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Message

Sandy, This is the draft paper by Elizabeth
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Thanks Alex,

A Decade of an Effective National Response to AIDS: A Review of the Ugandan Experience

authors: Elizabeth Marum and Elizabeth Madraa

DRAFT

Introduction

Ten years ago, Uganda was thought to be the "epicenter" of the AIDS epidemic in Africa. Rates of HIV infection were estimated to be the highest in Africa and indeed, probably the highest in the world. Today, however, Uganda is recognized as Africa's showcase for an effective response to the AIDS epidemic. Ugandan programs both for HIV prevention and for care of persons living with HIV/AIDS are models being adopted in many other countries.

After more than a decade of a comprehensive, concerted national response to the epidemic, Uganda has recorded a number of "firsts:" the first national leader to take a candid and aggressive stance; the first program for voluntary HIV counseling and testing; among the first AIDS prevention projects working with religious leaders, military groups, and in the workplace; some of the first mutual support groups for people living with AIDS; and as of February 1999, the first AIDS vaccine trial in Africa.

Many countries in southern Africa, which previously had much lower rates of HIV prevalence than Uganda, are now estimated to have significantly higher rates. At the end of 1997, UNAIDS estimated that 9.5% of Ugandan adults are HIV infected. In contrast, rates of infection in adults in South Africa are estimated at 13%, in Malawi at 15%, Namibia at 20%, Botswana at 25% and Zimbabwe at 26%.¹ UNAIDS projects that HIV has now infected over 47 million persons, with 33.4 million currently living with HIV infection, and 13.9 million persons worldwide have died as a result of AIDS. Those countries with the least resources to cope with the epidemic are the hardest hit. UNAIDS projects that 95% of all HIV infected persons live in the developing world and 95% of all deaths from AIDS have occurred in the developing world.² Such horrifying statistics have the potential to create a sense of hopelessness about the course of the epidemic, especially in the poor nations of Africa.

In this context, it is important to ask: What enabled Uganda to mount such an aggressive, and now apparently successful, campaign against AIDS, especially at a difficult time in Uganda's history? What have been the key elements in Uganda's response to the epidemic?

This article will describe and analyze the various components of Uganda's response, including the response of the Government of Uganda, non-governmental and religious organizations, and the international donor community, in particular the response of the U.S. government.

Candid, Consistent, and Strong Political Support

President Yoweri Museveni came to power in 1986 after a successful military campaign. It is particularly noteworthy that in 1986, when the extent of the epidemic was being realized, Uganda was emerging from 15 years of civil strife.

On several occasions, Museveni has described a phone call he received in 1986 from medical authorities of the Cuban military, where Ugandan soldiers had been sent for training, giving him the shocking information that "most" of the Ugandan soldiers were testing positive for the HIV

virus. Having led a successful military campaign against the previous government, Museveni has stated that he realized he would have to lead a similarly aggressive campaign against this new disease. He adopted a stance of candor and activism which has continued to the present. He also instructed government officials, not just those working in health but also those in all branches of government, to bring up the subject of AIDS whenever they were speaking in public and whenever they traveled about the country.

An early but undated brochure titled "Guidelines for Resistance Committees on the Control of AIDS" was prepared by UNICEF, and had an introduction written by the deputy director of the Directorate of Information and Mass Mobilisation of the National Resistance Movement (the name of the political system Museveni developed). Secretariat, though no mention of the Ministry of Health AIDS Control Program, suggesting that it was printed in 1986. It has a distinctly militaristic tone, with illustrations showing men and women in uniform, and begins, "Just as we waged a war against tyranny, we must now embark on a new fight against another deadly enemy: AIDS." Military terms such as "weapons, common enemy, soldier, germs, vigilance," etc. are used throughout, reinforcing the message that the epidemic threatened the nation in the same way as did previous regimes. One of the concluding statements in the booklet is, "Stop AIDS and restore the nation."

Thus, early on, the strong stance was established that "fighting AIDS" in Uganda was a patriotic act, unlike in many African nations, where talking about AIDS has until recently been seen as discrediting one's own nation, almost unpatriotic. This linking of patriotism and controlling AIDS has had numerous positive effects in Uganda.

Free press coverage of the epidemic has certainly been one of these positive results. The leading national daily newspaper has consistently published candid reports on all aspects of the epidemic, and this has been emulated by most other local newspapers as well. The one exception to press freedom related to condom advertisements. In the early 90s, Radio Uganda, the government owned radio station, was reluctant to air condom advertisements. However, USAID sponsored program successfully aired condom advertisements during TV coverage of the 1994 soccer World Cup series, and after that, the barrier seemed to be broken for condom spots on local media.

By October, 1986, the Ministry of Health had established a National AIDS Control Programme, which soon began an aggressive public media campaign which included radio messages, posters, billboards, and "community mobilization" for grass-roots activities and village level messages. A national sero-survey was conducted in 1987-88 by the Ministry of Health. Based on samples collected in both urban and rural areas of the country, it was projected that between one to 1.9 million persons were already infected with HIV, and surveillance reports from hospitals and health centers at that time indicated a doubling in reported AIDS cases every six months.⁴ A "sentinel surveillance" system was set up whereby twice annually, blood samples collected from pregnant women at selected health clinics and hospitals were tested for HIV. Initially there were only 4 sites, but this expanded to 20 sites by the end of 1998.

The Ministry of Health AIDS Control Programme became the STD/AIDS Control Programme in 1994, and considerable efforts have been made to strengthen the STD control system in the country. The Ministry of Health has also trained hundreds (more specific numbers are being calculated by ACP) if not thousands of various cadres of AIDS workers, including community

counseling aides, health educators, peer educators, and the like. The program has had considerable stability; between 1986 and 1999, there have been only three different managers of the programme, and the current manager has been in this position since 1993.

In recognition that the AIDS epidemic is not merely a health problem but also has many complex social, economic, and political implications, the government of Uganda established in 1991 the multi-sectoral Uganda AIDS Commission (UAC) to coordinate and monitor the national strategy to control AIDS. This commission is composed of national leaders from all walks of life, and its recommendations are implemented by a Secretariat composed of professional staff. The UAC has prepared the National Operational Plan to be used as guidelines for project implementors, and UAC also sponsored a number of Task Forces, such as on women and AIDS, youth and AIDS, and so forth. UAC has also encouraged the establishment of AIDS Control Programs in other ministries in addition to the Ministry of Health, and to date twelve such programs have been established in ministries including Defense, Education, Gender and Social Affairs, and others.

An extremely positive result of the president's candor and leadership has been an eagerness on the part of the general population to get involved. Unlike the case in many African countries where speaking out on AIDS branded one as an "AIDS victim", public involvement with AIDS activities in Uganda have been perceived locally as "politically correct" and the right thing to do. Many Ugandan scientists and researchers began studies on AIDS, and young university students and graduates became activists. As a result of both public approval from the highest levels, and the increasing availability of donor funds, "the best and the brightest" Ugandans were attracted to work in the field. Thus, Uganda today has a cadre of committed, capable scientists and public health workers, many of whom remain active in Uganda and some of whom have been recruited to work internationally. Ugandans are in visible positions of leadership at UNAIDS and are working for international organizations in many other countries, including Zambia, Malawi, Namibia, Kenya, and elsewhere.

Ugandan Activism to Combat Discrimination and Stigma

In addition to the President, Uganda has had the good fortune to have a series of articulate citizens talking openly about AIDS, including in some cases, their own infection status. Candlelight memorials and prominent "World AIDS Day" observations were begun as early as 1988. A popular Ugandan rock musician, Philly Bongole Lutaaya, returned home from Sweden and publicly announced that he was dying of AIDS. His death in 1989 had a profound impact on public awareness of AIDS and public acceptance of persons living with AIDS, perhaps similar to Magic Johnson's announcement in 1991 that he was HIV+.

In 1987, a group of 16 Ugandans, some with AIDS and others with family members with AIDS, organized to advocate against discrimination and stigma, and for better care for persons with AIDS, and thus The AIDS Support Organization, TASO, was born. TASO was led by Noerine Kaleeba, whose husband died in 1987. Kaleeba is a gifted public speaker who galvanized public support for persons living with AIDS. Although in fact her husband contracted the virus through a blood transfusion, and she herself did not become infected, Kaleeba carefully and deliberately allied herself with all women and men who were infected or affected by the epidemic. Her leadership helped Uganda avoid the divisive distinctions made elsewhere, including the U.S.,

Another national leader has been Major Rubaramira Ruranga of the Ugandan army, who openly talks about his infection, even while in uniform. Particularly compelling is his testimony that he has used condoms consistently ever since learning that he was HIV positive in 1991, and his wife remains uninfected to the present. There have been other articulate leaders as well, including a Protestant minister who, wearing his clerical collar, has disclosed that he learned he was infected when his first wife died. Now remarried to a woman who is HIV+, he openly discusses the fact that he and his new wife use condoms so that they do not give birth to a child who would either become infected or become an orphan.

The combined result of the openness on the part of the President, other government leaders, and concerned activists has been a markedly accepting and non-discriminatory response to AIDS. Although some stigma around AIDS still remains in Uganda, it is minimal and does not seem to have hampered the effectiveness of prevention programs.

Innovative National Programs

Uganda has had a long history of religious and non-sectarian non-governmental organizations (NGOs) active in the health field, including mission hospitals and NGOs such as the Family Planning Association of Uganda, the Uganda Red Cross, the YMCA and YWCA associations, etc. These and other NGOs quickly became involved in AIDS education activities, and soon AIDS-dedicated NGOs were also formed in Uganda. Kitovu Hosital, a large mission hospital serving Rakai and Masaka districts, began a mobile AIDS home care program which served as a model for other hospitals, and soon several hospitals in Kampala adopted this model.

TASO, The AIDS Support Organization, in addition to its efforts to combat stigma and discrimination, also began organizing clinics on the grounds of government district hospitals, and by 1990 TASO had seven active centers in Kampala, Masaka, Mbarara, Entebbe, Mbale, Jinja and Tororo. TASO has pioneered a community based approach to both care and prevention, and has served over 50,000 persons living with AIDS and their families.

Unlike many African countries which have been characterized by denial of the epidemic not only at the official level but also in personal life decisions, many Ugandans seem to have applied the President's stance of candor and acceptance to their personal lives and decision making. By the late 1980s, high awareness of AIDS and the risky behaviors which lead to HIV infection led many Ugandans to want to learn their sero-status, and people began donating blood in an effort to obtain HIV testing. Soon a consortium of Ugandan and international activists helped form the AIDS Information Centre for voluntary and anonymous HIV counseling and testing. The first AIC was opened in Kampala in 1990, and by 1993 AIC was active in four major urban areas.

AIC has pioneered the provision of "same day results" using rapid HIV tests, and has also pioneered the concept of "Post Test Clubs" which provide long term peer support for behavior change to anyone who has gone through HIV counseling and testing, regardless of sero-status. By the end of 1998, AIC had provided voluntary and anonymous HIV counseling and testing to over 400,000 clients. AIC has been selected by UNAIDS for a "Best Practices" case study.

Both TASO and AIC received "start-up" funds from USAID, and after a pilot phase, have

and extensive technical assistance from the U.S. Centers for Disease Control and Prevention. With CDC assistance and USAID funding, both AIC and TASO have developed computer databases on their clients which permit extensive analyses of the types of persons who request services, reasons for needed services, and the actual services received. Both of these agencies are using these data for management purposes and to improve the nature and quality of services. In addition to the direct services they offer clients, they also provide extensive training and capacity building to other local, national, and international agencies working in the field.

Although HIV counseling and testing and long term AIDS care are well accepted interventions today, it is important to point out that these approaches were not always endorsed by international agencies and donors. The Global Programme on AIDS of WHO did not recommend HIV counseling and testing as a prevention strategy, and this lack of endorsement by WHO resulted in a reluctance on the part of Ministries of Health in some African nations to adopt this intervention. Although USAID in Uganda has funded AIDS care since 1988 and testing and counseling since 1990, USAID in Washington did not encourage funding for either of these interventions in other African nations until recently.

Response of the Religious Communities

Mission hospitals were among the first to develop programs for AIDS care and support in Uganda, and religious organizations have also been active in AIDS education and prevention. The Islamic Medical Association of Uganda received a small grant from WHO in 1990 for a pilot AIDS education project, and then received a large grant from USAID between 1992 and 1995 for an intensive effort to train local religious leaders and lay community workers. This project documented increases in correct knowledge and decreases in risky behaviors among those exposed to project interventions.¹ The IMAU project was selected as a "Best Practices Case Study" by UNAIDS. The Protestant Church of Uganda organized a workshop for bishops and other religious leaders as early as 1991, and implemented an extensive AIDS education project in many dioceses. The Catholic church and mission hospitals in Uganda have provided considerable leadership in designing AIDS mobile home care projects and special programs for AIDS widows and orphans.

AIDS in the Workplace

In 1988, USAID funded an "AIDS in the Workplace" project implemented by the Federation of Uganda Employers, primarily aimed at the formal workplace such as banks, breweries, grain millers, etc. In 1989 USAID, through World Learning, Inc., also began funding HIV education programs for the uniformed services, including the army and the police. The Ministry of Defense has also received funds from the World Bank. These projects have for the most part used the "peer education" model of training volunteers to speak to their work mates on the job; training of managers, talks presented by health workers, and focus group discussions have also been held. Most of these peer educators have also reported that they extend their work to their neighborhoods and communities as well. The Federation of Uganda Employers and World Learning, with USAID funding, also produced one of Africa's first films about AIDS, *It's Not Easy*, as well as booklets based on a popular cartoon character, "Ekanya."

Outreach to Young People

In addition to traditional school based AIDS education projects (mostly funded by UNICEF),

behaviors. "Capital Doctor," funded by USAID, has been on the air since 1994; this radio program is very popular with young people who write or call in with questions about HIV/AIDS, sexuality, and other health matters as well.

Straight Talk, a monthly four-page newspaper targeting the 15-24 year old market, was first issued in 1993. *Straight Talk* has been funded by DFID, UNAIDS, and other donors. It is extremely candid in discussing all matters relating to sexuality, and is very popular among young people, who write in very explicit questions, openly giving their names in many cases. Each month 115,000 copies are printed and distributed to 1,343 secondary and tertiary schools, and to over 400 NGOs, churches, health units, and community based organizations. There are now 110 *Straight Talk* clubs in schools in Uganda. In response to *Straight Talk's* popularity, a similar four-page newspaper, *Young Talk*, was launched in early 1998 and targets a younger age group, 10-14 year olds. Each month 215,000 copies of *Young Talk* are distributed to 13,500 primary schools, over 500 teacher training tutors, and the same groups of community organizations who receive *Straight Talk*. Over 900 young people wrote letters to *Young Talk* in December, 1998, demonstrating the keen interest in the topics covered in these newsletters.

Assistance for Orphans and Children Affected by AIDS

In addition to recognition of the AIDS epidemic, by the mid to late 1980's, there was increasing recognition that the combination of civil war and the AIDS epidemic was resulting in increasing numbers of children who had lost one or both parents. The situation of AIDS orphans was particularly acute, as these children were more likely to lose both parents because of HIV transmission between couples. The current and projected numbers of orphans remain difficult to estimate, however, and estimates on the part of the government and international agencies have ranged widely, partly because of different definitions of "orphan" including children who have lost only one parent.

Based on the 1991 Uganda census, and the observations of local workers, there may be as many as 1.2 million children who have lost one parent, of whom 250,000 to 300,000 may be "double orphans" who have lost both parents. It is estimated that about half of orphans have lost parents due to AIDS; government policies however discourage identifying children as "AIDS orphans."

From 1989 to 1998, USAID provided funds to Save the Children UK (SCF) to work with the Department of Child Care and Protection (CCP) of the Ministry of Gender, Labour, and Social Development to develop national responses to the problems of orphans and children separated from their parents due to war. In 1991, USAID funded an assessment of the orphan situation in Uganda, and also funded a conference in 1992 to bring together all players in the child welfare arena. This process resulted in the government articulating policies and legislation regarding orphans, and in particular, policies supporting efforts to keep orphans in the community rather than in institutions or children's homes. As a result, the number of registered children's homes or orphanages in Uganda has declined from 75 to 46, and most of the remaining homes are providing an acceptable standard of care, with support from external donors.

Government policies and the Children's Statute of 1996 continue to emphasize the importance of keeping orphaned and vulnerable children in their home communities, with relatives, and there are now an increasing number of programs to assist "orphan households", families who have taken in orphaned children.

or grants to help the household begin an "income generating project" to supplement family income; some programs also provide funding for school fees for orphans. In spite of the large numbers of orphans in Uganda, less than 1% are institutionalized, and communities and families have for the most part been able to support these children.

The Uganda Women's Effort to Support Orphans, UWESO, was founded by First Lady Janet Museveni in 1986, and has provided national leadership in responding to the plight of orphans. Currently, UWESO emphasizes "micro-enterprise" projects to provide loans, grants, and technical assistance to help households with orphans. USAID has provided funds for several projects assisting orphans; most of these funds since 1995 have been for micro-enterprise projects assisted by FINCA, The International Foundation for Community Assistance.

Mass Media Campaigns

Most visitors to Uganda are quickly impressed with the prevalence of billboards, posters, other printed material, and spots on the radio and television that relate to AIDS. The film *It's Not Easy* has been widely shown throughout the country, not only on television but also through the use of mobile film vans. In addition to the remarkably successful *Straight Talk* and *Young Talk*, there have been other well designed media campaigns, films, and videos produced to inform audiences about AIDS, and to encourage positive behavior change. In February 1999, the USAID Delivery of Improved Services for Health (DISH) project launched a soap opera type video showing two couples (one young; the other middle aged) struggle with the decision to go for HIV testing and counseling.

STD Control and Prevention

Through the World Bank funded Sexually Transmitted Infections (STI) project and through the USAID funded Delivery of Improved Services for Health (DISH) project, since 1994 there has been an increased emphasis on the treatment and control of STDs in Uganda. After considerable delays in offshore procurement, STD drugs (funded by the World Bank STI project) are finally in country in adequate supplies, and distribution to rural health facilities is occurring. USAID has financed the building of a national reference laboratory at Mulago Hospital to study drug resistance.

Partner notification and treatment remain problematic, especially for women. Many men who suspect that they have an STD just go to local drug shops and buy as many pills as they can afford, which is often not the full course of treatment, and may not even be the correct drug. A socially marketed pre-packaged kit of drugs, condoms, and instructions for treatment of male urethritis, called "Clear-7," has recently been launched with USAID funding.

Condom Distribution and Sales

There have been considerable efforts in Uganda to promote condom use for HIV prevention. There was some resistance on the part of President Museveni and religious leaders in the early 1990's to condom promotion, but for the most part, this controversy seems to have died out. The Ministry of Health has distributed millions of condoms through health centers and NGO projects; purchase of these condoms has primarily been by WHO, USAID, and the World Bank STI project.

The Futures Group International (funded by USAID) launched a socially marketed brand called "Protector" in 1991, and since then other brands of socially marketed condoms, primarily "Lifeguard", funded by the German agency KFW through Marie Stopes International, have entered the market. The Futures Group estimated that in 1997, the total national condom consumption was 40 million pieces, including free condoms, social marketing brands, and private commercial brands.

International Donor Response

When the AIDS epidemic was being recognized, Uganda was emerging from two decades of civil strife, the public infrastructure and economy were in disarray, and there were little if any public funds to operationalize President Museveni's approach to the epidemic. Many of Uganda's educated and professional groups had either fled the country or been murdered.

The response of the international community, therefore, was another essential component in Uganda's campaign against AIDS.

The World Health Organization, through the Global Programme on AIDS, began disbursing funds to Uganda for AIDS control activities in 1986 with grants for research and funding for the AIDS Control Programme of the Ministry of Health. By the end of 1995, WHO had donated a total of \$14,559,525 to Uganda for AIDS activities ranging from ongoing support for the ACP to small grants to local hospitals and NGOs. WHO has also provided considerable technical assistance to Uganda ever since 1986, including a long term technical advisor for management who has been in country between 1991 and the present.

Since GPA was disbanded and UNAIDS established in 1996, there has been considerably less funds available for direct disbursement to Uganda than under GPA. Between 1996 and 1998, approximately US \$300,000 has been donated through UNAIDS. There was also a UNAIDS Country Programme Advisor in Uganda between 1996 and 1998.

In addition to WHO and UNAIDS, other UN agencies have supported AIDS projects in Uganda. The United Nations Development Programme, UNDP, has funded AIDS related activities in Uganda in 1987 and since then has contributed about US \$15.5 million. UNDP funds have supported the Ministry of Health, the Uganda AIDS Commission, the Prison's Service, and many non-governmental agencies involved in mitigating the impact of AIDS on children, families, and communities. UNICEF has focused on AIDS education for young people, both those in and out of school. UNICEF funding between 1986 and 1988 was approximately \$30 million.

The World Bank gave World Vision a \$4 million grant in 1990 for orphans activities, and in 1994 funded a multi-year "Sexually Transmitted Infections" (STI) project in collaboration with the MOH. Through the end of 1998, a total of \$19 million had been expended to promote safer sexual practices, improve the provision of STD care and pharmaceuticals, condom procurement, and community and home based care.

Since 1988, the European Union has supported the rehabilitation and recurrent costs of the National Blood Transfusion Service, and in particular, the Nakasero Blood Bank. Between 1988 and 1998, the EU contributed was approximately U.S. \$8.5 million.

The contribution of the United States has been considerable, through research activities funded by the National Institutes of Health, long term funding by USAID of innovative and effective projects implemented by Ugandan institutions, and long term, consistent technical assistance provided by USAID and the US Centers for Disease Control and Prevention.

USAID was the first large bilateral donor to provide funding and technical assistance to Uganda, and USAID has maintained an intensive level of support for AIDS activities up to the present. A hallmark of USAID funding for AIDS activities in Uganda has been the creative use of a variety of funding mechanisms. A USAID mechanism called "local currency" (funds generated by sales of donated commodities) was used to fund the MOH AIDS Control Programme activities and Ministry of Defense HIV prevention activities for soldiers; this mechanism was also used for Ugandan NGOs, including start-up funds for TASO and the AIDS Information Centre. Direct USAID funds in Uganda were first channeled through the USAID project called "HIV/AIDS Prevention in Africa" (HAPA); these funds supported the AIDS Education and Control Project implemented from 1988 to 1991 by a US based PVO, the Experiment in International Living (EIL). These dollar funds were used to initiate new activities, such as one of the first African "AIDS in the Workplace" projects, and also helped maintain activities and organizations after the start-up phase supported by local currency funds.

In 1991, USAID funded a cooperative agreement implemented by EIL, which later changed its name to World Learning, Inc (WLI); this grant eventually totaled \$16.4 million and extended for five years, until the end of 1995. Through this project, WLI maintained a "grant management unit" which provided funds for 14 local organizations involved in AIDS education, prevention, and care.

Since 1995, USAID has funded a wide range of AIDS prevention and care services. Activities funded under DISH include condom promotion and distribution, training of health care workers, mass media and local education programs, and continued funding for AIC and TASO. The total funding provided by USAID between 1988 and 1998 was approximately \$46 million.

USAID funding for HIV/AIDS activities has been accompanied by an intense level of technical assistance, and somewhat similarly to the situation at the Ministry of Health and WHO, there has been little turnover in staff. There has been one technical advisor on HIV/AIDS between 1991 and 1999, the current USAID technical advisor on STD prevention and control has been in office more than four years, and the current USAID Health Officer has been in Uganda nearly six years. This stability in personnel has been matched by consistency in policies and priorities, as HIV prevention has been a major objective of the USAID mission to Uganda since 1988.

DANIDA, the Danish aid agency, began funding AIDS activities in Uganda in 1991, and since that time has provided grants totaling \$5.6 million between 1991 and 1998. Services receiving DANIDA support include AIDS care, education, training of traditional health workers, and a newsletter called "Straight Talk" designed for youth.

The UK government began funding AIDS activities in the early 1990's; programs receiving funds include AIDS care and support, HIV testing and counseling, procurement of drugs for sexually transmitted diseases and opportunistic infections, condoms, and Straight Talk Foundation. Total

GTZ (German Technical Cooperation) has since 1991 supported an intensive program of IEC (information, education, communication) care and support, STD control, HIV testing and counseling, and community outreach in two districts in western Uganda; funding for this project has been about US \$1 million.

There has been long standing support collaboration in the health sector, especially in northern Uganda, from the Italian government, the Italian National Institute of Health, and various Italian mission groups. Since 1988 this collaboration has incorporated AIDS related services and activities at the major hospital in northern Uganda, Lacor Hospital, and has also assisted the District Health Office with community education, epidemiologic studies, and long term follow-up of a cohort of secondary school students. This Italian collaboration is also involved in a study of interventions to prevent mother-to-child transmission in Kampala, and future studies are expected to continue in this field and in vaccine development. Investment in AIDS related activities in Uganda on the part of the Italian collaboration is slightly over \$4 million between 1994 and 1998.

In addition to these large international donor agencies and collaborations, many smaller organizations have contributed to the Uganda campaign against AIDS. Medecins sans Frontieres (including the branches of France, Holland, and Switzerland), World Vision, CARE, Minnesota International Health Volunteers, Quaker World Service, and many church organizations have sent personnel and funds for activities related to AIDS in Uganda. It has been estimated that donor funds contribute about 70% of the total national expenditure on AIDS services and activities.⁶ The sustainability of the many successful and effective projects in Uganda remains uncertain, as they are now so heavily donor dependent.

Total donor contribution to AIDS activities in Uganda is difficult to tally, but based on the above, no doubt exceeds \$160 million since the start of the epidemic until the end of 1998. Most of these funds have been contributed in the decade between 1989 and 1998. Although this may appear to be a large amount, since the adult population of Uganda is about 10 million, in fact the contribution of the large donors equals only about US\$1.60 per year per adult.

AIDS Research

The various AIDS research projects in Uganda have resulted in significant increases in the understanding of the epidemic in the east African context. Most of these studies have been funded by the US government through the National Institutes of Health, though there is also an important collaborative project funded by the Medical Research Council of the UK. The MRC project includes a long term epidemiological study of a large population based cohort in Masaka district, a natural history cohort, social and behavioral studies, an intervention trial comparing behavioral change communications (IEC) with a combination of IEC and improved STD management, and a pneumococcal vaccine trial.

Numerous articles have been published from these studies, and it is not within the scope of this article to summarize all of these research projects and findings. However, some of the more significant contributions to scientific knowledge include findings relating to mother to child HIV transmission, which have documented a transmission rate of approximately 26%. On-going trials in Uganda are studying the effect of various regimens in reducing perinatal transmission and

NIH is funding a study of the effect of Vitamin A therapy on the morbidity and mortality of HIV infected infants and children at Mulago Hospital in Kampala.

A major NIH funded study in Uganda has not only documented the high mortality associated with dual infection with HIV and TB, but also demonstrated the value of preventive TB therapy in HIV+ persons, and with assistance from WHO and USAID, the AIDS Information Centre plans to implement a large scale effort to implement TB preventive therapy in AIC clients who are HIV+.

In 1994, the Uganda Virus Research Institute (UVRI) in collaboration with the US Centers for Disease Control and Prevention (CDC) initiated a study to identify all HIV genetic variants in circulation in Uganda to complement similar studies by the CDC in other countries. Although the initial purpose of the collaboration was related to improved diagnostic assays for the detection of HIV, the information gained from nationwide surveys of HIV strain variation is likely to be helpful in the eventual design of vaccines for use in Uganda. The UVRI/CDC collaboration is also assisting the AIDS Information Centre in a study of discordant and high-risk though still negative couples receiving on-going counseling and health education at AIC.

The recently concluded US funded trial of mass STD treatment in Rakai has ended with confusing results, as the trial found that mass treatment reduced the incidence and prevalence of STDs but did not reduce the incidence of new HIV infections in this cohort. Although these results have been disappointing, they have advanced the state of knowledge of the complex relationship between STDs and HIV incidence.

With funding from WHO and NIH, preparations for AIDS vaccine trials have been ongoing since 1993, and these years of building up the scientific, clinical, and logistic framework have resulted in the first vaccine trial in Africa which began in Uganda in February, 1999. The site of the trial, the Joint Clinical Research Centre in Kampala, was established in 1990 with funding from the governments of Uganda and USAID. For several years, there has been extensive consultation with legal, ethical, media, community, and religious groups across Ugandan society in preparation for the trial. Whatever the clinical results of this first vaccine trial in Africa may be, there is no doubt that preparations for vaccine trials have already significantly contributed to the training of many Ugandan scientists, and have enhanced the clinical research infrastructure of Uganda.

The Results and Impact of Uganda's Response to the Epidemic

By the end of 1998, more than 10 years after Uganda began its "war against AIDS," and with the infusion of more than US \$150 million into AIDS activities, it is clear that Uganda has achieved measurable success in this campaign. These results may be categorized in the following ways: large numbers of persons trained in AIDS education, almost universal knowledge of AIDS, evidence for behavior change, reduction in new infections, especially in young people, and significant accomplishments by AIDS intervention programs.

Training of Health Workers, AIDS counselors, peer educators and community health workers:

Training of various cadres of health professionals, counselors, community workers, and the like

government ministries, non-governmental agencies (TASO, AIC, Red Cross, etc), mission hospitals, religious organizations (inc Catholic, Protestant, and Islamic communities), international non-profit agencies (Pathfinder International, CARE, Medecins sans Frontieres, CONCERN, World Vision, AMREF, etc), and many others. Persons trained by these various groups range from Government ministers, parliamentarians, and physicians to grass roots community volunteers, local political leaders, and traditional healers.

With USAID funding alone, between 1991 and 1995, 26,219 persons were trained; most received five days or more of training.⁷ Between 1996 and 1998, USAID funded programs trained over 1000 nurses, midwives, laboratory technicians, and counselors. Thus, USAID funded programs alone have documented training of over 27,000 persons; though USAID has been the major donor of AIDS training activities in Uganda, it is by no means the only one. The Uganda Community Based Health Care Association estimates that there are over 20,000 community based health workers in Uganda; by this time virtually all have received some type of training in AIDS education and prevention. It is impossible to tally the total number of persons receiving some type of training as an AIDS worker from all these projects; but by now it must exceed 50,000 and may well be considerably more.

These various cadres of AIDS educators, trainers, counselors, etc have in turn conducted countless sessions educating members of their communities about AIDS. Between 1991 and 95, various local groups receiving USAID funding documented 1,782,933 contacts with individuals; between 1996 and 98, local community groups assisted by TASO recorded over 24,398 individuals who had received education and "sensitization" about AIDS. Between 1990 and 1998, the AIDS Information Centre had provided over 400,000 clients with the most intense form of education about AIDS-- HIV test results. It is impossible to document the total number of Ugandans who have received some type of AIDS education message; but it is reasonable to conclude that virtually all adult Ugandan citizens have benefitted from this intensive and extensive educational campaign.

Universal Knowledge of AIDS

The success of these education campaigns was documented in the 1995 Demographic and Health Survey (DHS) which found that 99.9% of men and 98.9% of women had heard of AIDS.⁸ Numerous other studies, project evaluations, and reports have also documented high rates of correct knowledge about AIDS in Uganda.⁹⁻¹⁰ Not only do Ugandans possess high rates of correct knowledge of the basic facts about AIDS, but many also articulate very sophisticated questions about such complex issues as breast-feeding transmission, discordancy in couples, and the window period between infection and positive antibody test results.

Behavior Change

There have now been many studies of reported behavior change to reduce risk of HIV infection. Though many of these studies are in the form of project evaluations and have not been published in the scientific literature, the consistency of findings is striking. Almost all of these studies have found: reductions in multiple partners, reductions in casual partners, a delay in the onset of sexual intercourse, and increases in condom use, especially in casual or non-steady relationships.¹¹⁻¹² Though concerns have been raised that since knowledge of AIDS is so universal, study respondents "know the right answer" and such self-reported behavior change is not a reliable indicator of true risk reduction. Though this may be true, the fact remains that the vast majority of

many studies, it should be noted that at least in the early to mid-90's, there was still considerable controversy about condom use, and admitting to condom use for many was tantamount to admitting to having casual or "outside" sexual partners. In this light, it is reasonable to conclude that though some self-reported behavior change represents a desire to give the right answer to an interviewer, the consistency of these findings across many studies and evaluations strongly suggests that some level of behavior change has truly occurred in Uganda.

Reduction in New Infections

The numbers of persons trained, educated, counseled, and cared for in Uganda is truly impressive, but ultimately these are indicators of project activities, not indicators of successful prevention of new cases of HIV infection. There are now a number of research and surveillance findings which indicate that the rate of HIV incidence, particularly in young people in urban and semi-urban areas, has declined significantly.

Sentinel surveillance data in Uganda based on blood samples collected from pregnant women attending antenatal or pre-natal clinics has shown a steady decline since 1992, when rates peaked at 30% in Kampala and Mbarara, the largest city in the western part of the country. These prevalence rates declined steadily beginning in 1993, and by 1997, 15% of pregnant women in these sites were HIV+.¹⁶

Concerns have been raised that these declines in prevalence of HIV in pregnant women may be due to decreased fertility in HIV+ women and/or increased mortality in women already infected, and not to declines in incidence. While both of these factors may occur in older women, they are unlikely to affect younger women who may become pregnant and HIV+ around the same time. Thus, the prevalence in younger women is thought to be a reasonable substitute for incidence data, which are not available outside of two research projects, both of which are in the southwestern part of the country.

Among the youngest cohort of pregnant women attending antenatal clinics, those who are 15-19 years of age, the HIV prevalence rate declined from 27% in 1992 to 6.8% in 1998 at Nsambya Hospital in Kampala. Among 15-19 year olds in Mbarara, in western Uganda, HIV rates declined from 27% in 1992 to 8.3% in 1998.^{17 18} Similar declines have also been observed among 20-24 year old women; at Nsambya Hospital in Kampala, rates in these women declined from 36% in 1991 to 12.8% in 1998; in Mbarara the comparable figures are 35% in 1992 to 13.3% in 1998.

The MRC project in Masaka district has also observed a statistically significant overall decline in prevalence from 8.1% in 1989 to 7.3% in 1997, the first cohort data to observe statistically significant decline in overall HIV prevalence in a general population in rural Africa. Additionally, MRC has observed a decline in HIV incidence in young women 13-24, the same age group in which significant declines in prevalence in ante-natal clinic settings have been described above.¹⁶ (awaiting recent numbers from Rakai)

This article cannot present all the data on prevalence and incidence in Uganda, but it is now clear that HIV prevalence in young pregnant women in urban and semi-urban areas of Uganda has declined significantly since the early 1990's and that these declines are probably partly related

in rural areas, and some health workers in more rural areas of Uganda are concerned that HIV incidence may not yet have declined in these areas. AIDS workers in Uganda are also concerned that public knowledge of these declining trends may result in a relapse into higher risk behaviors.

Preliminary analysis of data from the 1998 sentinel surveillance sites indicates that the declining rates have continued, which suggest that a relapse to higher risk behavior has not yet occurred, at least in urban areas.

Large Numbers of Ugandans now living with HIV infection

While it is very encouraging that infection rates have fallen so dramatically in Uganda, the sad reality is that many Ugandans are already infected-- perhaps as many as one million.¹ Although the declines in HIV prevalence in young women are very encouraging, HIV infection rates of 5% or more in very young pregnant women clearly have very serious implications for the future. The number of persons registering for AIDS care at The AIDS Support Organization, TASO, declined from around 6,000 per year between 1991 and 1994 to around 5,000 per year in '95 and '96, and then declined to 4,787 in 1997. Surprisingly, this increased by 56% in 1998, when 7,445 persons became newly registered TASO clients.²¹ Reasons for this increase are being explored but may be related to increased availability of VCT in district hospitals and health centres, increased education efforts at the community level, and, possibly, the resumption in late 1997 of the distribution of donated foodstuffs to persons with AIDS. If this increasing demand for AIDS care continues in the future, TASO and other AIDS service organizations in Uganda will be hard pressed to respond adequately to these many thousands with complex medical, social, economic, and psychological needs.

Access to Anti-retroviral drugs and drugs for opportunistic infections

In 1997, Uganda was selected as one of two nations in Africa to benefit from the UNAIDS Drug Access Initiative, which is intended to make anti-retroviral drugs more available in developing nations. UNAIDS has helped negotiate reductions in the price of these drugs for developing countries, and provides technical assistance for these programs. Even before the UNAIDS initiative, anti-retroviral drugs were available in Uganda on the private market, and over 500 Ugandans were known to be taking these drugs. To date, the UNAIDS initiative has had only a modest impact in increasing the numbers of persons who can afford the drugs, which cost over \$700 per month for triple combination therapy, including required laboratory testing and medical supervision. Unfortunately, there remains a serious gender imbalance, as most of those who can afford to participate in the program are males. In contrast, TASO, which charges only a very small token fee (equivalent to about 25 US cents per medical visit) has a cumulative client registration of 50,911, of whom 66% are female.²¹ Unfortunately, none of TASO's clients receive anti-retroviral drugs.

At the same time that only a tiny number of Ugandans can afford expensive anti-retroviral drugs, even simple antibiotics remain out of the reach of many Ugandans living with AIDS. Far too many Ugandans die of easily and cheaply treated opportunistic infections; even in Kampala tuberculosis, pneumonia, and fungal infections are inadequately diagnosed and treated in persons living with AIDS. Even simple palliative care, treatment of diarrhea and dehydration, and adequate nutrition remain elusive for many Ugandans living with HIV infection. Lack of access to simple care and cheap antibiotics is an even more serious problem in rural areas of Uganda, where over 80% of Ugandans live.

With the finding in Thailand that a short course of AZT can significantly reduce the rate of mother to child HIV transmission, there has been considerable interest in Uganda and elsewhere to implement this intervention. UNICEF is about to launch an effort in several hospitals in Uganda to provide short-course AZT treatment to mothers, and other donors as well may support projects to prevent mother-to-child transmission.

As research projects in a number of countries have increasingly documented that breast-feeding by HIV+ mothers is a significant contributor to mother-to-child transmission, health workers and AIDS educators in Uganda are now struggling with policy guidelines on breast-feeding. Poor sanitation and lack of access to clean water for preparation of breast milk substitutes is a serious concern; Uganda has had a cholera outbreak since late 1997 and cases continue to occur in Kampala. In this context, there is grave concern about the impact on infant mortality should Ugandan women stop breast-feeding.

Conclusion:

Early on in the worldwide AIDS pandemic, Uganda was recognized as one of the countries hardest hit by the disease. With great struggle and a concerted national effort, Uganda has now earned the reputation of one of the countries with the most successful AIDS control program. epidemic. Uganda's experience in dealing with the epidemic gives hope that even a very poor nation, emerging from civil war, can mount an effective response to the epidemic.

Key components in Uganda's response include candid political leadership and the linking of "fighting AIDS" with patriotic duty, and a citizenry who responded to this call for national action. A compassionate response from religious communities, and positive collaborations between government institutions, non-governmental organizations, and local grassroots initiatives have also made major contributions. Long term collaborations between Ugandan and international universities and researchers have resulted in important research developments and the training of many Ugandan scientists. A free press and creative, attractive publications for young people have also been important, as have the development of policies and practices to encourage family and community care of children orphaned by AIDS.

Generous and sustained donor funding, consistent donor policies, and technical assistance provided by experts with long tenure in country have empowered Ugandans to implement locally designed intervention and care projects. Total donor funding for AIDS in the last decade exceeded \$180 million, or about \$1.80 per year per adult Ugandan.

Of particular importance in the Uganda experience are the specific AIDS services which have been made available on a large scale. To a degree unmatched in any other nation in Africa, large numbers of Ugandans (over 400,000) have voluntarily requested HIV testing and counseling, a courageous personal decision in a high prevalence environment with few treatment options. And during the past 10 years, TASO has provided care to over 50,000 persons with AIDS in 8 locations throughout the country, and the TASO model is being replicated in many additional locations, both within Uganda and in the region.

Lastly, and perhaps most importantly, AIDS education and prevention efforts have been

testify publicly about how AIDS has affected themselves and their families. Their courageous examples have reduced the stigma and discrimination which have hampered AIDS prevention efforts in so many other countries. In spite of these inspiring accomplishments, many Ugandans, even some well known AIDS activists, are dying prematurely of easily and cheaply treated complications of HIV infection. The challenge for Uganda in the future will be to continue to mount an effective prevention campaign at the same time as providing effective treatment and compassionate care to the thousands of persons living with HIV infection.

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