

**Development of a National Overarching
HIV/AIDS policy for Uganda**

**A REVIEW OF THE HIV/AIDS
POLICY ENVIRONMENT**

Compiled for Uganda AIDS Commission

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1.0 INTRODUCTION

1.1 Background and Context

Uganda was one of the first countries to experience and recognize the presence of HIV/AIDS in 1982. Without pragmatic efforts to combat the spread of HIV in its early days of detection, HIV prevalence reached very high levels in some parts of the country by late 1980s. When the National Resistance Movement assumed power in 1986 it established the AIDS Control Program (ACP) in the Ministry of Health (MoH) with support from the World Health Organization (WHO). At the same time, several actors, local and international joined the fight against HIV/AIDS.

As a result of the socio-cultural, psychological, economic, moral, ethical and legal ramifications that are beyond containment by the health sector, the country responded by formulating and adopting a Multi-sectoral AIDS Control Approach (MACA) in 1992 and the National Operation Plan in 1993. The multi-sectoral policy and strategy adopted in the early 1990s, which calls upon the involvement of everyone individually and collectively, to join the fight against HIV/AIDS, marshalled a strong response which is yielding results. In 1992 the Government of Uganda established the Uganda AIDS Commission (UAC) with a mandate to co-ordinate a national Multi-sectoral AIDS Control Approach through the development of policies and implementation guidelines, integration of support, and the monitoring of all AIDS control programs and activities throughout the country.

Given the above mandate, between 1993 and mid 1990s UAC initiated the process of developing a comprehensive national HIV/AIDS policy, which culminated into HIV/AIDS Policy Guideline (1993), and Revised HIV/AIDS Policy Guidelines (March 1996). According to Stover and Johnston (August 1999), the process of developing a comprehensive national policy, which was managed by UAC called for, among others, collecting input from various actors, preparation of an initial draft policy, review and revision of the draft by the Technical Committee of UAC. This policy, however, did not go through the entire process of getting approved by the Parliament of Uganda, although many of the administrative policies contained in the document have been implemented, while those that require legislative action have remained pending. As a result, the policy guidelines have not been backed by any law and hence difficult to enforce the implementation.

It is against the above background and context that Uganda AIDS Commission, facilitated by a Consultant with support from United Nations Development Program (UNDP) carried out a detailed review of previous policy guidelines to inform the process of formulating an overarching HIV/AIDS Policy for Uganda.

1.2 Need for an Overarching National Policy on HIV/AIDS

As Uganda scales up the fight against HIV/AIDS, there is need to continually develop a strong and supportive legal and policy environment. The initial, general tendency was to handle HIV/AIDS (PHA) as any other epidemic addressed under public health regulations. UAC compiled and documented HIV/AIDS policy guidelines in 1993, that were revised in 1996. These guidelines which were prepared through comprehensive consultations across sectors and with partner consensus, have largely been the reference point for HIV/AIDS policies that have guided implementation of programs and projects in response to the epidemic in the country. A few administrative and operational policies have been developed by various sectors to guide interventions in specific thematic areas, although they have remained fragmented.

However, the dynamics and magnitude of the social, psycho-social and economic impact of HIV/AIDS call for formulation and articulation of specific and appropriate policy, legal and administrative instruments for containing the epidemic and protecting the rights of those at risk of infection, the infected and affected, and ensuring that the non-infected remain uninfected. The existing policy guidelines needed to be reviewed and updated for adaptation to make them consistent and relevant to the current HIV/AIDS situation coupled with current developments in the country and international level.

Further, although some of the guidelines have been applied in implementation, others were not operationalized. This was partly because they were not adopted as policies by the respective sectors. In addition, it should be noted that Uganda is a signatory to some international conventions, agreements and commitments that have not been ratified at country level for adoption.

As the country scales up the national response, a stronger, more supportive and conducive policy environment to foster positive behaviour change and facilitate well-co-ordinated implementation of identified HIV/AIDS national priorities is critical.

1.3 The HIV/AIDS Situation in Uganda and Consequences of the Epidemic

HIV/AIDS has been on the Ugandan scene for the last two decades with varied regional prevalence rates and socio-economic impact. By the end of December 2001, the number of people living with HIV/AIDS in Uganda was estimated at 1,050,555; 945,500 adults and 105,055 children under 15 years old (STD/ACP, June 2002). On the other hand, the cumulative number of reported AIDS cases as of end of December 2001 was 60,173 both children and adults. Of the 60,173 reported cases, 55,707 (92.5%) and 4,466 (7.5%) were adults and children aged less than 12 years respectively. However, since the mid 1990s national surveillance reports and other sources have consistently indicated a downward trend of HIV infection from 15% in the early 1980s to 8% in 2000 and 6.1% in 2001 and 6.5% in 2002 (STD/ACP, June 2002). The cumulative AIDS deaths since the epidemic began is estimated at 947,552 out of which, 852,797 are adults, with women being 427,153, men 425,644 and children 94,755.

When AIDS was first recognized in Uganda in 1982 the first response by society and Government was negligible partly due to lack of knowledge world-wide about the new disease (UAC, 1996), and possibly as a result of the unstable political situation in the country. Indeed,

from the early 1980s up to 1986 there were minimal interventions put in place to address the problem of HIV/AIDS, while it continued unleashing severe impact on society.

The epidemic poses one of the most serious challenges to development in the country. The impact of the disease has been pervasive, affecting all socio-demographic and economic categories of the population, with considerable short and long-term ramifications. The epidemic mainly affects the productive categories of the population in child bearing and economically active age bracket. As a result, labour shortage in the agricultural sector, which is not only the backbone of Uganda's economy, but also a source of livelihood and food for over 90% of the country's population has witnessed slow growth. Labour shortages as a result of HIV/AIDS related morbidity and mortality has also been documented in other sectors such as education, health and in industrial settings. In particular, the impact of the epidemic is epitomised in Uganda by the growing number of children without parents to care for them i.e., orphans. It is estimated that there are 1,650,000 orphans in Uganda (Wakhweya et al., 2002), while according to Uganda Demographic Health Survey - UDHS (2001), 14% of children in Uganda under 18 years of age are orphans.

The current sero-prevalence rate 6.5%, although reflecting tremendous decline, the intensified need for continued concerted efforts at policy and other levels to enhance prevention initiatives, treatment, care and support, mitigation of the impact, as well as co-ordination and research is still critical, and hence the need for an overarching HIV/AIDS policy for Uganda to strengthen and scale-up current efforts.

2.0 THE CURRENT POLICY ENVIRONMENT AND GAPS

2.1 Preamble

Prior to current efforts to develop an HIV/AIDS policy for Uganda, there was a general tendency to handle HIV/ AIDS as any other epidemic addressed under Public Health regulations. In the early 1990s, Uganda AIDS Commission (UAC) initiated the process of developing an HIV/AIDS policy through wide consultations across sectors and partners. The UAC in 1993 compiled and documented HIV/AIDS policy guidelines, which were revised in 1996 that have since provided a reference point for HIV/AIDS policy proposals. A few operational and administrative policies have been developed by various sectors to guide interventions in specific thematic areas. In this section, the policy environment in which HIV/AIDS interventions are implemented is presented, and the gaps in the existing policy guidelines as developed by UAC are identified to form a basis for the new overarching HIV/AIDS policy for Uganda.

2.2 Policy Environment

2.2.1 Open Policy on HIV/AIDS

The current efforts to combat HIV/AIDS are characterised by a policy of openness on the side of Government. This has spread to the wider civil society, lower level political and social institutions, and to an extent, the family. Political commitment from the highest level of Government, positive living and involvement of PHA, and the contribution of the UN bodies, bilaterals, and, generally, the international donor community, NGOs, CBOs, Faith-based and socio-cultural institutions, the private sector, individuals and communities have, in synergy, contributed to the current decline. What is, however, lacking is a publicised national policy and legislation framework that all actors can perform their mandates in an open manner.

2.2.2 HIV/AIDS in the Context of National Development Planning

Within the country's Vision 2025 and attendant Poverty Eradication Action Plan (PEAP), HIV/AIDS is treated as a development issue. The Multi-Sectoral HIV/AIDS approach is also considered to be an integral part of PEAP. However, in most Local Government Plans, HIV/AIDS is largely reflected as a health sector matter. Mainstreaming HIV/AIDS activities in overall planning and priority setting to conform to the multi-sectoral nature of the problem is an important aspect of a national overarching policy.

2.2.3 The Multi-sectoral Approach to HIV/AIDS

The multi-sectoral approach to HIV/AIDS prevention, control and care as developed in the early 1990s advocates for the active involvement of AIDS control activities by all members of society individually and collectively. It seeks to address not only HIV/AIDS prevention but also the active response to, and management of, all perceived consequences of the epidemic and emphasises organisational capacity building for sustainable activities among sectors and individual organisations.

2.2.4 The National Strategic Framework

A statement of the country's response to HIV/AIDS forms the National Strategic Framework (NSF) for HIV/AIDS activities for the period 2000/1-2005/6. The Framework builds upon the Multi-Sectoral Approach to the Control of AIDS (1993), and the National Operational Plan (NOP) for HIV/AIDS/STD Prevention, Care and Support 1994-98, and Programs for AIDS Control (ACP) in line Ministries. The framework highlights the need to place HIV/AIDS in the broader context of national policies on health and the poverty eradication programme. However, partly as a result of lack of appropriate policy, ongoing HIV/AIDS interventions have not fully benefited from reference to a common national program of action, consequently limiting the potential contribution of various stakeholders.

2.2.5 The Constitution (1995) and the Local Governments Act (1997)

The Constitution (1995) provides for a decentralized system of governance. The Constitution and the Local Governments Act (1997) bring issues of HIV/AIDS prevention, control, care, support, and mitigation to the grassroots. However, local governments need specific policy guidance to design and implement relevant interventions within their areas of jurisdiction, and to monitor the delivery of services. Current interventions in HIV/AIDS are largely top heavy. Capacity building at district and lower levels, bottom-up planning and co-ordination of responses to HIV/AIDS, is a matter of great concern. There is need for local governments to carry out continuous reviews of their respective HIV/AIDS situation in order to design appropriate interventions to fulfil their mandates.

2.3 Gaps in the Existing HIV/AIDS Policy Guidelines

New developments since 1996 in the area of HIV/AIDS prevention, care and support as well as increased knowledge and awareness of HIV transmission have all combined to lead to gaps in most policy proposals developed by UAC. Further, given the fact that the proposals were not discussed by Cabinet and approved by Parliament, they are in general not easily enforceable, as they are not backed by any legislation. The gaps per specific policy proposal and emerging observations are shown in a matrix of gaps below.

A MATRIX OF GAPS IN POLICY PROPOSALS DEVELOPED BY UAC (1996)

<i>Thematic HIV/AIDS Policy Area</i>	<i>Policy Proposal (1996)</i>	<i>Gaps in the Policy Proposal and Observation</i>
<ul style="list-style-type: none"> • Prevention and Control 	<ul style="list-style-type: none"> • Adopt quiet promotion and responsible use of condoms with appropriate education 	<ul style="list-style-type: none"> • Currently, "quiet" promotion of condoms has no policy relevancy as open promotion characterizes ongoing condom promotion practice • Reduced fears and suspicions have resulted into increasing "open" acceptance of the condom • Diminishing attack and controversy from religious and other pressure groups • Current approaches on condom promotion have not significantly attracted negative attention, nor has the population been much split due to this openness
	<ul style="list-style-type: none"> • Risky sexual behavior be minimized through education and by formulation and enforcement of relevant legislation 	<ul style="list-style-type: none"> • Formulation and enforcement of legislation on sexual behaviors is impractical • Voluntary change of sexual behaviour is the viable option. Enforcement of change using the law may infringe on other individual rights
	<ul style="list-style-type: none"> • Voluntary HIV testing be made universally available and accessible 	<ul style="list-style-type: none"> • High costs in equipment and personnel, including qualified counselors renders universal VCT problematic

<i>Thematic HIV/AIDS Policy Area</i>	<i>Policy Proposal (1996)</i>	<i>Gaps in the Policy Proposal and Observation</i>
	<ul style="list-style-type: none"> Informed consent with counselling and confidentiality be observed in voluntary HIV testing 	<ul style="list-style-type: none"> Many VCT centres have sprung up, most of them operating without adequately trained staff. For the above and other factors the relevant ethics may not be strictly observed Disclosure of information on HIV status remains acutely sensitive. VCT staff need to be sufficiently prepared to meet this challenge
	<ul style="list-style-type: none"> HIV testing shall not be included as part of a routine medical examination without the knowledge and consent of the patient 	<ul style="list-style-type: none"> The ACP of MoH continues to monitor prevalence through sentinel surveys and mothers attending routine antenatal examination at major health units In the case of the mothers above observation of ethics (or the lack of it) may need further scrutiny. Without specific consent, HIV testing constitutes an assault on the person tested
	<ul style="list-style-type: none"> All couples intending to get married be encouraged and counselled to take the HIV test 	<ul style="list-style-type: none"> Lack of non-committal. It leaves room for being optional Some religious groups and parents have made testing for HIV before marriage mandatory. For other groups it is simply optional but encouraged. Others do not mention it at all
	<ul style="list-style-type: none"> HIV testing shall not be mandatory for purposes of travel 	<ul style="list-style-type: none"> This has an international dimension as a country on its own cannot implement it

<i>Thematic HIV/AIDS Policy Area</i>	<i>Policy Proposal (1996)</i>	<i>Gaps in the Policy Proposal and Observation</i>
	<ul style="list-style-type: none"> Annual HIV testing shall be mandatory for students admitted under public sponsorship to tertiary institutions 	<ul style="list-style-type: none"> Annual HIV testing mandatory for students has never been enforced. The relevance of this requirement can be widely contested Fear that PHA soon become terminally ill, thus constitute a wasted resources has been overtaken by new developments that keep individuals active and productive over a long time
	<ul style="list-style-type: none"> For Life Insurance purposes, medical examination may include HIV testing 	<ul style="list-style-type: none"> Introduces discriminatory tendencies, and can be contested Largely market forces guide the insurance industry, service providers may need to exercise their policies within their existing policies. Wide variations exist in life expectancy among PHA; and unequal access to anti-retroviral drugs
	<ul style="list-style-type: none"> Counselling services shall be made universally accessible 	<ul style="list-style-type: none"> Universal access entails removal of cost, human resource and other related barriers
	<ul style="list-style-type: none"> All blood for transfusion must be safe 	<ul style="list-style-type: none"> Existing areas for policy backing to make it safe
	<ul style="list-style-type: none"> The use of blood substitutes be encouraged and supported 	<ul style="list-style-type: none"> Blood substitutes have not been vigorously promoted in IEC strategies Promotion of blood substitutes involves medical and socio-economic means. It is multi-sectoral

<i>Thematic HIV/AIDS Policy Area</i>	<i>Policy Proposal (1996)</i>	<i>Gaps in the Policy Proposal and Observation</i>
	<ul style="list-style-type: none"> Child bearing shall be discouraged among HIV positive women 	<ul style="list-style-type: none"> Marrying this with recent changes e.g. development of Nevirapine and other measures to minimize vertical transmission of HIV IEC on fact that not every expecting HIV positive women will have HIV positive child
	<ul style="list-style-type: none"> Pre-marital counselling shall contain a component on risks of having pregnancy when one or both of the spouses are HIV positive 	<ul style="list-style-type: none"> Recent changes have included the development of Nevirapine and other measures to minimize MTC transmission
	<ul style="list-style-type: none"> Appropriate AIDS control programs for out of school youths shall be developed and actively implemented 	<ul style="list-style-type: none"> Limited coverage vis-à-vis categories especially at risk e.g., young in-school girls, the poor, PWDs, street children, sex workers etc
	<ul style="list-style-type: none"> Individuals who know that they are HIV positive and engage in behavior that is known to promote HIV transmission shall be prosecuted 	<ul style="list-style-type: none"> Legislation for implementation is critical for this to succeed
	<ul style="list-style-type: none"> Appropriate and specific HIV education programs for all inmates and staff shall be instituted 	<ul style="list-style-type: none"> Can be administratively applied
	<ul style="list-style-type: none"> Compulsory HIV testing for all inmates and staff shall be done on conviction 	<ul style="list-style-type: none"> There may be no overriding justification or necessity for compulsory testing. It infringes on personal rights All categories of inmates, irrespective of their sero-status need to benefit from IEC and other prevention and control activities
	<ul style="list-style-type: none"> Legislation governing places and age limits for sale and consumption of alcohol shall be reviewed, publicized and enforced 	<ul style="list-style-type: none"> Enforcement of such laws is problematic Laws governing consumption and sale of alcohol have remained redundant for a long time.

<i>Thematic HIV/AIDS Policy Area</i>	<i>Policy Proposal (1996)</i>	<i>Gaps in the Policy Proposal and Observation</i>
	<ul style="list-style-type: none"> Unauthorized all night social and religious activities should be banned 	<ul style="list-style-type: none"> Raises contradictions with the existing law e.g., freedom of worship Potential to create antagonism with cultural values/norms e.g., what do you do with cultural ceremonies such as funeral rights? Banning is such a strong concept in issues of culture and religion.
	<ul style="list-style-type: none"> Public showing of sex (blue) video tapes and films be banned 	<ul style="list-style-type: none"> Pornographic materials are evident in various print and electronic media, which has enforcement difficulties.
	<ul style="list-style-type: none"> Legislation against sexual abuse of minors shall be reviewed, publicized and enforced 	<ul style="list-style-type: none"> Already provided for under defilement laws, only needs to be publicized Deterrent penalties against child sexual abuse have not been successfully executed.
<ul style="list-style-type: none"> Care, Support and Mitigation 	<ul style="list-style-type: none"> There shall be no discrimination against people living with HIV/AIDS 	<ul style="list-style-type: none"> There are gaps in the employment sector where fragmented policies are in place, with almost every organization having its own Less overt discrimination against PHA in health units and other places needs further examination and legislation.
	<ul style="list-style-type: none"> All indigenous remedies used in the treatment and prevention of AIDS shall be carefully monitored and screened for safety and efficacy 	<ul style="list-style-type: none"> Protection of the public against false claims through monitoring traditional care practices is not enough. False spiritual healing constitutes another form of public exploitation Claims of cure with application of "Chinese" and other foreign drugs may be another form of public exploitation. The law needs to be clear on approved standards.

<i>Thematic HIV/AIDS Policy Area</i>	<i>Policy Proposal (1996)</i>	<i>Gaps in the Policy Proposal and Observation</i>
	<ul style="list-style-type: none"> The government will share the responsibility of caring for PHA with the communities 	<ul style="list-style-type: none"> Obligation and responsibility of government anchored in the overall policy of government to its people. The responsibility of community apart from local governments cannot be legislated, but rather encouraged
	<ul style="list-style-type: none"> The care of orphans and other needy children shall be the primary responsibility of the nation and the local communities 	<ul style="list-style-type: none"> Provided for in the existing laws, but not much is being done Categorisation of needy children is wide and open to different interpretations
	<ul style="list-style-type: none"> Legislation affecting the welfare of inmates and staff shall be reviewed and enforced 	<ul style="list-style-type: none"> Inmates are one among various other categories of vulnerable
	<ul style="list-style-type: none"> Individuals suspected of being HIV positive shall be counselled and encouraged to be tested 	<ul style="list-style-type: none"> The challenge of suspecting people and inviting them for counseling is enormous The relevance of this is doubted.
	<ul style="list-style-type: none"> Appropriate support shall be availed to carers of AIDS patients 	<ul style="list-style-type: none"> Need for enhancement of this
	<ul style="list-style-type: none"> The onus of ensuring self protection against HIV infection lies with the care giver 	<ul style="list-style-type: none"> Needs sensitisation on HIV/AIDS issues
	<ul style="list-style-type: none"> Income generating activities shall be promoted to provide support to individuals and families affected by the epidemic 	<ul style="list-style-type: none"> Guidelines for implementation are required Resources for IGAs are enormous Requires assurance of availability of financial resources for this

<i>Thematic HIV/AIDS Policy Area</i>	<i>Policy Proposal (1996)</i>	<i>Gaps in the Policy Proposal and Observation</i>
	<ul style="list-style-type: none"> Legislation be reviewed and strengthened to protect legal and property rights of AIDS orphans, widows and affected relatives 	<ul style="list-style-type: none"> Needs to be broadened to include other categories whose vulnerability is increased due to HIV/AIDS and backed by legislation
	<ul style="list-style-type: none"> Religious organizations shall be encouraged and supported to offer more pastoral care and material support to AIDS patients in their parishes 	<ul style="list-style-type: none"> Administrative modalities and guidance for supporting this initiative are important
<ul style="list-style-type: none"> Organization and Co-ordination of HIV/AIDS activities 	<ul style="list-style-type: none"> The national STD control program shall be given priority support 	<ul style="list-style-type: none"> Need for consideration of other key institutions and departments in an integrated multi-sectoral fashion
	<ul style="list-style-type: none"> Collaborative links between health institutions and community based care centres shall be established and supported 	<ul style="list-style-type: none"> Policy guidelines for networking/collaboration are required
	<ul style="list-style-type: none"> Religious organizations shall be encouraged and challenged to develop and implement programs that lead to significant sex behaviour change 	<ul style="list-style-type: none"> Appropriate strategies to strengthen this, as part of building collaborative links
	<ul style="list-style-type: none"> Communities be sensitized and mobilized to address the HIV/AIDS epidemic on all fronts 	<ul style="list-style-type: none"> Policy proposal still appropriate in its present form
	<ul style="list-style-type: none"> Communities be supported to initiate and implement specific AIDS control programs 	<ul style="list-style-type: none"> Policy proposal still appropriate in its present form
	<ul style="list-style-type: none"> The Commission shall clear all AIDS control programs 	<ul style="list-style-type: none"> The mandate of the Commission is to co-ordinate and can offer guidance, but not to clear.
	<ul style="list-style-type: none"> Human resource projections shall be reviewed annually and appropriate corrective measures taken 	<ul style="list-style-type: none"> May be only relevant for selected sectors. In various sectors the level of unemployment is high

<i>Thematic HIV/AIDS Policy Area</i>	<i>Policy Proposal (1996)</i>	<i>Gaps in the Policy Proposal and Observation</i>
	<ul style="list-style-type: none"> Educational planning and implementation shall be guided by human resource projections 	<ul style="list-style-type: none"> Needs collaboration with other relevant sectors
	<ul style="list-style-type: none"> The government shall establish or strengthen appropriate systems, procedures and structures and mobilize resources for HIV/AIDS Control 	<ul style="list-style-type: none"> Policy proposal still appropriate in its present form
	<ul style="list-style-type: none"> Legislation and ethical standard for safe medical care, including traditional practice, shall be reviewed, publicized and enforced 	<ul style="list-style-type: none"> Policy proposal still appropriate in its present form, but requires relevant legislation
<ul style="list-style-type: none"> Research and Publication 	<ul style="list-style-type: none"> All local research efforts, especially in indigenous natural products, must be encouraged and supported 	<ul style="list-style-type: none"> Policy proposal still appropriate in its present form
	<ul style="list-style-type: none"> Clinical trials of anti-HIV drugs and vaccines shall be conducted 	<ul style="list-style-type: none"> Policy proposal still appropriate but requires setting of national standards to be adhered to.
	<ul style="list-style-type: none"> Unauthorized filming of AIDS patients is prohibited 	<ul style="list-style-type: none"> If voluntary consent is obtained this becomes ethical Legal guidance is required
	<ul style="list-style-type: none"> Filming and photographing of individuals affected by HIV/AIDS must be seen to benefit them 	<ul style="list-style-type: none"> Legal and ethical guidelines required as well as voluntary consent
	<ul style="list-style-type: none"> Legislation regarding the export of research data and materials shall be reviewed, publicized and enforced 	<ul style="list-style-type: none"> Policy proposal still appropriate but requires legislation
	<ul style="list-style-type: none"> Copies of all reports, video films and research papers on HIV/AIDS shall be deposited with the Uganda AIDS Commission 	<ul style="list-style-type: none"> Policy proposal still appropriate in its present form Modalities for implementation need to be worked out.

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