HIV/AIDS in Uganda:

The epidemic and the response

Compiled by Uganda AIDS Commission Secretariat 2002

Executive Summary

Two decades of HIV/AIDS in Uganda, the epidemic has entered the mature stage that presents enormous challenges of coping with the devastating social and economic impact in addition to the high HIV prevalence rates.

The sickness and deaths of productive Ugandans has created a dent in all development efforts at household, community and national levels and is burden on the rejuvenating health and social infrastructures. The ever-increasing number of orphans, usually at tender ages, some of whom HIV infected, is a source of great concern.

Through collective efforts by the government and non-government sectors at various levels and with sustained political support right from the highest office, the country's response concurrently tackled all possible ways of preventing the spread of HIV and mitigating the impact of the epidemic at individual, household, community and national levels.

Programmes and activities have been developed and implemented in the areas of mass awareness and education, voluntary counselling and testing, prevention of mother-to-child transmission and blood safety to promote positive behaviour and reduce on the transmission of HIV infection. Care and support activities targeting impact mitigation mainly focused on treatment of opportunistic infections, psychosocial support and income generation projects for affected households. Other partners ventured into ARV therapy, vaccine trials, social and biomedical research.

These efforts have been supported by openness, sustained political support and a conducive policy environment in the areas of women empowerment, freedom of press, universal primary education, decentralized governance and poverty eradication. The multisectoral approach to the control of AIDS provides the overall national policy guidance.

The country's response has gone through the stages of fear, panic and denial; commitment and action; fatigue and complacency and now renewed action as the epidemic matured. Ugandans have demonstrated a high level of commitment and innovativeness in fighting the epidemic at various levels with tremendous support from different development partners. Their efforts moved Uganda from the world's AIDS epicentre in the early 90's to a success story.

The country's response is, however, faced with the formidable challenges of reducing the near stagnant prevalence rates further and providing the necessary care and support to those infected and affected by HIV/AIDS. Emphasis is now being placed on complimenting the priceless resource of commitment with enhancing community capacity to appreciate the magnitude of the epidemic, design and implement community specific interventions to promote delivery of demand driven services by and for knowledgeable individuals and communities.

1. Background.

Uganda covers a total area of 236,036 square kilometres with an estimated population size of 24.7 million people. It is situated in Eastern Africa, bordered by Sudan in the north, Kenya to the east, Tanzania and Rwanda to the south and the Democratic Republic of Congo to the west. (Africa map showing location)

Selected development indicators

Indicators	Estimate	Year
GDP	\$6,349 million	1999
GDP Average annual growth rate	7.2	1990-99
GNP	\$6.8 billion	1999
GNP Average annual growth rate	7.7	1998-99
GNP per capita	\$320	1999
Average annual growth rate	4.8	1998-99
Average annual population growth	3.0	1990-99
Ages 15-64	11 million	1999
Urban population	14%	1999
Life expectancy at birth	42 male	1998
	41 female	
Average annual labour force growth rate	2.6%	1990-1999
Literacy rate	76% Male	1998
	54% female	
Infant mortality rate/1000 live births	101	1998
Total fertility rate	6.5	1998
Public expenditure on health	1.8%	1990-98
Agricultural productivity	\$345	1996-98

Source: World Bank: World Development Report, 2000

2. Evolution of the epidemic

The first AIDS cases were identified in 1982 in the southern district of Rakai District on the shores of the lake Victoria shared between Uganda, Kenya and Tanzania. A national sero-survey conducted in 1987-88 put the average prevalence rates at 9% of the adult population. By 1990, AIDS cases had been reported in almost all the districts of the country. Urban centres along the major road axes were the most affected areas. The northern part of the country saw increased infection rates in the early 1990s due to the breakdown of social infrastructure and population displacement due to armed conflicts.

Infection rates peaked in 1992 with some of the worst hit urban areas registering rates of over 30%. Declining trends were observed beginning 1993 but only officially

announced at the end of 1995 after confirming the trends. (Graph of declining trends)

The relatively sharp decline in trends from 1992 to 1998 has since been followed by a slow down in the decline. Rates in rural areas are levelling off or declining at relatively lower levels. The average adult prevalence rate was estimated at 8.3% by the end of 1999.

Heterosexual HIV transmission accounts for 75-80% of the total new infections, mother-to-child transmission including breastfeeding 15-25% and use of infected blood and blood products and transmission in health care settings 2-4%.

3. Impact

Ministry of Health estimated 1.44 million people living with HIV/AIDS by the end of 1999. More than 800,000 lives have been lost to AIDS bringing the cumulative total infections to about 2.2 million since the on-set of the epidemic. AIDS is currently the leading cause of death among adults and the fourth leading cause of death among the under five children. Life expectancy without AIDS is estimated at 54 years

3.1 Impact on the Individual and the community

The epidemic has had a devastating social and economic impact at individual, household and community levels. Besides the physical suffering from opportunistic infections, most people living with HIV/AIDS (PHAS) experience trauma, distress, stress and depression which affect their social lives. Although direct stigmatisation has greatly reduced, PHAs are still indirectly isolated and denied support or access to services in various settings.

The morbidity and mortality due to HIV/AIDS has greatly impacted on development efforts at household and community levels. The sickness and eventual deaths of adults in most families cut off income inflows and heavily draw on household savings to care for the sick. More family members especially women, are deprived of their time for gainful occupations and this generally reduces productivity at all levels. In more rural settings, a shift has been observed from labour intensive farming to the cultivation low labour food crops like cassava. This has grave implications on community nutrition needs and development and aggravates the poverty situation in communities. For an agro-based economy, the consequences for national development are clearly devastating.

Children and young people form one of the heavily affected population groups in communities. They are withdrawn from schooling to care for the sick or due to lack of school dues, denying them access to information and bright future opportunities. This is especially so for the girl child.

By 1999, over 1.77 million children had been orphaned by HIV/AIDS, the highest figure in the world. Traditional family structures are failing to cope with this catastrophe leaving most of these children without basic essential needs. This has led to early, usually forced marriages for girls, child labour and prostitution and an increase in child-headed families and street children. This leaves more vulnerable to HIV infection.

3.2 Impact at sector and macroeconomic level

In the health sector, HIV infection has led to the resurgence of other diseases like tuberculosis, pneumonia and meningitis. Providing appropriate healthcare to the increasing PHAs exerts a lot of pressure on the fragile health infrastructure that is struggling to with tropical disease and the poverty-related diseases of malnutrition and poor hygiene. A health facility inventory by the Ministry of Health in 1997 revealed that HIV/AIDS-related patients occupied more than 55% of hospital beds.

A World Bank study (Amstrong 1995) predicted gradual adverse economic implication due to the magnitude of the epidemic and the fact that HIV selectively affects adults in their sexually active ages coinciding with prime productive years. This is resulting into an impact on the size and quality of the labour force.

Loss of skilled labour in the public and private sectors is increasingly affecting productivity and increasing expenditure on the labour force. Preliminary findings of a survey on the trends and impact of HIV/AIDS on the public service in the country reflect that 15.2% to 27.4% of public officers are suspected to have died of AIDS between 1995 and 1999. The study estimates PHAs between 4.6-13.2% of all the public officers.

The study also shows that government spent about \$120,000 on HIV/AIDS related sickness and deaths of public officers in 1995, a figure that rose to about \$3,000,000 in 1999. These figures constituted 42% and 56% of total expenditures staff morbidity and mortality (medical and burial expenses, pension and gratuity) in 1995 and 1999 respectively. There is also an increase in indirect costs related to loss of skills and experience, hiring of new personnel, training and loss of manhours. The costs increase as production is affected. This situation most likely pertains in the private business sector. The impact on productivity at sectoral level gradually translates into grave implications for the national economy. There is an estimated annual loss to GDP of 0.9% due AIDS.

4.0 Evolution of the national Response

The country's response to HIV/AIDS between 1982 and 1986 was largely confined to the health sector, handled like any other epidemic. Most Ugandans thought of the disease as witchcraft and later a disease of the immoral which led to high levels of PHA stigmatisation.

The National Resistance Movement (NRM) took over power in 1986. In the same year, Uganda's Health Minister announced the existence of HIV/AIDS in the country during the World Health Assembly in Geneva. This admission, though not welcomed by most African leaders, marked the beginning of openness about the epidemic and served as a springboard for mass awareness campaigns spearheaded by President Museveni himself. This slowly demystified the disease as people gained more insight into their vulnerability to the infection and the prevention measures.

The establishment of the first AIDS control Programme in the Ministry of Health in 1986 marked the first structural response to AIDS. The Health sector has since been the backbone of the country's response. By 1987, it was recognized that AIDS was not only a public health problem but also a social and economic disaster that called for interventions from all sectors. Consultations into the multisectoral approach, spearheaded by the President resulted into the formulation and adoption of the national AIDS policy in 1992. This policy calls upon the involvement of everyone within their capacity and mandates to fight HIV/AIDS. The Uganda AIDS Commission (UAC) was legally established in 1992 under the Office of the President to lead supra-sectoral coordination of the multisectoral efforts. AIDS Control Programme Units were established in more line ministries by 1994.

Openness, political support and commitment marshalled tremendous support especially from the non-government, no-profit sector. By 1997, over 1200 agencies were implementing HIV/AIDS-related activities in the country. These comprise of government agencies, NGOs, CBOs, PHA networks, the private business sector and development partners including the expanded UNAIDS Theme Group members. UAC brings together these partners to review progress, identify gaps and set national priorities and strategies for implementation to ensure timely delivery and even coverage of prevention and care services. Over the years partners have made also invaluable inputs into the coordination roles of UAC and implementing sectors to promote harmony amongst key partners and unify the response.

The country has, since 1993, gone through three national strategic planning exercises including consensus building. The current National Strategic Framework (NSF) for HIV/AIDS Activities 2000/1-2005/6 recognises the development implications of HIV/AIDS and places the epidemic in the broader context of national development goals.

While recognizing AIDS as a development and crosscutting issue, the government made the significant step of mainstreaming HIV/AIDS in national poverty eradication instruments. AIDS has been integrated into four pillars of the Poverty Eradication Action Plan (PEAP). This implies that government will fund a portion of HIV/AIDS

activities at all levels through the Poverty Action Fund (PAF). PAF is a finance mechanism for PEAP priority programmes that also channels debt relief funds.

Efforts against HIV/AIDS have been supported by conducive policies in the areas of women empowerment targeting the elevation of women's social and economic status in society, freedom of press which promotes national coverage and timely delivery of prevention and care messages in the various languages; universal primary education which has increased school enrolment of orphaned children in primary schools; poverty eradication and decentralised governance which target taking service management nearer the populace.

Uganda's response therefore evolved in the political and policy arena, the scientific and technical field, and within communities.

5.0 Key interventions and progress.

The multiplicity of efforts by the various players at different levels administrative levels mainly focus on these broad interventions in prevention, care and impact mitigation:

 STD/HIV/AIDS mass information and education campaigns launched in 1986 equipped the public with key messages on vulnerability and prevention of transmission to facilitate informed individual decision-making. Messages targeted both the general public and specific high risk groups.

Awareness is now rate at 99.7% and knowledge at 78% of the general population. Population based studies reflect some positive change in behaviour. There is an increase in the number of sexually active persons who used a condom in the recent past, a reduction in the number of sexual partners and a slight increase in the median age at first sex. There has also been tremendous improvement in STD management in the country.

- Screening of blood for transfusion and careful recruitment of blood donors has resulted in over 98% bloody safety.
- Personalizing the risk of HIV infection through voluntary counselling and testing
 has proven critical in determining changes in behaviour, attitudes and
 intentions that would be necessary to reduce or eliminate individual risk of
 exposure HIV. VCT services were pioneered by an NGO, the AIDS Information
 Centre as early as 1990. Almost half a million people have accessed VCT
 services at the different branches and indirect sites of AIC in 21 districts.
 Government has embarked on national programme to expand VCT to all
 districts and counties so as to build on the post-test population.

- A study on the prevention of mother-to-child transmission (MTCT) using antiretroviral (ARV) drugs 1998-2000, revealed positive results of a reduction of 30-50% of HIV transmission. Prevention of MTCT is now being implemented in 5 major hospitals. The government is finalising plans to expand this service to all districts. There, however, unanswered ethical, social and economic issues of sustaining treatment for mothers, discouraging breasting feeding and encouraging placement feeding in limited resource settings and unhygienic conditions and maintaining confidentiality in a culture strong on breastfeeding.
- Improving the quality of life of PHAs has been the major drive behind care and support services. Treatment for common opportunistic infections (OIs) can be accessed at most government health facilities throughout the country at a minimal cost. Consultations have been done on prophylaxis with septrin and INH for tuberculosis. Some service centres are already providing these services.

Private, non-profit organizations like The AIDS Support Organization and faith-based organizations have greatly contributed to the well being of PHAs through provision of integrated services for care and prevention. This involves treatment of OIs, on-going social and spiritual counselling, home-based care to relieve pressure on hospitals and provision of credit facilities for income generating activities and vocational skills building for affected family members especially orphans. Formation of post-test clubs at most of the service centres provides the much needed social support to PHAs and is key in prevention and support activities in communities.

- Participation in the UNAIDS pilot project on provision of ARV therapy facilitated the development of the necessary infrastructure for administering ARV drugs. The major hindrance to access has been the cost of these drugs. National and global advocacy for price reductions has resulted in an increase in the number patients from around 1,200 since 1996 to above 5,000 between September 2000 and June 2001 corresponding to cost reduction. The government is targeting capacity development for this service at regional level while intensifying advocacy efforts for price reduction.
- Some partners have focused on the issues of ethics and human rights generally and more especially for those infected and affected. The public has been systematically sensitised on the rights of an individual in the context of HIV/AIDS. Along with other awareness interventions, this has greatly reduced on PHA stigmatisation and discrimination and reduced on the number of cases where relatives deprive widows and orphans of the deceased of their property.

Various initiatives are increasingly targeting economic support to dependants
of the sick or deceased to sustain income flow and develop vocational skills
especially for widows and orphans to sustain their lives economically. However,
these efforts do not benefit from a common policy and strategy but are rather
driven by community needs. A baseline study into the situation of orphans has
been commissioned. Findings will feed into policy formulation and strategic
planning process in this area by the end of 2001.

These and more interventions are largely supported by central efforts in the areas of advocacy to recruit more players and sustain action, information sharing to promote exchange of ideas and experiences and formulation of appropriate policies, standards, and guidelines to guide implementation. UAC and line ministries have played key roles in these areas.

The Ministry of Health established and maintained a strong surveillance system to monitor the epidemic. Population based studies are also carried out around the sentinel sites to obtain behaviour data. Additional epidemiological, bio-medical, vaccine and social research has been conducted in the country. Information generated feeds into the planning processes at various levels.

Uganda has shared experiences and learnt from achievements of neighbouring countries and the global community. The country for example played a key role in the conception and establishment of the Great Lakes Initiative on HIV/AIDS that seeks to promote partnership in addressing HIV/AIDS in the region.

6.0 Lessons learnt

- Political support and commitment from the highest level of leadership is the pillar for strong and sustainable action
- An understanding of local and religious values of various communities is essential for any successful strategy
- It is difficult to initiate and sustain advocacy for effective leadership in HIV/AIDS at all levels due competing priorities. It is however very essential.
- The involvement of civil society, faith-based organizations and PHAs in is invaluable due to their direct contact with communities.
- The support and participation of development partners in planning, resource mobilization and guiding implementation is key
- It is more cost effective to mobilize all available efforts and resources to fight the epidemic before it becomes unmanageable.
- AIDS cannot be handled by one sector alone. There is need for concerted efforts, each sector acting within its mandate. Areas of intersection should be handled in partnership to compliment capacity and avoid duplication of resources

 AIDS respects no territorial borders. Progress can only be achieved through combined efforts at regional and global levels.

7.0 Challenges

- The declining trends must be accelerated. The slow decline in the trends since 1998 presents challenges for HIV prevention strategies.
- Behaviour management is daunting task. Innovative strategies must be designed to influence positive behaviour.
- The orphan crisis poses one of the greatest challenges to the country's development efforts. The government has to come up with a clear policy and strategy to ensure that orphans in all communities develop into healthy and responsible citizens
- There is need to improve on the quality and coverage of care and support services for the increasing PHAs in communities so as to sustain quality and productive lives
- Advocacy must be intensified to recruit more actors and maintain action in all sectors and at all levels
- There is need to enhance capacity for coordination, planning and implementation especially at district and lower levels
- Adequate resources must be mobilized to expand and sustain interventions.
 Dependency on external support presents a huge challenge for sustainability of most of the proven interventions. The country cannot however manage to mobilize the estimated annual amount of \$250m.
- It is a fact that poverty drives AIDS and AIDS drives poverty. Poverty eradication efforts must be intensified to avert a development crisis

8.0 Scaling up the response

The country targets intensifying the response to overcome fatigue and complacency and design and sustain innovative strategies to further reduce on the prevalence trends. The scale-up programme targets some of these areas.

- Developing capacity especially at district and lower structures to plan and manage the epidemic
- Building AIDS competent communities. This targets mobilization and supporting communities to anticipate their own HIV/AIDS related problems, design specific interventions and implement where possible or seek for appropriate services from extension workers, CBOs, NGOs, and the district authorities. Some resources have been mobilized through the global District Response Initiative to build community competency. This will be complimented by almost 50% of the \$50m soft loan funds from the World Bank.
- There is need to intensify advocacy for HIV/AIDS activities. Special focus on leadership in all sectors and at various levels to ensure that AIDS is the agenda of all social and development programmes is the target.

- Expanding the scope and geographical coverage of key interventions in prevention, care and impact mitigation. This targets taking affordable services near the ordinary individual in any community.
- Mainstreaming HIV/AIDS in government sector and district planning and budgeting processes to mobilize local resources
- Expanding on the mechanisms for monitoring the epidemic and the progress of the response to collect the much-needed information to inform the planning processes especially at district and lower levels.
- Mobilize adequate resources from local and external resources to sustain the response.

9.0 Conclusion

Uganda has made a considerable dent in the progress of the epidemic. However, compared to the magnitude of the epidemic, this can only be regarded as modest progress not 'success". There is therefore no room for complacency. There are still more gaps. AIDS must be a priority in all social and economic development efforts. Substantial progress can only be achieved through expanding intervention and service coverage to all corners of the country by bringing all potential sectors and actors on board to fight the epidemic.