of state collapse decimated health care systems in the country and the general levels of STI infections were very high. Also, with a predominantly Christian population, male circumcision was less widely practiced than it is in Muslim communities and this may have aggravated the spread of the virus.

*The control of the epidemic in Senegal*

In Senegal, the virus has been kept under control from the start by a combination of social, political and historical factors, as well as the particular epidemiological characteristics of the virus in West Africa. The first six cases of HIV were diagnosed in 1986. Senegalese researchers found this to be a different and less virulent strand of the virus, HIV-2, which may in fact have had an impact on slowing down the development of HIV-1 (see below), also present in the country. However, beyond this basic 'epidemiological advantage', a number of other factors were important to the control of the virus in the country. While Senegal remains among the poorest countries in Africa, it has experienced relative political stability since independence in 1960, a factor that has limited abrupt displacement among the population, allowed the maintenance of traditional and local institutions and kept violent conflict to a minimum.<sup>31</sup>

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<sup>29</sup> See Barnett and Whiteside, chapters 4 and 5.

<sup>30</sup> *The National Strategic Framework for HIV/AIDS Activities in Uganda – 2000/1 to 2005/6* (Uganda AIDS Commission, 2000), p.9

<sup>31</sup> Karine Delaunay, 'Le Programme national de lutte contre le SIDA au Sénégal: entre prévention et normalisation sociale,' in M.E. Gruenais, ed., *Organiser la lutte contre le SIDA: Une étude*

In terms of public health, there were two important moves made by the Senegalese state that probably played a pivotal role in limiting the spread of HIV later. First, the urban areas of Senegal, the key trading ports, had since French colonial times a highly regulated commercial sex industry. In 1969, the state passed legislation securing the legal status of prostitution. Commercial sex workers of 21 years and older registered with the state and there was a general surveillance and treatment of STIs among them from the early 1970s under the Bureau of Venereal Diseases. A national programme to fight STIs was also launched in 1978, well before the appearance of HIV/AIDS, initially to work mainly with CSWs. Second, the colonial government had established the first blood bank in 1943 and as early as 1970, the state had launched a policy of safe blood transfusions controlling for immunological and infectious risks.<sup>32</sup>

Certain social characteristics may also have contributed to preventing the spread of the virus. With 95% of the population Muslims, male circumcision is widespread and fairly strong mechanisms of social control over the sexual activities of young women were perpetuated despite significant negative economic pressures and rapid cultural change.

This then was the pattern of the epidemic in the two countries. By the mid-1980s, Uganda was experiencing a full-blown epidemic, while Senegal was positioned, as a result of early identification of the virus, to head off the epidemic. It was the pattern of the epidemic, determined by its biological, epidemiological and socio-economic political characteristics, that defined the terrain on which action was needed – in Uganda, to bring the epidemic under control and in Senegal, to ensure against a generalised epidemic.

## 2.2 Action required to fight HIV/AIDS

Based on these patterns we can identify the main domains of intervention necessary to fight the HIV/AIDS epidemic. I attempt to lay these out in Figure 1 in a somewhat non-conventional manner. Four types of intervention are outlined: surveillance, prevention, care and treatment and addressing long-term causes and impact.

One of the most important insights to have been gained in work to counter the epidemic is that due to the complex factors driving the spread of HIV/AIDS in the first place, a response cannot be confined to the medical profession and thence the call for multi-sectoral approaches that would address the medical, social, economic and political aspects of efforts to control the epidemic. I have listed the types of actions distilled from the study of Uganda and Senegal under two broad categories of 'medical/technical' and 'social, economic and political' and indicated those that involve *both* dimensions. I have laid this out in this way specifically to highlight the *continued importance of the medical/technical aspects* of action within a multi-sectoral approach, something which I believe has not always been clear in the policy approaches pursued both by international and bilateral agencies and by national actors. This can be seen by the *number of measures that overlap the two dimensions*.

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*comparative sur les rapports Etats/société civile en Afrique (Cameroun, Congo, Cote d'Ivoire, Kenya Sénégal)*, ARNS, Paris, 1999.

<sup>32</sup> UNAIDS, Groupe thématique ONUSIDA/Senegal, *Lutte contre le SIDA: Meilleures pratiques, l'expérience sénégalaise* (June 2001).

**Figure 1: Measures to fight HIV/AIDS Epidemic**

<u>Medical/Technical Dimensions</u>	↔	<u>Social/Political/Economic Dimensions</u>
<b>Surveillance</b>		
<ul style="list-style-type: none"> <li>• Epidemiological surveys</li> <li>• Training</li> <li>• Laboratory work</li> </ul>		<ul style="list-style-type: none"> <li>• Education</li> <li>• Behavioural surveys</li> <li>• Research</li> </ul>
<b>Prevention</b>		
<u>Biomedical prevention</u>		
<ul style="list-style-type: none"> <li>• Screening of blood in blood banks</li> </ul>		<ul style="list-style-type: none"> <li>• Education</li> <li>• parenteral practices</li> <li>• mother to child transmission</li> <li>• counselling and testing</li> <li>• treatment of STIs</li> </ul>
<u>Behavioural Prevention</u>		
<i>Individual behaviour</i>		
	<ul style="list-style-type: none"> <li>• Education</li> <li>• condom use</li> </ul>	<ul style="list-style-type: none"> <li>• reduction of casual sex and number of partners</li> <li>• delay in first age of sex</li> </ul>
<i>Group behaviour</i>		
	<ul style="list-style-type: none"> <li>• Education</li> <li>• male and female circumcision</li> </ul>	<ul style="list-style-type: none"> <li>• common sexual practices</li> <li>• Social practices concerning women: eg, polygamy,</li> <li>• behaviour in military</li> </ul>
	<ul style="list-style-type: none"> <li>• behaviour of medical practitioners</li> </ul>	
<b>Care and Treatment</b>		
		<ul style="list-style-type: none"> <li>• Counselling</li> <li>• provision for decline in income</li> <li>• care for children</li> </ul>
	<ul style="list-style-type: none"> <li>• Education</li> <li>• Treatment opportunistic infections</li> <li>• Treatment general health</li> <li>• Hospitalisation</li> <li>• Anti-retroviral Therapy (ARV)</li> </ul>	
<b>Long-term Causes/Impact</b>		
<ul style="list-style-type: none"> <li>• lack of medical personnel</li> <li>• lack of hospitals and clinics</li> </ul>		<ul style="list-style-type: none"> <li>• Economic vulnerability</li> <li>• Migrant patterns of employment</li> <li>• 'Developmental' displacement</li> <li>• War and violence</li> <li>• Patriarchal social organisation</li> </ul>
	<ul style="list-style-type: none"> <li>• Poor education</li> <li>• Poor health</li> <li>• Low access to medicines</li> <li>• unhygienic medical practices</li> <li>• Loss of skilled people</li> </ul>	

At the core of any effort to fight HIV/AIDS must be the establishment of systems of *Surveillance* to monitor the spread of the virus, the onset of AIDS, the epidemiological characteristics of the virus in its social and geographical setting and the behavioural characteristics of the population hit by the virus. This comprises a complex set of activities that are expensive, requiring technical sophistication and long-term commitment of personnel and resources.

I have divided *Prevention* activities between those that can be understood as biomedical activities and those that relate to activities directed at changing sexual behaviour and practices. Because there is no vaccine for HIV/AIDS and because the spread of the virus in Africa and most developing regions has been overwhelmingly through heterosexual sex, immediate intervention has focused on efforts to promote behavioural change in the population at large. In Figure 1, I attempt to highlight those aspects of behavioural change that are directed towards individuals, where most of the educational and informational work has been targeted up to now, and those aspects that are related to the behaviour of groups where change must address deeply rooted institutions, particularly informal institutions relating to prevailing norms and values. This dimension has received much less attention in the policy discussion and analyses to date.

As the epidemic begins to reach its full impact, demands for *Care and Treatment* will continue to expand and become increasingly complex. Even in our two case study countries, where the fight against HIV/AIDS is more advanced than elsewhere, governments, private sector actors and associations are only beginning to face up to the challenges to care for People Living with HIV/AIDS. But developing this dimension of interventions is as important to success in prevention work as it is in dealing with the devastating impact on the lives of individuals, families, communities, work places and nations. Few people will choose to get a test and those who know their status may do little to change their behaviour if no care or treatment is available. The only way to make significant progress in prevention and to build a strong political constituency in favour of further action is to make care and treatment accessible as widely as possible within society.

The last category of interventions, *Addressing the long-term causes and impact of HIV/AIDS* comprises deeply rooted structural features of the epidemic and has received mainly lip-service from all quarters. I have tried to avoid a statement of these factors that is all-inclusive of the world's ills, but instead to underline those structural dimensions that appear to be directly contributing to the depth of the pandemic and that are most severely affected by its impact. Given the scale of the HIV/AIDS crisis, a comprehensive response must begin to explicitly address these deeper problems.

All the interventions discussed here require a major effort to resist the *stigmatisation* of people and groups infected with the virus. The early discussion of the virus in the developed world relating it to homosexuality and injecting drug abuse, the fact that the virus is spread through sexual activity and the taboos associated with so many aspects of sex have meant that those touched by the virus still suffer discrimination of the worse sort. Without a determined fight against stigmatisation little progress can be made in surveillance, prevention, care and treatment or addressing long-term dimensions of the epidemic.

The 'measures' or interventions outlined in Figure 1 form the basis for the quick review of achievements in our two case study countries in the next section and a guide to the discussion in the remainder of the report concerning the key aspects of governance and HIV/AIDS.

### 2.3 Achievements in Uganda and Senegal

Detailed accounts are available outlining the accomplishments in each of our case study countries across the measures of intervention laid out above.<sup>33</sup> Here I include only some of the highlights of the evidence of progress made.

Uganda was one of the earliest and hardest hit by the HIV/AIDS epidemic in Africa. The first cases of HIV were identified in 1983 and thereafter the number of reported cases expanded exponentially. Prevalence as measured by surveys of women attending antenatal clinics appears to have peaked in the early 1990s and declined through the decade, remaining stable from 2000 until now. Most spectacularly, in one urban surveillance site, Mbarara in western Uganda, prevalence was recorded at 30.2% in 1992 and had fallen to 10.6% by the end of 2001.<sup>34</sup> The data on actual levels of infection in Uganda as everywhere else are terribly imprecise, but the US Census Bureau/Joint United Nations Programme on HIV/AIDS (UNAIDS) after analysing all available information suggested that overall national prevalence probably peaked at about 15% in 1991 and had fallen to approximately 5% by 2001.<sup>35</sup> Ugandan sources suggest a national prevalence of 6.1% by year-end 2001, and DFID Uganda reported the most recent figure for 2002 at 6.5%.<sup>36</sup>

Especially important has been a marked decline in prevalence observed among young (15-19 year old) pregnant women, which is taken to be a better reflection of *incidence* of HIV – that is the number of new infections, which is what we really need to know – because the presence of infection in this age group is not likely to be biased by AIDS related deaths.<sup>37</sup> Studies of incidence are rare in Uganda, and indeed in all

<sup>33</sup> The most up to date summary of Senegal's experience is, UNAIDS, *Lutte Contre le SIDA: Meilleures Pratiques, l'expérience sénégalaise* (UNAIDS, June 2001) – much more comprehensive than the English account published two years earlier, UNAIDS, *Acting early to prevent AIDS: The case of Senegal*, UNAIDS Best Practice Collection, UNAIDS/99.34E (June 1999). On Uganda, the most comprehensive account is, Janice A. Hogle, ed., *What Happened in Uganda? Declining HIV Prevalence, Behaviour Change and National Response*, Projects, Lessons Learned Case Study (USAID, September 2002) and Uganda AIDS Commission, *The National Strategic Framework for HIV/AIDS Activities in Uganda – 2000/1 to 2005/6* (Kampala, UAC, 2000).

<sup>34</sup> Uganda STD/AIDS Control Programme, *HIV/AIDS Surveillance Report* (June 2002), p.5, Table 1. Two other sites record a similar drop, Nsambya and Rubaga.

<sup>35</sup> Janice A. Hogle, ed., *What Happened in Uganda? Declining HIV Prevalence, Behaviour Change and National Response*, Projects, Lessons Learned Case Study (USAID, September 2002), p.6.

<sup>36</sup> Uganda STD/AIDS Control Programme (June 2002), p.5 and communication from Angela Spilsbury, DFID, Uganda, 10 April 2003.

<sup>37</sup> Prevalence – what percentage of those sampled tested positive – is an imperfect measure, as it is based on data collected from 'sentinel surveillance' sites imperfectly distributed in the country (with some bias to urban areas), but nevertheless it is judged to be a cost-effective way to measure the infection rate. Aside from the fact that antenatal clinics are out of the reach of many rural people, the problem with this measure of prevalence is that an increase in AIDS-deaths or a decrease in fertility of AIDS affected women (due to STI co-infection, or decline in sexual activity) would show up as a lower prevalence rate – a bias downwards. It is also possible that since young women were more likely to become infected and also to become pregnant in the earlier years of the epidemic – overall prevalence

developing countries, as they are labour-intensive, time-consuming and expensive.<sup>38</sup> One landmark study in south-western rural Uganda has shown a decided decline in HIV incidence between 1989 and 1999, but of course the presence of researchers in the community and the educational value they brought was probably a major contributor to declining incidence of infection.<sup>39</sup>

In 1987 Uganda's Ministry of Health established four sentinel surveillance sites in hospitals with antenatal clinics, which expanded by the end of 2002 to 20, distributed to be representative of the whole country. Since 1986 the health services have also documented AIDS cases, which provide valuable insights for the fight against the virus, though the relatively small proportion of cases documented reflects the large number of people living with AIDS who still lack access to full health services.

By 2000, the Uganda Blood Transfusion Services (UBTS) claimed that screening was almost universal and blood safety increased to 90%. In 1990 the AIDS Information Center (AIC) was established to provide voluntary testing and counselling and expanded to four urban areas by the middle of the decade. As of 2000, some 400,000 people had been tested,<sup>40</sup> still far too few.

Women surveyed reported that condom use increased from 1% in 1989 to 16% in 2000, with the comparable figures reported by men increasing from 16% in 1995 to 40% in 2000. However, data from Uganda's PPAP, records condom use nationwide at only 20%, with negative attitudes of men still a major barrier.<sup>41</sup> Since 1994, new programmes were initiated for the diagnosis and treatment of STIs, however, Uganda lags far behind Senegal in developing the diagnosis and treatment.<sup>42</sup> By the mid-1990s, two in every three people surveyed were able to cite at least two ways to protect against HIV. Some 57% of women and 64% of men reported that they had sex

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may be overestimated at the start of an epidemic and underestimated in later years. See the important contributions of Justin Parkhurst, "The Crisis of AIDS and the Politics of Response: The Case of Uganda," *International Relations*, 2001, 15 (6): 69-87 and 'The Ugandan success story? Evidence and claims of HIV-1 prevention' *The Lancet*, Vol 360 (6 July 2002), pp.78-80. Hogle, ed. (p.2), suggests that, while prevalence based on antenatal data is an imperfect measure, in other African countries where the epidemic dates from about the same time as in Uganda and has been as severe, there has not been anywhere near the same decline in prevalence.

<sup>38</sup> A study of incidence requires repeated testing of a precisely defined and large enough cohort of people, keeping track of movements in and out of the cohort over a relatively long period of time.

<sup>39</sup> S M Mbulaiteye, C Mahe, J A G Whitworth, A Ruberantwari, J S Nakiyingi, A Ojwiya, A Kamali, 'Declining HIV-1 incidence and associated prevalence over 10 years in a rural population in south-west Uganda: a cohort study', *The Lancet*, Volume 360, Number 9326 (6 July 2002), pp.41-46. Of course, as the authors themselves remark, studies of incidence which involve long-term contact between researchers and residents, due to both the ethics of research and the educational messages mean that the studies themselves are one of the major tools to effect behavioural change that can lead to a decline in incidence.

<sup>40</sup> Uganda AIDS Commission, *The National Strategic Framework for HIV/AIDS Activities in Uganda – 2000/1 to 2005/6* (Kampala, UAC, 2000).

<sup>41</sup> Uganda Ministry of Finance, Planning and Economic Development, 'Uganda Participatory Poverty Assessment Process' National Report (final draft) December, 2002. This may be a reflection of the reluctance shown by President Museveni to emphasise condom use believing it creates a false sense of security, that men will not accept it and that condoms were still not universally accessible. The NRM published guidelines in the late 1980s that acknowledged condoms 'can reduce the chance of getting AIDS' but warned how ineffective they were. *National Resistance Movement Guidelines for the Control of AIDS: Action for Survival* (Department of Information and Mass Mobilisation, NRM Secretariat, printed with assistance from UNICEF, no date).

<sup>42</sup> Hogle, ed (2002).

with one or fewer partners and the median age of first sexual encounter among girls increased by six months between 1989 and 1995.<sup>43</sup>

### *Senegal*

Since surveillance began in Senegal prevalence of HIV has remained at about 1% among pregnant women attending antenatal clinics and between 15 and 30% among registered CSWs at the sentinel survey sites, with an increasing trend over time. Prevalence observed among young women (15 to 25 years old) is three to four times less than women 25 years or older. Since 1996, there has been a shift in the composition of those testing positive, with HIV-1 slowly overtaking HIV-2 in all groups – a tendency that may be worrying. There is clearly a higher prevalence among those who suffer STIs.<sup>44</sup>

The WHO assisted Senegal in establishing its sentinel surveillance system in 1989. From surveillance sites in four districts, the system expanded to cover 10 out of the country's 11 districts by early 2003.<sup>45</sup> Four groups are followed: pregnant women attending antenatal clinics; CSWs who are registered and attending the STD centre; men who attend the STD centre; TB patients and all hospital patients being treated by the infectious diseases and internal medicine services. Surveys of 'social behaviour' were launched in 1997 and a 'second generation' generation surveillance system was launched in 2001, with the aim of expanding surveillance to all regions and which includes a survey of sexual behaviour among high risk groups including the military, migrants, seasonal workers and 'mobile workers' (truckers, fishermen, etc).<sup>46</sup>

When Senegal launched its HIV/AIDS campaign in 1986 it worked quickly to ensure 100% safety in its blood banks, ensuring transfusions met international standards. As noted above, Senegal began major work in this area in 1978.

A behaviour survey conducted in 1997 drawing on some baseline data from 1993 documented significant progress in promoting individual behaviour change: 90% of those targeted by educational programmes could identify at least two methods of prevention; between 1993 and 1997, the proportion of the population reporting having sexual relations with at least one casual partner was cut in half; in 1997, 70% of respondents said they had used a condom at their last sexual encounter with a casual partner; between 1993 and 1997 there was an 80% increase in the number of people who said they were able to gain access to condoms; and there was an increase over the period in the number of people who used the health services for STI treatment. Also there was a marked rise in the number of young girls who had not had sex and a rise in the number of boys who had used condoms consistently. Sales of condoms increased sharply between 1995 and 2000.<sup>47</sup> At the same time two particularly worrying trends have emerged: first, in terms of prevalence, a declining trend of HIV-

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<sup>43</sup> Uganda AIDS Commission, *The National Strategic Framework for HIV/AIDS Activities in Uganda – 2000/1 to 2005/6* (Kampala, UAC, 2000).

<sup>44</sup> Ministère de la Santé et de la Prévention et le Conseil National de Lutte Contre le SIDA, *Bulletin Epidémiologique de Surveillance du VIH/SIDA: 1999, 2000, 2001*, no.9 (March 2002) and interview with Professor Mboup.

<sup>45</sup> Interview with FHI.

<sup>46</sup> *Bulletin Epidémiologique de Surveillance du VIH/SIDA: 1999, 2000, 2001*, no.9 (March 2002)

<sup>47</sup> UNAIDS, *Lutte Contre le SIDA: Meilleures Pratiques, l'expérience sénégalaise* (UNAIDS, June 2001), pp.18-19.

2 has been matched by a rising trend of HIV-1, and while women once constituted a minority of those infected, they now are the majority.<sup>48</sup>

### *In both Uganda and Senegal*

In both countries, the high proportion of cases of transmission from mother-to-child has been recognised. A relatively simple and cost effective antiretroviral treatment has been demonstrated to have great potential in reducing this important means of transmission of the virus. Thorny issues remain concerning breast-feeding of newborns. While developing programmes is now a high priority, especially in Uganda, progress so far has been slow.<sup>49</sup>

In both Uganda and Senegal efforts to promote behaviour change have remained largely directed at individual behaviour. Much less has been done to address the institutional barriers blocking change in the behaviour of groups. Some decided progress has been made among the armed forces in both countries.

In the HIV/AIDS programmes of both countries, Care and Treatment has been recognised as the biggest challenge facing the nation, yet, in both, the means to deal with mounting numbers of People Living with HIV/AIDS (PLWH) are woefully inadequate. Despite education campaigns, stigmatisation remains a major problem in communities and workplaces. Outside of hospitalisation, most of this work is being carried out by the non-governmental sector who face huge deficits in terms of skilled personnel and funds. Many of the specific issues related to care and treatment are taken up below.

It must also be said that even in our successful case study countries, very little has been done to address the long-term causes and impact of the epidemic. This obviously poses challenges far beyond the capability of single nation-states and it is unlikely that substantial progress can be made in this area without a transformation of the international efforts to fight the epidemic. Thus far, international agencies have focused much of their attention on attempting to promote campaigns for individual behaviour change in the countries hardest hit by HIV/AIDS.

## **2.4 Summary**

Uganda and Senegal have seen two very different experiences of the epidemic linked to epidemiological, social, economic and political factors. The most important insights from this brief consideration of the patterns of the epidemic are:

- Understanding the pattern of the epidemic is the first step to identifying the set of actions to fight it;
- Laying out these actions in a typology demonstrates that most have both medical/technical and social/economic/political dimensions;

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<sup>48</sup> *Bulletin Epidemiologique de Surveillance du VIH/SIDA* (March 2002).

<sup>49</sup> UAC, 2000. *Atelier de partage sur la prévention de la transmission mere-enfant du VIH au Sénégal, (Dakar, 31 mai 2000) Rapport Final*, Série, 'Recherches sur le Sida au Sénégal', no.4 (Dakar, Résé- Sida et Synergie pour l'Enfance, December 2000).



- Behaviour change must address both individuals and groups, but there has been little work on the latter;
- Both countries have made significant progress in surveillance and prevention;
- However, increased efforts need to be directed toward preventing mother-to-child transmission, care and treatment and addressing long-term causes and impact.

### **3. National and Central Leadership**

It has already become amply clear to the international community that the character of leadership at the highest levels of government has been decisive in diverse outcomes in confronting this epidemic. We hear a great deal about 'political will' and about prime ministers or presidents needing to personally take the lead in fighting HIV/AIDS. However, 'political will' has always been an elusive concept – a type of black box – 'you have it or you don't'. The 'quality of leadership' is also an elusive factor. Some will be better leaders than others and leadership involves a complex set of determinants: intelligence and vision; charisma (the ability to inspire); rhetorical and organisational skills; openness to innovation; willingness to take risks, make hard choices and set priorities; accessibility of ideas and information; and luck. These factors of course played a role in both Senegal and Uganda, though arguably the personality of the leader was more important in Uganda and the quality of the leading organisation was decisive in Senegal. Both supporters and opponents of President Museveni stress how his charisma, his closeness to ordinary people and his rhetorical skills played a crucial role in the HIV/AIDS campaign.

However important these person-specific characteristics of leadership are, there are other aspects of central leadership, which are more relevant in terms of potential application under diverse efforts to fight HIV/AIDS. We need to ask:

- What can be learned about leadership from these two very different cases?
- What led to decisions to act early and to act decisively?
- What permitted coalitions behind programmes of action?

The fact that similar commitment and mobilisation were achieved in two very different political systems facing two entirely different sets of governance challenges is cause for hope in identifying lessons. The two 'success stories' represent very different kinds of success – that is, one where early intervention kept HIV/AIDS under control and the other where concerted action in the context of a full-blown epidemic has seen early signs of stabilisation and even reduction of prevalence and incidence of the virus.

#### **3.1 Four key aspects of central leadership**

Four key aspects of central leadership, seldom pointed to in the literature on HIV/AIDS, emerge as pivotal in the fight against the epidemic:

- to achieve action at the highest level requires a situation where leaders have little to lose and everything to gain by engaging the fight with HIV/AIDS – the minimisation of negative incentives and the maximisation of positive;
- leaders must act on the basis of medical and scientific evidence;
- it must become illegitimate to occupy a position in government without full commitment to the fight against HIV/AIDS;
- central authorities are crucial to the mobilisation of social organisations.

*Nothing to lose and everything to gain – getting the incentives right*

The severity of HIV/AIDS was driven home to Museveni even before he came to power in 1986.<sup>50</sup> Within months of taking power in Kampala, Museveni's first Minister of Health, Dr. Ruhakana Rugunda, was sent to the World Health Assembly in Geneva where he announced the HIV epidemic facing the country.<sup>51</sup> This was in marked contrast to the attitude of other African leaders when confronted with the first hard evidence that HIV/AIDS threatened an epidemic. For some, like in Kenya, there were worries that acknowledging the epidemic publicly would devastate the tourist industry and turn away investment.<sup>52</sup> In addition to his recognition of the seriousness of the epidemic, there were two other factors that probably led Museveni to early action:

- 1) Museveni did not have to face the same dilemma as countries like Kenya since Uganda had been devastated by war, there was no tourism to speak of and investors had long stayed away from the chaotic Ugandan economy;
- 2) The international community, already enamoured by Museveni's openness to major economic reforms, made it clear that foreign funding to fight HIV/AIDS would be provided.

As early as February, Rugunda elevated Dr. Sam Okware who had been secretary of the Disease Surveillance Sub-Committee that had begun investigation of HIV/AIDS under the old regime (see below) to head the sub-committee and it began meeting on a bi-monthly basis. Some foreign experts who had played a key role in discovering the virus in Uganda, like Dr. J Wilson Carswell, believed that the new government was still being far too complacent during this period.<sup>53</sup>

It was in September 1986, when the foundations of the new regime had been firmly consolidated, that Museveni appeared to take a personal interest and a direct role in stepping up government efforts to fight the epidemic. Apparently, he was prompted to take new action when he learned that of 60 officers that he sent to Cuba for high-level

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<sup>50</sup> According to one of his advisers, he first heard that the disease was transmitted through heterosexual encounters in 1984-85, listening to a BBC report from Zambia. He called his commanders together at that time and warned them that they could be killed by promiscuous sexual relations

<sup>51</sup> The World Health Organisation's annual meeting took place 1-15 May 1986.

<sup>52</sup> According to FHI in Senegal, other African leaders saw HIV/AIDS as simply another crisis 'being imposed on Africa' by the international community. Edward Hooper, *Slim: A Reporter's Own Story of AIDS in East Africa* (London: The Bodley Head, 1990, p.162) reported that in December 1985, Kenya was the first sub-Saharan African country to report AIDS cases to the WHO, before it went into severe denial in 1986.

<sup>53</sup> Hooper, 1990, p.349.

military training, 18 (or 30%) had tested HIV positive.<sup>54</sup> Rugundu arranged for Okware and his Sub-Committee to brief the President on the state of the epidemic and the President responded by upgrading the Sub-Committee to establish the National Committee for the Prevention of AIDS, publicly launched at Kampala City Hall in October 1986.

The donor community clearly played a role in this process. UNICEF was present at the inauguration of the NCPA and, in January 1987, the World Health Organisation sent a mission to lay the groundwork for cooperation with the government. In February, an issue of the *Health Information Quarterly* was published documenting the severity of the epidemic, which was followed by the publication of articles in the international press.<sup>55</sup> That month, a second WHO team arrived, including Robert Downing who had played a role in identifying the presence of HIV/AIDS in the country, which assisted in drawing up a five-year action plan, published on 2 April 1987. This formed the basis for a donor conference organised by the Ministry of Health and WHO in May 1987 and the launching of the first AIDS Control Programme in Africa, which was based within the Ministry of Health. Donors pledged \$6.9 million to fund it through its first year, with \$14 million for the following four years.<sup>56</sup>

The government's openness and willingness to acknowledge the scale of the epidemic had its limits and was not problem-free. Journalist Ed Hooper reported the unease among government officials, including Rugunda and Okware, with the international coverage of the epidemic and with journalists investigating AIDS between 1986 and 1988. In early 1987, key foreign medical experts involved in the early work on HIV/AIDS, like Carswell, were forced to leave the country.<sup>57</sup> Nevertheless, the concerted action taken by Museveni's government was exemplary among those countries in Africa where HIV/AIDS had reached epidemic proportions.

In Senegal, the conditions under which President Diouf accorded high-level national attention to HIV/AIDS were very different. Senegal was not facing a full-blown epidemic when the government decided to act. Professor Souleymane Mboup and other university-based researchers had heard about the disease in 1983 and decided to undertake research in Senegal in collaboration with foreign academics. They discovered a virus in 1984-85 that was distinct from that found in Europe - HIV2 – and this discovery quickly gained international recognition for Mboup's team. This had a pivotal effect on the course of action taken by the national government. When the first six cases of HIV were identified in 1986, Mboup went to the then Director of Health, where he joined with Dr. Ibra Ndoeye who had been working on STIs among commercial sex workers. A triumvirate was formed between Ndoeye, Professor Awa Coll-Seck who was working on infectious diseases with the Ministry of Health, and Mboup and they met with President Diouf. The President was won over to the idea of

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<sup>54</sup> Almost everyone interviewed recounts the story of Cuban President Fidel Castro's warning to Museveni, apparently while attending a conference of the Non-Aligned Movement held in Harare 1-6 September 1986. See also Laurie Garrett, 'Allies of AIDS: Among warring factions in Congo, disease is mutating', *Newsday* July 9, 2000 <http://www.aegis.com/news/newsday/2000/ND000705.html>. See also *Economist*, March 1987 (cited in Hooper, 1990, p.270).

<sup>55</sup> Articles in *The Guardian* and *Time Magazine* documented the extent of the epidemic – cited in Hooper 1990.

<sup>56</sup> Hooper, 1990, p.184

<sup>57</sup> Hooper, 1990, esp. pp.-103, 117, 172, 287.

a campaign very quickly. Mboup had already gained international fame and medical experts were coming to Senegal. Work on HIV/AIDS was seen as something that added value to, rather than detracting from, Senegal's reputation. USAID made it clear they would provide support. On 29 October the government launched the Comité National Pluridisciplinaire de Prévention du VIH/SIDA (Multi-disciplinary National Committee for the Prevention of HIV/AIDS – CNPS).

*Leadership based on scientific advice*

In both Uganda and Senegal, Presidents Museveni and Diouf shunned the mythologies associated with HIV/AIDS and listened to expert medical advice, though it has to be said that Museveni took more convincing than Diouf. To their credit, both presidents put high value on what local and international medical experts were saying about HIV/AIDS.

Senegal, as indicated above, was fortunate to have within its senior medical establishment one of the world's leading researchers on HIV/AIDS, Dr. Mboup. This was a reflection of the fact that the country had a significant tradition of medical research and teaching, probably due to the status of Dakar at the heart of French colonial Africa.<sup>58</sup> The Ministry of Health also included in its senior ranks, highly skilled medical practitioners and researchers and, importantly, a relatively long-established programme of research and treatment of sexually transmitted infections (STI).<sup>59</sup> The Socialist Party, which had ruled the country since independence, whatever its weaknesses, had a highly educated cadre at the centre, who respected the work of the Senegalese academic and scientific community, which itself was in close communication with the scientific community in France and Europe. Thus when Mboup, Coll-Seck and Ndoye approached President Diouf, their findings and expert opinion were listened to and acted upon.

In Uganda, political authorities and officials in the Ministry of Health under the 'second regime' of Milton Obote were in as much a state of denial about HIV/AIDS as elsewhere in Africa.<sup>60</sup> People began dying in Uganda's Rakai district of a strange 'wasting disease' which by 1982 became known as 'Slim', but no one yet associated the evidence with what would later be recognised as HIV. In late 1983 and early 1984, a team of Ugandan and foreign doctors including Dr. David Serwadda, who was working at the Uganda Cancer Institute in Mulago National Referral Hospital and Dr. J. Wilson Carswell, a British surgeon with long experience in the country, had observed repeated evidence of Kaposi's sarcoma (KS) among young patients – all

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<sup>58</sup> Evidence of the sophistication of the medical research establishment is provided in the outstanding bibliographical review, Charles Becker, 'La recherche sénégalaise et la prise en charge du sida: Leçons d'une revue de la littérature' (Dakar, Réser-Sida, 2000).

<sup>59</sup> Charles Becker and René Collignon, 'A history of sexually transmitted diseases and AIDS in Senegal: Difficulties in accounting for social logics in health policy', in Philip W. Setel, Milton Lewis and Maryinez Lyons (eds), *Histories of Sexually Transmitted Diseases and HIV/AIDS in sub-Saharan Africa*, Westport, Greenwood Press 1999, pp. 65-96.

<sup>60</sup> The following is based on interviews with Dr. David Apuuli, Director General of the Uganda AIDS Commission, Sam Okware, Ministry of Health, Dr. Jesse Kagimba, Presidential Adviser on HIV/AIDS and two articles, Mark Schoofs, 'How African Science Has Demonstrated That HIV Causes AIDS - Proof Positive' *The Village Voice* (5-11 July 2000) and Jennifer Bakyawa, 'Disbelief, then Dawning Horror: How Aids First Came Here', *The East African* (20 January 2003).

from the Rakai district.<sup>61</sup> They knew of the work of another expatriate doctor in Zambia, a cancer surgeon Anne Bayley, who had documented similar evidence of KS in 1983 and suspected a link with the virus that was causing such a stir in North America. By mid-1984, Serwada and Carswell reported their suspicions to Dr. Sam Okware, an epidemiologist in the Ministry of Health's Disease Surveillance Sub-Committee, but his initial reaction was that this was not possible, since a disease of homosexuals was unlikely to be present in Uganda. Serwadda and Carswell quietly sent blood samples drawn from patients with Kaposi's sarcoma to Robert Downing at the Centre for Applied Microbiological Research, at Porton Down, in the UK. By October 1984, Downing reported back that the samples tested positive for Human T-cell Lymphotropic Virus (HTLV-III), as HIV-1 was originally labelled.

In the meantime, Dr. Anthony Lwegaba, a district medical officer in Rakai, was observing the impact of Slim, particularly on traders and smugglers in Kasensero and Lukunyu. By November 1984 he had submitted a report to the Ministry of Health raising the possibility that this disease was linked with the epidemic affecting homosexuals in North America.<sup>62</sup> This led to newspaper reports and in January 1985, President Obote ordered the Disease Surveillance Sub-Committee to investigate. The mission from the Ministry reported that the illness in Kasensero was due to poor sanitation. Apparently it was Dr. Carswell who, at his own expense, sent a selection of the blood samples collected by the team to Downing at Porton Down. When he reported back that the samples had tested positive for HTLV-III, he was appointed to the Disease Surveillance Sub-Committee and chaired a Clinical Committee on AIDS.<sup>63</sup> In June 1985, Carswell, profiting from a visit to the country by Anne Bayley and Robert Downing, organised a team to conduct a study in Masaka and Rakai which sampled all households discovering that only sexually active people had the disease.<sup>64</sup> Their report became the first authoritative study HIV/AIDS in the country and was published in the British medical journal, *The Lancet*.<sup>65</sup>

The doctors involved in discovering HIV/AIDS in Uganda were either foreigners or junior practitioners and political authorities were too preoccupied with holding on to power in a regime that was crumbling to undertake any serious action on HIV before the end of 1985.<sup>66</sup> This changed after Museveni's National Resistance Movement took

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<sup>61</sup> Kaposi sarcoma, a slow-growing tumour of blood vessels that was associated with death from other causes, was first discovered in Austria in 1872 among men of Jewish and Mediterranean ancestry. Cases of a particular aggressive form of KS were increasingly identified in Africa in the 1950s and 1960s among young people. It is now known to affect some 18 to 40 percent of people with AIDS. Smith, ed., 2001, p.406-07.

<sup>62</sup> Hooper, 1990, p.256.

<sup>63</sup> Included in this Committee were some of the key figures who were involved with early work on HIV/AIDS in the country: Roy Mugerwa, Nelson Sewankambo, Fred Kigozi and Richard Goodgame, and they wrote a report, 'AIDS in Uganda' which analysed 65 cases all admitted to Mulago Hospital between October and November 1985 and was published in *Health Information Quarterly* in early 1986 (Hooper, 1990, p.82).

<sup>64</sup> The team included David Serwadda, Nelson Ssewankambo, Roy Mugerwa, Ann Bayley, who had been working with KS cases in Zambia and Robert Downing

<sup>65</sup> Serwadda D; Mugerwa RD; Sewankambo NK; Lwegaba A; Carswell JW; Kirya GB; Bayley AC; Downing RG; Tedder RS; Clayden SA; et al, 'Slim disease: a new disease in Uganda and its association with HTLV-III infection'. *Lancet*. October 19 1985, 2 (8460):849-52.

<sup>66</sup> Of course, it must be acknowledged that Obote's regime was decimated by the civil war and could not concern itself with much more than security. All public services including health had been

power in January 1986. The new president gave his support to the crusading doctors and ordered the medical bureaucracy to make HIV/AIDS a priority. The donor community supported a huge research effort in which Museveni was said to take a personal interest.<sup>67</sup>

The importance of making decisions on scientific evidence is underlined by the apparent dilemma that faces leaders who can see much more immediate and widespread causes of death in diseases like malaria and tuberculosis. Especially in the early stages of an epidemic, leaders will only be convinced to invest resources and attention to HIV if they understand the epidemiological characteristics of HIV (its long period of latency, the way it can spread throughout a population and its incurability) and the way it will interact with other diseases like malaria and TB. Waiting to take action on HIV/AIDS until there is evidence of AIDS-induced deaths, will allow the virus to reach epidemic proportions. In Uganda, this is what effectively happened. In Senegal, by acting on the basis of expert scientific information, the epidemic has been kept under control. It is imperative that political leaders listen to the medical profession and act on the basis of scientific understanding.

What is more, the medical profession needs to play a pivotal role, in establishing the surveillance systems necessary to monitor the disease and progress in fighting it, to establish the clean hygienic processes in blood supplies and the administration of medicine (particularly parenteral, or injecting) practices, to carry out research, which in both countries was pivotal to campaigns to fight the virus, and to provide the kind of support that all other sectors require as they get involved in HIV/AIDS prevention and care and treatment.

#### *Fighting HIV/AIDS became a test of political legitimacy*

The impact of high-level political commitment to fight against HIV/AIDS and the all-out educational campaigns launched in both Uganda and Senegal created a situation where the epidemic was put beyond partisan politics. While Museveni faced many criticisms (though no serious challenges) from opposition forces, all publicly admired the role he played in mobilising the nation around the epidemic and none put the government's commitment to the fight against HIV/AIDS into question. In Senegal, even the radical change of administration in 2000, when Abdoulaye Wade became the first opposition candidate in the nation's history to win the Presidency, did not alter the central government's commitment to fight the epidemic. In fact, the team heading work on HIV/AIDS was retained in its entirety (while strengthened and encouraged to somewhat redefine its role). No one could occupy high office in either of these countries without demonstrating a commitment to continue the fight against the virus.

In Uganda, unity behind the HIV/AIDS campaign was achieved in part due to the overwhelming presence of President Museveni and his military organisation, given the context of the guerrilla war he had won. Museveni also left little room for open

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destroyed by the long period of unrest from the first uprising against Amin, through the second Obote regime.

<sup>67</sup> Hooper (1990), p.214.

political dissent once the NRM government adopted a policy.<sup>68</sup> But the unquestioned participation in the campaign was also driven by the fact that there were few families in the country, including the families of most major political actors, who were not affected by HIV/AIDS. As time went on, everyone knew someone who had died as a result of the virus and the images of its impact, at least in the urban areas, were pervasive. Doctors could not cure their own brothers and money and privilege was no shield to the virus. With the development of antiretroviral therapy and the access that the wealthy can gain to these drugs, this basis for the broadest possible coalition to fight HIV/AIDS may be weakened in the future (see discussion below). In Senegal, it was the prestige of medical authority, of Senegal's lead role in research on HIV/AIDS, that helped build political consensus behind the campaign and to solidify the coalition of support. Ibra Ndoye, the public face of the campaign in Senegal since it began, never joined a political party, ensuring that his work would not become partisan and his access to whoever held political authority.<sup>69</sup>

*Central leadership to ensure society's involvement*

In both Uganda and Senegal, it was leaders of the central state who acted first to rally the nation behind the fight against HIV/AIDS. They had the knowledge and the connections with the international community, but most importantly, the authority to convince a diversity of social groups to organise around HIV/AIDS. The central government in each case encouraged existing associations to take up work on the epidemic and helped to form new organisations.<sup>70</sup> In Senegal, the government's early response is one reason why the HIV/AIDS was arrested in its tracks. While the Parti Socialist was often criticised for over-centralisation and, while much of the discourse about achieving the kind of behavioural change that is necessary to slowing transmission of HIV/AIDS is geared towards mobilising 'civil society', it was the Parti Socialist's centralist character that allowed it to reach down through the associations to every corner of the country and that was responsible for the early awakening of the nation to the danger posed by the virus.<sup>71</sup> In a similar way, in Uganda, the centralist authority of the National Resistance Movement, and the military organisation on which it was based, also made quick dissemination of the message about HIV to every village possible once Museveni came to power.<sup>72</sup> It was Museveni's military organisation that in 1988 implemented the first national sero-survey to take place in Africa. The crucial role of centralist leadership in getting an all-out campaign against HIV/AIDS underway has also been demonstrated in Cuba and, in preliminary accounts from those working on the ground, in Eritrea, where despite criticisms from international actors about the lack of deference to NGOs and civil society, rapid progress was made in fighting the epidemic.<sup>73</sup>

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<sup>68</sup> See G.W. Kanyeihamba's account of 'correct politics' provides some insight here, *Constitutional and Political History of Uganda: From 1894 to the present* (Kampala: Oscar Industries, 2002), pp.267-68.

<sup>69</sup> Ndoye address to World Bank workshop, Dakar, 21 January 2003.

<sup>70</sup> For a more detailed discussion see the sections below on religious organisations and NGOs.

<sup>71</sup> The most articulate members of the NGO community recognise this. Interviews with Aminata Toure (UNIFEM) and Baba Goumbala (ANCS).

<sup>72</sup> This was not an automatic process. Hooper (1990, p.269) reported in 1987 that the NRM was slow to develop cooperation with the National Committee for the Prevention of AIDS.

<sup>73</sup> Bourne, Peter G., 'Asking the right questions: Lessons from the Cuban Health Care System', 2003 Health Equity Network Annual Lecture, at LSE, pdf file. United Nations, 'Eritrea tackles AIDS' (10

While a multi-sectoral approach and the involvement of a diversity of social organisations and associations was essential to the success of campaigns in both countries, as we show in later sections, the experience in both countries demonstrates how that was made possible through strong central leadership. Of course, in the absence of strong central leadership, there is no choice but to look to the organisations in society that can take up the fight against HIV/AIDS. But just as NGOs and community based organisations can never provide for the military security of a country, neither can they provide for security from an epidemic like HIV/AIDS. If central leadership is lacking, it is highly unlikely that sustained progress can be made to protect against the virus. Therefore, if donors find themselves working mainly with non-governmental organisations, then part of that work needs to encourage and assist these organisations to work towards putting into place the kind of central leadership that can sustain a campaign over time, including encouraging the expansion of social involvement.

### 3.2 Summary

Each of these four characteristics has implications for those wishing to emulate the success achieved by Senegal or Uganda, as well as donors wishing to contribute to institutionalising an emergency response to HIV/AIDS elsewhere:

- donors can help to ensure that positive incentives for active engagement in tackling the epidemic outweigh whatever negative incentives exist - as the epidemic progresses and it becomes nearly impossible for leaders to persist in strategies of denial, financial and technical support from abroad can tip the balance in favour of action;
- both local and international actors must press their leaders to privilege medical and scientific evidence as the basis for decision-making about HIV/AIDS as this is the only way they can be convinced of the urgency of action in the face of other diseases that are apparently more immediate killers - particular care and concern must be accorded to this in the context of efforts to develop multisectoral and participatory aspects of a campaign (more on this below);
- both local and international actors can actively work towards a situation where it is illegitimate for anyone to occupy a position in government without full commitment to the fight against HIV/AIDS – this is a question of politics engaging the battle over what constitutes acceptable behaviour for anyone in public authority;
- where central authorities are not taking the lead in the fight against HIV/AIDS, local and international actors cannot simply turn to the associational sector, but must couple a turn to civil society with an effort to ensure social organisations have both a vision and a plan to get central authorities to act (this is taken up further below).

The benefits of central leadership on all these fronts clearly can best be achieved where leadership is provided by a political party, rather than dependent entirely on the beliefs and abilities of individual leaders. In Senegal, it was arguably the culture and



programme of the Parti Socialist that was more important to positive action than the person of President Diouf. In Uganda, and indeed in Senegal since the election of Wade, action on HIV/AIDS has been determined by the individual leadership of a populist President and to be sustained over time gains must be institutionalised both within party programmes and within the organisations of the state.<sup>74</sup>

#### **4. Multi-Sectoral Approaches and 'mainstreaming' HIV/AIDS**

The epidemiological and social character of the HIV/AIDS epidemic has meant that biomedical responses are entirely insufficient to any attempt to bring it under control and deal with the short, medium and long-term impact on social, economic and political systems. This is evident if we refer back to Figure 1 outlining the measures necessary to confront the epidemic. In both our 'success stories' governments developed what is widely referred to in policy circles as a 'multisectoral approach', which involved both the cross-ministerial participation of all branches of government and a partnership between government agencies, religious organisations, the associational sector including NGOs, international donors and increasingly, the private sector.

Since the late 1990s, as the international donor community assessed the slow progress in fighting the HIV/AIDS epidemic in Africa, there has been increased emphasis placed on finding ways to 'mainstream' HIV/AIDS across all developing country government activities, to involve non-government actors in campaigns, and to get resources to fight HIV/AIDS into communities. The two most important instruments of multilateral assistance, the World Bank's Multi-Country AIDS Programme (MAP), launched in September 2000, and the Global Fund to fight AIDS, Malaria and Tuberculosis (GFAMT),<sup>75</sup> launched in 2002, both have attempted to further these objectives by requiring countries to demonstrate a commitment to mainstreaming and to a multisectoral approach as conditions for gaining new resources to fight the epidemic.

I would like to suggest a number of problems related to the current reigning template for the management of national HIV/AIDS campaigns:

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<sup>74</sup> One of the most precarious aspects of the many successes Uganda has achieved in development since 1986 is the overwhelming reliance on the President on one hand, and foreign donors on the other. Recent moves by Museveni to finally recognise the NRM as a political party and to move towards multi-party competition appear as potentially an antidote to over-reliance on the person of the president and these moves need to be coupled with greater institutionalisation of gains both within the NRM and within state organisations.

<sup>75</sup> The Global Fund is a non-profit foundation established in Geneva to act as a clearing house for donor funds and is administered by the World Bank, very much on the model of the Global Environment Fund. See, 'Bylaws of the Global Fund....' It was set up in 2002, with an initial pledge of 2.1 billion dollars. The initiative was first born in the US House of Representatives where there was a proposal to set up a Global AIDS and Tuberculosis World Bank trust fund. On the urging of the Secretary General of the United Nations at the UN General Assembly Special Session on HIV/AIDS (June 2001), a proposal was adopted to endorse a "Global Fund" followed by an endorsement from the G-8 in July 2001. The initial board of the Fund met in January 2002. Raymond W. Copson and Tiaji Salaam, 'The Global Fund to Fight AIDS, Tuberculosis, and Malaria: Background and Current Issues' Foreign Affairs, Defense, and Trade Division, Congressional Research Service, RS21340 (October 21, 2002).

- A 'multisectoral approach' is taken to mean *both* 'mainstreaming' HIV/AIDS in all government activity – eg, all departments incorporate an assessment of the impact of the epidemic on their work and design mitigating measures as well as action to combat the epidemic in their domains – *and* 'full involvement of non-governmental sectors' – religious, voluntary and private – in planning and implementing HIV/AIDS campaigns. These are two distinct goals requiring different measures and they do not necessarily go together.
- There is in the template an implicit assessment of the inability of organisations *within* the state, or public authority, to implement HIV/AIDS programmes and an implicit, virtually ideological belief, that NGOs, religious organisations and private sector organisations will be able to do better.
- In reaction to over-reliance on the health sector in the past, the model has tended to *secondarise* medical expertise, by treating ministries of health as just one among many co-equal (bureaucratic and incompetent) government ministries and the medical dimension of the fight against the epidemic as just one among many co-equal aspects of what must be a multi-dimensional effort.
- Most importantly, the establishment of supra-ministerial bodies effectively ends up in inadequate attempts to *reinvent* government and to replace what is essentially a *political challenge* of prioritising HIV/AIDS in government and non-government sectors with an *organisational fix*.

In this section I first argue that the successful experience of Uganda and Senegal has been misinterpreted. The template being imposed for the establishment of national commissions is over rigid and risks setting back the fight against HIV/AIDS.

Second, I take up the specific role of religious organisations. Again, both countries have achieved major success in getting religious organisations involved with the campaign against HIV/AIDS. I discuss the lessons of this experience as well as the dangers involved.

Third, mobilising the associational sector has been central to the success of a multisectoral approach. I discuss here the role that can be played by different types of associations, but also the need to carefully consider the relationship between the state and associational sector.

I conclude this section with a reflection on the problems of the reigning template mentioned above and the lessons derived from Ugandan and Senegalese experience.

#### **4.1 National commissions to fight HIV/AIDS**

Both the World Bank's MAP and the Global Fund require countries to establish a supra-ministerial and multisectoral national committee or commission to oversee a national programme. The Bank demands that 'a high-level HIV/AIDS coordinating body such as a national HIV/AIDS council or equivalent has been established to oversee the implementation of the strategy and action plan. This body should include broad representation of key stakeholders from all sectors, including PLWHA'.<sup>76</sup> The

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<sup>76</sup> World Bank, AIDS Campaign Team for Africa, 'Second Multi-Country HIV/AIDS Program (MAP2) for Africa', summary of World Bank documents pertaining to the Second Multi-Country HIV/AIDS Program for Africa (January 2002), p.15.

Global Fund requires the establishment of 'Country Coordination Mechanisms', which it describes as 'national consensus groups' made up of representatives from government, NGOs, the private sector, people living with HIV/AIDS, TB and Malaria, religious and faith groups, academic sector and UN agencies active in the country.<sup>77</sup>

The requirements imposed on countries to set up such central bodies supposedly grew out of an assessment of successful experience, particularly interpreted by UNAIDS, and presumably drawing on the experience of success stories such as Uganda and Senegal. While the imposed template for organising effective national campaigns against the epidemic rightly calls for action across government and the full involvement of non-governmental sectors, it is a rigid model that may hinder such national campaigns, even in our two case study countries.

#### *The Uganda AIDS Commission*<sup>78</sup>

When President Museveni decided to launch a nation-wide effort to fight HIV/AIDS in 1986 he formed the National Committee for the Prevention of AIDS (NCPA) within his office and chaired by himself. At the same time a National AIDS Control Programme was established in the Ministry of Health. Between 1987 and 1990, the NCPA held monthly meetings chaired by the President and attended by the major donors. By 1988, the NCPA included representatives from the most concerned national government ministries, all the major religions in the country and the NGO community, particularly the path-breaking NGO, TASO, set up by People Living with HIV/AIDS at the end of 1987. During the first four years of the campaign, the Ministry of Health, assisted by the WHO, developed the nuts and bolts of Uganda's fight against the epidemic through the National AIDS Control Programme.

The Ministry of Health's National AIDS Control Programme was the centrepiece of the government's efforts to fight the epidemic and quickly became bigger than the rest of the MOH. It was tasked with health education, the establishment of a blood bank and the development of care for people suffering from AIDS, especially treatment of the opportunistic diseases. By 1988, it had helped to launch major programmes on HIV/AIDS within the Ministry of Education and in the Ministry of Defence and had launched work with NGOs like TASO. The MOH worked closely with the WHO to develop the National AIDS Control Programme and established six units: (1) epidemiology in charge of surveys; (2) monitoring and evaluation; (3) information, education and communications; (4) care for people living with AIDS, especially in relation to opportunistic infections; (5) STD management; and (6) infection control and precautions, such as the use of condoms.

By 1990, with the urging of the World Bank, the President set up a team to form a Commission that would be housed under the Office of the President and would include 11 Cabinet Ministers, as well as religious organisations and NGOs. The mandate of the new Commission would be to coordinate responsibilities for fighting the epidemic among ministries through joint planning, to undertake monitoring and evaluation work and to share information. The UNDP was tasked with providing

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<sup>77</sup> Copson and Salaam, 2002.

<sup>78</sup> This account is based on interviews with major players in the National Committee and the subsequent Uganda AIDS Commission.

support to the new Commission. By 1992, the Uganda AIDS Commission was established, but right from the start it experienced problems.<sup>79</sup> The enabling legislation was unclear about its mandate or the relation of the UAC with the line ministries. It was difficult to achieve a quorum in meetings with 11 Ministers. The leadership was initially formed of expatriate Ugandans who earned foreign level salaries. While the UAC was not designed to engage in the implementation of projects, it quickly began to do so. Instead of taking the lead, the Ministry of Health was seen as the 'technical arm' of the UAC. Over the next three years, the UAC administered programmes largely funded by the UNDP. By 1997, when initial funding was spent, the donors were disappointed with the performance of the UAC and it was folded back under the authority of the MOH and remained moribund.

It was therefore extraordinary when, under World Bank pressure in 1999, the UAC was revived and placed back under the Office of the President. Dr. David Apuuli who had been Director General of Health Services from 1993 was appointed as the new Director General of UAC. The UAC was to spearhead a multisectoral approach that could receive funds from the newly established Multisectoral AIDS Programme (MAP) of the World Bank. The revival of the UAC caused considerable confusion and infighting between ministries over funds. Its mandate still remained unclear, as the original legislation setting it up, which remained in draft form as late as January 2003, still contained contradictory provisions. By making all ministries co-equal members of the UAC, the MOH was somewhat marginalized, despite the fact that all other ministries called on it for support to their own HIV/AIDS programmes. A great deal of overlapping and duplication of work became evident. This was accentuated when the UAC, called as well for the setting up of similar commissions at the District level - where the Bank hoped to see all funds distributed - as one began to see officials wholly unfamiliar with HIV/AIDS and health matters more generally chairing local HIV/AIDS initiatives.

Successive evaluations of the Uganda AIDS Commission have found that it tended unsuccessfully to duplicate what line ministries, especially the Ministry of Health, could do better; it tended constantly to engage (poorly) in implementation even though it was mandated largely to facilitate and coordinate; and it tended to veer (inefficiently) towards bureaucratic enlargement.<sup>80</sup> What is more, the World Bank's own evaluation of the early work funded through MAP found these problems broadly present in other experiences.<sup>81</sup> The donors reacted to continued UAC weaknesses by setting up a new Partnership Committee in an attempt to coordinate programmes and eliminate duplication and waste. The MOH continued its core AIDS Control Programme throughout this period attempting to insulate it from the vagaries of the UAC.

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<sup>79</sup> Evaluation Team, 'The Report of the Joint Evaluation of the Uganda AIDS Commission and Secretariat', final draft, rev.3 (Kampala, 16 October 1992), with participation from WHO, World Bank and UNICEF.

<sup>80</sup> UNAIDS, 'Final Report: Uganda AIDS Commission Review - September 2001', m.s., n.d., circa April 2002.

<sup>81</sup> World Bank, 'The US\$500 Million Multi-Country HIV/AIDS Program (MAP) for Africa: Progress Review Mission - FY01' (Washington, IBRD, November 2002).

*Conseil National de Lutte Contre le SIDA (CNLS) in Senegal*<sup>82</sup>

Right from the start of Senegal's campaign against the HIV/AIDS virus there was a recognition of the need to mobilise far beyond the health sector to fight the epidemic. Shortly after the first cases of HIV were diagnosed, on 29 October 1986, the government established the Comité National Pluridisciplinaire de Prévention du VIH/SIDA (the National Multidisciplinary Committee for the Prevention of HIV/AIDS – CNPS). The Committee immediately began to elaborate the Programme National de Lutte contre le VIH/SIDA (the National Programme of Struggle Against HIV/AIDS – PNL). From the beginning the CNPS included doctors, biologists, sociologists and members of NGOs and civil society. The programme had three main sections - epidemiological, clinical and educational - and set as its objectives:

- survey and measure the scale of the epidemic
- reduce the transmission of the virus
- ensure the safety of blood transfusions
- promote educational and information activities to avoid sexual transmission of the virus
- assist in psycho-social and clinical care of the sick
- reinforce the struggle against STIs
- develop and coordinate research activities

Over the next decade the CNPS made excellent progress. While the Committee fell under the authority of the Ministry of Health, it worked in close and constructive collaboration with other key ministries with support from WHO. It worked with the Ministry of Women, Children and the Family to put in place community services, with the Ministry of Education for a programme in schools which in 1990 established its own internal committee for nationwide education on HIV/AIDS, and with the Ministry of Work and Employment on a major programme of prevention in the workplace and for the protection of the rights of workers living with HIV/AIDS. From 1987, the CNPS worked with religious and political leaders to get them involved in the campaign. Unlike in Uganda the National Committee maintained a stable leadership under Ndoye, Mboup and Coll-Seck (see section above) and strong cooperation was achieved across the government and with non-governmental actors.

It was thus, somewhat odd, when, on 10 December 2001, the Conseil National de Lutte contre le VIH Sida (CNLS) was created by Presidential decree. It would be chaired by the Prime Minister with as vice-chair the Minister of Health and would include representatives of the key ministries, NGOs and civil society, people living with HIV, development partners (donors) and representatives of local communities and community and religious associations.<sup>83</sup> The move to form the CNLS appears to have been hastily undertaken to comply with the World Bank organisational template, in order for its proposed 'HIV/AIDS Prevention and Control Project' to gain access to

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<sup>82</sup> This account is based on interviews and speeches from the major actors involved in the original National Committee, those in the CNLC, donor personnel and Senegal CNLC, *Plan Stratégique 2002-2006 de Lutte contre le SIDA* (January 2003) and the draft, *Manuel de Mise en Oeuvre du Programme National de Lutte Contre le Sida* (January 2003) in two volumes and UNAIDS, *Lutte Contre le SIDA: Meilleures Pratiques, l'expérience sénégalaise* (UNAIDS, June 2001).

<sup>83</sup> Ministries included in the CNLS: Health, Hygiene and Prevention; Education; Youth; Defence; Family and National Solidarity; Social Development; Public Sector, Work, Employment and Professional Organisations; Foreign Affairs; Tourism; and Infrastructure, Equipment and Transport.

IDA funds under the 'second phase of the Multi-Country HIV/AIDS Program (MAP2) for the Africa Region' that was to come before the Bank's board on 17 January 2002.<sup>84</sup>

What ensued according to both long-time participants in the fight against HIV/AIDS in Senegal, as well as donor officials who had experience working with the CNLS, was a period of confusion and a battle between ministries over funds. The new Conseil National not only fomented discord between ministries, but also demanded that these ministries simply channel the new funds to local multisectoral initiatives. Ministries now had an incentive to duplicate work, rather than do what they do best as before. Various NGOs had long had relationships with specific ministries and developed specialised programmes for women or youth or in the military, or with the private sector. As one experienced donor official commented, the incentive structure introduced by the World Bank and UNAIDS supported Conseil was all wrong. One of the leaders since the very start of the campaign commented that it would now be more difficult to mobilise resources and suggested that the model was imposed without actually having been successfully tried anywhere in the world. He said that in the past when UNAIDS came with various organisational innovations the team in Senegal could refuse what did not seem appropriate. In a comment that summed up the problem, he asked, 'Pourquoi change une équipe qui gagne?' ('Why change a winning team?'). Officials involved since the start of the campaign desperately hoped that the new arrangements would undergo evaluation 'before it leads to a catastrophe'.

#### *A more generalised problem*

The problem of the organisational template imposed by the World Bank and the Global Fund (and UNAIDS) was not limited to Uganda and Senegal. At a meeting of the Commonwealth Ministries of Health in Africa in Entebbe at the end of 2002, there was heated discussion about the problems all ministries had encountered. In summing up priorities for action at the end of the meeting, the first priority was set as follows: 'There is need for clarification of roles, functions, coordination and implementation mechanisms of National AIDS Councils and MoH AIDS Control Programmes'. The first resolution noted 'the need for distinction between the implementation and coordination roles' of commissions and ministries of health, saying, 'the arising ambiguity could reverse progress of national responses to HIV/AIDS' and called for consultations between the national commissions, ministries of health and donors to 're-examine and further clarify roles and functions and redefine mechanisms for co-ordination and implementation'.<sup>85</sup>

One Ugandan official who attended the meeting argued that the Ugandan ministry's programme was strong enough to survive the imposition of a revived UAC in 1999, but the AIDS control programmes of other Ministries of Health, like that in Malawi, had virtually collapsed due to the establishment of a similar commission.

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<sup>84</sup> World Bank, 'Senegal-HIV/AIDS Prevention and Control Project', project ID SNPE74059, PID prepared 22 November 2001 and processed the following week. Report No. PID10681

<sup>85</sup> Commonwealth, 'Technical Report (draft) of the 36th Regional Health Ministers Conference of the Commonwealth Regional Health Community for East, Central and Southern Africa', held at Imperial Botanical Beach Hotel, Entebbe, Uganda, 18 – 22 November 2002, p.46 and Annex 1.

In the past, fighting epidemics has required the transformation of the conception of medicine within the profession itself and we can think of figures like the Canadian doctor Norman Bethune who undertook path-breaking work in the TB ridden slums of Canadian cities before going on to contribute to the development of notions like the 'barefoot doctor' in China during the tumultuous years of its revolution. As efforts are pursued to develop the 'multisectoral' approach, attention needs to be accorded to the centrality of the medical profession in fighting disease and to the development of its greatest traditions of social medicine. The medical profession and the public health sector occupies a special place in the fight against HIV/AIDS and, while in both Uganda and Senegal the sector's practices need to be strengthened and improved, its expertise and resources are required for the work in every other sector.

The World Bank and UNAIDS were absolutely correct to distil positive lessons from successful work on HIV/AIDS and to push governments that have been slow to respond to the epidemic to adopt them. While the Ugandan and Senegalese experience testify to the importance of developing a multisectoral approach to the fight against HIV/AIDS, they do not provide evidence that the organisational template imposed by the Bank and the Global Fund is appropriate. What is perhaps the most extraordinary is that this template was imposed even in successful countries and has threatened to undermine that very success.<sup>86</sup>

## 4.2 Religious Organisations and the fight against HIV/AIDS

Because progress in fighting the HIV/AIDS epidemic is so dependent on changing risky sexual behaviour the dissemination of information and education of the public at large is all important. In both Uganda and Senegal, like in most parts of the world, fostering open discussion about sexual behaviour touches on matters deeply personal and closely linked to specific moralities, values and religious beliefs. Early on in their campaigns political leaders in both countries saw the necessity of involving religious leaders and organisations. Not only were they needed to help influence the population, but the governments needed to ensure that they would be part of, rather than in opposition to, efforts to discuss the epidemic. Because AIDS was initially linked in the west to homosexual behaviour and injecting drug users, and even in Africa was initially linked to promiscuous sexual behaviour, enormous stigma was attached to the disease. No efforts of surveillance, prevention or care and treatment could be made without fighting stigma and religious leaders were recognised as playing an essential part.

In Uganda, President Museveni sought out leaders of the Catholic and Protestant majority Christian community and urged his officials to work with them and to avoid antagonising them. Initially, the President's own opposition to the promotion of condoms helped to reassure Christian leaders. From very early on church leaders were invited onto the national committees charged with fighting the epidemic. One reason the traditionally conservative churches were won over to the coalition to fight the epidemic was the extent to which their own clergy and parishioners were touched by the epidemic. Inventive actions were taken, as when the late star singer, Philly

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<sup>86</sup> It is perhaps telling that there is not one specific reference to a study on Senegal in the UNAIDS "Report on the Global HIV/AIDS Epidemic 2002", which may explain why consideration of organisational achievements there appear to have played no part in decisions on the Global Fund.

Lutaaya, came out openly as HIV positive and organised a concert in the Namirembe Cathedral, in the very early years of the campaign. People took the word of clergy members to heart due to their positions of authority in communities. Like in politics, crucial to the mobilisation of the religious groups was the early involvement of respected leading members of the clergy, like the late Bishop Yona Okoth who provided the space within the church for AIDS activists to operate. Canon Gideon Byamugisha played an enormous role in breaking down prejudice both within the church and in Christian communities when he revealed that his wife had died of AIDS and that he discovered after her death his own HIV positive status.<sup>87</sup> Church organisations have provided subsidies to people to have their status checked and have trained clergy and lay members in counselling. They could reach far into the rural communities, perhaps where even the NRM could not.

In Senegal, President Diouf and leaders of the National Committee also worked hard to involve traditional religious leaders of the majority Muslim community, which makes up some 95% of the population. Traditional religious leaders command enormous influence in the country. The government began by encouraging a survey among religious leaders, carried out by an NGO, which found that most had very poor information about the virus. On this basis a process of negotiation was undertaken. The Muslim NGO, Jamra, (not known for its tolerance having waged Islamist campaigns against drugs and 'perversions' in the past) worked with the highest Islamic officials in the country and the major schools of Islamic thought. The most controversial issue, as in Uganda, concerned the use of condoms and like in Uganda, religious leaders did not support the use of condoms but were won over to a position where they would not oppose either government or private sector efforts to promote condom use. A clear example of the way multiple messages were employed to achieve behaviour change came with the publication of *Guide Islam et SIDA*, which while disseminating the basic facts on the epidemic, emphasised how Islamic teaching could help in preventing the spread of the virus.<sup>88</sup> Religious leaders became particularly involved in treating those succumbing to AIDS. The Catholic Church came on board much later,<sup>89</sup> finally participating in a conference in Dakar organised by the NGO SIDA-Service in 1996 (though SIDA-Service itself was involved long before this).

International donors and international religious communities played an important role in winning over local churches and mosques. The World Council of Churches produced a pamphlet as early as 1987 entitled *What is AIDS?*, which had an important influence in local church circles in Uganda. USAID was instrumental in assisting church and mosque leaders to organise a conference in 1991 to learn about and commit to the fight against HIV/AIDS.

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<sup>87</sup> See his writings: *Am I My Brother's Keeper: Reflections on Genesis 4:9* (Ecumenical Association of Third World Theologians – Uganda Chapter, 1998); *AIDS, the Condom & the Church: Are Science and Morality Exclusively Antagonistic?* (Ecumenical Association of Third World Theologians – Uganda Chapter, 1998); *Breaking the Silence on HIV/AIDS in Africa: How can religious institutions talk about sexual matters?* (Tricolour Designers & Printers, 2000).

<sup>88</sup> Comité National de Lutte contre le SIDA, Association Nationale des Imams et Oulémas du Sénégal, ONG Jamra, *Guide Islam et SIDA: Recueil de Sermons et Conférences* (n.d.).

<sup>89</sup> In Uganda came into the multisectoral organisations only in 1985. As late as 1994, Charles Becker, a social historian long based in Senegal and working on HIV, berated the silence of the Church. 'L'église et SIDA en Afrique', *Afrique & Parole*, 39:2-4 (February 1994), also in *Perspective missionnaires*, 27: 66-76.



In both countries, as some religious AIDS activists themselves said, the state had to take the lead both to ensure a plurality of faith groups could be involved, but also to ensure that the messages of these groups came as supplements to secular public health messages and information. Some secular activists felt uncomfortable that government was putting its name to publications, which while constructive in mobilising members of religious communities, at the same time in citing the Qu'ran still spoke of God's instruction, 'don't go anywhere near sex outside of marriage. In reality this is a depraved act and a detestable road' adding 'If men transgress this divine warning, depravity will develop on land and sea as a result of their own sins'.<sup>90</sup> Others suggested that it was not enough to get traditional and religious leaders not to oppose the HIV/AIDS campaign and government promotion of condom use, but felt that secular government and non-government leaders needed to put pressure on the religious sector to discard old taboos and prejudices.

Some religious organisations have been major providers of health care and education in the absence of public authorities' ability to do so. While claims have been made that religious organisations have provided health care more cost-effectively than public organisations (a 'religious premium' on lower wage costs)<sup>91</sup> some of these tend to evaporate when it is noted that the government wage costs include a lunch allowance, as one consultant pointed out. There is a tendency to turn necessity into a virtue in this respect, particularly with aggressive faith-based initiatives in some of the donor countries. Instead, the activities of religious leaders and organisations should be welcomed, but in the context of developing a sustainable provision of public health available to all regardless of their beliefs. Governments need to be careful about being overly cautious or deferential to any religious group, since addressing the long-term causes and impact of the epidemic will require a transformation of social norms – some of which are explicitly religious or influenced by reigning religious ideas – towards women, towards children and towards sex. In Dakar brigades of street children organised by marabouts attend Qu'ranic 'schools', where they learn to recite prayers without learning to read and are organised to beg in the streets collecting a given quota each day. These practices have never been challenged because the marabouts command important blocs of votes.

### 4.3 The role of NGOs and the associational sector

As with religious organisations, the associational sector (NGOs, community based organisations, or CBOs, and professional associations) has been a pivotal player in both Uganda and Senegal's HIV/AIDS campaigns, particularly in getting messages on behaviour change to communities and in providing counselling and care and treatment to HIV positive people and people living with AIDS. However, what is often overlooked is the fact that the central state was pivotal, not only in creating the space

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<sup>90</sup> Comité National de Lutte contre le SIDA, Association Nationale des Imams et Oulémas du Sénégal, ONG Jamra, *Les Principes médicaux, coraniques et bibliques que tout croyant doit ire, savoir et appliquer* (n.d.), p.14. 'Dieu a dit dans le Saint Coran <<n'approchez point la fornication. En vérité c'est turpitude et quell detestable chemin>> (Verset 32-Sourate 17). Si les homes passent outré cet avertissement divin, la turpitude se développera sur terre et sur mer du fait de leurs propres pêchés'.

<sup>91</sup> Ritva Reinikka and Jakob Svensson, 'Working for God? Evaluating service delivery of religious not-for-profit health care providers in Uganda' (preliminary draft), October 2002.

for the associational sector to act, but in initially mobilising the sector around HIV/AIDS.

In Uganda, despite the hegemony of the National Resistance Movement on the political scene, President Museveni and his cadres saw the importance of NGOs to their general reconstruction efforts after coming to power in 1986 and created a favourable environment for them to grow. The international donor community was instrumental in providing funding for the NGO sector from the earliest days of the Museveni regime. In 1988, The AIDS Support Organisation (TASO) was founded by people living with HIV/AIDS and members of their families.<sup>92</sup> TASO was instrumental in the elaboration of the multisectoral approach in Uganda, a major player in efforts to establish the UAC, a close partner with UNAIDS and a pioneer in promoting voluntary counselling and testing as well as the piloting the use of antiretroviral therapies in the country.

Right from the start the Uganda AIDS Control Programme of the Ministry of Health worked with newly established NGOs, but the latter welcomed the first efforts to set up a Uganda AIDS Commission in 1992 to create a forum where they might play a more central role in the campaign. It was the effective collapse of the UAC that led NGOs to form UNASO, an alliance which brought together the many organisations involved in different aspects of work on the epidemic. They had initially attempted to work with District Directors of Health Services, but found their sporadic work was not sustainable and this led them to form a national coalition.

In Senegal, President Diouf's Socialist Party reached out to the associational sector to educate organisations about HIV/AIDS and to encourage the formation of new organisations to deal with the epidemic. International NGOs contributed as well, with the group, Environment et Développement en Afrique (ENDA) playing a central role right from the start, working with government from the top-down to establish associational activity. NGO activists themselves remember how it was the state that called associations together, that met with local women's organisations and told them about HIV/AIDS and urged them to develop activities. Once organisations like the Society for Women and Aids in Africa (SWAA) were established they worked on a genuinely voluntary basis with little financial support from the state or international sources during their first decade. There are now hundreds of associations involved in HIV/AIDS work, many of which are affiliated to the International Council of AIDS Service Organizations (ICASO), whose president locally sits in the CNLS and whose regional headquarters is in Dakar hosted by ENDA.

There is a particular dimension of NGOs' role in HIV/AIDS work, which is likely to ensure continued mobilisation and activity within civil society, unlike in many other dimensions of NGO work – that is, the organisations of People Living with HIV/AIDS (PLWH). Sustained bottom-up activity is now being promoted by these organisations and their role has been recognised by UNAIDS and the Global Fund. This is one example of how the epidemic is eliciting positive and collective responses and not only the negative and destructive responses cited in deWaal's work in the introduction to this report. The promotion, involvement and financing of organisations

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<sup>92</sup> The AIDS Support Organisation, 'Operational Strategy and Plan of Action, January 1999 to December 2002' (April 1999).

of PLWH will be pivotal to all dimensions of action, from prevention through care and treatment, including the many difficult issues related to rights and ethics. At the moment, the NGO sector is almost entirely dependent on donor funds with even long-standing organisations like TASO receiving 100% of their funding from abroad until very recently. While government provided a small proportion of funds to both TASO and the AIC, this has been reduced in the 2003/2004 budget in anticipation of new resources from the Global Fund. In Uganda, USAID has been encouraging the NGOs to develop financing initiatives to diversify their funding and to make scaling up of their work more viable. Thus far, TASO, for instance has done this by contracting with government to provide training. However, the involvement of NGOs, like TASO, as service providers in some cases appears to have reduced their ability to organise people.

One great danger to the best of the NGO work has been the manner in which international agencies, multilateral as well as northern NGOs, have cherry-picked the staff of local organisations. Thus some of the most experienced NGO activists from key organisations like TASO in Uganda and ENDA in Senegal have been hired to work in UNAIDS and other international organisations. This is done with little attention to the yawning gaps that are left in developing country NGOs.

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

In both Uganda and Senegal there are efforts by public authorities and NGOs to elicit the direct involvement of private sector actors in the HIV/AIDS campaigns. Transnational corporations have a weak presence in both countries, though Shell in Uganda, for instance, has already begun a programme of work with its employees. As the epidemic matures and the full impact is felt in the private sector corporations and businesses of all sizes are being faced with the death of skilled workers. Education on behaviour change, treatment of PLWH and financing new antiretroviral therapies will all require support from the private sector. To date, this work is only at an embryonic level.

#### **4.5 Summary: mainstreaming should strengthen government's role**

The realisation that HIV/AIDS requires a 'multisectoral' effort involving all branches of government and alliances with religious organisations, community based organisations, NGOs and especially people living with HIV/AIDS is now a firmly established lesson internationally. However, the organisational mechanisms necessary to bring this about need to be considered carefully and based on the specific conditions found in each country and community – **this is the central issue that now has to be recognised by the international donor community.**

Perhaps the single most important lesson from Uganda and Senegal remains the one drawn in section 3 above, central leadership is crucial to the fight against HIV/AIDS. Effectively, what the donor community has tried to emulate from the Ugandan and Senegalese experience was the single-minded effort under Presidents Museveni and Diouf to make HIV/AIDS a central preoccupation across their governments and to involve society fully in the effort. It is no accident that this was done, *not* through the establishment of 'supra-governmental' organisations, but by mobilising their political organisations and *existing* government departments. Uganda made its big leap

forward in fighting HIV/AIDS when President Museveni chaired the national committee and ensured all his ministries got involved.

- *Waging the political battle to mainstream HIV/AIDS*

For 'mainstreaming' to work, those who control the budgets of government and who negotiate the terms of foreign assistance with the international community – generally, finance and planning ministries - must have HIV/AIDS as a priority. Establishing this priority is above all a *political issue*, and no organisational fix can avoid this. The political battle needs to be waged to prioritise HIV/AIDS, much like poverty alleviation, in the national agenda.

- *Strengthen the medical response to HIV/AIDS*

Within the international effort to confront the HIV/AIDS epidemic there has been a healthy reaction to the impulse to treat disease as a purely biomedical problem. It is necessary to avoid what many may see as the 'tyranny of medical approaches' and the 'arrogance of the medical profession', but this should not be done at the expense of encouraging medical excellence and leadership – of the sort seen in both Senegal and Uganda. Particular attention needs to be paid to maintaining the capacity of the public health sector and the medical professions to fully play their role.

- *Getting the non-governmental sector to do what it does best*

Involving the non-governmental sector was important in both Uganda and Senegal in providing education for behaviour change and providing care and treatment. However, the organisational template being imposed by the Bank and the Global Fund, which attempts to promote these actors as co-equals with government ministries, is ill-conceived. Religious organisations can play an important role, but this can best be achieved in the context of a secular state led campaign. The associational sector, including NGOs, requires both an enabling environment created by the central state and new efforts on the part of the associational sector to secure funding from a diversity of sources. Work with the private sector on all aspects of intervention is only in its infancy and needs to be pursued vigorously by both government and NGO actors. People living with HIV/AIDS will form the most sustainable grass-roots lobby and action groups for persisting in the fight against HIV/AIDS and support to their efforts should figure high on the list of priorities of national and international funders. International agencies must avoid harming local NGOs by pilfering their staff.

The struggle to mainstream HIV/AIDS has to be undertaken head-on by winning the *political fight* to prioritise action on the epidemic, rather than requiring the creation of supraministerial committees. Engagement on HIV/AIDS should strengthen the overall capabilities of the public authority to ensure public health, not contribute to weakening these. Originally, the Aids Commission in Uganda was to be *temporary* to galvanise action in government and society. Societies construct governments to provide leadership and to ensure the delivery of basic public goods like security and public health that individuals and their private and public organisations cannot themselves deliver.

## **5. HIV/AIDS and the Governance Agenda**

In recent years discussion of 'governance' has curiously been purged of explicit reference to politics. However, as has been made clear in the previous sections, success or failure in the fight against HIV/AIDS is significantly determined within the realm of politics. In this section I take up nine dimensions of the battle against the pandemic, that I have identified as central to the governance agenda in developing countries. Necessarily I treat some in more depth than others. While I heavily draw on the lessons learned from the two case study countries, I believe these lessons are relevant to the wider universe of governance and HIV/AIDS and what I have argued is the difficult task of institutionalising an emergency response.

### **5.1 Democracy, rights and the imperatives of public health**

There is a tension between the principles of democracy and the respect for individual rights on the one hand and the imperatives of securing public health on the other. While it is fashionable at the beginning of the 21<sup>st</sup> century to see all things 'democratic' as unquestionably 'good', the experience of fighting the HIV/AIDS epidemic in Uganda and Senegal, as elsewhere, calls for a more nuanced understanding of the role of democratic organisations and institutions.<sup>93</sup>

In both Uganda and Senegal, the absence of effective political competition in the late 1980s allowed leaders in both countries to spearhead a nationwide campaign on HIV/AIDS almost overnight without needing to be overly deferential to potential opponents of the strategy. Programmes such as compulsory testing for new recruits to the armed forces in both countries received some criticism, but nevertheless have been important to ensuring against the further proliferation of the virus in this high risk group. Compulsory registration and regular testing of commercial sex workers in the urban areas of Senegal has played a pivotal role in containing HIV/AIDS, but some might object on rights grounds.

While rights advocates oppose the extension of compulsory testing for HIV to other groups, or the population at large, in other countries such programmes have had marked success in containing the virus. Compulsory testing for HIV/AIDS in Cuba was seen as draconian, and the limitations placed on the movement of HIV positive people were indeed draconian, but Cuba has succeeded in heading off the epidemic where others have failed. One leader of a woman's group in Senegal argued that there should be compulsory testing before marriage, but other experts involved in HIV/AIDS work were vehemently opposed to this largely on rights grounds. The most convincing grounds for opposition, however, is that Senegal has neither the health or legal infrastructure, nor the counselling capacity necessary to make any kind of universal or expanded compulsory testing viable. Without these, any extension of compulsory testing would be likely to be counterproductive. Ensuring the public

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<sup>93</sup> For a comprehensive review of literature on democracy and HIV/AIDS, which also makes a compelling argument in favour of the positive virtues of democracy in fighting the epidemic, see Ryann Manning, 'AIDS and Democracy: What Do We Know? A Literature Review', paper prepared for 'AIDS and Democracy: Setting the Research Agenda' a workshop held in Cape Town, April 22-23, 2002, organised by Health Economics and AIDS Research Division (HEARD), University of Natal Democracy in Africa Research Unit (DARU), University of Cape Town Institute for Democracy in South Africa (IDASA). See also the important article by Boone and Batsell (2001) cited above.

health has always involved a degree of coercion, even in today's established democracies, with some measures deemed to be of vital importance to public health assuming precedence over individual rights.

There are, however, compelling arguments in favour of the expansion of democratic institutions to fight HIV/AIDS. In both Uganda and Senegal, progress in transforming sexual behaviour was achieved only with the involvement of diverse societal organisations, from religious groups and traditional rural leaders, to women, youth and community organisations, as well as NGOs. Behavioural change can occur only when there is a plurality of messages that combine to reach the majority of the population. While government controlled media can disseminate uniform information, it is only when there is a plurality of media sources that people tend to listen to and trust what they hear. In Uganda, when still in private practice, Dr. Elioda Tumwesigye, now head of the Parliament's standing committee on HIV/AIDS, teamed up with privately-owned Capitol Radio to offer a programme on health matters and HIV/AIDS. He said this was made possible with the liberalisation of the media in 1994 and now there are some forty programmes that discuss health issues over the airwaves. Even government buys time on private radio for its own HIV/AIDS advertisements. Interestingly, however, one study reporting survey data from the mid-1990s argued that awareness of HIV/AIDS in Uganda leading to behaviour change was achieved more through social/personal networks than through mass media.<sup>94</sup>

As democracy is deepened in Uganda, with the government's recent recognition of party politics and opening of greater space for competitive electoral processes, education of politicians about HIV/AIDS becomes even more important. USAID is pioneering work with the Standing Committee in Parliament to increase legislators' substantive knowledge about HIV/AIDS.

Even if more coercive measures of testing and control may be judged necessary to fighting the epidemic, the legitimacy of such measures would be much more readily established if they were arrived at through democratic processes of decision making. The character of the HIV/AIDS epidemic is such that both individual sexual behaviour change and the transformation of social norms of sexual behaviour lie at the core of prevention and it is difficult, if not impossible, to secure these through coercion.<sup>95</sup> It is this that makes the case for democracy compelling.

## 5.2 Decentralisation and Privatisation of health services

In both Uganda and Senegal, the campaigns against HIV/AIDS were launched in an environment of health service reforms involving both the decentralisation of service delivery and the privatisation of service providers – or at least the arrival of private providers to compete with those in the public sector. The Global Fund and the World Bank, as well as many bilateral donors, especially USAID, are deeply involved in the development of decentralised delivery of resources for HIV/AIDS. Here, I can only

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<sup>94</sup> Rand Stoneburner, Daniel Low-beer, Tony Barnett and Alan Whiteside, "Enhancing HIV prevalence in Africa: Investigating the role of social cohesion on knowledge diffusion and behaviour change in Uganda", powerpoint presentation from HEARD, Durban, 2002, slide 26.

<sup>95</sup> While coercion, however unsavoury, has worked effectively in some family planning programmes, like Indonesia's under Suharto, the extent of change necessary here is more complex and impossible for government to monitor.

point to some initial observations about these programmes, but they warrant much more investigation in their own right.

In Uganda, President Museveni has been adamant about pushing resources out to the districts even if it means some funds will be lost. Early efforts by the World Bank to transfer funds directly to the district level floundered and project funding reverted to the Ministry of Health. However with the Bank's Multi-country AIDS Programme (MAP), new efforts have been made to set up District HIV/AIDS Committees, mirroring the UAC. Capacity at the district level remains woefully inadequate especially as decentralisation proceeded very rapidly. Despite aspirations to develop a multisectoral approach here, this usually exists in name only.

Senegal has a long experience of highly centralised government. However, in 1991 the government created a district level health system, with a further transfer of authority to local governments in 1996. By the year 2000, roughly 44% of HIV/AIDS funding went to the centre, 15% to the regional level and an impressive 41% to the district level, which demonstrates a genuine effort to ensure money reaches the operational level.<sup>96</sup> The pattern of the distribution of funding, however, was determined by donor zoning requirements rather than relative needs between the districts. This is a problem that appears to be shared in Uganda, underlining the need for government to establish clear criteria so that funds reach districts on the basis of need and epidemiological evidence rather than due to particular political connections.

In Senegal the central state has had to play a key role in training local actors and ensuring they have the financial resources to carry out their work. As of 2000, no regions received funds for HIV/AIDS from local authorities outside of Dakar. However, since then USAID has been working with local government units to provide a 'full package' of support for HIV/AIDS related work. Interestingly it requires local governments to raise tax revenues to finance, at least partially, campaigns against the virus as a condition for funding, something also being advanced by the World Bank's Multi-country AIDS Programme (MAP).

In both countries, health officials – even those deeply involved with, and supportive of, decentralisation measures – are worried about the rigid requirements imposed by the Bank and the Global Fund in terms of decentralising resources. This is because capacity at local levels of government remains terribly unequal and generally inadequate. Senegal's experience seems to demonstrate that appropriate medical expertise can best be developed first at the centre and, with training and increasing resources, be incrementally devolved to district and sub-district levels. The NGO community itself, generally supportive in principle of efforts to get resources out of Dakar and down to the communities argues that the framework offered by the Bank and Global Fund is inadequate (and was hardly discussed with the NGO sector). One NGO leader said that surveys conducted demonstrated that HIV/AIDS was fourth or fifth on the agendas of local governments. Interestingly, he said that a strong centre was needed to demonstrate to local governments why AIDS is important. At the same time, he argued for national level involvement of NGOs to ensure that resources would actually reach the associational sector at the local level.

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<sup>96</sup> Cheikh Mbengue and Allison Gamble Kelly, 'Funding and Implementing HIV/AIDS Activities in the Context of Decentralization: Ethiopia and Senegal', Abt Associates for Partnerships for Health Reform and USAID (February 2001).

In Uganda, when Museveni came to power, what had once been an efficient and well run health service had long since virtually collapsed. The issue was not one of privatisation, as the narrow base of health service delivery after years of war, political instability and economic decline had wrecked the public sector. What health care existed was almost entirely private. NGOs and church related organisations were encouraged to deliver health care as efforts were made to reconstruct the public sector. Cost-sharing (patient fees), long practiced at least informally through the payment of bribes and the like, was tolerated by the Ugandan government but never endorsed as policy by Museveni. In 2001 it was abolished in what some claim was a blatantly political move by the President to gain support before elections. While the abolition of cost-sharing has led to difficulties in supplying adequate drugs to meet demand, there have been reports of an expansion in the use of government health services.<sup>97</sup> Others suggest that cost-sharing was never a deterrent to the use of public services, but rather people were deterred by 'misconduct on the part of health workers, as well as perceived poor quality of service, including the dispensing of pain killers no matter what ailment one was suffering from'.<sup>98</sup>

Clearly, there are compelling reasons in the fight against HIV/AIDS to have an integrated health system, at least as a goal for the future. In Uganda, it was the fight against AIDS which provided the opportunity to develop a centralised system for monitoring disease.<sup>99</sup> The requirements of surveillance of the epidemic, of providing experienced counselling and testing facilities, of ensuring safe blood supplies and parenteral practices, of treating opportunistic infections and developing antiretroviral therapy in the future, all militate towards greater integration in approaches to public health, rather than dispersal to systems of private providers. This is an aspect of governance and HIV/AIDS that requires much more extensive research.

### 5.3 Action on STIs and commercial sex

The evidence on the link between STIs and HIV/AIDS is very strong. In Senegal the value of a developed system for diagnosis and treatment of STIs in stemming the course of HIV/AIDS was well proven. This combined with the absence of such a system in Uganda in the face of widespread prevalence of STIs and the potential contribution this made to the unfolding of the epidemic drives home the need for concerted action in this area. A study in Mwanza, Tanzania in the early 1990s, provided further evidence that treatment of STIs in the *early* stages of the epidemic can have a major impact on slowing its spread.<sup>100</sup>

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<sup>97</sup> Ministry of Finance, Planning and Economic Development, 'Uganda Participatory Poverty Assessment Process' National Report (final draft) December, 2002 and Ministry of Health, 'The Effects of Abolition of Cost-sharing in Uganda: Report on the Findings for 2001', WHO and MOH Uganda (June 2002).

<sup>98</sup> Interview, F. Golooba Mutebi. See also his dissertation, "Decentralisation, Democracy and Development Administration in Uganda, 1986-1996: Limits to Popular Participation", *Ph.D. dissertation*, London School of Economics and Political Science, University of London, 2000.

<sup>99</sup> Jim Holt of the WHO in 1987 said, 'We are using AIDS in order to establish an effective surveillance system for Uganda, and one that will operate for measles, cholera and other such diseases as well' (cited by Hooper, 1990, p.254).

<sup>100</sup> See Barnett and Whiteside (2003), p329 and K.K. Orroth et al, 'Syndromic Treatment of Sexually Transmitted Diseases Reduces the Proportion of Incident HIV Infections Attributable to these Diseases in Rural Tanzania', *AIDS 2000*, 14:1, pp.429-437.



The experience of Senegal's longstanding legal commercial sex sector and its probable contribution to the containment of the epidemic, argue strongly for the legalisation of prostitution and the regulation and imposition of health standards that legalisation would permit. These standards would include regular testing and treatment for STIs and making condoms easily available to sex workers. Legalisation would also allow greater organisation among sex workers whether in cooperatives or trade unions. It could have a positive knock-on effect in terms of allowing the sex industry to be taxed thus raising increased revenues for governments to spend on HIV prevention and AIDS care and treatment. Even in Senegal, reform is needed to reduce the legal age in this sector from 21 to at least 18 years old to reflect the reality of the sex 'industry' in urban areas and ensure the protection of the women and their clients involved.

Of course, much of transactional sex occurs outside the formal trappings of commercial sex workers and their clients where women are forced by circumstance and survival needs to engage in such transactions. The risk of transmission of HIV among this large group of women and the men who buy their services can really only be reduced by providing alternative sources of income and support.

## 5.4 Targeting high-risk groups

### Women and Children

Women are both socially and physiologically more vulnerable to contracting HIV and the impact of the AIDS crisis on children through the loss of parents to AIDS and the disruption of family and community life make specific work focused on both of these groups an absolute necessity. Some have argued that the campaign against the virus may have been waged on the backs of women, increasing social control over young women and their sexual behaviour. However, the overwhelming response garnered in Uganda and Senegal was that expanded education and the public discussion of sexual behaviour has increased women's room for manoeuvre and control over their own bodies. Nevertheless, even in these 'success stories', the representatives of women's organisations complain that there has been precious little specific information and education directed towards the needs of women. The epidemic has demonstrated the extent to which both formal and informal institutions governing the position of women in society need to be questioned with future legislative action considered concerning women's rights to property, their rights to support when husbands die of AIDS, their right to choose partners freely and their protection in the face of male violence, to name but a few.

As noted earlier, a key to prevention is implementing programmes to stop transmission from mother to children. Cost-effective means for doing so are now understood and this needs to receive high priority in Uganda, Senegal and elsewhere. In Senegal both northern and local organisations have pressed for the adoption of such programmes. However, in the CNLS' new strategy paper for 2002-2006, there were no more than two shallow lines on the question of orphans and vulnerable children, demonstrating that this is far from being a priority for the Senegalese authorities.<sup>101</sup> An important dimension of addressing the impact of the AIDS crisis is looking after

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<sup>101</sup> CNLC, *Plan Stratégique 2002-2006 de Lutte contre le SIDA* (January 2003).

what will continue to be a mounting number of orphans. Additionally, the burden women carry as care providers in families and communities needs to figure prominently in measures to mitigate impact.

#### Men who have sex with Men

In much of Africa, and Uganda is no exception, there are strong cultural taboos and stigmatisation associated with men who have sex with men. This has no doubt been reinforced in some countries, perhaps Uganda, by the somewhat arcane notions of the old left in which leaders like President Museveni were steeped, that homosexual behaviour is some sort of 'bourgeois deviation' developed within capitalist society. In Uganda and Senegal, men having sex with men, is still illegal and while more tolerated in Senegal, an imprisonable offence. After homosexual relations were legalised in the western countries not so long ago, it became clear that these sexual preferences were much more deeply rooted in society than had previously been realised and this, indeed was consistent with all we know of human history.

By maintaining formal legal sanctions against MSM and leaving unchallenged the informal stigmatisation of these practices, governments are not only violating individual rights, but perhaps more importantly, from a public health perspective, are pushing men into practices that will only contribute to the further expansion of HIV/AIDS. Men who have sex with men are forced to maintain heterosexual relationships, thus risking infection of their wives. Not all male to male sex is penetrative and therefore high risk. Nevertheless, little specific information reaches this community of men that could help them to take precautionary measures in their sexual relationships. The international community has so far been hesitant to confront this issue head-on for fear of alienating leaders in developing countries, but this silence is weakening the fight against the epidemic and needs to be reconsidered.

#### Injecting drug users

There is overwhelming evidence that injecting drug use with contaminated needles is one of the most efficient ways to transmit HIV. Much as with the commercial sex industry, denial of the problem and stigmatisation of those who use drugs, will not stop this source of transmission. Governments need to be urged to consider the legalisation and regulation of drug use which would likely lead to the elimination of this route of transmission of the virus. Such action would also have the added benefit of removing much of the basis of organised crime and illicit financial flows associated with the drug industry and probably would provide the terrain to stop the proliferation of harmful drug use altogether.

### **5.5 HIV/AIDS in War and Peace**

It has long been recognised that warfare and violent conflict have contributed to the rapid spread of HIV in Africa and there is an expansive literature on this issue. Not only are soldiers a high risk group (given their mobility, their removal from families, their command over resources to pay for or coerce women, etc), but military doctrines have tolerated and even encouraged conquering armies to engage in rape and sexual violence against women. In addition to testing, education and promoting behaviour change within their armed forces and transforming military doctrine, governments need to consider the most severe penalties for soldiers who rape or coerce women during the conduct of their operations. In Uganda, while there has finally been the introduction of screening for HIV on recruitment, there is only compulsory repeat

testing when serving soldiers or officers are being put up for promotion. There is a strong argument for regular compulsory testing, as is practiced in Senegal, given the proven risk associated with military forces.

While much has been written about how HIV/AIDS is both spread through warfare and may cause the kinds of social breakdown that lead to violence and war, little attention has been given to the possibility that HIV/AIDS can figure in the promotion of peace. There is a basis to believe that peace might be promoted through a common fight against HIV/AIDS on the principal that 'the enemy of my enemy is my ally' in regions where HIV/AIDS plagues communities on all sides of a battle. Prima facie evidence in Uganda does not support this hypothesis, as continued warfare in the northern part of the country has not abated despite the overwhelming attention the government has placed on HIV/AIDS. However, the common fight against the epidemic does not appear to have been put on the negotiation table by President Museveni, nor does there appear to have been any pressure from the donor community for him to do so. Like many rebel movements in Africa, the Lords Resistance Army of Joseph Kony has a particularly low level of education and a high level of sexual violence in its practice which make progress in this direction particularly difficult. This is an area that warrants more research and that should at least be considered by those participating in 'conflict resolution' efforts in Africa and elsewhere.

## **5.6 Rethinking Destabilising Economic Change**

The transformation of economic activity in many developing countries has brought with it displacement, labour migration and long-distance trading, all factors which while possibly contributing to economic growth may in fact be contributing to the spread of HIV. The World Bank has recognised that 'development' may indeed have contributed to the crisis. This phenomenon has received very little attention from national governments or international donors. It calls for a transformation of the cost-benefit analyses related to development projects in Africa and other areas threatened by the epidemic and the elaboration of mitigating measures.

## **5.7 Anti-retroviral Therapies**

The development of antiretroviral (ARVs) therapies in the developed countries have at least at present allowed the significant prolongation of life for those living with HIV. While bilateral donors and the World Bank were quick to rule out the use of ARVs in developing countries, on the grounds of both the expensive nature of the drugs and the complexity in their safe administration, pilot programmes in Uganda and Senegal have challenged this stance.

Senegal and Uganda are both piloting the use of ARVs among PLWH. They have entered negotiations with drug manufacturers to gain access to better prices.<sup>102</sup> Community pilots so far have demonstrated that people can follow the disciplines required for effective treatment. In each country, NGOs and the health

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<sup>102</sup> On the international confrontation with the pharmaceutical industry to modify the rules on access to technology for ARV drugs, see Ken Shadlen, "Patents and public health: developing countries and the WTO", typescript, DESTIN, LSE, November 2002.

ministries argue that when the full costs of the impact of AIDS to individuals, families, communities and work places is accounted for, the costs of developing ARV programmes is justified. Senegal was the first country in Africa to launch a major programme in 1998 and its progress is being closely monitored and is well-documented.<sup>103</sup> Of course, to scale up these programmes in the future, there will be a need for further action with the pharmaceutical companies at the international level and the need for increased support from the donor community.

In pursuing the expansion of the use of ARVs in the developing countries, two issues need close attention. On the one hand, as alluded to earlier, the availability of treatments to the wealthy could transform the way these individuals and their networks approach the political imperatives of engaging with HIV/AIDS. On the other hand, there is increasing evidence from the medical and scientific communities that the virus is developing resistance and mutations at a rapid rate and it is highly likely in the near term that it will be increasingly difficult to provide effective ARV therapies. Neither of these caveats diminish the importance of aggressively pursuing increased access to these therapies in the developing world, since experience, particularly in Senegal, demonstrates that they can form an important part – but only a part – of an overall effort to combat HIV/AIDS through prevention and care and treatment.

## 5.8 Financing the HIV/AIDS battle

The campaigns against HIV/AIDS in Uganda and Senegal have been heavily dependent on foreign funding. It is extremely difficult to get an accurate picture of the financial dimensions of the fight against the virus since 1986. This is, in part, due to the success achieved in mainstreaming the fight against the epidemic. A meaningful assessment of the financial dimensions of the HIV/AIDS campaigns in these two countries would require a specific research project.

Table 1 reports spending on HIV/AIDS, for Senegal and Uganda and those for African countries with a prevalence rate comparable or higher to Uganda in 1996, as analysed in the last major report on funding commissioned by UNAIDS. This data is clearly old and based on a very crude methodology, but it does permit us to make two observations about the pattern of financing HIV/AIDS campaigns. First, in terms of overall funding for HIV/AIDS work as reported by the governments of the two case study countries, donor funding accounted for 92% in Senegal and 93% in Uganda. With the exception of Botswana and Namibia, a similar level of dependency on donor funding was reported in all these countries. This pattern is likely to have remained the same up to the present.

Second, it is overwhelmingly clear from Table 1 that both Uganda and Senegal succeeded in attracting donor funding at a much higher level per HIV positive person than any of the other countries (the next nearest with less than half that level of funding was Rwanda). This represents the extent to which donor funds were, and it can be presumed, remain, directed at those countries demonstrating progress (and

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<sup>103</sup> See Alice Desclaux, Isabelle Lanièce, Ibra Ndoeye and Bernard Taverne, *L'Initiative sénégalaise d'accès aux médicaments antirétroviraux: Analyses économiques, sociales, comportementales et médicales* (Paris: Agence nationale de recherches sur le sida, October 2002).

generally complying with overall prescriptions for macroeconomic management imposed by the international agencies). Of course, this also raises a question about whether donor funds and their allocation according to success rather than need may have contributed to patterns of success and failure, but that question is beyond the scope of this study.

Between 1988 and 1997, approximately 10% of all foreign assistance to Uganda went to the health sector, second by the end of the period only to economic management.<sup>104</sup> In terms of central government expenditure on development, spending on health affairs and services during the 1990s, fluctuated between 6% and 11% of total annual spending, while recurrent expenditure on the health sector fell from around 4% a year in 1993/94 to only 2.7% in 1999/2000.<sup>105</sup>

**Table 1: Country-reported HIV/AIDS Funding 1996 (US\$ current and %)**

	Adult prevalence	Total Spent	Donor	Donor %	National Gov't	National %	Per HIV+
Senegal	1.77	4472457	4120457	92.13	352000	7.87	59.63
Uganda	9.51	37583490	35043490	93.24	2540000	6.76	40.41
Ethiopia	9.31	1305590	1195296	91.55	110294	8.45	0.5
Tanzania	9.42	2325849	2292516	98.57	33333	1.43	1.66
Côte d'Ivoire	10.06	7253659	6527853	89.99	725806	10.01	10.36
C African R	10.77	1953652	1661267	85.03	292385	14.97	10.85
Kenya	11.64	21483595	17946095	83.53	3537500	16.47	13.43
Rwanda	12.75	10224759	10224759	100.00		0.00	27.63
Mozambique	14.17	2880637	2880637	100.00		0.00	2.4
Malawi	14.92	6344172	5219539	82.27	1124633	17.73	8.94
Zambia	19.07	6214566	6023688	96.93	190878	3.07	8.07
Namibia	19.94	1199700	764000	63.68	435700	36.32	8
Botswana	25.1	2711640		0.00	2711640	100.00	14.27

Source: *Level and flow of national and international resources for the response to HIV/AIDS, 1996-1997*, (UNAIDS and Harvard School of Public Health, UNAIDS/99.25E (English original, April 1999), p.30.

The domestic tax base in both countries remains small. From fiscal year 1998/99 to 1994/95, Uganda's total revenue collection increased from about 5% of GDP to about 11% where it remained stable through 1999/2000.<sup>106</sup> In terms of composition, throughout the late 1990s over 80% of tax revenues were from indirect taxation. Theoretically, the struggle against HIV/AIDS could provide the basis for expansion of the fiscal strength of the state. This is a central *political* aspect of the fight against HIV/AIDS, but there is little indication of political movement in this direction in either country.

Table 2 reports the contribution of the international community to financing work on HIV/AIDS. Since 1996, as presented by UNAIDS. The sharp rise in the year 2000 has more to do with a change in reporting and the launch of the Global Fund than a dramatic increase in funding.

<sup>104</sup> Ministry of Finance, 'Sectoral Distribution of External Assistance, 1988-1997', datasheet.

<sup>105</sup> Data from diverse Ugandan government sources.

<sup>106</sup> Ugandan Bureau of Statistics and Ugandan Revenue Authority, datasheets.

**Table 2: Summary of disbursement and commitments to HIV/AIDS 1996-2002<sup>107</sup>**

US\$ millions current prices	1996	1997	1998	1999	2000	2001	2002
Bilateral	116	183	237	229			
G-7					451	562	875
Other DAC & EC					185	200	275
International foundations/NGOs	96	97	37	87	136	200	200
UN System	60	60	60	60	70	70	150
World Bank loans					272	275	295
GFATM					0	0	100
<b>TOTAL</b>	<b>262</b>	<b>330</b>	<b>324</b>	<b>316</b>	<b>1,114</b>	<b>1,307</b>	<b>1,895</b>

Source: UNAIDS, 'Five-Year Evaluation of UNAIDS' presented to the UNAIDS Programme Coordination Board, Lisbon 11-12 December 2002 UNAIDS/PCB(13)/02.2 (11 November 2002) Conference Paper 2, Tables 1, 3. Disbursements 1996-2000; appropriated commitments 2001-2002

Financing the battle against HIV/AIDS raises crucial political issues, both at the international level in terms of how funds are allocated between developing countries and in each domestic setting in relation to the allocation of budgetary resources. With progress in negotiations with the transnational pharmaceutical companies and within the WTO regulating the possibilities for generic production, coupled with demonstrable success in fielding ARV therapies in developing country situations, the possibility of improving treatment regimes in these countries is within reach. But this still poses enormous financial requirements and difficult choices in the allocation of scarce resources not only between varied sectors and the health sector, but also within the health sector itself. Providing ARVs to prevent mother-to-child transmission is already clearly cost effective and there is every reason why this should happen immediately. In Senegal, with relatively low levels of HIV prevalence, a commitment to use ARVs as a major plank in treatment is well within the realm of possibility even for such a poor country. Committing to ARV therapies in high prevalence countries poses a much greater financial challenge.

While economic calculus can help to make these difficult decisions, ultimately they are a matter of political decision. As governments commit to the fight against the epidemic the political debate can be expected to become more rather than less heated and complex.

## 5.9 Ethics of treatment and research

In Senegal, a group of mainly academic based researchers have consistently raised problems of the ethics of medical practice in the country and of research carried out by locals and foreigners working on HIV/AIDS. In April 2003, an important report was published by Amnesty International's medical group in Senegal on 'HIV/AIDS and human rights in a medical context'.<sup>108</sup> Even in Senegal, where standards of treatment are much better than the average in Africa, abusive and unethical practices

<sup>107</sup> The report states, 'The data in this table are derived from multiple sources as defined and reported in the UNAIDS source report. Inconsistent statistical reporting and the start of the Global Fund for AIDS, TB and Malaria has resulted in different categories pre and post 2000. Data for the UN system shows only expenditure that was not designated for HIV/AIDS by primary donors'.

<sup>108</sup> VIH/Sida et Droits de l'Homme en milieu médical sénégalais. Rapport d'un atelier tenu à Dakar, 18-19 juillet 2001 (in French, with Summary in English) Dakar, Amnesty International - Section Sénégalaise - Groupe médical, avril 2003. <http://www.efai.org>

encountered by people living with HIV/AIDS are common. The report documents instances of patients with HIV being refused treatment, tests undertaken without informed consent, research conducted without reference to international norms – all of which contribute to discrimination and stigma and weaken efforts at prevention. It lays out a set of ethical standards that medical systems and political authorities need to develop as central to the battle against the epidemic. Ensuring confidentiality in counselling and testing for HIV status is absolutely essential to promoting voluntary programmes. The ethics of research is particularly put to the test in work on HIV/AIDS and needs to form an important part of the design and approval of research projects. The same is true in the research and clinical experimentation with new drugs to fight the virus. The ethical dimensions of the fight against the epidemic have received scant attention by governments and within the donor and academic communities.

## 5.10 Summary

There are reasons to believe that the challenge of HIV/AIDS must be met by at least a willingness to re-examine some of the tenets of the 'good governance' model being promoted by the international donor community:

- Overall, the emphasis placed on democratising measures in the good governance agenda is confirmed through the experience of confronting the epidemic, though there should be a willingness to consider more compulsory testing when resources make this viable, invoking the imperatives of public health but providing guarantees for confidentiality and the protection of the rights of people living with HIV/AIDS;
- Compulsory measures to push funding for HIV/AIDS to local instances of government provide only a blunt instrument for ensuring that resources reach those who need them, so more flexibility should be written into new AIDS funding to ensure that decentralisation occurs only with the development of capacity;
- The agenda for private provision of health services needs to be reconsidered in the light of HIV/AIDS, where an integrated approach to public health care provision needs at least to be a long-term goal, even if resource constraints make it impossible in the short to medium term;
- Senegal's experience suggests that investing more resources to control sexually transmitted infections and legalising and regulating the commercial sex industry could make major contributions to the fight against HIV/AIDS, while both countries' experience demonstrates that targeting efforts of prevention and care and treatment to high-risk groups is justified in economic as well as epidemiological and social terms;
- There are important 'new' issues for the governance agenda raised by HIV/AIDS including: (a) the potential to use the fight against the epidemic positively to secure peace; (b) interrogating economic development strategies and projects for the potential impact they may have on the epidemic; (c) debating the resources to be allocated to new ARVs and negotiating the terrain with international agencies and pharmaceutical companies; and (d) considering the ethical dimensions of medical practice and research related to HIV/AIDS;

- It is impossible to imagine the maintenance and expansion of efforts to fight the HIV/AIDS pandemic without a commitment by the wealthy countries to continue to expand funding, but at the same time, the requirements of HIV/AIDS could serve as a strong argument to promote taxation and the construction of the fiscal base of central and local governments in the developing countries.

## **6. Conclusion and recommendations**

HIV/AIDS is a crisis of monumental proportions for the international community, which is undermining hard-won gains in the developing world. The measures that governments take will have a decisive impact on whether the crisis can be overcome or whether it leads to long-term impoverishment, and even state collapse and violence. I have not dealt with the impact of the pandemic on governance in this report, but instead analysed how governance may have an impact on the epidemic. The case studies of Uganda and Senegal demonstrate that the decisions and actions of politicians and government organisations can make a contribution to successfully containing the epidemic. There are many who argue that above all it is necessary to invest in community led response, but the case studies examined here demonstrate that successful community response over time must involve the strengthening of central organisations and the development of their leadership role.

The tensions involved in responding to the AIDS crisis - between emergency and developmental action, centralised and decentralised organisation, control and participation, the public good and individual rights - mean that we must look at governance analytically and politically, not merely as a checklist of functions and best practices. Emergency action is called for, but the nature of this emergency is long-term, so we must consider how to institutionalise an emergency response.

### **6.1 The key findings of the report**

#### **1. Central leadership is crucial to making progress**

While getting resources to communities and involving non-governmental actors has been crucial to successes in the fight against HIV/AIDS in both Uganda and Senegal, central authorities and state agencies have been pivotal in making this happen.

Beyond the individual characters of leaders and their commitment to fighting HIV/AIDS, we can identify several reasons why leaders were able to act:

*Threat:* If leaders understand the potential impact of the epidemic even on their ability to remain in power, they are not only more likely to treat it as an emergency, but are also more likely to be able to ensure a wide and deep coalition among political and economic power brokers behind a control programme.

*An issue of political legitimacy:* International and domestic actors can make HIV/AIDS an issue of political legitimacy, ensuring that no leader can long hold a position of public authority without committing to action.



*Acting on scientific evidence:* Too much of the early work on HIV/AIDS was about rights, and that tendency still marks the work of UNAIDS and many NGOs. Leaders need to take their decisions about the epidemic on the basis of medical and epidemiological evidence and every effort must be made to both keep that evidence central in advocacy and understandable to those in positions of power. The evidence establishes both the threat and the basis to make AIDS a question of legitimacy.

*Creating the incentives for action:* In both Senegal and Uganda, leaders became convinced that they had nothing to lose and everything to gain by committing to the fight against HIV/AIDS. Local and international actors through both political action and financial support can ensure as close to a positive-sum game as possible, where it is far less costly to act than not to act in the fight against AIDS.

## **2. Central leadership is necessary to developing multisectoral involvement**

*Involving religious groups:* The prestige of the central government was crucial in both Uganda and Senegal to efforts to bring religious leaders on board in the fight against HIV/AIDS. It created the space for activists within the schools of Islam and in the Christian churches to convince their leaders to actively participate. The authority of the central government was also important to convince religious leaders of the facts about the epidemic.

*Involving civil society:* Many countries still do not have a large associational sector and ignorance about HIV/AIDS is still widespread. In both Uganda and Senegal, central governments played a crucial role not only in opening the space for NGOs and other associations and community based organisations to act, but also in convincing them they should act and even in establishing new organisations to fight the epidemic.

*Rallying the government as a whole:* It takes political action at the highest level of government to ensure that all branches of the government that can contribute do contribute to fighting the epidemic.

## **3. Central leadership needs to set the tone for public debate:**

Because HIV/AIDS must be fought largely through changing individual sexual behaviour, especially to practice safe sex using condoms, and challenging long-standing group norms of behaviour, the widest and most open debate about the virus must be fostered and central leaders can go a long way towards setting the tone for that debate. Society needs to discuss sex openly, to be able to talk about condoms, penises and vaginas and about sexually transmitted diseases. Democratic pluralism is important to opening such a debate.

## **4. The organisational template imposed by the World Bank and the Global Fund needs to be applied more flexibly than it has been to date**

When the Bank belatedly took up the challenge of HIV/AIDS and promoted the Multi-country AIDS Programme it rightly recognised that past responses to disease were overly dominated by the medical profession and that it needed to use its influence to promote a multisectoral approach. However, it has gone to the other extreme in imposing a set form of organisation – the establishment of a

supraministerial national committee or commission to deal with HIV/AIDS – which in many countries, even successful ones like Uganda and Senegal, has sown confusion and rivalry between ministries, weakening governments (or pre-empting their strengthening) and likely set back the fight against the virus.

As problems in this model become evident, most agencies have seen the source of these problems simply in a lack of clarity in designating the respective roles of national commissions and ministries of health. This study has demonstrated that the problems of the model run deeper and in fact stem from the fact that what the model attempts to create is effectively a parallel structure to government. Instead, existing organisations of the public authority need to be reinforced and not weakened, if there is to be a sustainable capacity created to meet the challenge of HIV/AIDS (and other public health threats). This is a political issue and the political battle to allocate resources – both human and financial – and to rally the organisations of the state and society to the fight the epidemic cannot be sidestepped.

### **5. In pursuing a multisectoral approach it is crucial not to lose sight of the biomedical core that needs to play a special role in fighting the virus**

The medical profession and the health sector, as we demonstrated in Figure 1, play a vital role within a multisectoral approach and in all aspects of surveillance, prevention, and care and treatment, with specific contributions of their own to make and through support to others. While the practices of the profession may well need to be transformed, they are crucial to successfully institutionalising an emergency response.

### **6. Prevention activities dealing with behavioural change need to be analysed in terms of those that address *individual* behaviour and those that address the behaviour of *groups*.**

Due to the emergency nature of the AIDS crisis, outside of significant progress in addressing HIV/AIDS in the military, much less attention has been given to transforming the institutional norms that guide and inform group behaviour. This relates to community views on what is and is not acceptable sexual practice, to social practices in relation to male circumcision, to social practices like polygamy or female genital mutilation that render women more vulnerable and even to the practices of the medical profession that treat people as objects rather than subjects. Because the fight against HIV/AIDS is a long-term one, addressing these deeper norms and practices is what *institutionalising* the emergency response is about.

### **7. New 'development' projects and strategies need to be evaluated for their potential impact on public health, particularly in relation to the AIDS crisis.**

The World Bank has recognised that the AIDS epidemic may well have been fuelled by particular patterns of development. Projects that involve the displacement of large numbers of people (like dams) or the encouragement of migrant labour, or the development of long-distance movement of goods need to be evaluated for their potential impact on the spread of HIV/AIDS and mitigating measures, sustainable over time, need to be considered.

**8. Getting the balance right between control and participation/rights:**

A campaign against HIV/AIDS needs to consider forms of compulsory testing among particular high-risk groups (such as soldiers, prostitutes, long distance traders/truckers migrant labourers and others whose profession requires them to move long-distances over extended periods of time). This too is an aspect of 'institutionalising an emergency'. However, this will only be constructive if such testing can be undertaken on a regular basis and coupled with counselling and resources for treatment as without these such measures will be counterproductive contributing to complacency and stigma which could drive the epidemic underground.

Uganda began its campaign with messages of *fear* broadcast to the public, extremely controversial among NGOs and rights advocates, but perhaps a necessary contribution to shocking the public into awareness. But instilling a healthy fear must be coupled with counselling services and measures to fight stigmatisation.

The most important actors in civil society will for the foreseeable future be *People Living with HIV/AIDS*. They will be advocates for action and will ensure sustained participation from social organisations. Special efforts need to be taken to deliver resources to them, to safeguard their rights and to fight against stigmatisation in communities and workplaces.

**9. Controversial legislation needs to be considered in the interests of public health:**

Legislation needs to be considered decriminalising prostitution, injecting drug use and homosexuality, in order to regulate these sectors, monitor HIV prevalence and provide treatment. Legislation may also be necessary to reduce stigma associated with, discrimination against, and vulnerability of, people living with HIV and AIDS.

**10. Specific legislative and non-legislative measures improving the status of women:**

Property laws, inheritance laws and norms governing the status of women need to be considered in light of the AIDS crisis, where an attack against discriminatory rules may be crucial to provide social protection for women.

**11. Decentralisation and privatisation measures within the health service need to be reconsidered in light of HIV/AIDS:**

The AIDS crisis throws into sharp relief the nature of health as a public good. While decentralisation may be the best means to ensure that resources necessary to fight the virus and to care for those who live with it reach those who need them, this should be less an 'article of faith' and subjected to review in light of the AIDS crisis.

Similarly, as Uganda's experience with the abolition of cost-sharing has so far demonstrated, privatisation measures, which perhaps have been adopted out of necessity, need to be re-evaluated in light of the AIDS crisis.

Regardless of what combination of centralised-decentralised, public-private service delivery is adopted, HIV/AIDS underlines the importance of the goal of achieving an

integrated health service capable over time of dealing with the needs of surveillance, prevention, care and treatment and long-term impact of the epidemic.

**12. A theoretical possibility exists for the AIDS crisis to justify the expansion of the fiscal basis of the state and national governments and donors need to consider new local and national taxation reforms.**

Tax and crisis go together. While continuing to increase resources from the donor community to developing countries to fight HIV/AIDS, incentives for the development of local and national taxation systems need to be considered. This may be one of the more 'positive' dimensions of 'institutionalising an emergency response'.

## **6.2 Proposals for further research on Governance and HIV/AIDS**

There is a great deal more scope for further comparative research on governance and HIV/AIDS. There is a particular necessity in this area for enhanced communication between Anglophone and Francophone researchers. In carrying out the current study it became clear that researchers could profit by reading work across this language divide, as could policymakers. A further general issue is the need for more explicit discussion and attention to the 'ethical dimensions of research' in both academic and clinical research related to HIV/AIDS. Donors need to pay attention to this in the work they fund and need to assist developing countries in establishing the means to survey and enforce ethical standards in work under their jurisdiction.

Here I list some of the topics of research that could produce important insights for policy debate and action:

- *Impact on governance:* Further work is needed on the manner and ways in which HIV/AIDS will have an impact on the governance sector both in terms of the loss of personnel and the transformation of economies, as well as the legal challenges and resource constraints the crisis will impose.
- *Social cohesion as a key variable:* More research is needed on the role of 'social cohesion' in fighting HIV/AIDS and the extent to which it can be achieved through top-down and bottom-up processes. More in-depth case work is needed especially on understudied experiences like in Eritrea and Cuba;
- *Policy and action on parenteral practices:* There is enough evidence in recent articles and in work done by WHO over the years to warrant new research on parenteral practices in public and private health delivery systems, not to put into question the role of heterosexual sex in the transmission of HIV/AIDS, but to evaluate progress made in health care delivery that is patently relevant to fighting HIV/AIDS.
- *Policies towards STIs:* There is much room for historical and current analysis on different policy approaches to sexually transmitted infections, investigating both causal relations to HIV transmission and complementarities in preventative and palliative care. A good deal of work has been done on this from a medical scientific point of view and little or none from a governance perspective.

- *Policies on CSWs:* More research on policy approaches to commercial sex work and its particular relationship with the AIDS crisis needs to be carried out to pursue public debate about legislative innovation
- *Privatisation of health services:* While much research in governance has been carried out on privatisation of health services, there appears to be a need for new work explicitly in the context of the AIDS crisis
- *Financing HIV/AIDS work:* UNAIDS sponsored important early work on the financing of responses to the AIDS crisis, but this subject could benefit from much more detailed work that could contribute to developing a more realistic assessment of what has been achieved so far and ways to monitor this more accurately in the future.
- *AIDS and peace:* In this report I raised the potential role that responses to the AIDS crisis might positively play in peace negotiations. Much of the work on AIDS and war has been apocalyptic in character and little has explored the interests combatants on all sides of a violent conflict may have in fighting the common AIDS enemy.
- *Decentralisation and AIDS:* The voluminous work on the decentralisation of health service delivery could incorporate a more specific focus on HIV/AIDS and we need more studies that do this.

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**List of interviews and meetings**

<b>Interviews in Uganda</b>	<b>Organisation</b>	<b>Position</b>	<b>Date</b>
Dan Wamanya Ahimbisibwe	USAID	Programme Management Specialist	08/01/2003
Anonymous	Gay and Lesbian Alliance (GALA)		11/01/2003
Dr David N Kihurmuro Apuuli	Uganda Aids Commission	Director General	09/01/2003
Asingwire Narathius	Makerere University	Senior Lecturer Social Work	12/01/2003
Elise Ayers	USAID	HIV/AIDS coordinator Uganda	08/01/2003
Rev Gideon Byamugisha	Church of Uganda	HIV/AIDS activist	07/01/2003
Dr. Alex Coutinho	TASO	Director	11/01/2003
Dr. Ruben F. del Prado	UNAIDS	Country programme adviser	10/01/2003
Donald L. Elliott	USAID	Democracy and governance adviser	07/01/2003
Dr. Frederick Golooba-Mutebi	Makerere University		6-12/01/03
Dr Jesse Kagimba	Office of the President	Special Presidential Adviser on AIDS	11/01/2003
Dr. Elizabeth Madra	MOH	AIDS Control Programme	09/01/2003
Med Makumbi	USAID	AIM	08/01/2003
Dr. James Makumbi	MOD	Acting Chief Medical Services UPDF HQ	07/01/2003
Sabiiti Mutengesa	retired Col UPDF		27/12/2002
Nduhura Dennis Mwebaze	ACORD	Programme Manager	09/01/2003
Andrew M. Mwenda	Monitor	Editor	10/01/2003
Dr. Sam I. Okware	MOH	Commissioner of Health Services	10/01/2003
Dr. Peter Okwero	World Bank	Health specialist	08/01/2003
Major Ruranga Rubaramira	National Guidance and Empowerment Network of people living with HIV/AIDS	Coordinator	10/01/2003
Rev. Sam L. Ruteikara	Church of Uganda	Director/Ag Provincial Health Coordinator	08/01/2003
Prof John Rwomushana	Uganda AIDS Commission	Secretary	07/01/2003
Angela Spilsbury	DFID	Assistant Health Adviser	07/01/2003
Inge Tack	UNAIDS	Programme Officer	10/01/2003
Dr. Elioda Tumwesigye	Parliamentary Standing Committee on HIV/AIDS		06/01/2003
Jenny Yates	DFID		11/01/2003
Rob Yates	DFID	Senior Health Adviser	11/01/2003
<b>Interviews in Senegal</b>			
Bradley Barker	USAID	Technical Advisor, Senegal	22/01/2003
Dr. Abdoulaye Bathily	Assemblée Nationale	Député	20/01/2003
Prof Charles Becker	CNRS-Centre d'Etudes Africaines		20/01/2003
Simon Bond	First Council Br Embassy		20/01/2003
Dr Celestino Costa	UNICEF	Charge du Programme Santé	22/01/2003
Mbaye Marriang Diagne	SWAA	youth officer	24/01/2003
Ms Ramatoulaye Dioume	USAID	HIV/AIDS Specialist	22/01/2003
Mimi Gaye	British Council		21/01/2003
Georges Gonzales	UNICEF	communication	22/01/2003
Baba Goumbala	Alliance Nationale Contre le Sida	Secrétaire Exécutif	24/01/2003
Caroline Grant	British Council	ELT Manager	21/01/2003
Dr. Massaer Gueye	FHI/CDC		23/01/2003
Abadoulaye Gueye	UNICEF	women's health	22/01/2003
Prof. Souleymane Mboup	Le Dantec hospital	Virologist	24/01/2003
Andrew McNab	British Council	Director, Senegal	21/01/2003
Valerie Mouley Omar	SWAA	Executive Director	24/01/2003
Fatou Ndiaye	British Embassy	Coord., Projets de la Coopération	20/01/2003
Nafi Sar	SWAA	charge de prg au Senegal	24/01/2003
Bernard Taverne	IRD	Medical anthropologist	21/01/2003
Aminata Toure	UNIFEM	Programme Officer	23/01/2003
Julie van Domelen	World Bank	Lead Human Development specialist	21/01/2003
<b>Brief Meetings/Conversations</b>			
Keith Hansen	World Bank	Manager ACTAfrica	
Dr. Ibra Ndoye	Conseil National de lutte contre sida	Secrétaire Exécutif	
Mrs Fatimata Sy	FHI/CDC	Directrice	
Ed Hooper	Author		
Ian Hopwood	UNICEF	Rep for Senegal and Cape Verde	
Rima Al-Azar	World Bank	Consultant ACTAfrica	