C o n q u e r i n g S l i m
Uganda's War on HIV/AIDS[1]

Global Learning Process on Scaling up Poverty Reduction
Shanghai Conference, May 25 –27, 2004

Executive Summary

Uganda is generally regarded as one of the all too few success stories in Africa's effort to combat HIV/AIDS. Uganda has succeeded in reversing the rising tide of AIDS, where many of its neighbors have failed. What has accounted for this experience? Why has Uganda succeeded in reversing the spread of prevalence rates where other countries have failed? This case study explores the various facets of Uganda's national strategy to combat HIV/AIDS and the factors – social, political, and economic – which have contributed to this success. The role and contribution of faith leaders and faith based organizations, Christian and Muslim, is highlighted, as these have played critical roles in every aspect of Uganda's HIV/AIDS program. It also highlights some of the challenges, present and future, confronting the country as it attempts to consolidate past success and reduce HIV incidence even further.

Since the first cases were identified in 1982, HIV/AIDS rapidly developed into an epidemic in Uganda. A national sero-survey undertaken in 1987/88 suggested a national infection rate of 6-8 percent. This increased rapidly until 1992 when national prevalence (based on sentinel surveillance sites) reached its peak, at just over 20%.[2] Since then, the rate, happily, has showed a steadily declining trend. By 2002, the estimated national prevalence had declined sharply and was estimated at about 6 percent.

The foundations of Uganda's national strategy to combat HIV/AIDS are many and multifaceted – very strong political commitment led forcefully by President Museveni; massive mobilization and education efforts which contributed to public debates; openness about the problem and active efforts to mitigate stigma within the society; an extraordinary range of partnerships with special outreach to all of Uganda's main faith communities; and a conception of the disease that almost from the beginning diagnosed it as a threat to development and not just a health problem. The interrelations between all of these various elements of Uganda's program are highly complex and very dynamic.

The prevention model pioneered in Uganda – expressed simply as A, B, C – Abstinence, Be faithful, use a Condom – is considered to be the cornerstone of its success. How precisely these components have combined and what have been their individual relative contributions has been the subject of much debate and analysis. However, two points are worth noting in attempting to make at least an ordinal judgment of these three elements.

---

[1]This case study was prepared by Lucy Keough, Development Dialogue on Values and Ethics Unit, EXTSP, World Bank.

[2] Reported rates at ANC in 1992 were almost 30% in Kampala and about 16 % in other urban areas, which translates into a national rate of about 20%.

First, prevalence rates began to fall in the early to mid-1990's, implying that incidence rates had begun to decline several years earlier, perhaps even in the late 1980's. Secondly, while knowledge about condoms and distribution of condoms has increased since 1991, the use of condoms has remained relatively low. This suggest that the behavior change messages of abstinence and faithfulness targeted to at-risk groups early in the campaign against HIV/AIDS have played a pivotal role. There is widespread praise and acknowledgement across the world for Ugandan government authorities, that in formulating and implementing this policy, they reached out to a wide spectrum of partners, but did so in a non-confrontational way. Every player – government, private sector, civil society and faith communities – was encouraged to join the fight against HIV/AIDS, to contribute in a manner that was consistent with their respective basic values and beliefs, and which exploited respective comparative advantages. Great care was taken to guard against pitting the moral precepts of one group against another, particularly with respect to the faith communities and their views on condoms. Every constituency was given space, but in a non-threatening way that gradually allowed the consolidation of consensus.

Uganda's success in combating HIV/AIDS is the result of the cascading effect of multiple interventions. This series of activities, appropriately sequenced and, generally quite gradually scaled up, was built on a foundation of strong political commitment, openness to civil society with a special outreach to faith communities, and complementary measures beyond ABC, such as networking and support groups for people living with AIDS, blood screening, voluntary counseling (at least in urban areas) and training. What set Uganda apart was an unspoken understanding among a wide range of stakeholders, recognizing from the outset that everyone had a key role to play, and that success would depend on all actors moving in tandem and in a spirit of cooperation rather than confrontation.

The role of faith leaders and faith based organizations merits special credit. Faith based organizations did not assume an isolated role, but were intimately involved in all aspects of HIV/AIDS interventions. Partnerships with faith based organizations have permeated virtually every aspect of Uganda's HIV/AIDS program from its inception. Many of Uganda's key organizations – e.g. TASO, AID, UNASO – while not directly faith based themselves, have had longstanding and deeply rooted partnerships with faith based organizations, both Ugandan and international. The Uganda AIDS Commission has estimated that about half of the 2000 (approximately) non-governmental groups engaged in HIV/AIDS initiatives, spanning the range of education, prevention, counseling, care and treatment, are faith based. While most faith communities were opposed in principle to the use of condoms, few openly opposed government's distribution programs. The churches and mosques did not allow their initial reticence with respect to condoms to hinder their active contribution to the overall program. In parallel, the government was sensitive to the concerns of the faiths concerning condoms and avoided overly aggressive promotion. Thus the religious communities generally focused on the need to change behavior and the underlying values involved, while the government (and other non-governmental groups) promoted the use of condoms as a more central part of their programs.

Thus, each and every element of the overall program and a wide spectrum of stakeholders have been vital in Uganda's success in reversing HIV/AIDS trends. Their strength is in their combination: none of them would have been sufficient on its own to yield

such favorable outcomes. What stands out in the Uganda story is the respect for different views, the flexibility of the partners in addressing the issue, the adaptation of messages and programs, continuously over time, and the early and continuing forthrightness in addressing the full spectrum of issues raised by HIV/AIDS. It is a rare case of such dynamic partnership linking the very senior tiers of leadership with the communities of those affected, their families, men and women, young and old.

registered) there was generally good cooperation and exchanges between the two services. Government doctors in fact were often posted to mission hospitals. Mission hospitals were quick to join the ranks of the front line attack on HIV/AIDS, taking up a major responsibility for care of people living with AIDS.

II. Overview

This section will discuss the combination of government interventions that together can be said to comprise national Uganda's strategy to combat HIV/AIDS.

Government Institutional Response

The strong political commitment was translated into the establishment of an increasingly responsive government institutional structure. In October 1986, the AIDS Control Program was established within the Ministry of Health as the oversight and coordinating body within government for HIV/AIDS. As a precursor to the government's subsequent decentralization program, the Ministry of Health had already decentralized its AIDS initiatives through the already existing district health structures in the early 1990's. MOH went to every district and sub-county – more than 1000 to hold multi-sectoral meetings. The President directed all political leaders must talk about HIV/AIDS in all political rallies at all levels, down to sub-district levels. He gave the same message to churches and schools viewing schools as an entry point for getting messages to parents. Decentralization efforts continued, a move seen to empower local populations. A District AIDS Mobilization Project was established to promote awareness among local level government administrative staff, health workers and community leaders. In parallel, recognizing the danger posed by unsafe blood transfusion, a program to test and render the blood supply safe was initiated in the late 1980's.

The president established a National AIDS Prevention and Control Committee in 1986. This Committee was comprised of a broad base of government, non-government and faith leaders and organizations. It was tasked with launching public debate aimed at consensus around a national response and has been viewed as a precursor to the Uganda AIDS Commission to be established several years later.

By 1990, it was recognized that this was a multi-sectoral issue which posed a critical challenge to the country's development prospects. Resources – human and financial – and strategies beyond the scope of the Health Ministry were required. An Interim Secretariat was established, again with a broad cross section of government, private sector, civil society and faith based organizations. This led in 1992 to the formal inauguration of the Uganda AIDS Commission (UAC), administratively situated within the Office of the President. Under the Commission, which now numbers 12 members, the day to day work is carried out by a small technical secretariat. As UAC has evolved and expanded, it has focused on how to better reach out at the community level.

Religious leaders from all three major faiths – Catholic, Protestant and Muslim – have always actively participated in the Commission. Since 1995, two prominent Chairmen of the Commission have been religious leaders: 1995-98, Bishop Kauma of the Church of Uganda;

and since 1998, retired Bishop Barnabas Halem'Imana of the Catholic Church. The Commission has felt strongly that the participation of faith communities has added to its credibility and ensured sensitivity and relevance to local cultural and religious beliefs and practices.

Interventions at the community level represent a critical element in projects and programs supported by UAC. At present, UAC estimates that some 2000 NGO/CBO/FBOs are engaged in HIV/AIDS initiatives, spanning the range of education, prevention, counseling, care and treatment. Of this total, UAC estimates that perhaps 50 percent are faith based. (A mapping exercise, with the assistance of the African Medical Research Foundation (AMREF) is planned for later in 2004.) In addition, partnerships with faith based organizations have permeated virtually every aspect of Uganda's HIV/AIDS program from its inception. Many of Uganda's key organizations – e.g. TASO, AID, UNASO – while note directly faith based themselves, have had longstanding and deeply rooted partnerships with faith based organizations, both Ugandan and international.

As further evidence of Uganda's efforts to situate HIV/AIDS in a multi-sectoral context, a five year National Strategic Framework (NSF)was drawn up in 2000. This set three overarching goals:

- Reducing HIV prevalence by 25%;
- Mitigating the effect of HIV/AIDS;
- Strengthening the national capacity to coordinate and monitor HIV/AIDS across sectors.

A key objective of the NSF was meant to be integrated with other national planning frameworks, and their implementing ministries, including the Vision 2025, the country's long term planning perspective, the National Health Policy, the Local Government Act, the Plan for Modernization of Agriculture and Universal Primary Education. Perhaps most importantly, NSF is designed to mainstream HIV/AIDS with the five pillars of the Poverty Eradication Action Plan (PEAP): economic management, security and disaster management, governance, enhancing production and competitiveness and human resource development. Following a mid-term review process, the NSF was revised in early 2004, largely taking account of the conclusion that the earlier version paid insufficient attention to care and treatment issues. Increased access to home based care, palliative care and psychosocial support, and, especially, antiretroviral drugs have attracted increased support from multiple donors and organizations. Under the direction of the UAC, eventually 12 other key government ministries, notably, Education, Defense, Internal Affairs, Social Affairs and Agriculture, adopted AIDS Control Programs of their own. Some of these have lapsed into isolated cells within their respective ministries, with the notable exception of the Ministry of Education which continues to have an active outreach from late primary through secondary levels. This will be a challenge which the NSF must confront.

In 2001, a further reflection of Uganda's official on-going efforts to engage a wide cross-sectoral representation in the HIV/AIDS battle, the Uganda HIV/AIDS Partnership Committee was established under the UAC. This Committee comprises Self-Coordinating Entities (SCE) representing the following constituencies: Parliament, Government

One conclusion to be drawn from the above data is that the abstinence message resonated most with younger age groups. It also appears that declines in sexual indicators in some cases appear more pronounced in the early half of the 1990's as compared to the latter half, perhaps suggesting some "fatigue" with the abstinence campaigns.

Be faithful. Many experts believe that the single most important factor driving the AIDS epidemic is multiple sexual partners, and that over a lifetime, it is the number of sexual partners that matters most. Hence, sex outside of marriage, or a cohabitating relationship, is viewed as higher risk for the spread of HIV/AIDS. Hence, efforts to promote fidelity were aimed at both married and non married couples, reflecting the commonly held view that the single highest risk factor for the spread of HIV/AIDS is the number of sexual partners. Uganda coined the terms "zero grazing" (for monogamous, mainly Christian relationships) and " paddock grazing" (for polygamous, mainly Muslim relationships).

The primary sources of indicators for this are the UDHS data and the Global Program on AIDS Surveys for 1989 and 1995, supported by WHO. However, different coverage and sampling sizes mean that comparisons between the two sources should be seen only in indicative terms:[7]

- Extramarital sex, while much more prevalent among men than women, is declining.
    - Only 6% of married women reported extramarital relations in 1989 and 1995, contrasted with 23% of men in 1989, and 16% of men in 1995.
    - Between 1995 and 2000, some 3% of married women reported extramarital relations, with little variation between urban and rural rates. For men, nationally the rate was 14% in 1995, falling slightly to 12% in 2000, with significant differences between urban – 19% in 2000, down from 20% in 1995 – and rural – 11% in 2000 down from 14% in 1995.[8] This reflects widely differing expectations and norms between men and women for sex outside of marriage: women are expected to remain faithful to their husbands while extramarital relationships for husbands are often seen as a sign of wealth and strength.[9]
- Multiple Partnerships, declining for some groups, rising for others, are much more common among men than women:
    - Non-regular partnerships are more common with men than women: Between 1995 and 2000, the total number of women reporting sex with a non-marital, non-cohabitating partner increased from 12 to 14%, when the rate for men declined from 30 to 28%, but was significantly higher than for women.
    - Between 1995 and 2000, there was a near halving of the rates of single women reporting sex with two or more non-marital, non-cohabitating partners from 11 to 6%. For men, the rates actually climbed from 29 to 31%.

[7] The 1989 GPA Survey covered only 8 districts and the 1995, only 4 and both Surveys are thought to have over-sampled Kampala. The GPA Surveys are thus not comparable to the UDHS data and because of their varying sample sizes comparisons between the two should be seen as indicative only.

[8] Uganda AIDS Commission, Measure Evaluation, Uganda Ministry of Health, *AIDS In Africa During the Nineties, Uganda,* 2003

[9] And the Banana Trees Provided the Shade, The Story of AIDS in Uganda, UAC, September 2003.

Condom use. Condom distribution has increased remarkably in recent years – between 1991 and 2000, from 300,000 to over 20 million through the social marketing channels, which accounts for the great bulk of condom distribution within the country. Since the late 1980's there has been a significant increase about knowledge of condoms. Use of condoms however remains relatively low.

The source of the following data is the Uganda demographic household survey (UDHS)[10]:

- Knowledge of condoms is very widespread: Nationwide 33% of women knew about condoms in 1989; this increased to 88% in 2000; the respective data for urban are 62% to 97%, and for rural 29 to 86%. Among men, knowledge of condoms has always been high.
- Knowledge among women of where to get condoms has increased, but remains relatively low in rural areas. In 1989, 22% of women nationally knew where to get condoms; this increased to 53% by 2000. In rural areas 18% of women knew where to get condoms in 1989, which had increased to 47% by 2000. This means that about half of women in Uganda, mainly in rural areas, still do not know where to get condoms. Among men, nationally, 60% knew where to get condoms in 1995, which increased to 77%. Among rural men in 2000 about one in four did not know where to get condoms.
- Use of condoms remains low, especially among women. In 1989, only about 1% of women nationally (4% among urban women) had ever used a condom. By 1995, this had increased to 6% (23% for urban women) and by 2000 to 15% (39% for urban women). In rural areas, only 11% of women by 2000 had ever used a condom. Among men, some 16% reported ever using a condom in 1995 (41% for urban men), rising to 40% (74% for urban men) by 2000.[11]
- Condom use with non-regular partners has increased but for women is still relatively low. Between 1995 and 2000, the proportion of women using a condom at the last sex with a non-regular partner increased from 20 to 38% (for urban women from 46-59%, and for rural women from 11 to 30%). For men, during the same time period, the increase was from 36 to 59% (for urban men from 62 to 81% , and for rural men from 29 to 50%). Although counterbalanced by the decline in the number of non-regular sexual partner, sex with non-regular partners is regarded as the highest risk for the spread of HIV/AIDS, and these figures may suggest persistent unsafe sexual practices, especially in rural areas.
- One area where condom use has increase significantly is among commercial sex workers – perhaps approaching 100% in Kampala according to the 2000 UDHS data.

Two cautions regarding the above data should be borne in mind. Firstly, available data seems to indicate that the most significant declines in HIV/AIDS prevalence – and therefore in incidence – had occurred by the early 1990's. Thus the impact of increased condom use from 1995 onwards in declining rates of HIV infections seems questionable. Condoms are more likely playing an important role in keeping current levels of HIV

[10] Uganda AIDS Commission, Measure Evaluation, Uganda Ministry of Health, *AIDS In Africa During the Nineties, Uganda,* 2003

[11] In the UDHS, questions on the use of condoms were asked in the context of family planning. As such they may underestimate the use of condoms, especially when used for purposes other than family planning. These data are nevertheless useful as trend indicators.

infections in check at lower levels. Moreover, available data on condom use measure single use or use within a given time frame, not *consistent* use, which presumably would be lower. This would seem to support the conclusion that the impact of condom use on declining HIV/AIDS trends.

Some observers have felt that condom distribution has been overemphasized by the donor community who have sometimes tended to push condoms on resource-poor, donor dependent countries. Yet evidence seems to suggest that behavior change has been at least as important as condom distribution, and yet, traditionally this has received less attention. Dr. Rand Stoneburner, an epidemiologist who has worked on AIDS in Africa for a variety of public-health agencies, says experience in Uganda and elsewhere demonstrates that money and the drugs it buys alone will not stop the epidemic. Putting so much money into antiretroviral therapy while not giving proven behavior-change strategies their due is a mistake, he says. "We must support countries with a sincere commitment to provide social and political resources to turn this thing around and not create future generations dependent on foreign aid for pharmaceutical lifelong support," Dr. Stoneburner says. Uganda is already dependent on external donor funding for 80% of its capital expenditures and 52% of its recurrent expenditures.[12]

The promotion of condom use was never the most prominent element of Uganda's ABC strategy. Within the overall context of its multidimensional, multi-sectoral, approach, condom use was assigned a supporting rather than a leading role. The general perspective of many faith organizations is that condom use is appropriate only under given circumstances.

Comments on ABC

The ABC strategy is generally regarded as the cornerstone of Uganda's overall HIV/AIDS strategy and a major factor in bringing down and maintaining low rates of prevalence. However, ABC is only one segment of a broader approach. Uganda has made significant strides, and, indeed has been a pioneer, in a number of other areas of intervention: blood screening, prevention of mother to child transmission (PMTCT), and voluntary counseling and testing (VCT). ABC does not address at all the issues and rights of orphans and vulnerable children affected by HIV/AIDS, nor the need to recognize and revise harmful cultural practices, such as widow inheritance, wife sharing, and spontaneous sex during cultural rites and ceremonies, which may contribute to HIV/AIDS. Finally, the ABC strategy is geared exclusively toward prevention, when, in the current environment of improved, less expensive pharmacological approaches to AIDS and to opportunistic infections, there is widespread acknowledgement that more balance between prevention and care and treatment is required.

An important strength of the ABC approach is surely its simplicity. However, because issues around HIV/AIDS are more nuanced and complex, involving deep-seated culture and gender sensitivities, the ABC approach does have some shortcomings. It may not fully address issues of all stakeholders, especially women and children. One message of the

[12] United Nations Development Program, Uganda Human Development Report 2002, The Challenge of HIV/AIDS: Maintaining the Momentum of Success.

ABC approach, for example, to young women is to abstain from sexual activity until marriage and then somehow she will be protected by the marriage bond. A cruel irony is that women may be more at risk once they are married. It is fairly widely acknowledged that a young single woman has more power to assert herself in deciding safe sexual practices. Once married, she is much more at the mercy of her husband who, statistics show, is much more likely to be engaged in extramarital sexual relationships, unable to influence his high risk behavior or to negotiate safe sexual practices.

Some people living with AIDS feel that ABC may, perversely, result in some stigma, since an HIV+ status suggests non-adherence to one or both of the tenants of abstinence or faithfulness. Reverend Canon Gideon Byamugisha, an HIV+ Anglican priest (see below) frequently notes the difference between lawful sex and safe sex. "Unlawful sex" according to most religious teachings is sex outside marriage, but if this takes place with a condom, it is safe. In discordant or HIV+ couples, including married couples, sex can be lawful, but without a condom, it is not safe. ABC does not address this situation.

The use of condoms is still seen as diminishing male cultural norms. "Here in Uganda –perhaps in Africa in general – society that we won't recognize you as a man until you are married and have children. But AIDS educators tell us that the best way to avoid AIDS is to abstain from sex, which means you can't get married, or if you have sex, you have to use condoms, which means you can't have children."

Nevertheless, with significant caveats, research results confirm that the ABC-model has contributed significantly to the Ugandan success in the prevention of HIV/AIDS. Data indicate, especially among younger adults a delayed onset of sexual activity, and once in a relationship, a marked effort to be faithful, as well as the use of condoms particularly in non-marital, non-cohabiting sexual relationships. It has been a strategy which has enabled widespread collaboration and participation across a spectrum of society.

III. Analysis

So, what have been the results of this combination of interventions? The following paragraphs will trace the statistical measurement of HIV/AIDS in Uganda.

The Numbers: Since the identification of the first cases in 1982, HIV/AIDS rapidly developed into an epidemic in Uganda. A national sero-survey undertaken in 1987/88 suggested a national infection rate of 6-8 percent. This increased rapidly until 1992 when national prevalence reached based on sentinel surveillance sites reached just over 20%,[13] from which time it began to show a steadily declining trend. By 2002, nationally estimated prevalence had declined sharply and was estimated at about 6 percent.

The primary source for tracking the HIV/AIDS epidemic in Uganda has been data from surveillance of pregnant women in antenatal clinics (ANCs) at 20 sentinel sites throughout the country. Beginning in 1989 with six sites, these were gradually expanded,

[13] Reported rates at ANC in 1992 were almost 30% in Kampala and about 16 % in other urban areas, which translates into a national rate of about 20%.

increasing to 13 by 1993, 19 in 1995 and 20 by 2002. Although distributed throughout the country, most sites are in more urban areas, and in that sense are skewed. [14] They nevertheless are considered the best source of time series data tracking the progression of HIV/AIDS in Uganda.

In Kampala (Nsambya and Rubaga sites), average prevalence rates from ANC data, increased from 25 percent in 1989, peaking at 29.5 percent in 1992, and thereafter exhibited a steadily downward trend through 2002 when they had declined to 8.3 percent. For other major urban areas, median HIV infection rates among ANC attendees were 22 percent in 1989, dropped to 14 percent in 1990, but then increased to 17 percent in 1992, and, as in Kampala, dropped steadily through 2002 to about 6 percent.[15]

Outside major towns, HIV prevalence rates among ANC attendees has been slightly more erratic, but still follows the general pattern indicated above. The median prevalence rate for this population was about 4 percent in 1990, increasing to 8 percent in 1992, dropping slightly in 1993 but then increasing significantly in 1994 to about 12 percent. Thereafter the trend has been downward, reaching 4.6 percent in 2002.[16]

These aggregated trends mask considerable variation in the path of the HIV/AIDS epidemic in different geographic areas of the country. Aside from Kampala, rates have tended to be higher in those parts of the country which have seen conflict and/or represent transport corridors:

- In Jinja, directly east of Kampala (site of the Source of the Nile), the pattern is very similar to that in Kampala. Prevalence peaked in 1992 at 22% and then declined to about 5 percent in 2002.
- In Mbarara, in Western Uganda, along the trans-Africa highway that links Tanzania, Rwanda and the Democratic Republic of Congo, prevalence increased from 22 percent in 1989 to over 30 percent in 1992, after which it declined to about 10 percent in 2003. In Fort Portal (not part of the regular sentinel site system) located close to the border with the Democratic Republic of Congo, ANC data are available from 1991 to 1997. Here prevalence rates fluctuated around 20 percent in the early 1990's and then declined to 17 percent in 1997, the highest anywhere in the country in that year. Subsequent data are not available.[17]
- In Mbale and Tororo, in eastern Uganda, close to the Kenyan border, prevalence rates have been consistently below the national averages, rising from below 5 percent in 1989 to about 15 percent in 1992, and thereafter falling to about 5 percent in 2002.
- In northern Uganda, Gulu district, which borders Sudan and which has been the site of on-going conflict for years, the first sentinel site was established in 1993 and

[14] There has been some criticism of the use of data from antenatal clinics as a proxy for national prevalence rates. The sites represent only a few urban antenatal clinics, whereby the population is about 87% rural. Information is not available on the numbers of women tested every year or the share of the population they represent. Moreover, averages are calculated on a the basis of median values, and are unweighted.
[15] STD/AIDS Control Programme, Ministry of Health, HIV/AIDS Surveillance Report, June 2003
[16] STD/AIDS Control Programme, Ministry of Health, HIV/AIDS Surveillance Report, June 2003
[17] Uganda AIDS Commission, Measure Evaluation, Uganda Ministry of Health, *AIDS In Africa During the Nineties, Uganda,* 2003

reported an ANC prevalence rate of 27 percent. This fell to just under 12 percent by 2002. However, a study which analyzed a breakdown of these data found that among women in rural Gulu, which has seen violence and upheaval as a result of the activities of the Lord's Resistance Army (most recently in February 2004), HIV prevalence actually increased between 1995 and 1999, which the authors attributed to civil strife, population displacement and a breakdown of basic health services.[18] By contrast, two other districts in the north of the country, Moyo and Arua, which have not seen civil conflict and social unrest, have consistently reported prevalence rates of 3 to 5 percent, much lower than national levels, but also relatively stable throughout the 1990's.

While HIV prevalence data (the percent of the population infected with HIV) have been the most common data to track the epidemic, these are not ideal in several respects. As they measure cumulative infections over a period of years, declining prevalence reflects a decrease in the number of new infections, an increase in mortality (thus fewer people living with the virus) or a combination of the two. Hence prevalence could in fact be declining or stable while incidence (the number of new infections within a given time period) was increasing. While data on HIV incidence is a more accurate indicator of the evolution of the disease, these are not so readily available.

Prevalence data for young women is more closely related to incidence, since these have been sexually active for less time, a fall in prevalence is unlikely to be due to AIDS-related mortality and are therefore a closer proxy to rates of sero-incidence. In general, tracking time series data for three age groups, 15-19 years, 20-24 years and 25-29, at Nsambya, Rubaga, Mbarara and Mbale hospitals, reveals that overall trends in these four sites are similar, namely a spike in 1992 and a clearly downward trend after through 2002, with significantly more marked declines in the 15-19 year old cohort. However, in Mbarara, prevalence rates for the youngest group increased rather sharply from about 2 percent in 2000 to over 10 percent in 2001 and then dropped to about 6 percent in 2002. In Mbale prevalence rates among 15-19 year olds increased from less than 2 percent in 2001 to about 5 percent in 2002. For 20-24 year olds, there was a sharp rise from less than 2 percent in 2000 to over 10 percent in 2001 to below 8 percent in 2002.

One final indicator in determining trends in incidence worth examining is the total number of adult AIDS cases by age and sex. Data are available for December 1994 and for December 2002. In both years, for the younger age cohorts (15-19 and 20-24) there are 2-3 times more AIDS cases in females than males. Also, the age group which exhibits the highest concentrations of AIDS cases has noticeably shifted from 20-24 in 1994, to 25-29 by 2002, again suggesting declining incidence of the disease.

One conclusion which may be drawn from these numbers is that successes in Uganda strategy began to take hold in the early 1990's. Since prevalence rates generally began to decline after 1992, one can surmise that incidence rates must have been declining for several years before that. Of some possible concern is that, over the past few years, in a number of

[18] Fabiani M., Ayella E.O., Ble C., Accorsi S., Dente M.G,, Onek P,A., Declich S. Increasing HIV/-1 prevalence among pregnant women living in rural areas of Gulu District. AIDS. 2001.

sentinel sites, rates have either stagnated or, in some cases increased. This caused a number of observers to wonder if some newer initiatives are warranted at this time to safeguard and maintain past successes.

III. Factors of Success

The foregoing sections have described government policies and statistical measures of Uganda's experience in combating HIV/AIDS. This section will discuss what have been some of the underlying factors of success which have underpinned official government policies and programs.

Political Commitment

> *If you go into a field and see an anthill full of holes, and you put your hand into a hole and get bitten by a snake, whose fault is it?—President*

In the mid to late 1980's, AIDS was beginning to take hold in many African countries, but it was contained behind a wall of silence and denial. Few public or private leaders, secular or religious, had the courage and commitment to openly face the scourge of AIDS in all its dimensions. This wall of silence and denial provided fertile ground for the stigma and shame associated with the disease, thereby contributing to the further expansion of the epidemic. Contrasted with some of its neighbors, some fearing a negative impact from HIV/AIDS on their tourist industries, Uganda was much more candid about the epidemic and the threat it posed to Uganda's economy and society. Admittedly Uganda had less to loose; decades of civil war and unrest had meant it had no significant tourist industry. The strongest leadership initially came from President Museveni who himself had received an early "heads up" on the threat of HIV/AIDS in 1986 when nearly a third of some 60 soldiers who had been sent to Cuba for training were returned after testing positive for HIV.

Thus, almost from its inception, President Museveni's government recognized the threat posed by HIV/AIDS. Despite the immense challenges confronting the new government – an economy shattered by years of civil war, a near bankrupt government, rampant inflation, public health and education services nearly destitute, infrastructure deteriorated to the point of near collapse, and woeful shortages of basic consumer goods – it confronted the issue of HIV/AIDS head-on.

In May 1986, Dr. Rukahana Rugunda, the newly appointed Minister of Heath publicly announced to a World Health Assembly in Geneva, "Fellow delegates, I have to inform you that we have a problem with AIDS in Uganda, and we would like the support of the international community in dealing with it."[19] Other delegates, especially those from Africa were stunned at the simplicity and openness of this announcement concerning a disease still largely associated with homosexuality and drug use.

---

[19] Kaleeba, Noerine; Kadowe, Joyce; Kalinaki, Daniel; Williams, Glen; *Open Secret, People Facing Up to HIV and AIDS in Uganda,* Strategies for Hope Series, ACTIONAID, London, 2000.

For the next several years President Museveni toured extensively throughout the country, his charisma attracting large attendance at public rallies on a host of political and development issues. Some say he visited district in Uganda. He consistently closed each gathering with HIV/AIDS messages. Frequently alluding to African proverbs or storytelling, and making extensive of colorful images and earthy humor, his messages combined fear with knowledge about how to prevent the disease, coupled with exhortations about morality and national pride and patriotic duty. Building on the demands of a population now clamoring for a voice in civic affairs, Museveni called for an assault-like public information campaign about HIV/AIDS, opening the issue up for public debate with the aim of building broad based consensus on how to proceed and who should be engaged. Two partnerships were key here: a newly liberalized media and the religious communities throughout Uganda.

Many commentators have soundly lauded the efforts of President Museveni, noting that in the late 1980's taboos against public discussion of sex were strong and pervasive throughout Uganda. Despite considerable criticism --his manner was seen as brash and sometimes insensitive by some cultural and religious leaders – he persisted, exhibiting considerable political courage.

Openness, Partnerships and Networking

As in many other African countries, HIV/AIDS hit Uganda with bewildering effect. Certainly, initial reaction was fear, denial, panic and prejudice. In the early days of the epidemic, having "Slim" was a cause for shame and withdrawal from family and community. The enormous stigma attached to AIDS, led many people to seek cures promised by herbalists, spiritualists along with witchdoctors and other "quacks" who claimed they had cures. People traveled long distances and spent considerable sums of money and other household assets on these remedies. However, except for the palliative help of bona fide herbalists in caring for some associated symptoms, these efforts were in vain.

Gradually, however, the courage and openness demonstrated by the government and many community and religious leaders paved the way, albeit gradually, for a more open and candid national response to HIV/AIDS within the general public. Massive mobilization and education efforts taught people the basic facts of HIV/AIDS, how it was contracted, how it was spread and how it could be prevented. Openness enabled a multitude of leaders and organizations, including those from faith communities, to launch public information campaigns, to establish care and treatment facilities. Public information campaigns gradually shifted from messages of fear and recrimination to hope, comfort and dignity, which served to motivate people to seek out testing and adopt more positive, less risky behaviors. Openness meant that people could more easily access treatment. It gave them the power to translate information into action.

Champions. Uganda has been blessed with a number of HIV/AIDS champions – people coming from all walks of society, uncertain of how their disclosure would affect them personally, who nevertheless had the courage and the commitment to openly declare their HIV status. Their actions contributed significantly to the pursuit of openness that was so much of an underpinning to Uganda's overall efforts to combat "Slim," making it easier for other HIV+ people, with less celebrity, to seek counseling, get tested and, if necessary, formulate positive living strategies for themselves and other people living with AIDS. The courageous action of Uganda's early pioneers has been complemented by many unsung, unknown people who have disclosed their own status within their communities, thereby helping to open HIV/AIDS up to public debate.

Among the most prominent early champions was **Philly Lutaaya,** a popular Ugandan musician who, returning from Sweden in early 1989 was the first celebrity to openly declare he had AIDS. He toured the country widely, appearing at churches, mosques and schools, with a more proactive and positive message, which contrasted with the government's public information campaign, largely based on fear. "You get AIDS, you die!" In some of his concerts Lutaaya met with scorn and ridicule, reflecting the deep-seated denial which prevailed at that time, and accusations that his interests were commercial more than anything else. When he died later that year, there was a tremendous outpouring of grief and compassion. The documentary, *Born in Africa,* which tells the story of the last months of Lutaaya's life has informed and inspired millions in Uganda and throughout Africa and contributed significantly to lessening stigma attached to the disease. Following his death, the Philly Lutaaya Initiative was born in 1991, aimed at combating stigma and giving hope and dignity to people living with AIDS. This program has trained hundreds of HIV+ people to speak out publicly about their personal experiences in living with AIDS, targeting especially vulnerable groups such as adolescents, street children, commercial sex workers and truck drivers.

NGOs and faith based organizations were focal targets of outreach as the government sought "non-electronic," creative, prevention, education and behavior change agents that would be sensitive to local conditions and respected members of the community and would be able to engage a wide range of stakeholders in fighting "Slim" – politicians, community leaders, educators, students, administrators, commercial traders, commercial sex workers, none of whom is traditionally involved in "health" issues. This was especially important in the extreme post-civil war poverty in which many households found themselves.

From the early days of the epidemic, the military was a prime target of AIDS control initiatives. The AIDS Control Program in the Ugandan army, one of the oldest in Africa, has been engaged in education and mobilization efforts since 1989. The media has was also enlisted as an important change agent and partner in the fight against HIV/AIDS. When Museveni came to power the media comprised a small number of state controlled newspapers and radio stations. In the early 1990's the media was largely liberalized and became an important forum to discuss and inform the public on a number of topical issues, key among which was HIV/AIDS.

Among the early champions who fostered candor and openness about HIV/AIDS came from an unlikely source – the military. **Major Rubaramira Ruranga** disclosed his HIV+ status in 1989, at considerable risk to a promising career in the military. Major Ruranga has remained one of Uganda's most tireless HIV/AIDS crusaders. Still in the military, he is a long-standing member of the Uganda AIDS Commission. In 1995, he founded the National Guidance and Empowerment Network of People with AIDS (NGEN+). Shunning any suggestion of victimization, the strong message of NGEN+ and of Major Ruranga is how best to channel the positive energies of people living with AIDS.

The role of Religious Leaders

> *"Religion in inextricably woven into every aspect of life in Uganda. For most Ugandans, religious beliefs play a major role in their sense of personal identity, their thought patterns, their moral judgments and their perceptions of the disease." Open Secret, People Facing Up to HIV and AIDS in Uganda.*

Within the context of Uganda's overall efforts to combat "Slim," religious leaders and faith communities have played a central role. As in other African countries, faith-based organizations have profound influence with communities and households on a wide array of issues – spiritual and practical. No other institution has comparable access to communities through well developed networks on the ground. Faith institutions, especially at the local level, inspire greater levels of trust and confidence than governments, donors, or secular non-governmental groups. Faith based organizations, well grounded in local culture, have been uniquely positioned among Uganda stakeholders in the fight against HIV/AIDS to mobilize communities and influence values and behavior change, which have been the critical elements in the country's success. In the early days of the epidemic, when the focus of the government's efforts were on prevention, it was the faith based health services who recognized that patient care was woefully neglected. Similarly, there were very few counseling services available from health workers; instead most counseling was done by volunteers, many trained and administered by religious organizations. Faith based organizations have been significant sources of home based care, psycho-social counseling, care of orphans and vulnerable children, and increasingly, in the pharmacological treatment of the disease, including the provision of antiretroviral drug therapy.

Uganda's religions: Christianity is the majority religion in Uganda, representing about 66 percent of the population, almost equally divided among Protestants and Roman Catholics. Approximately 16 percent of Ugandans are Muslims. A variety of other religions including traditional indigenous, Hindi, Baha'I, and Judaism, make up the balance. The basic tenets of all religions--that a spiritual realm exists and that spiritual and physical beings can influence one another--permeated much of Ugandan society. World religions and local religions have coexisted for more than a century, and many people established a coherent set of beliefs about the nature of the universe by combining elements of the two.

Government saw in the early days of the pandemic that a successful policy would require moral and spiritual leadership and they were quick to reach out to faith communities, reminding them they have a responsibility to become engaged as a reflection of the trust and dependence they generated within their congregations. Medical clinics and hospitals supported by all three major religions in Uganda – Catholic, Protestant, and Muslim – have provide a full range of medical care, counseling and social support. Nevertheless, in the early days of the epidemic many religious leaders condemned those living with the disease as sinners, justly incurring God's punishment, thereby further entrenching already deep rooted stigma and discrimination. Some observers pointed to the need for additional training of clergy in technical matters related to HIV/AIDS as a vehicle for also addressing stigma.

At present, UAC estimates that faith based organizations represent about half of the (approximately) 2000 non-governmental organizations engaged in HIV/AIDS initiatives, spanning the range of education, prevention, counseling, care and treatment. (A mapping exercise, with the assistance of the African Medical Research Foundation (AMREF) is planned for late 2004.) In addition, partnerships with faith based organizations have permeated virtually every aspect of Uganda's HIV/AIDS program from its inception. Many of Uganda's key organizations – e.g. TASO, AID, UNASO – while not directly faith based themselves, have had longstanding and deeply rooted partnerships with faith based organizations, both Ugandan and international.

The response of the Christian Community

There are a host of Christian organizations which have joined the battle against HIV/AIDS, spanning a gamut from those directly associated with institutional church based communities as well as a range of Christian affiliated groups. The following section highlights some of the larger and more well known. But it is by no means comprehensive, as the heroic efforts of many groups which, for reasons of capacity or funding, operate on a smaller scale.

The **Catholic** community in Uganda was among the first to commit itself to the battle against HIV/AIDS. In the late 1980's the Catholic church was providing basic health services throughout the country through a system of some 200 lower level heath centers and regional hospitals, at the time thought to represent perhaps 25% of the country's health infrastructure. These facilities were quickly overwhelmed with "Slim" patients, and in response the Uganda Catholic Medical Bureau formulated a more structured and scaled up program. The Uganda Catholic Secretariat created new post of AIDS Program Coordinator as well as a special desk for HIV/AIDS within the Catholic Medical Bureau. They began training counselors, launched an information/education campaign, including a widely distributed letter in September 1989 from the Catholic Bishops of Uganda urging stressing the need for love and compassion for AIDS patients and those affected by the disease, most especially orphans. "Let each one of us look into his or her innermost self, in order to find out what this epidemic means for him or her here and now. It challenges us in all aspects of our living." Catholic churches and mission hospitals designed mobile home care projects and special programs for AIDS widows and orphans. Medical services focused on programs for home based care and treatment of opportunistic infections. Within the Secretariat, other initiatives were launched, including policies and programs for advocacy, especially for

orphans an vulnerable children, and additional education programs, both within communities and formal Catholic-supported schools.

In 2001, the Uganda Catholic Secretariat determined that despite past efforts and successes, HIV/AIDS activities had not been sufficiently or effectively integrated into various church based activities. The decision was that additional mainstreaming and scaling up could only take place within the context of an integrated more comprehensive strategic plan. Following extensive consultation among a wide range of government, civil society and faith based representatives, a Strategic Plan for HIV/AIDS Activities 2001-2006 was formulated. This plan lists a number of priority areas across a range of prevention, mitigation and institutional capacity building. The overarching goal has been to mainstream HIV/AIDS prevention and control in all departments throughout the Church structure at the national, diocesan and parish levels. The Plan sought to provide a mechanism which would promote linkages and synergy with a view toward efficiency and cost effectiveness. Today, each of the 19 Catholic diocese has a focal person for HIV/AIDS who works through schools and other community services, targeting adolescents and young adults especially. Most parishes have programs, albeit of varying size, from quite small up to one program of valued at $1 million. Nevertheless, the Secretariat office still feels a need for greater coordination among all these initiatives in order to scale efforts up even more with greater impact.

As with other African countries, the **Anglican Communion** has been at the forefront of HIV/AIDS advocacy and care and support services. As early as 1991, it organized a workshop for bishops and other religious leaders and began to formulate and implement extensive HIV/AIDS education programs in many dioceses.

Reverend Canon Gideon Byamugisha: Perhaps best known, both within Uganda and internationally, among Uganda's pioneer early champions in the fight against HIV/AIDS is Canon Gideon. He was ordained as a priest in the Anglican Church of Uganda in 1992, shortly after the death of his wife in 1991. Once he discovered that his wife had tested, posthumously, positive for HIV, he himself went for testing and discovered, he too was HIV+. For three years he lived with his secret, telling only close family members. Three years later in 1995, Canon Gideon disclosed his status to his Bishop, Samuel Ssekkadde, who was very supportive, encouraging Canon Gideon to continue to advocate on behalf of people living with AIDS. Thus Canon Gideon became the first practicing priest in Africa to break the silence, and openly declare his HIV+ status. Since then, Canon Gideon has campaigned tirelessly and courageously against the stigma and discrimination associated with HIV/AIDS. His efforts have mobilized grassroots and community action and increased understanding of the many difficult and multifaceted issues around HIV/AIDS and the acceptance of people living with the virus. His focus is very pointedly on living positively with AIDS and helping HIV+ people to remain productive, contributing members of society. He has been an especially articulate spokesman helping to unbundled some issues within the ABC strategy which are more complex and nuanced than might at first appear to be the case. Canon Gideon oversees an HIV/AIDS program under the auspices of the Church of Uganda. He also works with World Vision 's Hope Initiative and serves as a Commissioner on the UAC. The Swazi people call him "SIPO" which means "Gift from God." UNAIDS has called Canon Gideon a truly brave son of Africa.

The special leadership of Reverend Canon Gideon Byamugisha, the first priest to declare his HIV+ status, and the support given to him by his Bishop Samuel Ssekkadde, provided an early and powerful message which transcended the Anglican Community.

In addition however, several other initiatives are worth mentioning. On the outskirts of Kampala, **Namirembe Diocese,** said to be the "Mother" of all Anglican Dioceses in Uganda (it used to cover the entire country, along with Rwanda, Burundi and Boga-Zaire, now the Democratic Republic of the Congo), has been in existence for some 100 years. Its Health Department since 1992, has, through its integrated HIV/AIDS and general health program, been deeply involved in the fight against HIV/AIDS. Training and mobilization are the central focus of its activities. Training efforts seek to train trainers down to the parish level in a holistic array of personal hygiene and health, reproductive health, nutrition, and HIV prevention, care and support areas. It supports voluntary counseling and testing, provision of medical supplies for the treatment of opportunistic infections along with a program of home visits. Among its mobilization and sensitization activities it has developed an entire prayer service around HIV/AIDS messages, whose liturgy is designed to raise awareness, combat stigma and promote solidarity around HIV/AIDS. This liturgy has been used in other Anglican Communions around the world.

Namirembe Diocese has four specially targeted programs:

- The Child to Child Program is targeted at children below the age of 13, both in primary and Sunday school contexts. It aims to safeguard children from HIV/AIDS

and other diseases, and offer basic training in home care. It aims to provide children with a sound information basis to cope with peer pressures as they enter their later teens.

- The Youth to Youth Program is designed to help adolescents to positive change in morals and behavior, safeguard them from HIV infection, support peer groups and involve them in home care support.
- The Positive Parenting Program is designed to give parents improved skills at communicating with children and with each other on issues of gender relations, health and hygiene and HIV/AIDS.
- The Post Test Club is a support group for people who have tested positively for HIV/AIDS which provides very modest material support, along with emotional and spiritual guidance.

The Muslim Community

The **Islamic Medical Association of Uganda** (IMAU) has played a leading role in educating Uganda's Islamic community, especially religious leaders, about HIV/AIDS and in mobilizing community responses. Its interventions have been published in a UNAIDS series on best practices.[20] Established in 1988, by 3 Muslim medical doctors who shared a common sense of alienation in a country where Islam is a minority religion (estimated at 16% of the population) IMAU originally sought to support Muslim health officials in Uganda. By the late 1980's IMAU had joined the fight against HIV/AIDS, pioneering the first HIV/AIDS prevention program oriented toward the Muslim community. In September 1989, IMAU held a National AIDS Education Workshop, with support from the Ministry of Health and the World Health Organization, aimed at shaping the response of the Muslim community to HIV/AIDS. The workshop was attended by every district Khadi in Uganda.[21] The Mufti of Uganda declared a "jihad" on HIV/ADS. Following the workshop, IMAU organized a series of workshops at the district level for imams, laying the foundation for the eventual Family AIDS Education and Prevention through Imams Project (FAEPTI).

FAEPTI, launched in 1992, trained Imams and teams of community volunteers in correct knowledge and information about AIDS, wherever possible linking these messages to passages in the Qur'an. A first step was to undertake a baseline survey in two districts (Mpigi and Iganga) to assess knowledge and practices relating to the disease. Some 2000 people responded, revealing widespread knowledge of how HIV is transmitted, but beyond that, a great dearth of information, including about mother to child transmission or the risks associated with certain religious cultural practices, including circumcision and ablution of corpses. Based on the presumption that prevention messages are more likely to resonate if the messengers are trusted members of the community, Imams were encouraged to incorporate HIV/AIDS prevention messages in their spiritual teachings. Community workers were trained in five-day workshops in sexually transmitted diseases, risk perception, methods

[20] UNAIDS, *AIDS education through Imams: A spiritually motivated community effort in Uganda;* UNAIDS Case Study, October 1998.

[21] The structure of Ugandan Muslim clerics is as follows: the Uganda Muslim Supreme Council is headed by His Eminence, the Mufti. Below the Council there are 33 district Khadis, each of whom oversees approximately 6 county sheikhs. Each Country Sheiks oversees 30-40 Imams each of whom heads a mosque and who provide spiritual support to about 75 families.

aimed at behavior change, issues relating to women and adolescents, effective communication and counseling.

The project began in two districts and within five years had expanded to ten more. More than 8,000 religious leaders and community volunteers, about half of whom were women, have been trained who have provided support and counseling to over 100,000 households. IMAU has ensured the active participation of women in every level of its AIDS education efforts, recognizing that the ability to gaining the confidence of women in the community with AIDS education messages would only be possible with women volunteers. Thus every Imam was required to have both a female and a male assistant. These female volunteers have especially targeted teenage girls, who statistics have shown are at higher risk to contract the disease than are teenage boys. Women in the community have been encouraged to establish income earning micro projects. Reportedly the resulting empowerment has helped women to stand up more to their husbands, demanding safe sex practices, and to refrain from seeking partners outside marriage to ensure sufficient household income for expenses such as school fees.[22]

Home visits by volunteers were an key aspect of the project, providing a more personal approach which complemented mass media campaigns. The presumption was that safe sexual practices would be more likely to be adopted if perceived as the norm within the community. Volunteers were provided with bicycles and income earning activities to sustain their motivation. A second survey, two years into the project's implementation period, suggested very positive results, including some revision in cultural practices that would help to contain the spread of HIV/AIDS and, among those responding, fewer sexual partners and increased condom use.

The issue of condoms during the first year of the project generated controversy and debate which project organizers found to be too divisive. Hence, the issue was set aside for more than a year. (Despite this however, more than 200,000 condoms were distributed " informally" and the topic of condom education arose spontaneously at frequent gatherings and workshops.) During this time IMAU established a dialogue, providing religious leaders with a vehicle to voice their concerns. Alluding to the basic tenant in the Qur'an concerning the protection of life, IMAU underscored their intention was to promote only responsible condom use after failure of other defenses against AIDS, adding that parents who ignore condoms leave behind orphans. In response to concerns that condoms would promote promiscuity, IMAU said that Muslim knew about alcohol, but this did not mean they necessarily consume it. After about a year, there was sufficient "comfort" and consensus and condom education was adopted into the formal curriculum of FAEPTI.

FAEPTI gave rise to two follow-on projects:

- Community Action for AIDS Prevention (CAAP) With support from UNDP, and based on a community based education approach, CAAP is training religious leaders and community volunteers from both the Muslim and Christian faith communities,

[22] UNAIDS, *AIDS education through Imams: A spiritually motivated community effort in Uganda;* UNAIDS Case Study, October 1998.

mainly in the Kampala region. Given the high population density of Kampala, emphasis is placed on AIDS education and prevention messages in mosques, churches and community gatherings. An innovative feature of CAAP is that it has reached beyond faith leaders and is engaging boda boda drivers (bicycle taxi drivers) and market vendors to pass on AIDS messages in the course of their commerce with clients.

- Madrasa AIDS Education and Prevention Project (MAEP): With some funding from UNICEF, MAEP has developed a series of age-appropriate AIDS education curricula (36 lessons of about 40 minutes each) explaining, HIV/AIDS transmission, prevention and control, care of AIDS patients. Using the vehicle of the madrasa, which are informal schools attached to mosques designed to provide religious instruction, the HIV/AIDS curriculum is given in parallel and makes frequent reference to music, dance and drama. The program operated in 350 madrasa schools in Kamuli and Mpigi Districts and reached more than 20,000 children between 19951998.

Importance** of **Organization and Networking. In addition to the direct contributions of the faith communities, and a further reflection of the openness and political commitment, there is a host of organizations and networks of people living with, or supporting those who live with, HIV/AIDS, many of which receive significant indirect support from religious groups. These combine to provide an environment where people are encouraged and empowered to seek voluntary counseling and testing, and, if positive, provide comfort and support to people and their families living with the virus, making it easier for the them live positively. Such support networks are generally credited with helping people to personalize risk, thereby contributing to behavior change. Compared with other countries, Ugandans are more likely to receive HIV/AIDS information through friendship and personal networks (including faith based) than through mass media. Many consider this type of information to be a better means to bridge the gap between information and behavior change.[23]

Among the earliest organizations providing care and support to people living with AIDS is **TASO, The AIDS Service Organization.** The first indigenous AIDS organizations in Africa and considered by many to set the standard for HIV/AIDS organization, TASO was founded in 1987 by Dr. Noerine Kaleeba and some 15 other colleagues. Many of TASO's early founders were HIV positive or had a close family member who was HIV positive, a unifying experience which gave them a particular sensitivity to issues of stigma, discrimination and the need for care and treatment and quality of life.

TASO's adopted the slogan "Living Positively with AIDS," thus focusing on living with, rather than dying from, AIDS. The direct implication was to combat stigma and ignorance, and opening up the AIDS issue, bringing it into the public domain. TASO called on those living with AIDS to live responsibly, and on the rest of society to recognize their responsibility to support those infected. Whereas the government's messages were

[23] Green, Edward; Nantulya, Vinand; Stoneburner, Rand, *What Happened in Uganda, Declining HIV Prevalence, Behavior Change and the National Response,* United States Agency for International Development, September 2002.

effectively, "If you contract HIV/AIDS, you will die," TASO was among the first organizations both to encourage people to find out their status and to offer hope and dignity to people with AIDS. The range of services provided by TASO includes counseling (pre-test, post-test, prevention, couples and bereavement) by trained counselors; medical care at clinics held three times weekly at TASO's various branches, home care support services, health and nutrition education, social support, including food distribution and school fees for children, capacity building and training. TASO pioneered the notion of revealing one's status to at least one other significant person which became known as "shared confidentiality within a limited circle." This had the effect of opening up additional vehicles for care and support.

From modest beginnings, TASO has expanded to become the largest AIDS service organization in Uganda. TASO by 2002 had 8 counseling/treatment centers spread around the country, with plans to establish an addition two by 2005 including one in the troubled northern district of Gulu. TASO has also provided considerable training, supervision and on-going support to other organizations, thereby replicating the TASO approach to larger number of organizations, including many faith based. TASO established counseling units in seven government hospitals outside Kampala and trained their staff in counseling skills.

TASO has seen a steady increase in the number of new clients – 13,807 in 2002, compared with 8,703 in 2001 and 6,634 in 2000. Expectations in 2004 are for a new case load of about 300 per month. TASO ascribes this increase, not to increasing prevalence rates but to improved access to better quality services and increasing openness to the disease and finding out one's sero status. Also in 2002 a total of 69,104 counseling sessions were provided in all of TASO's centers. TASO is planning to offer antiretroviral drugs (ARVs) beginning later in 2004. As part of the planning process, it will re-screen all clients and for those with CD4 counts below 200, an estimated 600 cases to whom ARV will be offered.

The AIDS Information Center (AIC). In the late 1980's when the wildfire of HIV/AIDS was spreading unchecked, a demand emerged for tests that would reveal one's sero status. The national blood bank was overwhelmed with people offering blood donations as a proxy method of getting tested (safely and in confidence), but this was considered an expensive misuse of blood banking services. Some policy makers in Uganda were quite farsighted in their appreciation of the links between care and prevention. As far back as the early 1990's, Uganda was beginning to place significant emphasis on voluntary counseling and testing as one element in an overall prevention strategy. This was ahead of similar efforts among its African neighbors as well as the Global Program on AIDS and other international organizations. Collaboration between the Ministry of Health and a group of national and international NGOs and the World Health Organizations, led to the establishment of AIC in 1990.

Counseling was a new "job description." There were at the time few testing facilities in Uganda and almost none with affiliated counseling services. Quite apart from the emotional stress of delivering what was at the time, in effect, a death sentence, patients needed to understand the difference between HIV and AIDS. It was difficult to explain that patients had a fatal disease which might not yet have become symptomatic. Few doctors, within an overwhelmed health system, had the time to provide this sort of counseling. Training of an army of a new kind of health care personnel, many of whom were not health

workers but volunteers, many from faith communities, many of whom were people living with HIV/AIDS, was required

Offering its services anonymously, AIC provided voluntary counseling and testing, initially in the course of two visits (pre- and post-testing) over a two week period. In recognition of the persistence of stigma, AIC is careful to ensure the confidentiality of its clients. Since 1997, rapid testing and same-day protocol has been adopted. With today's technology, test results are available in under an hour. Its services are heavily subsidized –USh 1000 for youth, USh 4,000 for adults, compared to a cost of USh 13,000. AIC also has an " executive" program for wealthier clients where facilities are plushier and confidentiality is strictly observed. For this segment of their clientele the charge is USh 20,000, or some USh 7000 above cost. AIC works in close collaboration with TASO and will frequently refer its clients who have tested positive to a TASO branch. Post test clubs, especially among the youth, are very active and engaged in advocacy in schools and community groups.

In the first 11 months after opening, AIC had more than 9000 clients, compared with its target of 5000 for a full year. Beginning with one office and four regular staff, AIC has since expanded to a nationwide organization with 5 branches and 70 satellite testing sites in health centers, community centers and churches spread over 27 districts. A significant expansion into northern districts is planned for the coming years Between 1990 and 2002, AIC cumulatively served more than 700,000 clients. In 2002 alone, AIC had some 110,000 clients of which about 30% were between 15-24 years, compared to 70,000 in 2001.

A few of AIC data for 2002 are worth quoting. While in general, AIC data mirror national data in declining rates of HIV prevalence, still, 22% of first time testers in 2002 were HIV+. The pattern of sero-positivity by age group shows the sharpest declines in the 18-24 year cohort, from about 20% in 1992 to about 11% in 2002, while rates for 25+ years have declined but much less markedly, from about 32% in 1992 to about 25% in 1992. Sero-positivity was noted to be especially high among children under 12 at 25.3% in 2002. By gender, prevalence rates historically have been consistently and significantly higher among women than men, in 2002 about 25% and 15% respectively. For the younger cohort, 12-17 years, AIC data show a drop in prevalence rates for girls from about 11% in 1992, to about 2% in 1997, and then a steadily increasing rate to about 5% in 2002. This compares with a much flatter pattern among boys of the same age, from about 4% in 1992 to just over 4% in 1992.[24]

Associations of People Living with HIV/AIDS. Critically important among the networks are the large number of networks for people living with AIDS. Many of these are associated community based, non-governmental and faith based organizations. There is a national People Living with HIV/AIDS (PLH) group which functions as a national advocacy group and has close ties with religious leaders and faith based groups. PLH appears very active and well informed with a holistic comprehension of the full scope of HIV/AIDS strategy issues. Behavior change communication is a prominent part of many of its program activities.

[24] AIDS Information Center, Annual Report, 2002

UNASO. The umbrella organization for HIV/AIDS interventions is the Uganda Network of AIDS Service Organizations **(UNASO),** founded in 19997. UNASO serves as a central networking/coordinating body for all local agents with HIV/AIDS initiatives underway with a view toward promoting a more rational coverage and use of resources, thereby improving access to HIV/AIDS support services in some underserved areas of the country. UNASO also serves as a central clearing house for information dissemination, to share best practices and to advocate with government policy makers. UNASO currently has about 500 members, about one third of which are faith based organizations. UNASO views faith communities as especially important partners, pointing to their vital role in prevention, community mobilization, behavior change and care and support. UNASO's current business focus is on strengthening district level networking structures.

NACWOLA. One especially noteworthy and impressive network is the National Community of Women Living with HIV/AIDS in Uganda, or **NACWOLA.** This is a network of HIV+ women, many single parents who provide each other with emotional support and practical assistance. NACWOLA has close ties to local religious members are frequent public speakers at church and community gatherings. NACWOLA members report greater empowerment among themselves and women in general in Uganda in the country's generally more open environment about HIV/AIDS and sexual issues:

> "Not so long ago if a woman tried to discuss sex with her partner, he would view her as a prostitute. A woman was expected to be humble and wait for her husband to make advances. In. African culture, it was taboo for a woman to show sexual desire, or express dissatisfaction. You could never complain, even if your husband was having "away matches" (extra-marital affairs) you couldn't object...Now you find that, through a lot of sensitization....the old taboos are gradually being broken. Women are starting....to persuade their husbands to use condoms."[25]

Among NACWOLA's top priorities are women's inheritance rights. They teach their members about women's legal rights and assist in preparation of a will. Another priority is guidance on disclosing one's HIV status to children. NACWOLA members, as mothers, are keenly attuned to children's sensitivities and worries. An important element is the Memory Project. Modeled on a project originally developed by a London children's charity, Barnardo, Memory Books help to prepare children for the impending death of a parent. Traditionally Ugandan parents do not discuss death with children, but the situation of HIV/AIDS has rendered that no longer appropriate in many, especially poor, households where children may have to cope with minimal adult guidance. Memory Books, put together by mothers and children recount family history, important life events and significant people who have shaped a child's life experience. They provide children with a sense of identity.

Efforts to reach out to youth have been a special focus of Uganda's strategy. Most recently, under the guidance of President , a strategy to actively reach out to school children was formulated. Concerned that past gains could be lost without a special effort to provide

[25] Kaleeba, Noerine; Kadowe, Joyce; Kalinaki, Daniel; Williams, Glen; *Open Secret, People Facing Up to HIV and AIDS in Uganda,* Strategies for Hope Series, ACTIONAID, London, 2000.

school children with better information, the Presidential Initiative on AIDS Strategy for Communication to Youth (PIASCY) was launched, in collaboration with the Ministries of Education, Health, Gender, Labor and Social Development and Local Government. Building on the on-going policy of universal primary education, the initiative seeks to use the school system as an entry point to reach some 7 million school children. The methodology has been to develop training manuals for teachers to be able to deliver age-appropriate messages across a full range of HIV/AIDS, gender, reproductive health and STD issues. These messages are intended to be shared at least bi-monthly in school assemblies, as well as in club meetings and classroom settings. In developing these training manuals there has been significant collaboration with other community leaders, and, especially with faith leaders.

Straight Talk newspaper, since 1993, has become an important forum for young people to voice their concerns about emerging sexuality, reproductive health and HIV/AIDS. Straight Talk provides candid and truthful information aimed at empowering youth and developing healthy life skills. Straight Talk, registered as an NGO in 1997, was initially aimed at adolescent (15-19 years) audiences. While this age group remains its primary focus, it has also has expanded its activities to now include Young Talk (10-14) and Teacher Talk. A new initiative, Parent Talk is due for its first publication later this year. From its outset, Straight Talk has liaised closely with leaders from all key faith communities in Uganda to ensure that messages, approaches and information were conveyed in a manner which was respectful of local culture and religious teachings. From quite modest beginnings, Straight Talk now publishes some 230,000 monthly, some of which are inserted into a popular daily newspaper, The New Vision, but most are distributed to schools nationally. Young Talk now publishes some 400,000 copies per month and Teacher Talk, some 250,000 copies per quarter. Three local language newspapers are printed quarterly (80,000) for out of school adolescents. The newspapers all stress age-appropriate messages concerning postponement of sexual activity, avoiding early pregnancy, relationship issues and messages and information about HIV/AIDS. A popular feature of Straight Talk is letters which young people write in asking questions about sexuality, reproductive health and HIV/AIDS. The candor with which these are written (letters may be anonymous or signed) has provided a wealth of information for Straight Talk and for other government and non-government organizations to design messaging for young people. A recent edition of Straight Talk (March 2004) is focused on religion. Headlined "Religion helps to keep you safe," it has a series of articles shaped around both Christian and Muslim teachings, written both by religious leaders, including Canon Gideon Byamugisha, and by young people, in support of the contention that religious beliefs can help young people in handling emerging issues of sexuality, in resisting temptation, and avoiding risky behavior. Straight Talk also has radio shows, presented weekly by youth, in English and five local languages. Straight Talk is credited by Ministry of Education staff in providing a safe and reliable forum to educate youth about HIV/AIDS.

Traditional healers. Among the more interesting partnerships sought out by the Uganda AIDS Commission and the Ministry of Health is the Traditional and Modern Health Practitioners Together Against AIDS, or THETA. HIV/AIDS stimulated numerous attempts at collaboration between modern and traditional medicine, with the strong support of President Museveni. THETA was established in 1992 with support from TASO and Doctors without Borders as a collaborative clinical study with traditional healers to evaluate the

effectiveness of various herbal remedies in treated opportunistic infections and other symptoms associated with HIV/AIDS. The result was the creation of an on-going organization, now operating in 10 districts which continues to foster collaboration and complementarity between traditional healers and biomedical health practitioners to counsel and care for people living with AIDS in areas such as improved nutrition, treatment of opportunistic infections and other related symptoms. Community level initiatives are frequently undertaken in partnership with local faith leaders and organizations. Another aspect of THETA's program is clinical observations of a number of herbs and their effects on a variety of HIV/AIDS related symptoms. The issue of property rights, namely the remedies for which a groups of traditional healers/herbalists feels to have some proprietary rights, has arisen several times in these trials, thus far without any resolution. An important element of the program is referral by traditional healers to biomedical facilities when this is medically appropriate.

*V. **The Challenges Ahead***

Despite widely acknowledged success, Uganda still faces a huge challenge in reducing HIV/AIDS prevalence. In Kampala, the estimated rate is still about 8%. For Uganda as a whole, this is still the leading cause of death among its most productive age groups, those 15-49.

Prevention vs. treatment: Many policy makers and service providers have recognized that past efforts in Uganda's program have concentrated heavily on prevention. Among the more prominent challenges will be antiretroviral drug treatment. Along with Cote d' Ivoire, Uganda was the first country to pilot test ARVs in Africa. Costs have plummeted, generics have become more available and there are substantially increased resources available. US monies from the President's Emergency Plan for AIDS Relief, PEPFAR is already financing expanded access to ARVs[26] (although this funding is limited to braded drugs). Funding under on-going sources, e.g., the World Bank supported MAP and the Global Fund, for ARVs is also likely to increase. The challenge for Uganda's health system – both public, private and that supported by non-government and faith organizations –will be to build capacity to deliver treatment including ARVs, including training of staff, assurance of quality control, reinforcement of distribution systems and appropriate storage facilities. It is estimated that about 18,000 people are receiving ARV treatment at present. The "3 X 5" target is 60, 000 which many see as feasible. Government is in the final stages of formulating a national policy on ARVs, but the question of whether these will be free, subsidized and to what extent remains outstanding. Faith based groups seen by many as likely key players in the expansion of ARV treatment since they are regarding as having sound logistics and accountability and they are able to reach the poor better. Some programs already have established community adherence teams to monitor patients on treatment.

Challenge of coordination. With Uganda's success has come an ever increasing number of agents and organizations anxious to become engaged. Several observers point to a

[26] PEPFAR funding will only support branded drugs. A number of observers have noted that more people could be provided with treatment if PEPFAR monies would support generic drugs. On the other hand, other care providers gratefully acknowledge that any additional monies are available for lifesaving drugs. The differential between generic and branded is variously estimated at 1:2 to 1:5.

particular need for improved coordination especially at the district and sub-district levels between the local government authorities and health services and the whole gamut of non-governmental partners, especially the multitude of faith based organizations, with respect both to an equitable distribution of services and in terms of medical standards and protocols. This will be particularly important with increased access to ARVs.

Stigma continues to be a significant challenge. While the degree of openness which Uganda has fostered – at all levels – has no doubt been a major factor in its success in combating HIV/AIDS, stigma persists, posing high economic and social costs to many HIV+ people. A number of critics still point to faith leaders as a continuing source of stigma, linking HIV/AIDS to sin and God's punishment. Women are especially vulnerable to stigma, both within the family and within the workplace. Women continue to risk being thrown out of the house and separated from their children by their husbands if they reveal HIV+ status. Faith communities have a special role to play here in continuing to broaden and deepen their efforts to combat stigma, discrimination and exclusion. Income generating projects, especially for women are an additional avenue to provide empowerment and independence which has a significant impact on .

Funding. This report has not discussed the issue of funding. While there is and will be significant incremental resources from multiple sources available, especially for treatment, at the national level, at the level of individual grass roots, community based projects, inadequate funding poses a significant constraint to efforts to expand and scale up the scope of their activities. This appears to be largely a reflection more of inadequate processes and procedures to get funding down to the local level. Ironically, a number of projects reported that the process of decentralization was compounding this situation, since funding processes, and in some cases accountability procedures, were particularly weak between central, district and sub-district levels.

Thus while Uganda has realized laudable progress, much remains to be done in combating "Slim."