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**THE SOCIO-ECONOMIC IMPACT OF HIV AND AIDS
ON RURAL FAMILIES IN UGANDA:
AN EMPHASIS ON YOUTH**

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and
Gunter Hemrich**

PREFACE

The HIV epidemic is a new, complex phenomenon in the world today. It is challenging accepted ways of understanding health and human development in our societies and demanding new forms of expertise and holistic responses. It is raising conceptual, ethical and programmatic issues, many of which still need to be named, all of which need to be raised for discussion and exploration.

This series of papers is presented in the hope that the tentative explorations contained in these pages will help readers to see new issues, to see old issues in new ways, and to see the questions many of these issues raise for the accepted ways of doing things.

The issues included here have been identified by the HIV and Development Programme of United Nations Development Programme. The papers have been written by the Programme's staff and other concerned people. The views expressed in the papers are those of the authors and may not necessarily reflect those of the United Nations Development Programme.

We would welcome these papers being reproduced in whole or in part by any person wishing to understand and explore these issues further. We would be grateful for acknowledgement. We would also be interested in suggestions for further papers and in comments on the series.

There is a sense of urgency associated with this epidemic, which is often not felt in other areas. There is a need to find effective, sustainable and compassionate ways of responding. We hope this series contributes to this quest.

Elizabeth Reid
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1. SUMMARY

1. While youths are among the most vulnerable groups to HIV infection, they are also the most promising agents of behaviour change. Young men and women are vulnerable to HIV infection because they begin sexual activity at an increasingly younger age, tend to have multiple partners and have restricted access to information on safer sexual practices. In addition, the interplay of a wide range of factors -- war and instability, the loss of the appeal of agriculture as a profession, economic hardship and the absence of income-generating opportunities, the increase in drop-out school rates and alcohol/drug abuse -- have contributed to the creation of a high risk environment for rural young men and women. An increase in poverty and illiteracy, lack of opportunities, and the erosion of social values and family life education act as catalysts to high risk sexual behaviour.
2. Young women are more susceptible to contracting HIV than young men for biological, health-related and socio-economic reasons, but also because they have until recently been neglected by HIV/AIDS education interventions.
3. The HIV epidemic follows a different pattern in each village and district. Geographic and ethnic factors, agro-ecological conditions, religion, gender, age and marital status play a role in the pattern and impact of HIV and in people's perceptions of the disease. Even within one district, two villages can have radically different agro-ecological conditions and customs that determine sexual behaviour and attitude towards HIV and AIDS. This has critical implications for the design of HIV interventions -- namely that district-specific approaches are essential.
4. Available seroprevalence data for rural areas may not always be reliable and indicative of the spread of the disease in a given area. Districts believed to be only marginally affected by HIV and AIDS may appear so only because there are no sentinel sites or other monitoring mechanisms in place.
5. The HIV epidemic is disproportionately affecting young rural women. There are far more women who have lost their husbands to AIDS than men having lost their wives in the three districts visited. Young widows with dependent children tend to become entrenched in poverty as a result of socio-economic pressures related to HIV and AIDS. The AIDS stigma, for instance, which largely results from the prevailing stereotype that it is the women who are responsible for transmitting HIV, is undermining traditional coping mechanisms accessible to young widowed women and changing the socio-economic fabric of the extended family.
6. The assumption that 80%-90% of Ugandan men and women are aware of HIV and AIDS and know how to protect themselves does not apply to the rural areas visited, particularly not to young rural women. Myths, misconceptions, superstitions, stereotypes and stigmatization are widely prevalent in Tororo and Gulu districts. The less people know about the disease, the more negative they tend to be about HIV-affected families and the stronger the stigmatization. What is particularly significant is that individuals tend to blame their partners for transmitting HIV, not themselves for engaging in high risk sexual behaviour.

7. In general terms, school children are better informed about HIV and AIDS than out-of-school youths; school boys are better informed than school girls; out-of-school men are better informed than out-of-school women; and older women are better informed than younger women.
8. There is a need to differentiate between school and out-of-school youths. As HIV initiatives are already targeting school children with some success, it is most important to reach out-of-school rural youths, particularly girls. In rural areas, girls tend to drop out of school at the P3 or P4 level and do not benefit from HIV education which begins at the P5 and P6 level. Out-of-school youths, including those who drop out, make up the majority of rural young people.
9. If behaviour change is to be effective, it should involve the youth itself in the generation of appropriate messages and should address socio-economic and cultural realities that influence sexual behaviour. Creating a forum for discussion and for interactive learning, where respect for HIV/AIDS as well as for young people's social and sexual needs co-exist, can help create an enabling environment for the generation of appropriate messages.
10. Behaviour change strategies that do not address socio-cultural norms, including early sexual behaviour, STDs, alcohol and drug abuse, bar and disco culture, ritual cleansing and wife inheritance, etc. but only hinge on sexual behaviour per se are not likely to be effective, particularly among youths. If behaviour change is measured in part in terms of changing patterns of alcohol/drug use, frequency of bar visits, etc., a more accurate picture of behaviour change would emerge.
11. Traditional norms and customs concerning wife inheritance, oral or written wills, widows' rights to land and property, etc. often tend to overrule the implications of HIV and AIDS. This needs to be taken into account when designing interventions.
12. Behaviour change is also conditional on communication, negotiation and assertiveness skills, motivation and perseverance for men as well as for women.
13. The fact that behaviour change is a continuous process and a change in lifestyle rather than an occasional exercise in self-control needs to be addressed in the design of interventions.
14. Women's socio-economic status and the breakdown of the institution of marriage in some areas, need to be addressed, in particular: alcohol brewing/distilling as a major economic activity for young rural women and the need to create alternative income-generating opportunities; bride wealth, which has become unaffordable for many young men; and the growing number of informal unions between men and women which translates into a loss of legal rights for women living with their partners outside of marriage.
15. Many young men and women, want to be tested for HIV (sometimes along with their children), but they do not have access to information and facilities. Pre-testing counselling and practical advice on how to persuade a partner to take the HIV test are key components. A major issue to be addressed, however, is transport cost, which is often prohibitively high, especially for women.
16. A strong youth programme aimed at increasing opportunities and creating choices for young people in rural areas through income-generating activities, leadership and management training, recreation, health education, and communication/negotiation skills is in itself a strategy to respond

to the HIV epidemic. This is in line with the Uganda AIDS Commission approach which specifies that "prevention activities should be integrated into mainstream health programmes and other programmes dealing with community, women and youth development."

17. As a group, youth includes children (ages 10-14), adolescents -- some of whom are parents, particularly girls -- (15-18 years) and young adults, most of whom are parents (19-25 years). These groups may have to be targetted separately, given the fact that their lifestyles, sexual behaviours and learning abilities differ. Childhood/adolescence, marriage and parenthood are often very close together for girls/young women. This needs to be taken into account when designing interventions.

18. The HIV epidemic is having an adverse effect on the already overburdened and under-resourced agricultural extension service. Highly qualified civil servants and technocrats are increasingly dying of AIDS and are not being replaced. In some districts, it is becoming difficult to implement agricultural programmes as a result of HIV and AIDS: extension staff are frequently attending burials. Every time there is a burial, the work week is reduced from six to three days (Tuesday, Wednesday and Thursday) as civil servants have to take Saturday, Sunday and Monday off (Friday is the official day of rest) to travel to the village and attend the burials. HIV interventions targetting rural youth through the agricultural extension service may be ineffective, without appropriate measures to strengthen extension.

2. INTRODUCTION

2.1 Overview of Youth and HIV in Uganda

Uganda is one of the least urbanized countries in Africa, with over 90% of the population living in rural areas. About half the population of the country is under 15 years of age (8.5 million), according to the 1991 Population and Housing Census, while those under 25 years make up about 67% of the population. Youth, as defined by the government of Uganda, includes boys/girls and young men/women from 10 to 25 years of age.

Agriculture accounts for over 60% of GDP, claims about 98% of export earnings and over 40% of government revenue, according to 1987 figures. Farming is labour-intensive, with 60%-80% of the labour for food and cash crops for household consumption and local markets provided by women.

The Acquired Immunodeficiency Syndrome (AIDS) is the most serious health problem in Uganda today and the leading cause of death for adults: About 1.5 million people (10% of the total population and 20% of sexually active men and women) are estimated to be infected with the HIV virus.¹ Since 1982 when the Human Immunodeficiency Virus (HIV) was first recognized in the country, 41,193 cases have been reported. However, according to the Uganda AIDS Commission, this represents only a fraction of the actual number of people infected with HIV due to under-reporting and under-diagnosis.

According to some estimates, up to one million men and women could become infected with HIV in the next five years as seropositivity rates have been rising by about 25%-30% per year since 1988. The projected population of Uganda could plunge from 30 to 20 million by the year 2010 as a result of the HIV epidemic, it has been argued by some epidemiologists. While estimates of the magnitude of the HIV epidemic vary, the common denominator of all projections is that the demographic structure of the country is undergoing considerable transformation.

Nearly 80% of those infected with HIV are between the ages of 15 and 45 -- the heads of households and parents of families which have on average more than seven children. * Children having lost one or both parents to AIDS are estimated to be in the vicinity of 115,000 and rising, and some experts fear that this figure could increase five-fold in the next five years. War, an increase in children born out of wedlock and the collapse of health services account for the overall rising number of parentless children, estimated at between 400,000 and 1,100,000. About 69% of all parentless children in Uganda are between 10 and 19 years of age. According to one estimate reported by UNICEF, half the children in Uganda under 15 years will have lost one or both parents by the year 2,000.²

¹ Uganda AIDS Commission Secretariat, Uganda National Operational Plan for HIV/AIDS/STD Prevention, Care and Support, 1994-1998, p. 1.

² UNICEF, Safeguard Youth From AIDS, New Phase of UNICEF Support for AIDS Control Programme in Uganda, April 1992.

TABLE 1: ESTIMATED CURRENT AND PROJECTED MAGNITUDE OF HIV AND AIDS

	1993 Currently living with HIV and AIDS		1998 Projected ¹ living with HIV and AIDS	
Age/gender	HIV	AIDS	HIV	AIDS
0 - 14 years both sexes	115,759	37,314	220,581	60,209
15- 19 years both sexes	131,600	5,881	159,800	8,796
20 - 49 women	571,200	55,584	693,600	82,993
20 - 49 men	529,200	52,416	642,600	78,403
50 +	168,000	14,063	204,000	21,035
Total	1,515,759	165,157	1,920,581	251,436
Maternal orphans ²	300,090		886,390	
Adults	Cumulative deaths 1993-1998			
Children	565,070			
	250,437			

Source: *Uganda National Operational Plan for HIV/AIDS/STD Prevention, Care and Support, 1994-1998.*

1 Projections are calculated under the assumption that the current level of intervention for prevention is maintained.

2 Cumulative number of children below 15 years who have lost their mother due to AIDS. Some of these will also have lost their father. Some (not included in the figure) will have lost their father only.

The economic repercussions of the HIV epidemic at the macro level are already being felt in the public and private sectors. Overhead costs are increasing as a result of rising medical expenditures, absenteeism from work and training of replacements, according to the National Operational Plan for HIV/AIDS/STD Prevention, Care and Support, 1994-1998. The Plan predicts a shift in national investments from long-term to short-term, indicating that investment and productivity in agriculture and industry are endangered. Labour shortage as a result of HIV and AIDS mortality and morbidity may well result in a crisis in the traditionally labour-intensive agricultural system in areas that have been severely hit by the HIV epidemic. National capacity-building efforts may be imperiled and decline in income is expected to affect the balance of payments.

Geographic location, age and gender are key variables in the incidence of HIV and AIDS. Prevalence of HIV varies considerably from district to district. Infection rates are at their highest in urban centres (in the town of Mbarara and the city of Kampala, 24-36% of ante-natal mothers are HIV positive) and in the southern districts of Rakai and Masaka, where more than 12% of the entire population is believed to be infected with HIV.

According to the Uganda AIDS Commission, the vast majority of new infections occur as a result of sexual transmission (84%), followed by perinatal transmission (14%), which are also a result of earlier sexual infection, while other routes of transmission account for only 2% of new infections.

HIV infection increases rapidly between the ages of 11 and 19, especially among girls of 15 to 19 years, who are five times as likely to become infected as boys.³ Girls in the 20-24 age group are twice as likely to be infected as boys. Peak infection occurs between 15 and 24 years, which implies that 15-year-old girls with AIDS are infected before or during puberty. There are 10% more women among the newly infected with HIV than men, largely as a result of women's vulnerability and inequality before the law.

Clearly, the need to target rural youths, who are among the most vulnerable groups to HIV and AIDS, is urgent. Prevention of sexual transmission is the main strategy. This is recognized in the 1994-1998 National Operational Plan for HIV/AIDS/STD Prevention, Care and Support of the Uganda AIDS Commission:

"The main emphasis of the Plan will be prevention of HIV-infection through behaviour change, promotion of STD-care and condom use for targeted groups of people with focused educational messages. The promotion of behaviour change will focus not only on the individual behaviour, but will equally focus on the collective behaviours, and the norms and the values of the community." "In order to achieve this," indicates the Plan, "it is necessary to give first priority to children and youth and to start addressing norms and values right from school entry, gradually making it more specific as the child grows." The second priority of the Plan is to address the status and needs of women, including rural women, and the third is to address cultural and traditional customs and specific sites with concentration of situations of risk.

The Plan identifies three age groups for youth: 6-10, 11-14 and 15-20 year olds and indicates that different approaches need to be developed for each age group. It also recognizes that as less than half the child/youth population is in school, out-of-school youths will be addressed with appropriate approaches.

Gender issues are accorded top priority in the National Operational Plan for HIV/AIDS, given the fact that the pattern of sexual transmission of HIV infection is determined by the social, legal and economic relations between the sexes. Women are identified as a "highly vulnerable group" for the following reasons: a) less than half of the women can read and be reached by written messages; b) rural women do not often participate in discussion and decision fora; c) women do not often receive services from extension or outreach health workers; d) women are economically and socially dependent on men. The Plan also recognizes that customs and socially accepted practices including wife sharing, divorce practices, widow inheritance, polygamy, property inheritance practices and the lack of income-generating opportunities for single women increase their risks and restrict their decision-making status vis-a-vis high risk situations. Rural women are one of two target groups identified by the Plan in urgent need of intervention.

³ UNICEF, SYFA, New Phase of UNICEF Support for AIDS Control in Uganda, April 1992.

A critical point recognized in the Plan is that while women are targeted as a particularly vulnerable and disadvantaged group, men have a key role to play in interventions designed to reach and benefit women. In particular, it is indicated that "A meaningful decrease in HIV risk in Ugandan society will require changes in male behaviours and attitudes concerning gender relationships and sexuality." In particular, norms, values, practices and relations between men and women create situations and sites (alcohol drinking, visits to bars, discos and social functions) with increased risk of sexual transmission of HIV infection.

Lastly, it is clearly indicated that "prevention activities should be integrated into mainstream health programmes and other programmes dealing with community, women and youth development." HIV/AIDS initiatives are to be decentralized and the RC system will be the key instrument of implementation. According to the Plan, "NGO support will be encouraged to develop activities to reach specific sites and populations, such as: trading centres, make-shift markets, bar girls and prostitutes, etc. and in the areas of home/community based care and support to surviving family members in the form of e.g. income-generating projects."

2.2 The Research Team

The research team consisted of the international consultant on HIV and AIDS and field research, the national counterpart on HIV and AIDS and the Associate Professional Officer (APO) from the Rural Youth Programme, ESHE, FAO. In each district, the team worked closely with YFP Field Officers, Subject Matter Specialists on Women and Youth, Agricultural Extension Officers and HIV councillors.⁴

2.3 Methodology

2.3.1 Selection criteria:

Kabarole, Tororo and Gulu Districts were selected on the basis of the following criteria:

1. Geographic, agro-ecological, ethnic and linguistic diversity to ensure a representative picture of the country.
2. Low, medium and high HIV infection rates and AIDS cases. According to surveillance reports of the Uganda AIDS Commission, Gulu ranks among the highly infected districts, Kabarole among the medium infected districts and Tororo among the districts with a low rate of infection.

⁴ In Kabarole, the research team included: Mr. S. Kamba, YFP Field Officer and Ms. Deborah Mouhoumouza, former teacher. In Tororo, the team worked with Mr. Haumbahatagata, YFP Field Officer, Mr. A. Ofono, Agricultural Extensionist, Ms. Helen Onyango, TASO Councillor and Ms. Deborah Musuane, Field Officer. In Gulu, the team comprised Mr. Otto Alli, YFP Field Officer, Ms. Florence Opoka, Gulu Government Hospital AIDS Councillor and Senior Nursing Officer, and Mr. William Odu, AIDS Councillor, Gulu Government Hospital.

During the field work, however, this criterion turned out to be largely irrelevant and inaccurate. Tororo, for instance, is considered to be among the districts with a low rate of HIV infection. This is, however, primarily due to the lack of data and the absence of research activities in the region. The only available data for Tororo concern HIV infection rates from antenatal clinic attendees which stand at about 13.2% in 1992 – a comparatively low figure.⁵ Part of the reason for the paucity of data is that there is only one NGO, The AIDS Support Organization (TASO), providing assistance with regard to HIV/AIDS in Tororo. A handful of other projects have HIV components but there is no coordination between them and the Ministry of Health or TASO. TASO has baseline data which have not been compiled or analysed on a systematic basis.

In terms of the number of reported AIDS cases by district and intensity of population, Gulu has the third largest number of AIDS cases in the country, but this may largely due to Lacor Hospital, which attracts people from many other districts and collects data on a systematic basis. According to this indicator, Kabarole and Tororo are close together in the low to medium category.

TABLE 2: DISTRIBUTION OF REPORTED AIDS CASES BY DISTRICT AND INTENSITY PER 10,000 OF POPULATION

District	Intensity of Reported AIDS Cases per 10,000 of Population
Kabarole	11
Tororo	12
Gulu	40
Kampala (highest in the country)	96
Moyo (lowest in the country)	1

Source: UNICEF, SYFA, *New Phase of UNICEF Support for AIDS Control in Uganda*, April 1992.

With regard to the number of parentless children in the three districts, Gulu ranks "high", Kabarole ranks "medium" and Tororo "low," as shown in the table below. However these figures can also be misleading: in Gulu, for instance, many of these children are war orphans and not children whose parents have died of AIDS. Similarly, in Kabarole, many of the children are born to unmarried mothers and are necessarily from families affected by HIV and AIDS.

TABLE 3: PARENTLESS CHILDREN RESULTS DERIVED FROM THE 1991 NATIONAL POPULATION AND HOUSING CENSUS

District	Total Population	Number of Children	Number Without Parents	Percentage
Kabarole	746,800	448,517	67,911	15%
Tororo	555,574	312,332	38,970	12%

⁵ Progress Report on AIDS Control Programme, Ministry of Health, 1.5.-30.9.92.

Gulu	338,427	190,895	40,840	23 %
Mpigi (highest)	913,867	269,869	90,193	33 %
Mbale (lowest)	710,980	398,576	39,240	10

Source: Ministry of Labour and Social Affairs.

Thus, after carefully considering statistical shortcomings, the difficulties involved in classifying districts according to one indicator, and the complexity of infection patterns within a given region, ranking districts according to "low," "medium," and "high" HIV rates or according to the number of reported AIDS cases ceases to be a valid and useful criterion. It may be more accurate to argue that each district has high, medium and low infection rates which vary considerably from one village to another, as the pattern of AIDS can differ radically from one community to another.

3. The third criterion was to conduct field work in districts where little research has already been undertaken; where there are few local and international NGOS active on AIDS, and where the need for intervention is great.⁶ Virtually no research has been conducted in Gulu, largely due to insecurity and distance from Kampala. Similarly, Tororo, as mentioned above, has been largely neglected by HIV researchers and NGOs. Kabarole has a comprehensive AIDS Control Programme supported by GTZ, but this has a limited radius at present, focusing mostly on urban centres and along the main road.

4. The fourth criterion was to visit two villages per district, one with an active Young Farmer Society (YFS) and another with an inactive YFS, as YFS were used as entry points for the field work on HIV and AIDS. Where possible, one of the two villages was off the main road. In Gulu, however, due to security reasons, both villages had to be chosen close to the town. The team first made a comprehensive assessment of the YFS, evaluating on-going activities, analyzing constraints and identifying ways of reviving youth groups before dealing with the socio-economic impact of HIV and AIDS and Knowledge-Attitude-Practice of youths on HIV and AIDS.

2.3.2 Procedure

In Kabarole District, the research team briefly visited Kantarara Village, but focused on Nyankuku and Bwabya villages. In Tororo District, field work focused on Kabosa Zone 2 and Bumanda villages, while additional research on HIV and AIDS was also conducted in Kwapa Village which borders Kabosa 2. In Gulu, research focused on Lawiye Adul and Layibi villages.

The first day was spent at the district headquarters, where meetings were held with key district officials, including District Administrators (DA), District Agricultural Officers (DAO), District Medical Officers (DMO), District Education Officers (DEO), Agricultural Assistants (AA), Field Assistants (FAs), NGOs involved in HIV and AIDS activities, Youth Organizers and Field Officers for Young Farmers. These meetings enabled the team to assess YFP activities in the districts and to get an overview of the impact of the HIV epidemic on agriculture, health and rural communities.

⁶ We are greatly indebted to Dr. Tom Barton of the Child Health and Development Center for his advice on the selection of the districts and on research methodology.

On average, the team spent three days in each village and applied Rapid Rural Appraisal and Participatory Rural Appraisal techniques. The first day began with informal talks with the Resistance Council Chairmen (RC1) and YFS leaders and was followed by transects. Focus group discussions with the YFS members focused on constraints, felt needs, reasons for the decline of YFP and lessons learned from the old YFP.

On the second day, focus group discussions on Knowledge-Attitude-Practice (KAP) on HIV and sexual behaviour were held with young men and women separately. Assessing situations of risk, identifying obstacles to behaviour change and identifying strategies and appropriate messages for HIV education involving the youths themselves were among the key objectives of these discussions. Focus group discussions developed into participatory HIV sensitization fora with lively contributions, question/answer sessions with the researchers and condom demonstrations. In-depth semi-structured individual interviews with HIV afflicted and affected families and youths were also conducted, with assistance from TASO or other trained AIDS councillors. Interviews with key informants on the impact of HIV and AIDS on agriculture and farming systems were also undertaken.

The third day included a visit to the local primary school where grade 7 (P7), and on one occasion female P6, pupils completed a questionnaire on HIV/AIDS and sexual behaviour. The number of respondents varied from school to school and from district to district. The KAP school questionnaire was followed by a focus group discussion on HIV/AIDS with the pupils and the teachers separately, a general talk on felt needs of school youths and on the role of the youth programme.

3. MAIN FINDINGS

The findings of this report concern only the villages, and to a certain extent, the districts visited. Given the diversity of the country and the complexity of HIV infection patterns discussed above, they cannot be applied to Uganda as a whole.

3.1 General Findings on HIV and AIDS

1. In Kabarole, HIV infection rates for the town of Fort Portal are estimated at 25%-30% and are steady; in semi-urban areas, HIV infection rates are between 12% and 14% and rising, and in rural areas they are estimated at 6%-9% and are also rising.⁷
2. In Gulu, HIV infection rates, according to Lacor Hospital data from ante-natal screening, show that 13%-15% of women from 16 to 40 years of age are HIV positive. Blood donor samples show similar rates of infection. Lacor Hospital has no data on rural areas.
3. In Tororo, for every reported person infected with HIV in the district, there are 50 others infected, according to the general manager of TASO, Mr. Geoffrey Dilothe. With a multiplication factor of 50, he believes that Tororo should rank among the "high" HIV-infected districts in the country.
4. The incubation period of the disease appears to be maturing in Kabarole and Tororo districts, as most of the widows interviewed had lost their husbands during the past three to 12 months).
5. The HIV epidemic is affecting the most productive age group in the villages. While it is impossible to obtain exact figures of AIDS cases, a basic but significant indicator is the incidence of AIDS in every family. Some families have more than one member suffering from AIDS. "Every home is affected by AIDS in Kwapa village," said Helen Onyango, a TASO AIDS councillor in Tororo. "Either a relative is suffering, a family member is dying, or someone suspects he has AIDS." "We are burying almost everyday; not a day goes by without burials," said one man in Kabarole. "Every village, every household, every family in Tororo has people affected by AIDS," argued Mr. Dilothe of TASO.
6. However, HIV and AIDS follow different patterns in each locality and it is difficult, if not erroneous, to generalize about a district on the basis of two villages. Geographic and ethnic factors, agro-ecological conditions, religion, gender, age and marital status play a role in the pattern and impact of the HIV epidemic and in people's perceptions of the disease. Even within one district, as was the case in Tororo, two villages can have radically different agro-ecological conditions and customs that determine sexual behaviour and attitude towards HIV and AIDS. It is therefore practically impossible to design nation-wide interventions for the epidemic.

⁷ Source: GTZ findings, observations and estimates. The data is derived from ante-natal surveillance which may not give a full picture for rural areas.

7. The impact of HIV and AIDS at the district level has been highly disruptive, as a significant number of highly qualified civil servants and technocrats are dying and are not being replaced. In Kabarole, the former DA and two, possibly three, of his staff have died in the past year from the disease. In Kantarara village, one extension worker who was very active with the YFP recently died of AIDS, signalling the downfall of the youth group.

The DAO in Tororo further noted that it is becoming increasingly difficult to implement agricultural programmes as a result of HIV and AIDS: extension staff are attending burials continuously and whenever the Department calls a meeting, only five out of 10 or 12 people are able to attend. Every time there is a burial, the work week is reduced from six to three days (Tuesday, Wednesday and Thursday) as people have to take Saturday, Sunday and Monday off (Friday is the official day of rest) to travel to the village and attend the burials. Thus, the HIV epidemic is exacerbating the problems of an already overburdened and under-resourced agricultural extension service.

3.2 Profiles of Families Affected by HIV and AIDS

The section below consists of four in-depth profiles of families affected by HIV and AIDS. The reason they have been reproduced in full in the main body of the text is that they provide a comprehensive picture of the socio-economic impact of HIV and AIDS on the lives of rural families, focusing on young men and women. Analyzing the socio-economic impact of the HIV epidemic in segments, as is done in section 2.3, can often conceal the cumulative impact of the disease. This section is intended to assist in a better understanding of the impact of HIV and AIDS and of the dynamics of coping mechanisms adopted by rural families.

Profile 1

Mary, who lost her husband to AIDS, is 42. She has 8 children, 25, 23, 20, 18, 16, 14 and 10 years of age, and an infant of 18 months. They live in Kwapa Village, Tororo District. Mary's husband, a policeman in Mbale district, died of AIDS in July 1992. He was a TASO client. She and her youngest child are HIV-positive and have tuberculosis. Her 23-year-old boy is retarded.

Mary is also a TASO client and, as she is not receiving any help from her late husband's family, TASO is her only source of support. Her family is suffering from severe food shortages. "There is almost no food in the house," she said. She tries to provide two meals a day but finds it difficult, and five to six times a month, she only prepares one meal a day – millet porridge.

Mary only grows millet and cassava, but last year the millet crop failed and this year the cassava is still too young to be harvested. When her husband was still alive, they grew beans, maize, rice, cassava and millet, occasionally using hired labour. These days, because of labour shortages and lack of cash with which to employ labour, she has had to reduce the number of crops under cultivation. It is only on rare occasions that she employs casual labourers. Most of the time, she has to do all the farm work herself but is too weak to do so properly.

With only two crops, she finds it difficult to provide a balanced diet for the household. The family eats mostly millet bread, sometimes with greens or beans and rarely with meat. When her husband was alive, she remarked that the diet was varied: flour, beans, powder milk, fish, rice and

cooking oil were bought on a regular basis. Hygiene was better because they could afford soap. In addition, she used to dry and sell some cassava and then use that money to buy essential goods. These days, she has reduced the acreage of the cassava shamba (garden) and there is no extra produce to sell. As a result, only rarely does she have money for salt, sugar, soap and beans.

The children who are over 10 years are helping her in the shamba and she is making a conscious effort to teach them how to grow food: "I am trying to teach them as much as I can before I get too weak; this is their only hope... I have to teach them how to grow food if they are to survive," she said.

The older children (10 years and up) work to supplement the household income. Three of them work in neighbouring fields as casual labourers, another buys soybeans whenever there is a little extra cash, fries it and sells it at the market, and yet another makes rope out of sisal fibre.

The impact of the husband's death on the family has been devastating. Mary emphasizes the loss of financial security and sharp decline in living standard as the most significant change. The economic hardship has put a lot of pressure on the children. They are maturing faster than she thinks is right for them, she remarked, and even though she realizes the danger involved, she added: "I have no choice; I have to make sure that even the youngest ones become independent before I die."

Her 20-year-old son recently ran away from home: "He was fed up with going hungry. There was no soap, no salt, no sugar, and sometimes not enough food in the house. He did not have proper clothing. One day, he disappeared and then we heard that he went to his cousin's sister far away from here. He left last April and has never been back since." He is now unemployed and does not assist his family. Mary fears that he may have run away because of the stigma attached to the family as a result of AIDS -- a stigma which he found too hard to bear. She never sees him and does not even know how he is surviving in his new home. Her greatest fear is that he will end up loitering and drinking in the nearby town.

Mary fears that some of her other children may follow his example and run away to relatives to escape from the AIDS stigma and the poverty. Her inability to take care of her children properly is devastating to her, as is the process of watching her whole family disintegrate. She worries that one day her sons and daughters will lose contact and will not be to help one another in times of need.

All her children have been stigmatized and ostracized from the extended family and the community. "Yesterday," Mary said, "my son came back from school in tears; his friends would not let him play with them because his father had died of SLIM." This has happened many times, she added, but "it saddens and depresses me more than anything else. To see my children go through this [humiliation] because of their father and myself is unbearable. And there is nothing I can do about it. I went to see the teacher to ask him to talk to the pupils, but I have done this many times before and nothing happened."

Mary considered education to be critical for the future of her children, but remarked that the AIDS stigma seriously jeopardized their chances of finishing school. Their future, she added, was largely dependent on the education they received and their perseverance as farmers.

Mary herself has been ostracized from the community and from the immediate family. She said that even though her late husband's family is in a position to help her and has the resources to do so, they refuse: "They are not willing to help me," she added, "because they do not want to help me. They even want to take the house [we live in]."

Her husband left her 12 cows, but she has already sold 7 to support the family, pay school fees for the children and medical bills. "After I sell the last five cows, I will have nothing," she added, indicating that the cows are her last vestige of security. She said that from now on she will be forced to rely on the children to raise cash.

Mary has never tried to talk to her children about HIV and AIDS. In fact, she said she had never told her children that she and her late husband were suffering from the disease. Her children know that she has AIDS but have found out from other people, during their father's funeral. When asked why she had not spoken to her children about AIDS, she replied that she found it too sensitive and painful now that she was also infected with HIV. She had tried to tell her children several times in the past, she said, but could not bring herself to do it. She said she would prefer an outsider to tell her children about her condition.

The story of Mary's eldest daughter, Rose, 25, married, and mother of a 4-year-old child, clearly delineates the impact of AIDS on rural families, and especially young women. Rose has finished primary school and attended four years of secondary school.

Rose had left her husband behind nearly six months ago to come and take care of her mother. She is very torn by this decision because on the one hand she wants to look after her mother, but on the other hand, she fears she might not have a marriage or a family to go back to. Her husband's village is far away and she is unable to visit him, even periodically. Rose worries that her husband might have already found another wife, or that he will refuse to take her back when she returns. She described being under enormous pressure, having to nurse her mother at the expense of neglecting her own husband and child. But her mother has no one else to help her, she added. Rose fears that if she does not stay, her mother will die and then, she wondered, "What will happen to her children?" Her siblings are all young and she will have to assume responsibility for at least five of them. Not only does she not have the means to support them, but she also fears her husband may not agree to take them in.

Rose grows and cultivates millet and cassava on her father's land for about four hours each day. Next, she tends to the housework and to her siblings. When the children return from school, they fetch water and fuelwood. She has difficulty managing the family all on her own while also taking care of her sick mother and indicated she had suddenly become a single parent of a large family. Controlling and disciplining the children, especially the boys, was her main worry. Her mother was trying hard to keep the family together, she said, but was getting too weak. Rose felt that no matter how hard she tried herself, the children refused to listen, particularly the adolescents.

Rose has learned about HIV and AIDS from her friends. Young men and women do not bother much about AIDS, she said. This she attributed to "negligence" on their part, largely a result of the fact that youths do not believe AIDS can "happen" to them. She has a lot of young women friends between the ages of 16 and 25 who have lost a partner to AIDS and fear they may be infected. "Some young women fear testing," she said, "try to deny the problem and forget all about it. When they suspect they may have AIDS, they become careless and go on a [sexual] rampage --

their argument being 'What about the days when AIDS was not there? People were still dying.' Even those young women who want to protect themselves from AIDS find it difficult to do so because boys do not respect girls who ask for condoms. They associate condoms with promiscuity and immorality. In general terms, she said, men and women her age are not faithful to their partners.

Rose remarked that these days many young girls are having sex to buy clothing, shoes, cosmetics and have extra pocket money. She attributed early sexual behaviour and multiple sexual partners partly to weekend beer parties and discos. Her description of these social events was as follows: About 30 to 40 boys and girls get together, with the consent of their parents. Some parents also join the parties. Children as young as 10 years thus begin drinking and engaging in sexual activity. The parties can last from two to seven days with continuous drinking and dancing. Rose pointed out that these days, youths dance "western style," which means that there is constant body contact, while traditional dancing does not involve direct physical contact. When people hold each other close, she added, they are easily led to sexual activity. "Almost none of the youths have condoms with them at the discos and even fewer use them" she added. About 10 years ago, discos were also popular in boarding schools but they were abolished under the pressure of the HIV epidemic. Those who are in school are more sexually active than those who are not in school, she thought.

Rose mentioned that one of the reasons why young people drink heavily is because girls learn how to brew the local beer from a very early age so that by the time they are 12, they can distil alcohol on their own. Alcohol, then, has become part of youth culture and is to a large extent socially acceptable. For young men, she said, drinking and casual sexual partners goes along with the lifestyle involved in smuggling in border towns where sex is easily available.

Rose feels uncertain about her future, about her own family and her siblings. She used to have a business of her own but lost all the capital. Now, she does not know how to start another business so that she can make a living and is not sure if she has a home to go back to.

She said what she needed most was counselling to help her cope with AIDS and practical advice on how to help her mother, siblings and herself.

Profile 2

Joseph, 33, has AIDS. His 30-year-old wife, who also has AIDS, has been sick for nearly two years and has gone back to her family to die, leaving behind 4 girls, 4, 6, 7 and 10 years old. Joseph has been sick for two years. His two sisters and four brothers also died of AIDS. He and his family live in Kantarara village, Kabarole District.

The household is now headed by his mother, but the family lives with Joseph's brother whose wife left him some years ago. Joseph's own house recently collapsed but he could not repair it because he is too weak. Joseph has some land which has not been cultivated for the past two years, ever since he got sick. His brother can hardly manage farming his own land singlehandedly; he is unable to tend to Joseph's land and their mother is too old and frail to help on the farm. Most of her time is taken up caring for the children and for Joseph.

None of the children are in school. The family exhausted its savings long ago, when Everlesto and his wife first got ill and sought costly treatment. Not only does the family not have money for

school fees, said Joseph's mother, but the children were not getting enough to eat and there was no money for Joseph to buy medication even though he was now in a lot of pain. When he first contracted typhoid and malaria, Joseph began treatment, but now he did not have enough money to complete it. He has never been visited by a health worker.

In fact, Joseph said that nobody was helping him and his family in the village. He said that the RCs were more involved in collecting taxes and enforcing the law rather than assisting families in need. Initially, Joseph said, the elders in the village held a few meetings to discuss HIV and AIDS, but they could not agree on how to proceed and dropped the issue.

Joseph's mother does not know whom to turn to. Her main concern is her grandchildren: "What will happen to them when I die, with no one to look after them?" she said.

Profile 3

Edith, a widow in her late 30s, has seven children, 25, 23, 22, 19, 18 and 12 years of age. They live in Tororo District. Edith was married when she was 13. Her husband died in April 1988 from AIDS. She also has AIDS, is bedridden and incoherent at times. She is a TASO client.

Edith was severely undernourished, exhausted, and unable to lift herself upright on the bed. The bed had no sheets and was soiled. Edith was emaciated and had not washed in several days. She shares the hut with her daughter, who is 19, has had five years of primary school, and is not yet married, but has a child of two years. When Edith's husband died, she sent her daughter to Kenya to work as a housemaid for two years, earning 6,000 US\$ per month. Her daughter entrusted her salary to her landlady for safekeeping but at the end of two years when she was about to return home, the landlady kept the money. Her daughter returned home without any savings. At present, her daughter is the only one taking care of her. "Without my daughter, I could not have managed. I would not be alive today," Edith said.

None of her sons are working. When her husband died, they all dropped out of school because she could no longer afford to pay school fees. Now they cannot find jobs. One of her sons is married and is living nearby. He only has a small cassava shamba which is not enough to feed his own family, let alone his mother and sister.

When her husband was alive, the family grew potatoes and sorghum on their 3-acre plot. Some of the sorghum was sold to buy soap, salt, meat, fish and paraffin. These days, Edith only grows cassava and millet. The husband's family has not claimed the land yet, but she fears this may happen at any time. When she feels strong, she works as a casual labourer to earn some cash. The daily wage of casual labourers is about 1,000 US\$ (about US\$.80). She would like to grow beans to diversify and improve the family diet but cannot do so at present as her yields have declined drastically. The old cassava shamba is nearly finished and the new one is too young to harvest. In addition, she said she tried to harvest millet this year but was unable to because the general body pain was too severe and she did not have the strength to work in the shamba. At present, the family does not grow enough food for subsistence.

Her diet consists of cassava, millet and a few greens. Edith's daughter tries to prepare two meals a day, but often they only have one. Eating the same food -- boiled cassava without sauce (there is no money to buy oil with which to prepare the sauce) -- has made Edith lose her appetite,

she said. "I cannot eat the same food every day anymore. I need some variety," she said. Edith had not eaten fruit for at least a month.

Edith has received no moral or material support from her late husband's family or from the village. No one ever comes to see her. Attitudes toward her and her family were very negative, she said. She does not want to ask for help from her husband's male relatives because she fears that their wives will suspect that she is sexually involved with them.

When she is not bedridden, Edith works from 5:00 am to 9:00 pm. This long workday exhausts her but she cannot afford to rest because she and her daughter would not have enough to live on. She described this as a vicious circle she could not escape from: on the one hand, she cannot grow enough food to feed herself and her family because she is too weak and hungry, while on the other hand she needs to eat properly in order to be strong enough to work in the shamba.

Edith's daughter, Florence, is 19 years old, has five years of primary education, and is the mother of a two-year-old child. She shares the hut with her mother and manages the household. One of her brothers is a farmer and a few times a year he gives them some cassava. Her other two brothers are being trained as prison wardens.

She cannot earn money during this period because the weeding was finished and there is no other work in the shambas. To raise cash, she has decided to brew adjono (local beer) as a last resort. She said she can earn 4,000 USh (a little over US\$3) a day selling adjono, while she only earns 1,000 USh (US\$.80) from farm work. It takes her 10 days to prepare adjono.

Florence has had no time to herself since her mother fell ill and hinted that her life was not her own since illness hit the family. She is depressed and feels helpless. Her mother has never talked to her about HIV or AIDS. Florence does not even know her mother has AIDS. She must suspect it, but does not want to admit it.

Profile 4

Patricia, 19, lives in Kwapa village, Tororo District, with her father's family. A 42-year-old hotel manager in Malaba (a small town near the Kenya border), he lost his wife to AIDS three weeks before we interviewed his daughter. Her mother's grave, which was right outside the hut, was still fresh. Her father, who is infected with HIV and sick, has two wives and a third partner in Malaba town who is also infected. His second wife, who shares the same house, has three young children living with her (two twin girls and one boy), but she does not think they are infected.

Patricia and her one-year-old son also have AIDS. They have aggressive herpes zoster on their bodies and her child has severe diarrhoea and dry coughing. During the interview, her baby was too weak to breastfeed and flies were swarming its eyes, mouth and open sores. She was not covering the open sores of the child, not for lack of caring but because of the futility of the gesture, she said.

Patricia's entire immediate family is infected with HIV, including her 10-year-old brother and her 7 and 14 year old sisters. When Patricia was asked how she thought her younger siblings got infected, she replied she was not certain whether this was through caring for her late mother or through sexual activity.

A farmer with primary school education, Patricia grows maize, cassava and groundnuts. Her family often does not have enough to eat because the cassava shamba is almost finished and they do not have another one ready for harvesting. She wants to grow more cassava but her father insists on growing millet. The family diet consists of millet bread and vegetables.

Patricia described her mother as the pillar of the family and said that her death had a devastating impact on the family. Now she has to rely on her stepmother with whom she, her late mother and her siblings never got along. Her brothers and sisters are neglected because their father still has his second wife and family. Patricia's stepmother has assumed responsibility for her siblings and, at the moment, they are all in school. But her mother's death is too recent and she does not know if her siblings will remain in school next year.

Patricia shares the cooking and other household work with her stepmother. She brews adjono in order to raise cash, but brewing is seasonal and for the rest of the time she does not engage in any income-generating activity. With the money she earns from adjono she buys soap, meat, matches, paraffin and clothes.

As she receives no help from anyone, Patricia has coped with her mother's death and her family's illness with great difficulty. She is severely depressed, apathetic and remote. It appears that she is so bewildered by what is happening to her family that she is unable to react. According to TASO, which regularly visits her father, Patricia has deadened herself to pain, anxiety and stress. She said she knows that her baby, her brother and sister, her father and herself were going to die and there was nothing left for her to do and nothing to hope for.

The most important thing in her life was school. She said she liked learning in a group and sharing interests with other people. She felt that education would give her a brighter future and a purpose in life. "I had dreams and I could try to make them happen" she added. But when she got pregnant, her father stopped paying school fees and she dropped out.

Patricia would like to see a youth group in her village encourage girls to develop skills and create income-generating opportunities that will keep them away from "bad company," as she put it. She said she had been misled as an adolescent because she did not have the confidence to stand up to boys and refuse sex. She would like to see young women have more opportunities than herself, she said and identified idleness, drinking and the absence of creative opportunities as the biggest problems for youths.

3.3 Analysis of the Socio-Economic Impact of HIV and AIDS on Rural Families

HIV and AIDS affect men and women very differently. The socio-economic impact of the HIV epidemic on rural families has different repercussions depending on whether it is the man/father or woman/mother who dies. It should be emphasized, however, that the analysis below may only be applicable to areas undergoing a peak in deaths as a result of AIDS, particularly among men. This appears to be the case in Kabarole, Tororo and Gulu.

A significant first finding is that in all three districts there are far more women who have lost their husbands to AIDS than men who have lost their wives. This trend was confirmed by AIDS councillors. In Tororo, Helen Onyango of TASO reported that only 5 of her 62 clients are widowers. The rest are young widows from 15 to 35 years. The reason for this is partly that men often have more than one wife. Many Christians and Muslims alike in Uganda are polygamous. In Tororo, 42% of all marriages are polygamous. Men who only have one wife tend to remarry soon after the death of their HIV-infected wife thereby transferring responsibility and care of the children to the new spouse. Some men begin looking for a second wife before their wife dies. When a woman/mother dies, the children are being cared for by the new wife. However, there are cases where the new wife does not tolerate the children who are then sent to the maternal aunt.

3.3.1 The Implications of HIV and AIDS for Widows and their Families

Before analyzing the socio-economic impact of the HIV epidemic on young widows, it is important to assess what happens to widows in general (including war widows and widows whose husbands die from causes other than AIDS) in order to isolate the impact resulting from HIV and AIDS alone.

In general terms, widows in Uganda face the following scenarios:

- * they risk having their husband's land confiscated, as women do not have the right to inherit land. Sometimes they also lose rights to land use;
- * they may lose their property to the husband's family, unless the husband has left a will. Property acquired during marriage belongs to the husband, according to customary law. Women do not inherit property when their husbands die. Legally, a wife (or wives) can claim 15% of the husband's estate but most women are not aware of their legal rights;
- * they may be inherited by the late husband's brother or near male relative and if they refuse, can be forced to return to the parental home. When they are not inherited and remain in the conjugal home, they are often without protection;
- * the only security for widows is their sons (13-15 years or older) who can claim land and property; in some cases, younger sons who are physically strong enough to stand up to the extended family and claim their father's property and land may be able to offer their mothers and families some security;
- * they often have sole responsibility for the children;
- * they suffer a significant loss of cash income, as a result of which their standard of living can decline drastically;
- * they often lose access to support services as it is usually the men who have access to inputs, credit and extension services; and
- * they are overworked, have little time to themselves and are thus hard to reach and mobilize.

The HIV epidemic does not only contribute to the rise of female-headed households on a large scale. What is significant about women whose husbands have died of AIDS is that they are younger and thus tend to have dependent children who need to be looked after and who cannot contribute to farm work and/or off-farm income-generation activities.

a. Women and their Families May Become Entrenched in Poverty

The interplay of a wide range of socio-economic problems resulting from the HIV epidemic often pushes women whose husbands have died of AIDS and their families below the poverty threshold, directly threatening the survival and well-being of their families. Even more importantly perhaps, female-headed households affected by AIDS become entrenched in poverty, as, in addition to the loss of labour and cash income, women have fewer legal rights than men, are often less literate than men, and have limited access to support services, credit and inputs. The result is a marked increase in poverty among AIDS widows. This feminization of poverty, a key characteristic of the socio-economic impact of the HIV epidemic, has far-reaching consequences for rural societies, and particularly youths, with girls/young women being most affected. Given the scale of the HIV epidemic in Uganda, the marked increase in poverty among young women and their dependent children is likely to have a profound impact on the nation as a whole, particularly on food security (as it is the women who are responsible for food production). For this reason, it is critical that interventions in the area of HIV and AIDS address this trend to mitigate its impact and arrest the crippling effect on Uganda's predominantly agricultural economy.

b. Women and their Families May be Stigmatized and/or Ostracized

The AIDS stigma, in particular, can sever the access widows would otherwise have to assistance from the extended family and the community. Much depends on how the husband's family reacts to the death of a son. Often, the widow is blamed for transmitting the disease to the son and is accused of promiscuity and immorality. Stigmatization may result in loss of respect within the extended family and the community, abuse and repression. Several young widows in Kabarole, Tororo and Gulu noted that their husbands' families could have helped them if they wanted to, implying that the problem was not lack of resources but contempt and stigmatization. Some women are harassed and forced to leave their village and migrate to the towns where they can escape from the stigma, earn their living as petty traders and re-marry in anonymity. The situation is worse for women who only have girl children, as the latter do not inherit land and property.

Ellen, a 52-year-old grandmother in Bwabya, Kabarole, described how her 23-year-old daughter was forced to leave her husband's village after his death to AIDS. She brought her two children to her parents' home and, unable to face the stigma, went to Kasese town to earn a living as a trader. This displacement, said her mother, has demoralized both her daughter and her children. Her daughter only occasionally sees her children and the strain on the old woman and her husband, who are too old and weak to care for their grandchildren properly, is only increasing with time.

Figure 1: The AIDS Stigma

c. Women may Develop a Crippling Anxiety Over their Sero-Status and the Sero-Status of their Children

If a man is known to have died of AIDS or if a woman suspects that her husband may have died of AIDS, the possibility of herself and/or her children being infected with HIV becomes "crippling," in the words of one young widow. The greatest anxiety of a woman over her sero-status concerns

her children rather than herself. A woman having lost her husband due to war may worry over the future of her children but she knows she can rely on herself to support her family. A woman having lost her husband to AIDS and who suspects she may be infected cannot rely on herself. This makes her helpless and, in the absence of assistance from the extended family and community, there are often no alternatives open to her.

Almost all widows interviewed in the three districts wanted to know their sero-status. Few women know where to turn to in order to get information and counselling on HIV testing. Most are not aware that there are testing facilities available in a nearby town. Ellen, a 52-year-old grandmother from Bwabya, Kabarole, mentioned that neither she nor her daughter were aware that one could be tested for HIV. The fact that AIDS widows feel the need to know their sero-status suggests that their state of helplessness can be overcome and need not be permanent. Providing women with information on HIV-testing and counselling is critical but may not be enough, however, as transport costs to the clinic can be prohibitively expensive, particularly considering that HIV testing requires at least two or three hospital visits.

One young widow in Kwapa, Tororo mentioned that even if she tested HIV positive, she could at least start making provisions for her children and plan their future. The viewpoint that it is better to know one's sero-status even if this is positive was echoed by young widows in all villages. In fact, most of the HIV-infected widows who already knew their sero-status are far from helpless. One woman in Bwabya, Kabarole, has left an informal will with the RC1 and given copies to the elders of the village. Others are trying to find out how they can secure the future of their girl children. One widow in Gulu who was already sick with AIDS decided to open a bank account for her eldest daughter of 16 years who was to care for the rest of her siblings. Both women recommended that widows be informed of alternatives so that they could plan the future of their children accordingly.

Most widows interviewed, with the exception of those who were TASO clients or clients of the Gulu Hospital AIDS unit, were not aware of the existence of wills. TASO and Gulu Hospital clients had difficulty accepting the rationale behind the will at first, but later recognized it as an absolute necessity for the survival and well-being of their families. Similarly, most women do not know how to open bank accounts and how to go about getting information with regard to their legal rights.

d. Widows Who are Inherited may Infect the Extended Family with HIV

Originally a social security system and safety net for widows who do not inherit land or property and have few legal rights, wife inheritance has become an acute problem as a result of the HIV epidemic.

According to tradition, in many parts of Uganda, when a man dies, his widow is inherited by his brothers or near male relatives. Wife inheritance is closely linked to the bride wealth paid by the man upon marrying a woman. The bride price effectively signals that a woman becomes the property of her husband and his clan.

Wife inheritance greatly facilitates the spread of HIV and has the potential of infecting several families very rapidly. When widows are inherited by their late husband's brother, they risk infecting them as well as their co-wives. If any of the wives has children, they may also be infected

with HIV. In some cases, widows whose husbands have died of causes unrelated to HIV may become infected with HIV if the brother-in-law is already infected.

In all three districts visited, widows are trying to challenge this institution to protect their families. However, there is considerable resistance to change, particularly among male family members. In some instances, this is a result of ignorance. For instance, a man who sees his late brother's widow looking healthy may ignore the possibility that she may be HIV-positive.

What is more alarming, however, is the fact that even though some men are aware of the dangers of wife inheritance, they insist on inheriting a widow at any cost. It appears that this may be linked to the bride wealth: as wives and their children are the property of the clan, if they are not inherited the clan loses claim to this wealth.

The fact that men insist on inheriting widows even when they have good reason to suspect that they may be HIV-positive is puzzling. Most HIV and AIDS initiatives do not deal with the issue of wife inheritance as it is a private and sensitive matter. TASO and ACORD are trying to challenge the institution, but find it a formidable obstacle to their work. TASO's greatest challenge, according to TASO Councillor Helen Onyango, is to convince elders and male relatives to discontinue wife inheritance. Only three out of ten times does TASO succeed in overruling customary practice.

In many parts of Uganda, wife inheritance continues. This implies that a) HIV/AIDS initiatives do not address the issue of wife inheritance; b) the imparted knowledge does not address the wife inheritance issue effectively; or c) the impact of this knowledge is neutralized as a result of women's inferior legal and socio-economic status, and the absence of negotiation/assertiveness skills.

Given the critical role that wife inheritance plays in the infection and/or transmission of HIV, there is an urgent need to address this problem, sensitize men and women and help families find alternative coping strategies.

The case of Agnes (see Figure 4), points to the fact that with some help, women can successfully resist wife inheritance. Agnes' husband probably did not die of AIDS and thus she did not have to face the AIDS stigma. However, the fact that she was able to stand up to the family, resist being inherited and remain in her home is significant in itself. In addition, elders pointed out that given the devastating impact of wife inheritance, proper sensitization addressing the dangers involved could play a catalytic role in eradicating the practice.

Miriam, a widow from Gulu, lost her husband to AIDS and is herself very sick with AIDS. Her brother-in-law tried from the very beginning to inherit her but she categorically refused, so as not to infect him and his wife. He has repeatedly told her that he does not care if she has AIDS and is willing to take the risk of becoming infected. He harassed her for almost a year, and when she still held firm and refused, he cut off all financial support to her and her four children. Now he is trying to claim the land that his brother left jointly to them. The paradox of her situation is striking: Miriam has been abandoned because she wants to protect her brother-in-law and his family from contracting AIDS. Once she refused him, she said, she became ostracized from the entire family and cannot rely on them for anything, not even moral support. Miriam's resistance to inheritance had a very high price attached to it, leading to a further deterioration of her family's well-being.

Figure 2: Widows' Dilemma: Being Inherited or Being Abandoned

3.3.2 Focus on the Socio-Economic Implications of HIV and AIDS for Orphans

The impact of the HIV epidemic on orphans depends on a variety of factors, including the socio-economic status of their families, their age and the age of their siblings. The following trends were observed:

a. Orphans May be Uprooted from the Towns and Sent Back to the Village

Youths whose parents die of AIDS in the towns are usually taken back to the village. Very often, the youths have to adjust at once to being orphans as well as to adapting to village life. In some cases, they may have never lived in the village and feel estranged from their new surroundings. The return to agricultural work is often looked down upon by city youths. In addition, the security and stability of family life is abruptly disrupted and there is no social safety net or mechanism to help youths through this transition. Family life education often ceases, thereby increasing risk behaviour among youths.

b. Orphans may Run Away from Home to Escape the Stigma and Poverty

In some cases, orphans may run away from home or from the extended family home to escape the AIDS stigma and the poverty that AIDS-afflicted and affected families are subjected to. A case in point is Mary's 20-year-old son, Paul, (see AIDS Profile 1), who left home to escape from the AIDS stigma and from poverty. He is now unemployed and his mother fears he may become a delinquent.

As a result of AIDS, Tororo district is for the first time seeing the emergence of street children,

Sarah, a 20-year-old widow, has two daughters, 2 1/2 years and 4 months old, both of whom are infected with HIV. Her husband died of AIDS at the age of 23, one month before we interviewed her. He was a temporary helper with the Ministry of Public Works. She is a TASO client and lives in Kwapa village, Tororo District.

Sarah was inherited by her husband's brother, according to custom. This was the only way she could have remained in her husband's home where she feels she belongs. If she had not been inherited, she would have had to go back to her family. Her husband's brother, a farmer, is supportive but cannot help her financially. He is married and has two children, 8 and 10 years old. Sarah is now working on her husband's land but fears that as she does not have sons, she may not be able to keep the land. She said she does not dare raise the issue with the family and hopes that her brother-in-law will support her. If he does not, she will have no alternative but to return to her parents.

Sarah is still healthy and has not yet felt the full impact of her husband's death. Her most immediate problem, beside the possible loss of rights to use the land, is her relationship with her brother-in-law. She said that he visits her regularly at night. As she is infected, she does not know how to handle the situation. She has explained to him that she is infected and he knows that his brother had AIDS. "He sees that I look healthy and wants to take the chance. He is not worried [about AIDS]. What can I do? I have warned him," she said. Sarah has not considered using condoms and is too shy to introduce the subject with her brother-in-law. Her co-wife is jealous of her and Sarah fears she may be chased away if she does not act according to custom. She wants to stay in the village even as an inherited second wife, as this is to her the best alternative.

Her brother-in-law does not help her financially and she works alone on her husband's 8 acres of land. She grows potatoes, cassava, millet and sorghum, but would also like to grow maize, beans and groundnuts to have porridge for the children and to sell some for cash. As she does not have cash at present, she intends to hire labourers and pay them in kind, even if this means that she has to reduce her family's food intake. She sells cassava to raise cash and also works as a casual labourer.

Figure 3: Defying the Dangers of Wife Inheritance

most of whom are orphans, according to TASO. Several TASO clients, aged between 8 and 14 years, left their villages to work in the town as boda-boda (hired cyclists transporting people and goods).

c. Orphans may be Taken out of School and Sent to Work

Under the pressure of the AIDS stigma which often severely hampers the ability of young widows to earn a living, orphans may be sent in the capital or abroad to make up for the loss of income and to help support younger siblings. A case in point is Edith (AIDS Profile 3), who after her husband's death sent her 14-year-old daughter to work as a housemaid in Kenya.

d. Orphans may be Sent to Live with Relatives or Neighbours

During the last funeral rites, a new head of family is appointed and the future of the orphans is decided upon. If both parents have died, the orphans are dispersed to various relatives. The disintegration of the family often means that adolescents and young men and women do not receive adequate attention and guidance from relatives, particularly family life education. Grandparents in particular often find themselves unable to control and discipline adolescents.

Losing a parent to AIDS means that orphans have to assume new roles and responsibilities within the nuclear as well as extended family. One AIDS widow in Bwabya, Kabarole, who has six orphans expressed grave concern about the impact of HIV and AIDS on her family: "The children are lonely and sad without any family around the house while I work in the fields. I do not know how to comfort them. I tell them they have to be self-reliant from now on, that they cannot even rely on me as I also fear I am infected. I know I am asking them to grow up before their time, but I see no other alternative if they are to survive."

Traditional roles, duties and responsibilities of family members become blurred, as AIDS places additional demands and pressures on orphans, particularly economic uncertainty, stigmatization and emotional insecurity. Girls appear to be carrying the brunt of the burden within the home and are given more responsibilities and duties than boys. They are taken out of school to work at home and on the farm and to sell produce in the market.

Some young women may be forced to break up their families to assist their HIV-infected parents. Rose (AIDS Profile 1) left her husband behind in January 1993 in order to take care of her mother who is suffering from AIDS. She is very torn by this decision because on the one hand she wants to take care of her mother, but on the other hand, she fears she may not have a marriage or family to go back to, as her husband may decide to take another wife. Even if he does not take another wife, however, Rose fears he may be engaging in high risk behaviour now that she is away but feels

Agnes, in her mid-30s, lost her husband 6 years ago but not to AIDS. She has 5 children, 17, 15, 10, 8, 6 years and an 8 month old baby. She has P4 education.

Agnes successfully resisted being inherited. Her husband, a farmer, who she believes was bewitched, left a will which stipulated that she was not to be inherited. His brothers tried to overrule the will but did not succeed and she was able to also keep his land and house.

Even if her husband had not left a will, Agnes said, she would have resisted being inherited. "Poverty is not an excuse for wife inheritance," she said. "Life is usually actually worse when a widow is inherited: widows become a burden to the co-wife who grows to hate them, may be jealous and seek revenge. Inherited widows are rarely happy and become slaves after the initial sexual interest of the brother-in-law wears off." She thinks women can resist being inherited but that self-assertiveness largely depends on how they are raised and on the type of relationship they had with their husbands.

Figure 4: Successfully Resisting Wife Inheritance

she does not have the right to confront him with it as she has "abandoned" him.

3.3.3 The Impact of HIV and AIDS on the Household Economy and the Family Value System

The impact of the HIV epidemic on the nuclear family ranges from break-down to disintegration, depending on whether one or both parents have died. The section below will analyse the socio-economic impact of HIV and AIDS on young widows, focusing on how the nuclear family breaks down and how the extended family network is strained to breaking point as traditional coping mechanisms collapse.

a. *The Household Economy Becomes Impoverished*

Having already depleted meagre resources and savings toward costly treatment for husbands suffering from AIDS and/or for funerals, widows suddenly find themselves deprived of labour, cash income and access to credit, inputs and support services. In widow-headed households with many young children and elderly and/or infirm family members, the impact can be devastating. The following coping mechanisms may emerge:

i. *The Working Day may be Lengthened*

Almost all widows interviewed mentioned that their working day had increased by two to four hours to make up for labour shortages and loss of income. One of the consequences of this coping mechanism, however, is that children were left unattended, their meals were poorly and hastily prepared and the widows' own health and diet deteriorated as a result of exhaustion and less food intake.

Older children (10 years and above) are also working longer hours to assist single parents and their contribution to agricultural activities increased significantly. Those who have lost both parents and are living with relatives are more likely to work longer hours than children who have only lost one parent and remain in the nuclear home. Children assume greater responsibility in gathering fuelwood and fetching water, to allow their mothers more time in the shambas.

James, a 19-year-old youth in Nyankuku, Kabarole, moved back to the village one year ago, after his father's death. A driver in Kampala, his father died five days after burying his two-year-old daughter who some suspected had AIDS. He also died of a "long illness." James lives alone in his father's house. His grandmother, a widow in her early 60s, lives nearby but has virtually no control over him. His half-sister, Miriam, who is 15, divides her time between the homes of James and her paternal uncle.

The young man has 3 acres of land where he grows bananas, sweet potatoes, beans, cassava, maize and eucalyptus trees. But both he and his grandmother are disillusioned with agriculture, which they believe condemns people to subsistence.

James and his half-sister stopped going to school because there was no money for school fees. His grandmother is worried about his future, but does not know what to advise him. James wants to move to a nearby town and become a driver. He wants to leave the land to his siblings, he said, because he does not belong in the village, where he feels "like an outcast."

Figure 5: Dislocated from the City to the Village

Maria, 33, widow, has five children, aged 2, 6, 8, 12 and 13. Her husband and his other wife died of AIDS in 1991. He was a cook in Makerere University in Kampala and used to send her money regularly. Her relatives abandoned her and she now farms two plots of land (2 and 3 acres) her husband left her. She sells banana juice to raise cash for casual labour. Maria has extended the working day by about three hours during weekdays and has virtually eliminated the few hours of rest she used to have on Sundays. She reported feeling increasingly weak, overworked and exhausted, and feared she might get ill, but did not now know how else to make up for the loss of income.

Figure 6: More Work, Less Rest, Poorer Health

Loss of agricultural knowledge was not observed in any of the three districts. This may be either because HIV has not hit the areas visited as hard as districts where loss of agricultural knowledge has been reported, such as Rakai and Masaka, but also because the disease is only now reaching its peak and the full impact is only beginning to be felt. In addition, agricultural knowledge is transmitted through women (mothers and grandmothers) and in the villages visited, there are more men than women dying of AIDS.

ii. Land Area Under Cultivation may be Reduced

Reducing land area under cultivation to accommodate labour shortages was the most commonly observed coping strategy among widows in the villages visited. Agricultural productivity tends to decline and families may become more vulnerable to crop failure. In Tororo and Gulu districts, vulnerable farming systems trigger periodic food shortages which are acutely felt by AIDS-affected families.

iii. Cash Crops may be Substituted by Less Labour-Intensive Food Crops

As a result of labour shortages and lack of resources for pesticides and other inputs, cash crops may be substituted with less labour-intensive (and often less nutritious) crops. Widows in Kabarole gave up growing tomatoes, a major cash crop, which they previously grew jointly with their husbands due to lack of money for fungicides. Rice and millet, which are labour-intensive, are also often abandoned in favour of maize and cassava which require less labour.

iv. Planting and Weeding may be Delayed Leading to Poor Harvests or the Loss of an Agricultural Season

When a family member dies, relatives stop working in the shambas and do not engage in agricultural activities anywhere from a week to several months, depending on the age of the deceased. At times, the entire village may stop agricultural activities for a week. If three people die consecutively, then farmers may neglect their shambas for three or more months. As a result, the time of planting is often delayed and some families may lose an agricultural season. The impact on food security can be severe and households may experience food shortages. Failure to comply with this custom can lead to beating or to ostracism from the family. There is evidence, however, that this trend is changing as people are forced to disregard cultural norms and resume agricultural activities after two or three days of mourning, particularly in Gulu.

Jane, 23, has two children, 4 and 2 years old, and lives in Bumanda village, Tororo. Her husband, a farmer, died of AIDS one month before we interviewed her. Both of her children have been sick for a long time, and she believes they are also infected with HIV.

Jane has not been able to work in the shamba for at least three months due to her husband's illness and the fact that the family has lost three other members in the last month, two of whom are suspected to have died of AIDS. She is already experiencing food shortages and about once a week prepares only one meal a day. The family diet consists mostly of cassava and millet bread, occasionally with smoked fish. She said she had no money to buy salt or cooking oil.

Figure 7: When AIDS Disrupts the Production Cycle

v. Shambas may be Neglected and/or Abandoned

HIV-infected men and women may be unable to engage in agricultural activities as they grow weaker and eventually abandon the shamba. Joseph of Kantarara, Kabarole abandoned his land

because he was too weak to farm (AIDS profile 2). If AIDS widows are themselves infected with HIV or already ill, they are often weak and therefore unable to work in the shamba. In Kwapa and Bumanda villages, several widows had ceased farming because they felt it was pointless to grow food when they did not know if they would survive the season. This was echoed widely across villages: "Why plan for tomorrow when you know you will go [die] today?" said one man in Kabarole. In other instances, if a mother has a sick child, she may have to neglect the shamba in order to care for it. Therefore, the impact on agriculture may also be indirect.

Victoria, 33, has five children 2, 4, 7, 8, and 9 years of age. She lives in Bwabya village in Kabarole. Her husband died of AIDS in early 1993 and she fears that the 2-year-old and she may also be infected. Victoria has been unable to plant this year and the land has been neglected because of two other burials in the family (her husband's two brothers). Each burial means that she cannot work on the land for at least a month, she said.

Figure 8: Abandoning the Shamba

Once shambas are neglected, AIDS-afflicted families become almost entirely dependent on relatives or neighbours for food and basic necessities. In extreme cases, AIDS-afflicted families may experience severe food shortages and hunger. A case in point is Edith (AIDS Profile 3) of Kwapa village, Tororo. A widow suffering from AIDS, she was severely undernourished as a result of skipping meals regularly and confining her diet to one or two foods. Edith was caught in a vicious circle of being unable to grow food because she was not getting enough to eat and was therefore not strong enough to work in the shamba.

However, it should be noted that while agricultural labour shortages were observed at the family level in all villages visited, these were not acute enough to have a significant effect on agricultural productivity at the village level.

The extended family network is also often unable to withstand the strain of the impact of the HIV epidemic. Poor families, in particular, with infirm children and grandparents that take in one or several orphans find that they cannot support even their own children properly.

In Elizabeth's case (see Figure 9), the impact of HIV and AIDS coincided with her husband's paralysis and her own illness. The burden of the fatherless children has virtually made it impossible for the family to cope. Elizabeth herself needs to go to the hospital to receive treatment but says that her sick child and husband are more in need of treatment than herself. Yet, the weaker she gets, the more difficult it will be for her to take care of the children and the infirm. Her case illus-

Elizabeth, 36, has 8 children from 3 to 20 years old, seven of whom are in school, including one who has a congenital disease. Her parents are dead and her elder brother died of AIDS. Her sister and brother-in-law also died of AIDS in 1987 at the age of 22 and 25 respectively, leaving her with four orphans. Two of them have since died of AIDS (2 years and 8 months old) and the other two (13 and 11 years old) are in school.

Elizabeth's husband, an education officer, will retire this year due to a congenital disease that has left him half paralysed. His condition is deteriorating rapidly and Elizabeth now has similar symptoms. Neither of them are able to work in the shamba anymore and it is the children who are growing the food. When her husband retires, the orphans will have to drop out of school, she said. Elizabeth is at a loss over what to do with the orphans, pointing out that she does not even know how she will be able to take care of her own children. "If my husband dies, how will I manage with 10 children?" she said.

Figure 9: When the Extended Family is Unable to Bear the Brunt

trates the fact that in many cases, the extended family may be in a weak position to cope with the HIV epidemic in the first place. In such cases, the HIV/AIDS burden may strain the extended family network to breaking point.

The same applies to Patricia from Kwapa village, Tororo (see AIDS profile 4), who has witnessed her entire family become infected with HIV. Her stepmother is already burdened with caring for four orphans and a sick husband. Patricia's fear is that when she dies, there will be no one to look after her children. Sometimes, she said, this makes her think it may be better if the children do not survive her.

Sometimes, the extended family may not consist of more than one individual. The case of Rebecca (figure 10), a young woman who heads a household of 11 girls/young women and does not have any support, is not unusual. Rebecca does not have access to any income-generating activity except for beer brewing. As she does not even have enough food for three meals a day, she cannot think about how she will be able to ensure that her children as well as her brothers' orphans, will stay in school. Rebecca said that if she had access to training for an income-generating activity that would help her supplement her income and could belong to a youth or farmer group, her situation could improve significantly.

b. The Health Status of the Nuclear/Extended Family may Deteriorate

i. The Nutritional Status of the Family may Decline

Loss of access to labour in the shamba may result in declining agricultural productivity which in combination with loss of cash income often leads to a deterioration of the quality of household diet and a reduction in the number of meals. Malnutrition is on the rise in Gulu among HIV-affected families. Lacor Hospital's Assistant Medical Superintendent said that kwashiorkor, which was never a problem in the past, had since three years ago become the main reason for child admission in the hospital, especially during the "hungry season".

It should be noted, however, that in Tororo and Gulu the decline in the quantity and quality of food consumption may also be the result of the "hungry season" (May-July) which affects poorer families, rather than a result of the HIV epidemic, per se. It can be argued, however, that HIV-affected families are harder hit during the "hungry season."

Rebecca, 35, was separated from her husband 10 years ago. She now takes care of her three children in addition to the three children that her brother left. A customs officer in Arua District, her brother died in 1992 and his wife died in 1993 of AIDS. Both her parents are dead. Her sick stepmother lives with her. She is also taking care of her late husband's 17-year-old daughter from another wife and her young child. Rebecca is the head of an 11-member household, all of whom are women.

Rebecca came to this village when her brother died. He left two acres of land where she grows maize, groundnuts, cassava and sweet potatoes for consumption. The children only work in the shamba on Saturdays. She sometimes hires casual labourers and pays them in kind. She brews waragi, but said it is hardly an income-generating activity as it is labour-intensive and yields very little profit. As she has no other alternative, however, she continues to brew and with the cash buys soap, salt and fish/meat. She only serves two meals a day: leftovers for breakfast and sorghum, sometimes with potatoes and greens, for dinner. During the "hungry season," (March to April), she works as a casual labourer for 500 USH (\$.45) a day and provides one meal a day for her family.

Her children are 13, 11 and 8 years old and are all in school. Now that her sister-in-law is dead, she is unable to pay school fees for the orphans. She foresees that they will have to be taken out of school and is pessimistic about their future.

Figure 10: When a Widow has to Support 11 People

Hunger among HIV-affected households was not witnessed in Kabarole. These families may have reduced the number of meals per day and resorted to a less varied diet but they still had enough to eat. This may be due to the fact that land is more fertile in Kabarole and farming systems are more resistant than those in Tororo and Gulu. Farming systems in Tororo (with the exception of Iyolwa county) and Gulu are more fragile. In Tororo, the soil is less fertile and food crops like cassava, sorghum and millet are more labour-intensive and need more attention. The seasonality of crops is also an important factor. In Kabarole, for instance, matoke can be harvested all year round. This is not the case with sorghum and millet in Tororo. Tororo is also suffering from drought and its sandy soils may be affected more severely. The district has a high population density and the land is cultivated beyond carrying capacity. In addition, the diet in Tororo is poorer because fresh vegetables are not readily available throughout the year. Vegetables (greens, tomatoes, eggplant, okra and pumpkin) are only available during the rainy season. In addition, vegetables need extra preparation, oil and spices which poor people cannot afford. Lastly, people in Tororo are not aware of the nutritional value of vegetables.

Declining agricultural productivity and loss of income often force widows to modify the family diet and, in particular, to:

- * Limit the Household Diet to One or Two Staple Foods

As a result of reducing the number of crops under cultivation and/or switching to less labour-intensive crops, the diet becomes restricted to one or two starches (finger millet and cassava, matoke, or poshio [maize porridge], often of poor nutritional value, that are served with a vegetable sauce. Few widows had money for meat/fish, cooking oil and some were no longer able to afford salt.

In Bwabya, Kabarole, one widow said that her family's diet changed drastically after her husband's death. When he was alive, she regularly bought oil for frying, milk, sugar, salt, maize flour for porridge, and soap. These days, she can only afford paraffine, salt, matches and soap. Food preparation has suffered as a result and the quality and nutritional value of the household diet have been affected.

- * Reduce the Number of Meals

Widows may be forced to reduce the number of meals they provide for their families. In Kabarole, the number of meals was in some cases reduced from three to two and in Tororo and Gulu from two to one. Young widows reported regularly skipping meals (especially lunch) thereby jeopardizing their health and their ability to take care of their families.

Joan, a widow in her early 30s, lives in Kantarara village, Kabarole, with her five children. Her youngest child is 3 and her oldest is 10. Her husband, an extension worker, died, most probably of AIDS, a year ago. Since then, she began skipping lunches in order to devote more time to the shamba. She also said that the quality of food she prepared for her children had suffered because she had less time to make nutritious meals and fewer vegetables and beans.

Figure 11: Less Time to Prepare Nutritious Food

- * Sell Part of their Produce to Buy Essential Goods and Medicine

Widows may be forced to sell part of the food they grow in order to maintain basic levels of hygiene and tend to their children's medical needs. Selling food crops to buy soap, matches and drugs was common, particularly in Tororo.

ii. Resources for Essential Medical Care and Treatment May be Depleted

Families affected by HIV and AIDS are required to spend most of the household budget treating family members with AIDS. As a result, there is often little money left to tend to children's health needs. The first expenditure to be cut when the household budget has been depleted is essential drugs, according to Helen Onyango of TASO Tororo. Widows are often reluctant to use the household budget to tend to their own medical needs and will postpone treatment in order to accommodate the needs of their children. The long-term consequences of this strategy are often disastrous for the family and by the time women go to the doctor, they are already quite ill and unable to care for their children.

c. Education may be Discontinued

According to TASO Tororo, one in five children of HIV-affected households in the district remain in school. HIV-affected families are often forced to take their children out of school either because they have no money for school fees or else because they need the children's labour. Families who receive orphans are faced with the dilemma of having to select which children to put through school. Boys are usually chosen over girls. In some cases, when all children cannot be accommodated, relatives are forced to select their own children over the orphans.

The AIDS stigma sometimes pressures children to drop out of school. In the case of Mary, (AIDS Profile 1), her son was virtually ostracized from school because his father had died of AIDS. Mary feared that skipping school could lead to dropping out of school altogether.

d. The Value System of the Nuclear and Extended Family may be Eroded

The socio-economic impact of HIV and AIDS is beginning to have an effect on the value system of the family as traditional norms and customs are breaking down under the pressures triggered by the HIV epidemic. The result is that the social fabric of the extended family is showing signs of erosion and the close bonds that hold family members together are disappearing. The ramifications of this erosion have yet to be felt fully.

Esther, a nurse, whose HIV-positive husband died of lung cancer in October 1991, has three children, 21, 18 and 16 years of age. Her first born wanted to become a doctor but as Esther did not have enough money for all three to go to school, he is now a Nursing Officer and is not paid a full salary. Her second child is in Teachers' College in Mbale District. The third is in Senior 4 in Kampala. Esther lives alone in the village and her children visit her only during the holidays.

She has one acre of land which belongs to her father-in-law but it is not enough to provide for her family. She sells passion fruit and bananas to raise extra money. Her salary as a nurse is only 13,000 Sh per month, all of which is spent toward school fees. Fees for one term for her daughter in S4 amount to 80,000 US\$. Esther sent her children to Kampala and Mbale to get their education due to the war and has not wanted to uproot them. Esther never left the village during the war. She tended the crops during the day and "I went to the bush to sleep at night; I kept quiet." The reason she did not leave the village was that she had to provide for her children and sick husband. "You must go hungry, you must go without clothes, you must make everything you possibly can to make ends meet and provide for the children," she said. And yet, Esther was devastated by what she called the near total lack of opportunities for children without education. Their only alternative, she said, was to return to the village where they had land.

Figure 12: When Paying for Education Becomes a Struggle

To give but some examples:

- i) the stigma attached to those infected with HIV is, as discussed above, in some cases, breaking up families and distancing mothers from their children;
- ii) parents are forced to either send their children to work or to take them out of school. In both cases, youths are being deprived of family life education which is instrumental in establishing a code of conduct between men and women and husbands and wives. Family life education is critical in the social development of young men and women, ensuring the transmission of family values, mores and norms, establishing a social/sexual code of conduct and setting limits in sexual conduct. Many parents attribute early sexual activity and multiple/casual partners to the disappearance of family life education;
- iii) in some areas, families are being forced to adjust burial rites and ceremonies to cope with economic pressures resulting from HIV and AIDS. Firstly, the mourning time is being shortened to only three or four days. Secondly, less money is being spent. And thirdly, the drinking and socialization taking place during burials is changing to discourage substance abuse and casual sex; and
- iv) traditions such as ritual cleansing⁸ and wife inheritance are threatening the well-being of the extended family as a result of the HIV epidemic but no acceptable alternative mechanisms have been developed.

3.4 Youth and HIV: Knowledge, Attitude and Practice (KAP)

3.4.1 Knowledge⁹

In all three districts, it was observed that HIV education initiatives primarily concentrate along the highways but do not reach villages even a few miles off the main road. Knowledge of HIV and AIDS is directly linked to distance from towns and roads. In general terms, people were better informed about HIV and AIDS in Kabarole than in Tororo and were very poorly informed in Gulu.

A recent ACP evaluation reported that "Awareness of AIDS [in Uganda] was found to be almost universal. Levels of basic knowledge about AIDS, particularly sexual transmission, were very high."¹⁰ As a result, HIV and AIDS initiatives are now focusing on the next step – translating

⁸ In many parts of Uganda, the spouse of a deceased person has sexual intercourse with a family member to be "cleansed" and to free the dead person's spirit.

⁹ Knowledge and awareness appear to be used interchangeably in AIDS terminology, despite the limitations of this tautology. While the distinction between knowledge and attitude can in some instances appear unclear, knowledge is interpreted as what shapes attitudes. This does not preclude, however, the fact that the relationship between knowledge and attitudes is a dynamic one, with one reinforcing the other and vice versa.

¹⁰ R. Moodie, A. Katahoire, et al., An Evaluation Study of Uganda AIDS Control Programme's Information, Education and Communication Activities, ACP (MOH) and WHO, 1991.

knowledge into behaviour change by empowering people to make informed decisions about sex.

In all six villages visited, the professed 80-90% awareness of HIV and AIDS that was quoted by many district officials, was incorrect. In one focus group discussion in Lawiye Adul in Gulu, 4 out of 13 women had never heard about HIV and/or AIDS and 8 did not know the modes of transmission. In four villages in Tororo and Gulu, villagers initially denied that the HIV epidemic was a problem in their communities and attributed it to witchcraft.

The TASO general manager in Tororo argued that "People may know what AIDS is [in Tororo], but they lack even the most basic facts about the disease." One reason why knowledge of HIV and AIDS has not been effectively imparted is that often it is taught in a top down one-way process rather than shared in an interactive manner. Teachers make assumptions about the level of knowledge of men and women that are often erroneous. When out-of-school youths do not understand something, they may be reluctant to ask questions for fear of being ridiculed. This is especially true of out-of-school girls.

Our focus group discussions revealed that even when people knew the basic facts about the disease, they understood very little about the dynamics of HIV and AIDS. Knowledge of the modes of transmission and prevention exists largely on a theoretical level: people can quote how the disease is transmitted but they do not understand how this may actually happen to them. As a result, this knowledge is academic and abstract, rather than practical and tangible, and does not relate to the individual's own life experience. It is the kind of knowledge that comes from memorizing rather than grasping issues. And even when women did have the basic facts about HIV and AIDS, they were not confident with what they knew about the disease and did not feel empowered by this knowledge. One reason for this is that most HIV messages have been health-oriented and have not been integrated in the overall social context.

This partly explains the prevailing stereotype that was observed in all three districts -- that it is the women who are responsible for spreading HIV. This stereotype has inflicted a heavy stigma on women and is a formidable obstacle to behaviour change as many men absolve themselves from responsibility by automatically blaming the women for the transmission of HIV.

Another factor which demonstrates that people have not understood the basic facts about the HIV epidemic is the abundance of misconceptions. In Gulu and Tororo, some people thought that those with blood type O are less likely to get HIV. A point of concern in all three districts was the transmission of HIV through mosquitoes. In Bumanda, Tororo, it was argued that someone who has malaria always tests HIV positive. In Kabarole, women and men believe that those who have syphilis or gonorrhoea do not get infected with HIV. Abstinence was perceived to be unhealthy, especially among young males. One male youth said that teachers at school had told them that if they abstained from sex, the tail of the sperm would fall off.

The significance of sexually transmitted diseases (STDs) in the spread of HIV is still unknown to most rural Ugandans and the incidence of STDs appears to be very high. In Tororo, STDs are rampant but men and women know very little about them. In Kabarole, people were more aware of STDs and usually sought treatment. Some young people, however, said that the cost of seeking medical attention was prohibitive. In Gulu, many women did not know much about syphilis and gonorrhoea and did not know that STDs can be treated. Some women knew about HIV and AIDS but not about STDs. In Bumanda, Tororo District, some people suffering from STDs were using

veterinary drugs given to them by retired Veterinary Officers. Both men and women were eager to have more information on STDs and how they can be prevented.

On the whole, five general observations were made in all districts concerning knowledge of HIV and AIDS:

- a. Adult men are far better informed about HIV and AIDS than adult women.

Men are more mobile, have more access to information and have more leisure time to socialize and exchange ideas. HIV and AIDS are often discussed in the bars, for instance. In addition, some men have the opportunity to attend HIV sensitization seminars. Not a single woman in the villages we visited had attended one. Training of religious leaders and opinion-makers has also tended to be male-oriented and none of the men who had been trained and sensitized in HIV-related issues had shared the knowledge with their wives or fellow villagers. In addition, health and community workers who are engaged in HIV sensitization tend to be men. Many reported that women were "not interested in health issues," but when they were asked if they had actually approached women to discuss HIV and AIDS, they admitted that they rarely did so. In Nyankuku, Kabarole, women said that no health workers ever visited their village but pointed out that since most health workers were men, they could not discuss with them intimate problems such as sexually transmitted diseases (STDs) and HIV in the first place.

- b. School youths are far better informed than out-of-school youths.

Although school and out-of-school youths are not distinct groups, one can trace substantial differences. School youths have direct access to information, greater opportunities and more choices in life. They are easy to reach, organize and monitor and for this reason they have been targeted extensively by governmental and non-governmental organizations working on HIV and AIDS. HIV education is now part of the school syllabus at the P5 and P6 levels. Findings from the school questionnaires distributed in three districts reveal that schoolchildren are considerably better informed about HIV and AIDS than out-of-school youths. In one school in Gulu, young boys and girls were even knowledgeable about condoms, in sharp contrast to out-of-school youths. Teachers confirmed that school boys are beginning to use condoms.

Out-of-school youths consist mostly of young men and women who have had little or no schooling. They constitute over 50% of the youth between the ages of 15 and 19.¹¹ Young women are by far the majority in this group. Out-of-school youths are hard to reach and difficult to target. They have little access to information, are often intimidated and lack self-confidence. They are rarely given the opportunity to learn about health issues and even in the rare instances where sensitization sessions are held, they are not specifically invited, made welcome and involved in discussion.

- c. School boys are better informed than school girls.

In all the schools visited, boys of 13-15 had a better understanding of the issues than girls of the same age. This may largely be a result of the fact that many young men have a P7 education while most girls drop out at the P3-P4 level before they begin HIV education at

¹¹ UNICEF, *Safeguard Youth From AIDS, New Phase of UNICEF Support for AIDS Control in Uganda*, April 1992.

the P5 and P6 level.

- d. Adult women are better informed than young out-of-school girls.
Several adolescent girls (married as well as single) in the six villages visited had never heard about "SLIM." In Nyankuku, Kabarole and in Bumanda, Tororo, out-of-school girls had heard about the disease but had confused information about transmission and prevention. Adult women appear to be better informed, mostly because they are more confident in raising sexual issues with their husbands while younger women feel too shy or intimidated by their spouses.
- e. Sex/HIV education within the family is almost non-existent.
In all three districts, parents do not discuss sex or HIV with their children. Some parents fear that talking to their children about sex and HIV may encourage them to become sexually active. Others find it too sensitive and embarrassing.

Most adolescents learn about sex and sexuality from their friends. For instance, the Medecins Sans Frontieres AIDS Control Programme in Moyo District found that only 16% of the people surveyed had subsequently discussed HIV with their children. HIV education campaigns have not been very successful in breaking down this taboo. Perhaps even more significant is the fact that in all three districts, young women who had lost their husbands to AIDS and were themselves infected, had not revealed to their children the cause of death of their father or their own sero-status. Edith (AIDS Profile 3) has not been able to tell her daughter about her condition and has not talked with her about HIV. Another widow in Bwabya, Kabarole, whose husband recently died of AIDS had not even considered telling her children about HIV and AIDS because they were not sexually active. When it was pointed out to her that children in the village were known to start at an even younger age than her children, she was surprised but said she could not bring herself to think that her children could ever be infected with HIV. With only one exception, infected widows had never discussed AIDS with their children. A frequently given explanation was: "I could not bring myself to tell my children." Often, it is during the burial that children find out the cause of death of their father from relatives or neighbours and their mother's sero-status.

3.4.2 Attitudes

"Youth still feels free from AIDS" remarked the DMO in Tororo, indicating that youths are carefree, fearless and feel they are invincible. This is largely true of rural youths whose attitudes can be extremely cynical. "The only medicine to AIDS is death itself," said one young man in Bwabya, Kabarole. A 25-year-old woman who recently died of AIDS in the same village, was reported to have had sex with "everyone she could mess with" in search of revenge.

The fact that in Tororo and Gulu villagers initially denied that AIDS was a problem in their communities partly shows that proper sensitization has not taken place and also explains why many people attribute HIV and AIDS to witchcraft. For some, witchcraft is a far more acceptable explanation than AIDS, which is associated with immorality. In Gulu, many people thought that AIDS was a form of punishment for evil deeds. A born again Christian in Tororo wondered if AIDS was the incurable disease that, according to the Bible, would come at the end of the world. Denial of the problem and witchcraft were not prevalent in Kabarole where people talked openly about HIV and AIDS.

Attitude is directly linked to knowledge or the absence of knowledge. The fact that many rural youths have largely an abstract knowledge of HIV and AIDS explains why they blame the HIV positive partner for transmitting HIV rather than themselves for engaging in high risk sexual behaviour. As a result, messages are not internalized, knowledge is ignored or dismissed, and does not translate into behaviour change. In Gulu, Mr. James Lomoro, District Inspector of Schools, argued that even actors are not abiding by the messages they communicate through plays addressing HIV and AIDS. HIV messages are viewed as a nuisance, he added, and when they recommend pre-marital abstinence, young people laugh it off.

The less people know about the disease the more negative they tend to be about HIV-affected families. Some men and women suggested isolating people with AIDS in camps, and since "these people are going to die anyway", they thought that resources should be reallocated toward HIV prevention for those who are free of HIV. Attitudes toward AIDS organizations can also be negative. In Bumanda, Tororo, some people blamed TASO for the spread of HIV, claiming that TASO helped sick people recover and resume sexual activity. As a result, clients do not want to be visited by the TASO vehicle, and councillors often have to park their car far from the client's home.

Tradition is often stronger than knowledge and it can make people overlook the dangers of HIV, according to Helen Onyango of TASO Tororo. For instance, a father who has lost a son to AIDS may still encourage his daughter-in-law to be inherited. And as discussed above, wife inheritance has not been challenged yet except in isolated cases, despite the dangers it entails.

Attitudes toward the "faithful partner" prevention strategy, are ambivalent and concern was raised over trusting one's partner: "I have a [girl]friend who lives in a village about five miles from here," said a young man. "I go there, perhaps every two weeks. How can I know what she does when I am not there?" Another one said: "The girls around here are very smart. They attract you in all ways and tell you they are healthy. What can we do?" And another: "How can we live without eating?" referring to the difficulty of being faithful to one partner or resorting to abstinence.

Attitudes toward blood testing were overwhelmingly positive, particularly among young women who feared they may be infected with HIV. Testing for HIV before marriage was also raised as a must. Some youths were sceptical about the reliability of the AIDS test and did not understand the need to have more than one test to account for the "window period." Youths wanted practical advice on how to go about persuading a partner to get the AIDS test. The need for communication and negotiation skills emerged as a critical issue in HIV prevention among young people.

3.4.3 Practice

a. Early Sexual Activity

Adolescents are most at risk because they tend to experiment more than married couples and have many sexual partners. For girls, adolescence may be very brief as childhood, marriage and parenthood are often very close together.

It has been reported that sexual activity in Uganda begins between the ages of 10 and 15 and that the average age of first sexual intercourse for boys and girls in Uganda is about 15 years.¹² Preliminary findings of a research proposal on the sexual behaviour of out-of-school adolescents (15-18 years of age) indicate that for both sexes, the reported age of first sexual activity is from 8 to 14 years and that penetrative sex begins at about 13 years. Some studies have found that more than 40% of girls have had sexual intercourse before the age of 14 years.¹³ Factors contributing to early sexual activity include poverty, overcrowding and urbanization.¹⁴

In Tororo District, a study of adolescent mothers conducted in 1990 revealed that 70% became sexually active between the ages 10 and 14 while 10% became active before the age of 10. These figures correspond closely with our findings.

Youths in all three districts are engaging in sexual activity increasingly younger for the following reasons:

- i. Children share the same hut with their parents until they are 10-12 years old. Lack of privacy means that children are present when their parents have sex, become curious and want to try it themselves.
- ii. Parents do not talk to their children about sex. Oftentimes, youths become sexually active before they are aware of the consequences and dangers involved not only in terms of HIV but also in terms of pregnancy and the contraction of STDs.
- iii. Parents do not spend enough time with their children and many youths, feeling neglected, turn to sex to compensate for the lack of attention.
- iv. When girls and boys visit each other, they bring cousins, relatives and friends along with them. They sometimes spend the night with the extended family or friend. These occasions provide opportunities for sex.
- v. Poverty often means that youths lack basic essentials and are willing to have sex in exchange for food, clothes, shoes, school fees, and other rewards or favours. In one school in Tororo district, most of the sexually active P6 girls had sex in return for food, clothing, money or a gift.
- vi. In homes where alcohol is consumed by one or both parents, sexual activity among their children begins earlier, sometimes as early as 6-8 years.
- vii. In Lawiye Adul, Gulu, boys of 13-14 years of age leave the parental home and are given their own separate homestead. This practice means that the family exercises little control over the

¹² NICEF, SYFA, ibid.

¹³ Uganda AIDS Commission, National Operational Plan for HIV/AIDS/STD Prevention

¹⁴ Bukisa, E., Rubagiza, J., Kavuma, L., Banura, C. and Lwanga, J., Research Proposal to Assess the Knowledge, Attitudes and Practices of Adolescents Towards HIV/AIDS and STD Infections in Two Selected Areas with a View to Develop Strategies for Behaviour Change, February 1993.

sexual behaviour of their children thereafter. Parents argued that this custom encouraged early sexual activity.

- viii. According to one school questionnaire, 27 out of 184 primary school children in Uganda who had had sexual intercourse reported that it was "forced."¹⁵ Forced intercourse may be violent and may result in lacerations and bleeding, thereby increasing the risk of HIV transmission.

Opinions on the onset of sexual activity varied considerably in the districts visited. Sexual activity in Tororo begins at around 10 for boys and around 8 for girls, according to Ms. Penninah Namusi, TASO Councillor Supervisor. School girls start having sex at 13 years and schoolboys at 15 years, but girls who are not in school can start as early as nine years of age, reported teachers of Kwapa Primary School. Parents in Nyankuku village in Kabarole said that children begin sexual activity at around 10 years. Women in Bwabya village, Kabarole, indicated that youngsters become sexually active from 8 years upward and this is directly connected to alcohol consumption. In Bumanda, Tororo, parents said that girls start sexual activity at 12 years and boys at around 14 years.

The phenomenon of "sugar mummies," older affluent women who seduce and often marry younger men in the belief that the latter are free from HIV, and "sugar daddies," is recent and not widely prevalent in rural areas as it is in urban areas. In Nyankuku, Kabarole, where there is a technical college/trading center nearby on the way to the primary school, many schoolgirls are befriended by older men who promise them money and luxuries. Girls reported that the risk of being approached for sex increased on their way to or from school, on the way to the well and on the way to the market.

b. Early Marriage/Unions and Childbearing

In all three districts, people reported that young men and women are getting married or raise families without being officially married at increasingly younger ages these days. In Tororo, according to one TASO Councillor, girls marry as young as 13 and 15 years of age. Some boys marry at 16. Girls may already have one or two children before they marry. In Nyankuku, Kabarole, men marry at 18, women at around 15 and some marriages are arranged. Teenage

The link between education and early sexual activity is highly controversial and opinions vary as to whether education delays or encourages early sexual activity and whether it plays a role in the number of sexual partners youths have. Opinions seem to be equally divided both among youths, teachers, parents and opinion leaders.

Male youths in Nyankuku village believe that education has contributed to early sexual behaviour because "girls don't fear boys anymore and so they play sex at an early age." A youth leader in Kabarole believed that boarding schools have increased encouraged early sexual activity largely because they have deprived youths of family life education. Many parents argued that school children today are given freedom too suddenly and do not know how to handle it. When rich men from the town approach schoolgirls in the village with motorcycles and expensive attache briefcases promising gifts, girls do not know how to respond since they have not been taught how to deal with this type of situation. An additional problem is that a number of girls are having sexual relations with their teachers in primary school.

Opinions also vary as to the vulnerability of school versus out-of-school youth to HIV; county officials and extension workers in Kabarole believe that school youths are not afraid of HIV and therefore tend to be more sexually active and have more casual partners. Others argued that school youths are more aware of HIV and thus more likely to protect themselves and be faithful.

Figure 13: Sexual Activity Among School and Out-of-School Youths

¹⁵ Bagarukeyo, H. KAP study on AIDS among school pupils in Kabale District, 1991

pregnancies and high divorce rates are a big problem in Kabarole district. In Gulu, divorce rates are high these days because, according to a farmer, people are not prepared for marriage.

One of the reasons for early marriage is the rising cost of living and the economic value of women. The bride wealth, which the groom pays for the bride, in Gulu, for instance, used to be a gift of 5 or more cows. One criterion for the amount to be paid is the level of education of the bride. These days, as cows are not available, bride wealth is paid in cash. Early marriage means early realization of the economic value of a daughter and parents who are struggling to raise many children may choose to marry off their adolescent daughters earlier than they would have in different circumstances.

As bride wealth rates are increasing, however, many young men have to wait many years before they can marry. Their options are: a) to live with women and not be formally married; this option, which is widely prevalent in Kabarole and Gulu, may encourage high risk sexual behaviour as unmarried men may be less inclined to be faithful to their partner; and b) to live alone until they are able to provide the bride's family with the bride wealth (which could amount to several years), in which case they may have multiple sexual partners, become infected with HIV and eventually infect their wives-to-be.

In Kabarole and Gulu, these changes in courtship/unions are jeopardizing women's socio-economic status: In the past, women in Kabarole indicated, when women got pregnant, men had to marry them, pay the bride wealth and assume responsibility for the children. These days, they often abandon the women they impregnate or else they do not (often cannot) pay the bride wealth. If a man does not pay the bride wealth, the couple is not considered to be officially married, according to customary law, and women's status within the community is at best precarious. She does not have the social recognition and legal rights that married women enjoy. This trend largely explains the large number of orphans in Kabarole. Women argue that when men do not feel obligated to marry pregnant women or pay the bride wealth, they are free to have more partners and shoulder fewer responsibilities.

The reason for the crisis within the family was largely attributed to the war. Insecurity, displacement of people, break-up of families, raping, death, and poverty all contribute to the breakdown of traditional courtship, marriage, and an erosion of the social fabric as a whole. The HIV epidemic has also compounded this trend by adding new pressures on to young men and women.

c. *Multiple Sexual Partners/Casual Sexual Contacts*

In Kabosa, Tororo, one young man said that by the age of 20, a man may have had as many as 50 sexual partners. A recent TASO questionnaire revealed that at any given time, men had up to 3-5 partners and women had up to 2-3 partners. According to the same source, in the past men had up to 8 partners. Both sexes admitted to having multiple partners in and out of marriage in all three districts. In Kabosa, women said that as many as 3/4 of married women were unfaithful to their husbands. Women blame the men and men blame the women for promiscuity.

3.4.4 Conclusion: Implications of KAP on Behaviour Change

Very few rural youths appear to be making informed decisions on sexual behaviour in the face of HIV and denial of the problem continues to prevail. "Let come what comes... AIDS is only for the day; during the night it is not there," said one man in Bwabya, Kabarole. Echoes of this argument were heard in all three districts. Some were underpinned with despair, others with hopelessness and apathy.

As argued above, one of the main reasons why few people are translating knowledge into behaviour change is that the knowledge they have is largely academic and abstract and they have difficulty internalising it. Another reason is that the knowledge of HIV and AIDS is not contextualized within a social framework, but is isolated in a strictly health/sexual level. Sexual behaviour may be very difficult to change in isolation from social norms, customs and leisure activities available for young people.

Thus, alcohol and drug abuse, bars and discos, are not tackled as issues that significantly influence social and sexual behaviour, and messages promoting faithful relationships may be hard for youths to rationalize. For instance, for a male youth who feels he has no opportunities in the village, has little education, drinks heavily and frequents the local disco regularly, and is restless and demoralized, the "faithful partner" message is both abstract and irrelevant. He may not identify with it and have little use for it.

A conversation among two young men in Kabosa village, Tororo, is particularly illuminating in terms of the limitations of knowledge people have of HIV and AIDS but also in terms of the significance of the socio-cultural context.

"I am married, my parents died, I must be careful."

"You are married, but how can you be careful when a woman passes by, more beautiful than your wife?"

"Can I accept to lose my life, just because of a beautiful lady?"

"The problem is when you are drunk."

"When I am a little drunk, I go home. There I can drink more and go to sleep."

In this case, the first young man is trying to remain faithful by resorting to heavy drinking, which may at first glance appear to indicate behaviour change but is a very deceptive and dangerous type of behaviour change which may even backfire in the long run. Yet, at first glance, it could qualify as behaviour change in terms of risk to HIV. The second young man also points out that behaviour change is sensible, but relates that common sense dissipates with drinking.

People's knowledge of HIV and AIDS often contains big gaps which prevent them from effecting behaviour change. For instance, many young men and women, single and married, expressed the desire to be tested for HIV as a first step toward changing their sexual behaviour. Most, however, had not gone for testing either because they did not know where to go or else because they thought it was very costly. One youth in Kabarole estimated the cost of an HIV test around 10,000 US\$ when in fact it is available for 500 US\$. Another youth in Tororo thought that an HIV test cost at least 7,000 US\$.

To conclude, behaviour change strategies that do not address socio-cultural norms, including early sexual behaviour, alcohol and drug abuse, bar and disco culture, ritual cleansing and wife inheritance, etc. but only hinge on sexual behaviour per se are not likely to be effective, particularly among youths. This may also explain why behaviour change is reported to be very difficult to measure. If behaviour change was also measured in terms of changing patterns in alcohol consumption and drug use, frequency of bar visits, etc., perhaps a more accurate picture of behaviour change would emerge.

This may also explain why previous strategies like "Love Carefully," and "Zero Grazing" have had a limited impact in Uganda. In Bumanda, Tororo, zero grazing was described by young men as an ideal that is very hard to put into practice, particularly during social occasions like burials where drinking is an integral part of the festivities. If behaviour change is to be effective, it should involve the youth itself in the generation of appropriate messages and incorporate social and cultural factors that influence sexual behaviour. For instance, one youth in Kabosa, Tororo, who had tested negative in 1992, advised his friend to go and get tested with his partner. To persuade her to go for testing and break the ice, he suggested that he tell his girlfriend "Let's go to town and I will show you how much I love you."

In addition, youths requested practical advice on alternatives to abstinence and were eager to discuss and share ideas rather than be told not to engage in sexual activity. Creating a forum for discussion, where concern about HIV and AIDS as well as respect for young people's sexual needs co-exist can help generate appropriate messages.

3.5 Youth and Condoms: Knowledge, Attitudes and Practice

While faithful relationships and abstinence are by far the most important and effective strategies against HIV/AIDS, condom use is especially important for youths, particularly adolescents and single young adults of both sexes.

Men believe that women dislike condoms because they fear they can remain inside their bodies. Women claim that "men completely resent the idea of condoms," especially those who are not educated. Both men and women believe that bringing up the subject of condoms shows lack of respect towards the partner. Some young men in Kabarole and Tororo had completely misunderstood the purpose of the condom and thought they should use it with their faithful partner. In Bwabya, Kabarole, a young married man wanted to use condoms for child spacing but feared bringing it up with his wife thinking she might think he was being promiscuous. In Bumanda, men said that they would only use condoms with their wives and not with a girlfriend, because the latter would think the men were infected. Young men and women pointed out that after drinking, few people would think of using condoms. Even if one remembered to use a condom, they would ignore it.

Condoms were the least used means for HIV prevention in all three districts. Knowledge of condoms was low among male youths and very low among female youths. To some extent, condoms are still associated with prostitutes or at least with immoral behaviour. One woman in Tororo said her husband brought condoms home and told her it was medicine. Very few men and women had ever seen a condom and proper condom use was almost entirely absent. A minute number of men actually bought and used condoms. In Bwabya, Kabarole, 2 out of 22 men in a

focus group discussion had used condoms. In Bumanda, Tororo, 4 men out of 25 had used condoms. Among women, in all six villages only between one and three women had heard of condoms and almost none had seen one. School youths had a much better understanding of condoms and in one school in Gulu, pupils had even had a condom demonstration. Teachers reported that pupils are open to using condoms.

Proper use of condoms is very limited. The fact that condoms can only be used once and then have to be disposed was not known to many people and using one condom for each round of sex was not obvious to either men or women. This has raised confusion on many levels. In Gulu, some young men, particularly soldiers, wash condoms and use them several times over. Sometimes they even share them among each other. In Bwabya, Kabarole, one young man told a story about how he got drunk one night and wanted to have sex. To be safe, he thought he would use three condoms. When he was half way through the sexual act, he said he thought to himself: "Do you eat sweets wrapped in paper?" He threw the condoms out, feeling "cheated." Inaccurate and/or inadequate information on condoms can easily backfire and discourage or alienate people from using them. In Kabosa, Tororo, the reliability of condoms was questioned and some youths were concerned that condoms may be appropriate for certain but not all sexual practices.

Both male and female youths overcame their shyness very quickly and were eager to be informed. In all cases, they invited condom demonstrations. Young women in four out of six villages inquired about the existence of female condoms, pointing out that male condoms were "useless" as women had no control over them. This brings up an important point: that condoms are primarily geared to men. Discussing how to introduce condoms in a relationship and when to use them is just as important as teaching people how to use them properly. Young women are eager to know more about condoms and to learn how to use them properly. Most, in fact, pointed out that even if they never used them, having the knowledge and option to use them was invaluable. Referring youths to places where they can obtain them and/or obtain more information on condoms is also critical.

An important point to mention on condom promotion is that assumptions on people's understanding of condom use should be kept to a minimum. Women were often not aware that the matooke (plantain) or cassava that were used during the sessions were merely demonstration tools. Some thought that they were supposed to insert the condom-clad cassava or matooke in their vagina. Given people's very limited knowledge of and familiarity with condoms in rural areas, condom promotion should deal with medical, family planning, STD and social dimensions and address specific needs, such as their reliability in certain sexual practices.

3.6 Factors Contributing to Situations of Risk Among Youths

Uganda has undergone continuous political, economic and social turmoil and change over the last two decades. The interplay and dynamics of change have shaped the lives and attitudes of rural youths and have, in some instances, exacerbated the adverse impact of the HIV epidemic on rural families.

3.6.1 War, Civil Strife and Demobilization

War and civil strife have had a profound effect on every facet of people's lives. In Tororo and Gulu, many men and women had to abandon their villages altogether and flee to the towns in search of security. Some continued to farm during the day and slept in the bush at night. Nearly all parents, however, were forced to send their children away and were separated from them for extended periods of time, sometimes even years. Often, children were sent to live with relatives or friends in the towns. After the end of the war, when families began returning to the village, the youths found themselves caught between town and village life and thus between the modern and traditional lifestyles and values. For many youths, the town has become synonymous with opportunity, easy money, and a chance to escape from the hardships of village life, particularly agriculture.

The war had a three-fold impact on young women: they stopped attending school; they married at an increasingly younger age; and they became more vulnerable to the HIV virus (many young women were raped during the war¹⁶ and reports from Gulu indicate that a very high proportion of soldiers are infected with HIV).

While the war is now over, demobilization is cause for alarm in the spread of HIV. From 1992 to 1994, the government intended to demobilize 5,000 soldiers. In Kabarole and Gulu there is already a high concentration of demobilized soldiers. According to Mr. Egac Rodney Ades, Deputy District Executive Secretary in Gulu, many demobilized soldiers joined the military after P7, at the age of 17 and are still very young. Infection rates among them are very high and their attitude towards HIV is often very casual. A soldier's profession is "to kill or to die" and AIDS is, for many soldiers, just another disease. "They are reckless and do not care about HIV/AIDS; their argument is that if bullets have not killed them, AIDS cannot either," said one woman in Nyankuku, Kabarole.

HIV-infected soldiers returning to the villages may be spreading HIV/AIDS to their wives and partners. Many young women are tempted to have sex with soldiers because the latter are associated with power and prestige, and often, they give their girlfriends food and clothing. Few girls are aware of the dangers of HIV infection and even those who may be aware of condoms are not necessarily able to negotiate with their soldier partners to use them.

In Gulu, several girls reported that forced sexual activity has not ceased and that "home guards" force them to have sex, to the point that they fear fetching water from the village well and going to the market to sell their produce.

3.6.2 Changing Attitudes Toward Agriculture

The combination of a diverse range of factors -- including war and civil strife, declining producer prices, the rising cost of living, and drought -- has made agriculture less appealing as a profession among an increasing number of male youths in Kabarole and Tororo districts. In Bumanda village, Tororo, youths mentioned that falling prices for agricultural products are discouraging young farmers. In fact, according to the deputy DAO in Kabarole, attitudes toward

¹⁶ In fact, according to one AIDS councillor in Gulu, men were also raped for revenge.

agriculture are becoming a serious problem in the district. "If you ask a child: 'What does your father do?' You will get the answer, 'Nothing, he is a farmer,'" said the deputy DA. Agricultural productivity in Tororo district is declining because the youth is losing interest in agriculture, according to the DA. "If you look in the gardens you will find only the elderly," he explained. "A man is not supposed to work on the farm. Most work is done by women and children.

Many youths are engaging in petty trade across the border which is more profitable, easier and more promising. This has created an "artificial" labour constraint: young men are not engaging in agricultural activities even though they are often unemployed, have no other occupation or source of income and their work is desperately needed on the shamba.

The adverse impact of the HIV epidemic is further reinforcing negative attitudes and disillusionment with agriculture. In Kabarole youths argued: "Why should [we] dig when [we] may die [from AIDS] next year?" Another said: "How can we think about planting when we do not know if we will be still alive for the harvest?"¹⁷

3.6.3 Economic Pressures/Lack of Income-Generating Opportunities

Youths who do not engage in agriculture have very limited opportunities in the village. Young men who are not in school, in particular, tend to loiter and drink heavily. For young unmarried mothers with children, many of whom are illiterate and have no access to training, credit and support services -- the only way to earn a living is through brewing beer and distilling alcohol. According to the accounts of several women, brewing and selling beer in their houses often means having men drinking around the home and this encourages high risk sexual behaviour.

The absence of on- and off-farm income-generating opportunities in rural areas is encouraging migration to urban centers. Out-of-school youths tend to move to urban centers in search of employment opportunities as housemaids or hawkers. In Tororo, some youths go to Kenya to work on sugar estates, but many more engage in smuggling and petty trade across the border, taking foodstuffs and cotton into Kenya and bringing sugar, bread, and manufactured goods into Uganda. Smuggling has become a way of life for many youths.¹⁸ Those who are unable to find jobs in urban centers may spend several months being idle. Survival under these conditions is precarious and desperate living conditions often leads to loitering and alcohol/drug abuse. Some young girls resort to prostitution in order to meet basic needs.

3.6.4 Increase in School Drop out Rates

The rising cost of living and economic pressures have led many youths (particularly males) and their families to contest the value of education, inducing many youths to drop out of school, especially girls. About 60% of pupils in Uganda enrolled in P1 drop out before they reach P7,

¹⁷ FAO's TSS-1 report on "The Effects of HIV/AIDS on Agricultural Production and Rural Livelihood Systems in Uganda" also found that young men's participation in farming activities is "marginal." In Gwanda village, Rakai district, young men prefer fishing and trading to agriculture because of the quick and high returns and because it is easier work.

¹⁸ According to some district officials, smuggling is now starting to decline, as a result of trade liberalization and the revival of the consumer goods industry (textiles, sugar, soda and beer are getting cheaper.

according to government sources for the period 1981-1987. Nearly 60% of girls dropped out of school between 1977 and 1983, according to another estimate.¹⁹ In Tororo, only one in five youths go to school, according to the DA. Attendance in Primary 1 is estimated at 40-60%, but falls to 10%-20% at P4-P7. Only 15% of children in Tororo complete P7. A USAID study in Gulu District reported that 71% of boys and 86% of girls dropped out of school between P1 and P7 in 1990.

Most pupils drop out of school because their parents cannot afford to pay for the school fees. When families have to choose which child to send to school, boys are chosen over girls. In all three districts, girls tend to drop out of school at P3 or P4, that is, before they are taught about HIV/AIDS. Marriage is a major reason why girls drop out of school: parents do not often see the need to spend money on their girl children when they know that the latter will eventually leave the home.

School enrolment in some districts is declining not only due to the rising cost of school fees but also because the rising cost of living often means that the children's labour is needed at home (children are involved in weeding, bird scaring, etc.). Similarly, many young men find it more attractive to earn a living through petty trading rather than go to school or engage in agriculture, particularly in Kabarole and Tororo districts. Even teachers are abandoning their profession to engage in petty trading. In the case of children, first, they tend to skip school only occasionally, but eventually they drop out altogether. Some are encouraged by their parents, according to the District Education Officer.

Some parents do not value formal education anymore because they feel they are losing control over their children as a result of it. "In the past, children obeyed their parents, stayed with their parents and helped their parents," said one grandmother in Nyankuku, Kabarole. "Now children go to school, leave the home and do not listen to their parents. I do not know if it is the fault of the school or not, but it certainly seems that way" she concluded. This argument was echoed in all three districts.

3.6.5 Social Factors Contributing to High Risk Behaviour Among Youths

The interplay of the above-mentioned factors and the devastation brought about by the HIV epidemic have contributed to the idleness, loitering and hopelessness which prevails among many rural youths. This is reflected in changing social norms and values, and in the way that young men and women relate to each other and interact socially.

a. Alcohol and Drug Abuse

In all three districts, drinking is central to the economy and social life of the family and the community. By and large, the women brew beer and distil alcohol and the men consume it. Local brews include tonto (in Kabarole), waragi (nationwide), quete and adjono. Tonto is obtained from fermenting banana juice by adding sorghum. Distilled tonto yields waragi. Adjono is a type of millet brew. Nearly all alcohol is home-made and is a substantial source of cash income for many households. Half a liter of tonto sells for 50 US\$ in the village. A tin of waragi (24 liters) is sold

¹⁹ UNICEF, SYFA, 1992, op.cit.

for 18,000 US\$. One family in Bwabya village earned about 40,000 US\$ a year from the production of alcoholic drinks. Some families raise money for school fees and for medical treatment while others buy food, paraffin and soap for their families from the sale of alcohol. Some women use the money they get from adjono to hire labour for the shambas.

Poverty and the lack of income-generating activities for women are the principal reasons for alcohol production. For AIDS affected families, brewing and distilling alcohol is often the only means of support. Faibe (see AIDS profile 3) indicated that she could no longer support herself and her mother through agricultural activities without preparing adjono.

Teachers in Kabarole attributed high alcohol consumption to Uganda's protracted war and political turmoil, indicating that people have become demoralized, lost interest in the future and in the future of their children, and resorted to drinking. Many villagers pointed out that alcohol consumption increased substantially during the war as a result of fear, insecurity, dislocation and hardship.

Women and girls who brew alcohol often use young children to sell it. As alcohol is readily available at home, children may begin drinking as early as 8 years of age and learn how to prepare it from 5 years upward. Girls of 12 years are able to prepare it without any help. Some women in Kabarole said that originally they gave their children alcohol to cure coughs and worms.

In addition, the sale of alcohol has given rural women some financial independence: women get to keep the money they earn from brewing and distilling. Some said that this independence has freed them from the confines of the home: "If one's husband has many girlfriends and the wife has her alcohol business and he does not control her movements every night, a woman may also seek other partners," said one woman in Bwabya, Kabarole. At the same time, several women cited alcohol as one of the worse problems facing rural families today and said it contributed to the high divorce rates.

In Tororo, waragi is considered a food and traditionally guests thank their hosts "for the cooking," after drinking together. Some people drink waragi instead of tea in the morning. When a child is given a name, it is also given alcohol to mark the occasion.

In conclusion, drinking is a critical economic activity, an integral part of village culture and a catalyst in social interaction. Most villages have makeshift bars. Kabosa, Tororo, has only 40 families and two bars, offering beer at 600 US\$. "Drinking is a duty one has to fulfil," one man said in Tororo. Male youths in Kabarole said that men who do not drink are fools, and identified drinking with virility. Youths admitted that when they are drunk, it is very difficult to exercise self-control in terms of sexual activity.

Men drink considerably more than women and out-of-school young men tend to drink more than schoolboys. Women do not drink as much as it is not as culturally acceptable. Wives do not drink with their husbands -- a husband who drinks with his wife is looked down upon by his peers, according to young men in Tororo.

Many young women expressed great concern about their husband's drinking and argued that alcoholism is on the increase. Some men, they said, spend a disproportionate share of the family budget on alcohol at the expense of school fees for their children. Other women worry that under

the influence of alcohol, their husbands become careless and have more casual sexual contacts. "They leave early in the morning and come back late at night; we have no time to discuss HIV/AIDS and sex because they are always drunk when they come home; sometimes we know they meet other women in the bars and we fear that they may be infected with AIDS" one woman in Bwabya, Kabarole, said.

In Kabarole, women also raised the point that when their husbands come back drunk from the bar, they demand sex. If their wives suspect they have other partners and refuse to have sex, their husbands may beat them and force them to give in. Many women indicated that if a woman succeeds in fending off her husband, he has the power to send her away and get another wife. In Uganda, as in most cultures around the world, sex is perceived to be a conjugal right that cannot be contested on any grounds. Mothers with young children are especially reluctant to take chances and refuse to have sex with their husbands, even if they suspect them to be infected with HIV. Women also said that whenever they have solicited the assistance of RCs and religious leaders to speak to their husbands about their drinking and multiple partners, their behaviour would improve for one or two weeks and then old patterns would be re-established.

In Kabosa, Tororo District, women wanted influential persons from the district or from outside the village to sensitize their husbands to the dangers of alcohol. When asked if the elders could wield some influence in curtailing alcohol abuse among men and particularly male youths, this was rejected categorically: "The elders have lost the respect of the people because they lost respect for themselves when they started drinking heavily," one woman said.

At present, HIV/AIDS initiatives do not address the problem of alcohol abuse for various reasons: a) the direct link between alcohol and high risk sexual behaviour has not been fully appreciated; b) alcohol production is closely linked to the survival of many poor families, so much so that when the DA in Kabarole tried to take measures to curtail alcohol consumption in the district, he was almost ousted; c) it is feared that linking the AIDS campaign to alcohol may backfire and alienate people from adopting safer sexual practices.

Drug abuse is also a serious problem among male youths in some districts, particularly in Kabarole. Marijuana ("bhang" or "sativa") and "mairungi" from Somalia are used widely in schools, according to Douglas Musana, Manager of the Health Information Center in Fort Portal. Some boys start as early as 10 years of age. In Gulu, drug use is not a recent phenomenon, but consumption has increased significantly among young men in recent years. Some youths in Layibi, Gulu, smoke opium which is also grown by adults as animal feed.

Drug use is not directly responsible for the transmission of HIV but contributes to high risk behaviour that leads to contraction of the HIV virus, much like alcohol abuse. Drug use has not been addressed by HIV/AIDS initiatives as a factor contributing to high risk sexual behaviour.

b. Bars and 'Discos'

Discos, which constitute one of the most popular forms of entertainment among youths in Uganda, can be a catalyst to sexual activity. The term "disco" is used to describe gatherings of 20-30 youths, between 13 and 30 years of age, where heavy drinking and dancing take place in private homes (see also AIDS profile 1 for a description of discos). High school pupils usually take their younger sisters and brothers to the discos.

Alcohol drinking is an integral part of disco culture: "If you are not drunk you have not gone to the disco," one young man in Kabarole said. Sometimes there is an entrance fee of around 200 US\$ or else people collect money to buy alcoholic drinks from the bars.

Discos have largely eradicated traditional courtship. One boy in Kabarole said, "you dance with a girl, then you go [and play sex]... there is nothing more to it..." Another mentioned that body contact during dancing makes it "impossible" to resist having sex afterwards. Traditional dancing does not involve direct body contact but western-style dancing is increasingly popular these days. After dancing western-style, youths said, sex is only "a small step."

Discos were recently banned by RCs in an effort to reduce high risk sexual behaviour but they continue clandestinely. In Kabosa, Tororo, discos took place twice a week in the old days, but at present, they occur mostly spontaneously, usually in the dry season.

To conclude, the interplay of diverse factors -- war and instability, the loss of appeal in agriculture as a profession, economic hardship and the absence of income-generating opportunities, the increase in drop-out school rates and alcohol/drug abuse -- have contributed to the creation of an environment of high risk behaviour for rural young men and women.

HIV education and mitigation interventions need to address the socio-economic realities of young people's lives if it is to be effective. A last important point is that young men and women, particularly those who are not in school, do not have access to recreational activities, and most importantly sports. Young men, in particular, often said that a football could be a popular antidote to early sexual activity. Footballs do not exist in any of the villages visited. Few schools have footballs/netballs. In western societies, sports have long been a favoured activity among adolescents and young men and women for reasons similar to those stated by youths in Uganda. In the absence of even the most basic forms of recreation, it is hard to envisage HIV prevention messages creating an impact on young people.

BIBLIOGRAPHY

ON AIDS

Action for Youth: AIDS Training Manual, League of the Red Cross and Red Crescent Societies & World Organization of the Scout Movement

AIDS Orphans: A Community Perspective from Tanzania, by Mukoyogo C., & G. Williams, 1991.

Ainsworth, Martha & Mead Over. The Economic Impact of AIDS: Shocks, Responses and Outcomes, World Bank Discussion Draft, June 1992.

Kabarukayo, H., Shuey, D., Babishangire, B. and K. Johnson. "An Operational Study Relating to Sexuality and AIDS Prevention among Primary School Students in Kabarle District of Uganda," AMREF, April 1993

Barnett, Tony and Piers Blaikie. AIDS in Africa: Its Present and Future Impact, London: Belhaven Press, 1992

_____. "Community Coping Mechanisms in the Face of Exceptional Demographic Change," Final Report to ODA, Executive Summary, July 1990

de Bruyn, Maria. "Women and AIDS in Developing Countries," Social Science and Medicine, Vol. 34, No. 3, 1992, pp. 249-262.

Bukisa, E., Rubagiza, J., Kavuma, L, Banura, C. and Lwanga, J.,
Research Proposal to Assess the Knowledge, Attitudes and Practices of Adolescents Towards HIV/AIDS and STD Infections in Two Selected Areas with a View to Develop Strategies for Behaviour Change, February 1993.

Children and AIDS: An Impending Calamity: The Growing Impact of HIV Infection on Women, Children, and Family Life in the Developing World, UNICEF, 1990

"Community-Based HIV/AIDS Research - Whither Community Participation? Unsolved Problems in a Research Programme in Rural Uganda" prepared by Seeley, J., Kengeya-Kaayondo, J., and D. Mulder, Social Science & Medicine, Vol. 34, No. 10, pp. 108-1095, 1992

Decosas, Joseph & Violette Pedneault, "The Demographic AIDS Trap for Women in Africa: Implications for Health Promotion," Paper presented at the VII International Conference on AIDS, Florence, Italy, 16-21 June 1991.

"The Development of a Community-based HIV/AIDS Counselling Service in a Rural Area in Uganda," prepared by Seeley, J., Wagner, U., Mulemwa, J., Kengeya-Kayondo, J., & D. Mulder, AIDS Care, Vol. 3, No. 2, 1991

District Mobilization for Prevention and Control of AIDS in Uganda.
Trainer's Guide for Health Workers, AIDS Control Programme, August 1991
Trainer's Guide for Community Leaders, no date.

du Guerny, Jacques & Elisabeth Sjoberg. "Inter-relationship Between Gender Relations and the HIV/AIDS Epidemic: Some Possible Considerations For Policies and Programmes," Division for the Advancement of Women, Center for Social Development and Humanitarian Affairs, UN at Vienna, 1993

Dynamics of Spread of HIV-1 Infection in a Rural District of Uganda, abstract, prepared by Maria Wawer, David Serwadda, Stanley Musgrave, Joseph Konde-Lule, Maako Musagara, Nelson Sewankambo, 1991

The Effect of HIV/AIDS on Agricultural Production Systems in Tanzania, FAO TSS-1 RAF/92/T01/A, Morogoro, September 1993

Expert Group Meeting on Women and HIV/AIDS and the Role of National Machinery for the Advancement of Women Report, Vienna, 24-28 September 1990

"The Extended Family and Support for People with AIDS in a Rural Population in South West Uganda: A Safety Net with Holes?," by Seeley, J., Kajura, E., Okongo, B., Wagner, U. & D. Mulder, AIDS Care, Vol. 5, No. 1, 1993

Gillespie, Stuart. "The Potential Impact of AIDS on Food Production Systems in Central Africa," FAO Nutrition Planning, Assessment and Evaluation Service, Food Policy and Nutrition Division, 1988

Gray, William. "The Potential Impact of AIDS on Agricultural Production and Consumption in Malawi," FAO, April 1991

The Hidden Cost of AIDS, The Panos Institute, 1992

HIV/AIDS Prevention Trainer's Guide, Partners For a World Without AIDS, Federation of Uganda Employers, Experiment in International Living, no date

"HIV Risk Factors in Three Geographic Strata of Rural Rakai District, Uganda," prepared by Serwadda, D., Wawer, M., Musgrave, S., Sewankambo, N., Kaplan, J., and R. Gray, Current Science, 1992

Hunter, S., Bulirwa, E., & E. Kisseka. "AIDS and Agricultural Production: Report of a Land Utilization Survey, Masaka and Rakai Districts of Uganda," 1993

The Implications of HIV/AIDS on Social and Economic Development in the Lao People's Democratic Republic: Strategies for Preventing an Epidemic, Conference Report, September 1992.

International Federation of Red Cross and Red Crescent Societies. World Disasters Report, 1993

Jena, Dirk. "Analysis of Audience Research and Identification of Family Life Issues for a National Population Communication Strategy," FAO/Ministry of Information and Broadcasting, Republic of Uganda, May 1992

Kagera Region Formulation Mission: Integrated Planning for Development and AIDS Intervention Programming. UNDP Reconnaissance Mission Report, March 1993

Kimani, Lillian. "HIV/AIDS Impact on the Family," Paper Presented at the First Kenya HIV/AIDS Conference, 21-23 April 1993.

Marum, Elizabeth. The HIV/AIDS Epidemic and US.AID Strategy, Kampala, March 1993

Medecins Sans Frontieres. Report on the AIDS Control Programme, Moyo District, Northwestern Uganda, January-December 1992

Mehryar, Amir H. "Surveys of Sexual Behaviour and AIDS-Related Knowledge, Attitudes, Beliefs and Practices Sponsored by GPA/WHO: A Summary of Main Findings and Implications for Intervention," March 1992.

Moodie, R. & A. Katahoire, et al., An Evaluation Study of Uganda AIDS Control Programme's Information, Education and Communication Activities, ACP (MOH) and WHO, 1991.

The National Youth Council Statute, Republic of Uganda, 1993

Norse, David. "The Socio-Economic Impact of AIDS on Food Production in East Africa," Paper Presented for the VII International Conference on AIDS, Florence, Italy, June 1991

Overseas Development Natural Resources Institute. "The Potential Impact of AIDS on Food Production and Consumption: Tabora Case Study - Tanzania,"

Obbo, Christine. "HIV Transmission: Men are the Solution," February 1991

Over, Mead. The Macro-Economic Impact of AIDS in sub-Saharan Africa, World Bank Paper, June 1992.

Progress Report on AIDS Control Programme, Ministry of Health, 1.5.-30.9.92

Research on Educational Aspects of AIDS in Uganda: An Inventory, prepared for UNICEF/Ministry of Health by Verner Kristiansen, May 1991

Safeguard Youth From AIDS: New Phase of UNICEF Support for AIDS Control in Uganda (Summary Document), April 1992

Turinde-Kabali, Asaph. "The Knowledge and Accessibility of AIDS Information to out-of-school Adolescents: A Study of Kiboga sub-county, Kiboga District," B.A. Research Paper, Makerere University, July 1992

van der Meeren, Rachell. "AIDS Education for Behaviour Change," Preliminary Findings Among the Bakiga of Kabalé & Rukungiri Districts, April 1991

Uganda AIDS Commission Secretariat. Uganda National Operational Plan for HIV/AIDS/STD Prevention, Care and Support, 1994-1998, Kampala, October 1993.

Uganda AIDS Control Programme. 1993 Plan and Budget, Ministry of Health, 1993

UNDP. Regional Bureau for Africa, Confronting the Socio-Economic Impact of AIDS in sub-Saharan Africa, Project Document

USAID. The HIV/AIDS Epidemic and USAID Strategy, March 1993

USAID-Funded HIV/AIDS Prevention Projects in Uganda, February 1993

USAID Support for the AIDS Information Center, February 1993

USAID Support for the AIDS Support Organization (TASO), February 1993

WHO. AIDS Series, Vol. 10: School Health Education to Prevent AIDS and Sexually Transmitted Diseases, 1992

ON UGANDA

Action Plan for Agricultural Policy Agenda, Agricultural Policy Committee, Report of Working Group 9B: Agricultural Extension Planning, Vol. 1, December 1990

Papers from the National Seminar on Youth Work in Uganda, Lweza Training Centre, June 1991.

UNICEF, Uganda Women's Needs Survey, 1988

UNDP Programming Mission on Poverty Alleviation and Rural Development. Report of the Agricultural Group, September 1992.

World Bank. Staff Appraisal Report, Agricultural Extension Project, September 3, 1992; this document has a restricted distribution and may be used by recipients only in the performance of their official duties. Its contents may not otherwise be disclosed without World Bank authorization.

Young Farmers of Uganda Programme. Monthly and Yearly Reports.

_____. National Workshop for Field Officers/Young Farmers Report, 1992.

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Biographical Note

UNDP HIV-RELATED LANGUAGE POLICY

Language and the images it evokes shape and influence behaviour and attitudes. The words used locate the speaker with respect to others, distancing or including them, setting up relations of authority or of partnership, and affect the listeners in particular ways, empowering or disempowering, estranging or persuading, and so on. The use of language is an ethical and a programmatic issue.

UNDP has adopted the following principles to guide its HIV-related language.

Language should be inclusive and not create and reinforce a Them/Us mentality or approach.

For example, a term like "intervention" places the speaker outside of the group of people for or with whom he or she is working. Words like "control" set up a particular type of distancing relationship between the speaker and the listeners. Care should be taken with the use of the pronouns "they", "you", "them", etc.

It is better if the vocabulary used is drawn from the vocabulary of peace and human development rather than from the vocabulary of war.

For example, synonyms could be found for words like "campaign", "control", "surveillance", etc.

Descriptive terms used should be those preferred or chosen by persons described.

For example, "sex workers" is often the term preferred by those concerned rather than "prostitutes"; "people living with HIV" or "people living with AIDS" are preferred by infected persons rather than "victims".

Language should be value neutral, gender sensitive and should be empowering rather than disempowering.

Terms such as "promiscuous", "drug abuse" and all derogatory terms alienate rather than create the trust and respect required. Terms such as "victim" or "sufferer" suggest powerlessness; "haemophiliac" or "AIDS patient" identify a human being by their medical condition alone. "Injecting drug users" is used rather than "drug addicts". Terms such as "living with HIV" recognize that an infected person may continue to live well and productively for many years.

Terms used need to be strictly accurate.

For example, "AIDS" should only be used to describe the conditions and illnesses associated with the significant progression of infection. Otherwise, the terms used

include "the HIV infection", "HIV epidemic", "HIV-related illnesses or conditions", etc. "Situation of risk" is used rather than "risk behaviour" or "risk groups", since the same act may be safe in one situation and unsafe in another. The safety of the situation has to be assessed each time.

The terms used need to be adequate to inform accurately.

For example, the modes of HIV transmission and the options for protective behaviour change need to be explicitly stated so as to be clearly understood within all cultural contexts.

The appropriate use of language respects the dignity and rights of all concerned, avoids contributing to the stigmatization and rejection of the affected and assists in creating the social changes required to overcome the epidemic.



HIV AND DEVELOPMENT PROGRAMME

Issues Papers

- 1. The HIV Epidemic and Development: The Unfolding of the Epidemic,**
Elizabeth Reid, 1992, *(also available in French, Spanish).*
- 2. The Economic Impact of the HIV Epidemic,**
Desmond Cohen, 1992, *(also available in French, Spanish).*
- 3. Female Genital Health and the Risk of HIV Transmission,**
Regina McNamara, 1991.
- 4. People Living with HIV: The Law, Ethics and Discrimination,**
Julie Hamblin, 1992, *(also available in French, Spanish).*
- 5. Sharing the Challenge of the HIV Epidemic: Building Partnerships,**
Elizabeth Reid, 1992, *(also available in French).*
- 6. Placing Women at the Centre of the Analysis,**
Elizabeth Reid, 1990, *(also available in French, Spanish).*
- 7. Behaviour Change in Response to the HIV Epidemic: Some Analogies and Lessons from the Experience of the Gay Communities,**
Adam Carr, 1991, *(also available in French).*
- 8. Women, the HIV Epidemic and Human Rights: A Tragic Imperative,**
Julie Hamblin and Elizabeth Reid, 1991.
- 9. "A Tora Mouosso Kele La" A Call Beyond Duty: Often Omitted Root Causes of Maternal Mortality in West Africa,** Alpha Boubacar Diallo.
- 10. Gender, Knowledge and Responsibility,** Elizabeth Reid, 1992.
- 11. The Role of the Law in HIV Policy,** Julie Hamblin, 1991, *(also available in French).*
- 12. Young Women: Silence, Susceptibility and the HIV Epidemic,**
Elizabeth Reid and Mike Bailey, 1992, *(also available in French, Spanish).*

13. **Children in Families Affected by HIV Epidemic: A Strategic Approach,** Elizabeth Reid with John Williamson, 1993.
14. **Approaching the HIV Epidemic,** Elizabeth Reid, 1993, *(forthcoming)*.
15. **The Feeling of Infinity,** Elizabeth Reid, 1993, *(forthcoming)*.
16. **Loving Someone Living with HIV,** Elizabeth Reid, 1993, *(forthcoming)*.
17. **Men and the HIV Epidemic:** *(forthcoming)*
 Changing the Focus, Elizabeth Reid, 1994.
 HIV and the Challenges Facing Men, Kathryn Carovano, 1994.
18. **Creating the Possibility of a Movement for Social Change:** *(forthcoming)*
 Breaking the Silences, Elizabeth Reid, 1994.
 Living with HIV, Elizabeth Reid, 1994.
19. **Towards an Ethical Response to the HIV Epidemic in Africa,** Elizabeth Reid, 1994, *(forthcoming)*.
20. **Confidential Sharing in Communities,**
 Capt. (Dr.) Ian Campbell and Alison Rader, 1994, *(forthcoming)*.
21. **Women's Stories: Living with Risks and HIV,** Beth Easton, 1995, *(forthcoming)*.
22. **The Processes of Social Change,** Elizabeth Reid, 1995, *(forthcoming)*.
23. **Living Within the HIV Epidemic:** *(forthcoming)*
 Living with HIV Infection, Elizabeth Reid, 1988.
 Two Voices, Elizabeth Reid, 1988.

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Statement

**James Gustave Speth
Administrator
United Nations Development Programme**

As Delivered

**HIV/AIDS Panel Appearance
Foreign Operations Subcommittee
House Appropriations Committee
Washington, DC
28 April 1994**

Mr. Chairman,

As the world enters the second decade of the HIV epidemic, there is a growing consensus that the challenges which the epidemic presents for people and for development must be confronted in new, innovative and vigorous ways.

Infection rates in adult populations can, and have, increased from two per cent to 25 percent in only a few years, before people are even aware that their communities have been imperiled. That is what happened in Malawi and Zambia.

In numerous African cities, HIV infection rates have reached 1/4 to 1/3 of the populations between 15 and 50. The HIV epidemic has the capacity to decimate whole communities.

In Kenya, it is estimated that GNP will be 15 percent lower by 2000 because of HIV/AIDS. This fact alone should be sufficient for the epidemic to be viewed as a disaster; a health disaster and a development disaster, all too often invisible in its early stages, and much in need of a massive and immediate response.

The epidemic affects people who are responsible for the support and care of their children, the elderly and extended family members. This means that by the year 2000 apart from the estimated millions of adults who are infected, sick or dead, hundreds of millions of dependents will have been affected: traumatized by the loss of their parents or children, left destitute, with families scattered or children homeless.

The extent of illness and death caused by the epidemic can, if we let it, deplete critical segments of the labour force, undermine the public sector capacity to govern, lead to social and civil unrest and adversely affect every sector of the economy. It is precisely for these reasons that this epidemic is a development challenge and a highly strategic one.

Mr. Chairman,

These consequences are not occurring in isolation. They are deeply imbedded in other challenges to sustainable human development: poverty,

unemployment, indebtedness, manmade and natural disasters and the status of women, to name only a few. These factors also contribute, in turn, to the expansion of the epidemic. Poverty is caused by HIV-related illness and AIDS deaths exacerbate existing poverty and create household indebtedness.

The epidemic is steadily wiping out hard won development achievements. In many parts of the world it is becoming a leading cause of child mortality and morbidity. Because of their social, economic and sexual subordination in many societies, women are disproportionately affected by the epidemic. A quarter of the world's households are headed by women; the proportion of women-headed households below the poverty line is increasing.

Mr. Chairman,

Some preliminary studies from Harvard University indicate that economic losses related to HIV and AIDS in a number of seriously affected countries could soon begin to exceed total foreign aid to those countries.

Will the world wait until the HIV disaster reaches its peak? Or will the world community provide now the resources for investments in education, health and social welfare and the technological development required to enable these nations to continue to function? Will there be global social safety nets to allow nations rendered poor by this epidemic, and the poor within nations, to survive?

The first decade of the epidemic has yielded significant research in the social and medical sciences and has afforded us many insights into the complex issues surrounding HIV and AIDS, thanks to the efforts of WHO and many others. Approaches have evolved which deserve continuing support.

But just as development theories of the past are being questioned, we must continue to innovate in our collective response to the HIV epidemic. We cannot put our thinking or behaviour into neat pigeon holes. UNDP recognizes that there are no simple formulas for policy, strategy and programme development for the epidemic. Approaches will necessarily vary depending on the stage of the epidemic in a country or a region and must be based on national capacities and opportunities.

In countries where the epidemic has already deepened, a blend of programmes is emerging; prevention and care, support and treatment,

programmes of assistance to survivors, and programmes addressing the broader scientific, psychological, social and economic implications of the epidemic.

UNDP's own involvement with the epidemic dates back almost a decade. Our primary aim is to assist countries to better understand the relationships between development and the HIV epidemic and to strengthen understanding of its potential psychological, social and economic causes and consequences.

We are not medical professionals; we are development professionals and HIV/AIDS is, in part, a development challenge. Our approach focuses on capacity building both within the government and within the nation as a whole. We work to build the capacity to anticipate HIV/AIDS, to plan, and to cope with its human, community, and developmental consequences.

We also take into account the need for the fullest collaboration among the many partners involved. These include, in particular, the World Health Organization, other UN agencies, USAID and other bi-lateral partners, community based groups, NGOs, research institutions, private sector groups, and most importantly, the affected communities.

Mr. Chairman,

The collective understanding of the epidemic and its impact is growing. One of the most striking lessons we have learned is that individuals and communities can be mobilized and empowered by it. We see this in every region.

Wherever the virus has spread, communities have responded, to provide care and support, to stop further infection, to assure the rights of the affected, to minister to their spiritual and emotional and physical needs. But individuals, families and communities cannot carry this epidemic alone.

There must be a partnership between governments and communities and the international community. Governments must provide an enabling environment that will evoke, nourish and sustain these responses. But more needs to be done.

Over 80% of new infections are occurring in the developing world, yet only 6% of global funds for HIV goes to developing countries, largely through health sector agencies, nationally and internationally (*World Development Report 1993*). More resources are urgently needed.

The closest the world comes to a global safety net is the current system of development assistance or foreign aid. However, this system is flawed, not only because of its overall low levels, but in the way it is programmed. Its allocation is unrelated to levels of poverty or the promotion of sustainable human development. Less than 7% of global foreign aid is spent on human priority concerns of basic education, primary health care, maternal and child health, safe drinking water and nutritional programmes (*Human Development Report 1992*).

If development assistance is to be able to help provide a safety net for the world's poor, it will have to be based on principles requiring that aid be directed to priority concerns for human survival, human rights and sustainable human development.

I am pleased to report that within the UN system, progress is being made to ensure a more comprehensive and collaborative response to the epidemic in support of national efforts. UNDP is working closely with its UN system partners and with the international community to more clearly define the issues, to reassess our collective strengths and comparative advantage and to forge a more effective system-wide partnership in response to this urgent and compelling issue.

Mr. Chairman,

Thank you for giving me an opportunity to address this subcommittee on an issue which is posing an unprecedented challenge.

* * * * *

SP9412.ENG

PLACING PEOPLE AT THE CENTRE OF THE RESPONSE TO THE HIV EPIDEMIC

by *Mina Mauerstein-Bail* *

The HIV epidemic and its impact on development is a complex topic, primarily because the nature and the extent of the challenges posed by the epidemic to governments and communities, and ultimately to human development are yet to be fully chartered. It is, however, already clear that the epidemic has profound implications for every aspect of national development and, if ignored or inadequately responded to, it could leave devastating consequences. The World Health Organization (WHO) estimates that by the year 2000, there will be a total of 40 million HIV infected persons. An increasing proportion of all new infections is occurring in developing countries, 65-70 per cent now, 90 per cent by the year 2000. An increasing proportion of adults becoming infected are women; at present, over one third, and at least 50 per cent, within the next 10 years. Increasing numbers of infants are being infected and children left without parents. The majority of all infected adults are in the 15 to 40 age group, the most economically and reproductively active group. At the same time, while research on the development of vaccines and chemotherapeutic treatments is moving forward, knowledgeable experts estimate that appropriate drugs and vaccines may not be available at least within the next 20 years. And even then, issues of cost and availability - especially in developing countries - will have to be addressed.

Knowledge of the social and economic costs and impact of any disease is important in formulating appropriate responses. In the case of HIV infection, this is particularly important not only because of the extent of the epidemic and the speed of its spread but also because it is anticipated that HIV-related illnesses and deaths will have a more adverse impact on families and communities than other fatal diseases. This is because of the clustering of HIV deaths in families and communities and the associated social disruption and because of the stigma and discrimination associated with the disease. In many places, human and communal survival is already threatened and children and the elderly have been left without support. The extent of the epidemic, the age groups it particularly affects and the consequences of this on communities and the economy mean that the HIV epidemic has the potential to impact on all aspects of development.

The HIV epidemic is more than a health issue. It impacts on a wide range of areas outside the health sector, including social and economic development, social welfare, education and training, employment, defence and law enforcement.

The response to the epidemic must show a sensitivity to the multitude of ways in which this epidemic has changed the lives of people all

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over the world. Only by understanding the human impact of the disease can we begin to address the very urgent and compelling needs it has created.

This means that national and international responses will need to encompass all aspects of the epidemic. In countries where the epidemic has already deepened, a spectrum of programmes is emerging, from prevention to care, support and treatment programmes, to programmes of assistance to those surviving after the death of a family member, through the programmes addressing the broader social and economic implications of the epidemic. These broader issues include, for example, the depletion of the labour force, the potential impact on the productive sectors of the economy such as agriculture, mining, industry, transport, the worsening of poverty, increasing homelessness and social and political unrest.

These consequences will not occur in isolation, but will be deeply imbedded in other obstacles to development: poverty, unemployment, indebtedness, and natural disasters, to name a few. These factors also contribute, in turn, to the expansion of the epidemic. Poverty caused by HIV-related illness and death deepens existing poverty and increases indebtedness.

The development of appropriate policies and strategies will be critical in ensuring an effective response to the epidemic. The issues upon which policies are needed are often extremely complex: moral, social, cultural, religious, psychological and legal factors must be taken into account. The epidemic forces discussion of sensitive issues about which frank public discussions may not be customary: sexuality, discrimination, and dying, for example. The very sensitivity of the issues requires a widespread consensus on appropriate responses. The diversity of options necessitates discussion. To achieve consensus, politicians, public health

officials and community leaders will need the courage to overcome discomfort and to speak openly, honestly and compassionately.

The mandate of UNDP is to assist developing countries accelerate the process of capacity building both within the government itself and within the nation as a whole, through support for human resources development, institution building, strategic planning and management and the promotion of human development. Through its network of 113 field offices around the world, UNDP has the capacity for on-going dialogue with, and the provision of flexible support to, recipient governments in over 150 countries. The greatest part of UNDP's resources are allocated to countries and people most in need.

UNDP's involvement with the epidemic dates back to 1987 when it began responding to requests from governments for support to HIV/AIDS programmes. In 1988, a formal Alliance to Combat AIDS was signed between WHO and UNDP. This Alliance provides for a complementary programme of action between the two agencies, building on their respective mandates and areas of competence. Under this Alliance, UNDP has been supporting the development and implementation of national AIDS programmes within the framework of the WHO Global Programme on AIDS. In fact, UNDP is the largest financial contributor to the WHO Global Programme on AIDS and since 1987 has provided more than 30 million dollars for country level prevention and control programmes. As the epidemic evolved, it became clearer that while there is no doubt that HIV remains a major public health problem, the nature of the epidemic, the speed of its spread and its socio-economic consequences demand a multi-sectoral, inter-disciplinary response with the fullest collaboration among the many partners involved. These include governments, international agencies, community-based

groups, NGOs, research institutions, private sector groups, and most importantly, the affected communities.

In recognition of the wider developmental dimension of the epidemic, the Governing Body of UNDP has given specific directions to UNDP within the general context of social and economic development:

- (a) to enhance our understanding of the developmental dimensions of the epidemic;
- (b) to support community-based programmes and programmes for women; and
- (c) to strengthen national capacity to minimize the adverse effects of the epidemic.

Essential components in UNDP's strategy on HIV/AIDS and Development include support for strengthening and expanding community-based programmes and programmes for women within the framework of its support to governments for the development of multisectoral policies, strategies and programmes.

Why are these essential components of our strategy? In 1990, WHO estimated that there were between 8-10 million people worldwide infected with HIV; of these 3-4 million are women. The number of infected women rose sharply during the second half of the 1980's and, in some areas of Africa, Latin America and the Caribbean, there was more than a four-fold increase over a 2 to 4 year period. It is estimated that during the next decade prevalence rates among women will equal and, in some cases, exceed those of men.

Because of their social and sexual subordination in many societies, women are disproportionately affected by the epidemic. The dynamics of sexual, social and economic relationships

between men and women mean that many women are unable to protect themselves against sexually transmitted HIV infection, the predominant mode of infection. Globally, it is estimated that 60 per cent of all cases of infection occur through vaginal intercourse. For Sub-Saharan Africa, the estimate is 80 per cent.

As wives and sex workers, women are at risk of sexual transmission. As mothers, women must deal with the implications of HIV infection for unborn children. As mothers, aunts, sisters, grandmothers and daughters, women will have to care for the children orphaned by the epidemic. As care givers, women bear the burden of caring for sick and dying partners, children, relatives and neighbours, while attempting to hold the family unit together in the face of sickness and death. On all these counts, women are disproportionately affected.

An understanding of the factors that affect women is critical to any effective measures to contain the spread of HIV and to deal with its effects for both men and women. The vulnerability of women to HIV must be understood in the broader context of deeply embedded social and gender inequalities which lie at the heart of women's inability to deal effectively with the risks and needs created by the epidemic. Unless the interaction between HIV infection, cultural values and the rights and needs of women is recognised, the fundamental change required to stem this epidemic is unattainable.

While women require urgent consideration in the response to the epidemic, interventions must mobilize all sectors of society, including individuals, and, in particular, men, families, communities and governments. The means for reducing the risk of infection must be available, accessible and affordable. Infected people need hope and need to be able to live positively and productively. They require access to counsel-

ling, treatment, support services and hope for their children who will survive them. Survivors need support to carry on.

UNDP recognizes that there are no simple formulae for policy, strategy, and programme development for the epidemic. Approaches will vary depending on the stage of the epidemic in a country or a region, but everywhere the role of community-based organizations will be central. The impact of the epidemic is so devastating that individuals, infected and not infected, need support. Throughout the world, communities have responded to this need, a need for assistance to change behaviour and for sustenance, when infected. The unfailingness of this response in affected communities justifies hope and the belief that the world will find ways to respond to the epidemic.

The need for psychological, emotional and financial support for people affected by HIV, for education and prevention programmes, and for the care and treatment for people with HIV can be addressed in a constructive and cost-efficient way by self-help initiatives and community-based programmes.

Community-based organizations can play multiple roles within a national strategy. They can facilitate behaviour change at the level of individuals, families, groups and communities. They can provide psychological, emotional and social support to affected families and survivors. They can provide home and community-based care, counselling and treatment. They can provide emergency support to families and communities, food and financial support. They can represent the needs and interests of the affected. They can lessen fear, stigma and discrimination. They can provide long-term assistance, including training, employment creation and income generation.

Communities around the world have started groups and programmes which respond directly to their needs and concerns. Amongst the better known of these in Africa are the AIDS Support Organization (TASO) in Uganda, the Chikankata Hospital Community-Based Care and Counselling Programme in rural Zambia, The Family Health Trust, The Umbrella Organization for community groups working with HIV in Zambia, and Wamata in Dar-es-Salaam, Tanzania. In Asia, the Duang Prateep Foundation, Klong Toey, and Empower in Thailand have initiated innovative community-based approaches to HIV/AIDS.

There must, however, also be a complementary and mutual reinforcement between the community response and the government response. In many countries, structures and mechanisms for effective interaction between these groups are not well established or lacking altogether. Collaboration and co-ordination among all participants is essential for an effective national response.

The extent to which national strategies and programmes succeed in effectively responding to the impact of the epidemic - an impact which will touch every aspect of personal, communal, social, political and economic life - will, to a great degree, be influenced by the ability of communities and governments to complement and reinforce each other.

We need to learn more about indigenous responses to the epidemic and how we, the international development community, can best support government and communities to plan, implement, monitor and evaluate effective HIV-related programmes.



**BRIEF PROGRESS REPORT
ON MAINSTREAMING HIV AND DEVELOPMENT
1990-1995**

Background

The mandate of UNDP is to promote human development by assisting developing countries accelerate the process of capacity building both within the government itself and within the nation as a whole. Because of the nature and scope of the HIV epidemic, human development will be placed in jeopardy and the nature of technical cooperation challenged and changed.

In recognition of this, UNDP:

- * from 1987 began committing its country-level funds (country IPFs) to strengthen national capacities to respond to the epidemic;
- * in 1988, entered into the WHO/UNDP Alliance to Combat AIDS; and
- * in 1990, appointed a policy adviser to the UNDP Administrator on HIV/AIDS and Development.

The main areas of responsibility for the Policy Adviser were to create awareness within UNDP of the development ramifications of the epidemic and to build its capacities to take the HIV epidemic into account in all aspects of its work (mainstreaming).

To this end a Policy Framework for the Response of UNDP to HIV and AIDS (DP/1991/57) was prepared within the framework of the WHO/GPA Global AIDS Strategy and submitted to the UNDP Governing Council in 1991. The Policy Framework states that UNDP will strengthen its capacity to increase understanding throughout the organization of the changes the epidemic will make in the nature of technical cooperation and to facilitate the introduction of such considerations into policy dialogues and policy development (mainstreaming). To achieve this end, it recognizes that UNDP will need to strengthen its capacity to respond to requests for financial, technical and other forms of assistance and to increase the capacity of the whole donor community to work effectively and collaboratively (para. 15).

It further states that UNDP will assign staff, including HIV and development specialists, according to need and within resource constraints, to ensure that the organization has the capacity to respond on an informed basis to requests for assistance. These will be

placed at appropriate levels and locations within the organization. It states that a full-time senior policy and programme adviser will be appointed at headquarters and will liaise closely with the HIV and Development focal points in the Bureau for Policy and Programme Support (BPPS) and the Regional Bureaux and in the Country offices (para. 30).

The delivery mechanisms for mainstreaming HIV into UNDP's work were identified in DP/1991/57 as (paras. 16-25) global programming, interregional programming, regional programming, Country programming, Special Programme Resources (SPR), Project and programme design, HIV-specific projects and project components, United Nations Volunteers, United Nations Capital Development Fund, Technical cooperation among developing countries (TCDC). In 1993, the use of TSS-1 funds were added as a delivery mechanism.

The Policy Framework (DP/1991/57) outlines the major means by which the HIV epidemic was to be integrated into UNDP's ongoing work in order to ensure that UNDP, other United Nations agencies and government counterpart staff fully comprehend the development dimensions of the HIV epidemic and that they are able to perform the various advocacy, managerial, programming and coordination roles and tasks required to implement this policy (para. 19).

In January 1992, UNDP established the HIV and Development Programme with the objective of strengthening the capacity of UNDP, and nations, to respond to the development challenges of the HIV epidemic in a collaborative, timely and effective manner (see attached Terms of Reference).

Implementing UNDP's mainstreaming mandate

The paper entitled "Mainstreaming the Policy and Programming Response to the HIV Epidemic" reflects on the experience of UNDP in carrying out its mandate to integrate into all aspects of its work a sensitivity to and a concern for the HIV epidemic. It should be read in conjunction with the paper which will outline the steps taken to implement this mainstreaming mandate.

The mainstreaming strategy developed by UNDP included the following elements:

- * Theoretical development
- * Constituency building
- * Programme development
- * Personnel management and support
- * Programme and project monitoring and review

Capacity Building

The capacities identified to implement this strategy included a think-tank unit, direct technical support, programme backstopping and documentation, monitoring and evaluation. A series of capacity building initiatives were undertaken to ensure that these capacities were in place:

- * in-house discussions (face-to-face, over time)
- * the development of training materials; for example, the "HIV and Development Workshop" which has been used with a variety of levels of UNDP staff
- * identification and dissemination of programming lessons
- * training of staff and consultants; for example, the training of consultants to assist in the process of establishing and sustaining national networks on ethics, law, human rights and HIV
- * seminars
- * issues papers and other publications
- * contributions to UNDP's strategic thinking on human development trends
- * project and programme appraisal
- * programme support and development missions to country offices
- * substantive guidance to all units

Institutional Structure

In order to implement this mainstreaming strategy, UNDP has set up two different types of institutional arrangements: mainstreaming-dedicated staff and mainstreaming-supportive staff. Mainstreaming-dedicated staff at Headquarters are currently located in the HIV and Development Programme. This unit comprises approximately 8 professional staff. One of these positions is funded from UNDP's core (PSDA) budget, the remainder from extra-budgetary sources.

These headquarters dedicated staff have recently been supplemented by the appointment of mainstreaming-dedicated staff in 22 Country Offices. The terms of reference for these HIV and Development National Professional Officers are to:

- a) Increase understanding of the epidemic as a pervasive development issue within UNDP, within governments and among all concerned individuals, groups and institutions.
- b) Strengthen national capacity to develop, implement, monitor and sustain effective and sustainable broad-based programmes that address the epidemic and which mobilize the human and financial resources of communities, NGOs and the private sector as well as those of governments.

- c) Strengthen the capacity of the UNDP Country Offices to contribute to the process of achieving a broad-based national response to the epidemic and to assist in the development of appropriate approaches to evaluation.
- d) Contribute to the in-country capacity of the UN system to integrate the causes and consequences of the epidemic into all aspects of national development.

In the interim before the establishment of UNAIDS, these staff may also, on request, assist the HIV Interagency Working Group on matters relating to UN system coordination and collaboration. In addition to on-going support, the HIV and Development Programme recently held a residential training workshop for these staff (as well as mainstreaming-supportive staff) during which the concepts and skills of mainstreaming HIV into good development practice were explored and refined.

Mainstreaming-supportive staff include the staff of UNDP's two regional projects and the extensive network of HIV and Development Focal Points. The main focus of the work of the staff of the Africa and Asia/Pacific regional projects are inter-country initiatives and concerns. They also provide assistance to the HIV and Development Programme in its mainstreaming responsibilities.

Since 1991, UNDP has had in place an extensive network of HIV and Development Focal Points. These are in all Country Offices and in each unit (or sub-unit) at Headquarters. These focal points are the point of contact between the HIV and Development Programme and individual staff members. They are responsible for ensuring that UNDP's policies and approaches are understood and integrated into the work of all staff.

HIV and Development Programme
UNDP
May 1995



ISSUES PAPER

MAINSTREAMING THE POLICY AND PROGRAMMING RESPONSE
TO THE HIV EPIDEMIC

Mainstreaming: HIV as a Development Issue

1. It is now commonplace to argue that policy and programming responses to the HIV epidemic need to be multisectoral and multidimensional. But what has happened on the ground has generally been a far cry from this. There continues to be a narrow understanding of the epidemic, both its causes and its consequences, and policies and programming responses have in most countries continued to be focused on a narrow set of conditions and issues.

2. An important objective of UNDP's activities, undertaken as part of the UN system response, has been to strengthen understanding of the epidemic as a developmental issue. In pursuit of this objective UNDP established in 1992 the HIV and Development Programme with one of its strategic programming areas to "mainstream HIV....for example, in village self-help schemes, food security systems, regional planning approaches, etc., through studies, workshops, training and technical assistance" [HDP Strategic Programming Areas, 1992-1993]. UNDP has argued that development is causally related to the spread of HIV infection; that development affects what is feasible in terms of the response to the epidemic, and that efforts to strengthen the development performance of countries can themselves worsen as well as improve the possible policy and programming responses to the epidemic. Unless these developmental parameters are adjusted, through a strengthening of national policy and programming responses, there will be an intensification of the social and economic costs of the epidemic which will increasingly undermine all of the national and international efforts to achieve sustainable human development.

3. To take a few examples related to UNDP's priority areas for the present planning cycle and the next [Sixth] cycle.

- * Poverty is clearly a major factor in leading to behaviours which increase the transmission of HIV, and furthermore the numbers of those destitute will be raised as a result of the epidemic - both directly and indirectly. Research undertaken as part of the UNDP Regional Project for Asia and the Pacific in Thailand and the Philippines on households affected by the epidemic, has established not only short-term effects on family incomes, but longer-term consequences caused by the

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erosion of assets and reduction in employment which threatens family survival.

- * Creating the conditions essential for sustainable agriculture will become even more intransigent given the actual and predicted effects of changing agricultural labour supplies - particularly its gender and age distribution - on rural systems of production and infrastructure. That the effects are severe is confirmed by studies of the impact of HIV on agrarian systems undertaken by FAO, with financial and technical support from UNDP, in Zambia, Tanzania and Uganda. The results of these studies are presently leading to a re-examination of agricultural policy and programming in all 3 countries as well as in FAO.
- * Environmental objectives will become increasingly unattainable as the epidemic worsens economic performance and undermines the national capacity to respond not only to the epidemic but to other developmental priorities. In many countries, public services are now suffering the loss of skilled and professional labour which threatens their effective functioning at the same time as programmes of retrenchment are being put in place. How to mainstream HIV in programmes of public sector reform in high prevalence countries remains a critical challenge, and one which UNDP is attempting to address in countries such as Zambia where adult HIV infection rates may be as high as 25%.

4. What is needed is a more complex understanding of the epidemic than has existed hitherto, together with an increased capacity for designing and implementing more effective policy and programming responses. All of these conditions need to be present for an effective worldwide response to the epidemic, of which UNAIDS is an important component. **Mainstreaming HIV has to contain all of these - a more complex understanding; a capacity for improved design of programmes and projects through new processes which are socially inclusive; and new and different and more participatory systems for implementing programme responses.**

If these conditions are not met then policies to mainstream HIV may produce outcomes similar to attempts to mainstream gender, where UNDP and others have much experience. At least one eminent development practitioner has argued that "Mainstreaming gender has been a way of forgetting about it". There is more than a grain of truth in this observation. The lessons of UNIFEM and others need to be captured in any attempts to mainstream HIV for, unless they are, then efforts to do for HIV what has signally failed for gender will

lead to similarly disappointing and ineffective outcomes.

An Example: Legal, Ethical and Human Rights

5. It may be useful to turn to the example of HIV and legal, ethical and human rights where UNDP has played a significant role in raising awareness of the central importance of an enabling framework of laws and rights, and in strengthening national capacity to respond. Too often policies for HIV are seen as having separate components, and human rights is sometimes just another of these elements. But this misses the essential point; that everything to do with HIV has to be founded in a set of appropriate ethical principles. This objective cannot be achieved through the imposition of "standards" from outside nor by setting up human rights watchdogs, although the latter may have some value. To be effective policies need to be based on a collaborative approach that seeks to protect human rights and establish supportive ethical principles through working with affected communities and their allies, irrespective of whether one is addressing issues of prevention, research, care or whatever.

Mainstreaming here entails a process - working collaboratively with the legal and affected communities to strengthen national capacity in the area of ethics. In so far as this process is successful there will be opportunities for improved programming across the range of development practice and NOT just in areas of narrowly defined projects for HIV. Thus non-discriminatory labour practices are relevant and important for all workers but they are absolutely crucial for effective workplace programmes for HIV prevention and care. Similarly, establishing new relationships of confidentiality and trust are critical for the kinds of socio-behavioural research on the epidemic which is needed for an effective programming response to HIV. This is also equally valid in other areas of development where research is too often extractive, externally defined and inadequately founded in any acceptable set of ethical principles.

Mainstreaming HIV: Some Practical Proposals

6. The final objective of mainstreaming HIV is self evident: to ensure a more effective policy and programming response to the HIV epidemic. How best to achieve this objective is much more problematic. UNDP has had much experience in this area in recent years upon which to build. There will need to be prior capacity building for a broad range of development practitioners in order to bring about the desired set of outcomes. This capacity for

mainstreaming is not currently in place, and will need to be created and strengthened if a more integrated approach to HIV is to be feasible.

7. An **intermediate objective**, which is essential for achieving the objective of better programming for the epidemic, has to be to establish in development practitioners ways of reasoning and responding such that in their daily work they automatically understand the relevance of what they do for the HIV epidemic. This is quite different from proforma approaches to mainstreaming; it demands understanding of the issues raised for development by HIV, and a personal and professional commitment to pursue policies and programmes which effectively address the problems of the HIV epidemic. How are these human capacities to be strengthened? This is the familiar problem of development; ownership of process and responsibility for outcomes, achieved through processes which are collaborative and supportive.

8. Many things can contribute to the achievement of the objectives outlined in paras 6 and 7. But it is important to realise at the outset that there is no single solution or way to proceed. As with much else in development there will have to be a process of trial and error, and it is crucial that there be opportunities for reflection and learning. There is no known technique for mainstreaming which is applicable everywhere, at all times and under all conditions. But there are ways of moving closer to both the intermediate objective of better development practice which integrates HIV, and thus to the achievement of better and more effective policy and programming responses.

9. What are the steps required at the present time to move the UN system response towards mainstreaming for more effective programming? The following is an illustrative listing of some of the strategies currently followed by UNDP in pursuit of this objective.

a. Development practitioners need to start from a base of common understanding of the epidemic if there are to be genuinely collaborative solutions to difficult problems. This common base of understanding does not presently exist amongst the organizations of the UN system, nor within national governments, nor within the private sector [including NGOs, CBOs etc]. Given that the proposed Thematic Working Groups of UNAIDS are to work collaboratively in support of the National AIDS Strategy, there will have to be activities to create a common understanding both within the cosponsoring agencies COs, other UN agencies and donors, and national organizations. This strengthening of capacities needs to relate both to specific HIV programming and to other development activities

which affect the course of the HIV epidemic.

UNDP has attempted to move forward understanding of the epidemic and strengthen national capacity to respond through such activities as the HIV and Development Workshop where the participants have been drawn from across the development spectrum. An extension of these Workshops is essential for mainstreaming the epidemic; both specifically for the COs and for their counterparts in the national response. The Thematic Working Groups stand little chance of succeeding unless they start from a common understanding of the epidemic, including how to mainstream HIV in their development activities. UNDP has an instrument [HIV and Development Workshop]; extensive experience in capacity building for development, and, as the manager of the system the Resident Coordinator has the responsibility for an effective UN programming response to the epidemic across the spectrum of development within country.

b. There are UN agencies which are critical for effective responses to the epidemic and where mainstreaming HIV should have a central role. These include, FAO, IFAD, UNDCP and ILO. UNDP has involved some of these agencies in its training programme, with some success in raising awareness of how development is affected by the epidemic and what might be the feasible ways to mainstream HIV. An important instrument for mainstreaming has been the use of TSS1 funds to support agencies so as to create conditions favourable for programme innovations [mainstreaming].

c. Attempts to mainstream are less than fully successful because those designing programmes and projects often do not have the capacity to mainstream HIV. By the time that programmes and projects are reviewed it is usually too late to influence what has been designed and will be implemented. In some ways this is the core of the problem: to try to ensure that programmes which affect and are affected by the HIV epidemic do take account of what needs to be done, and can be done. This is an intractable problem, but one which is amenable to solution. There is here a role for training, for programme staff in agencies and other donors, for consultants, in government and in NGOs etc. UNDP has been attempting to improve programming skills for mainstreaming through a number of training activities in many regions, including training of trainers workshops. A recent innovation has been the training of consultants for legal and ethical programming as a way of influencing a critical input in the design of programme responses worldwide. Developing better design skills for consultants and programming staff within COs is a minimum first step for effective mainstreaming. UNDP has some

experience with this, and the appointment of National Professional Officers for HIV, and their training, is an important step for more effective mainstreaming of HIV in UNDP's programming response to the epidemic. But training is only the first step towards mainstreaming and will need to be supported in other ways if it is to lead to a sustained change in programming responses.

d. There are many other ways to generate insight and commitment to mainstreaming. These include activities to strengthen national capacity for applied socio-economic research, not just on the epidemic as traditionally defined, but on those structural conditions which often determine the speed of spread of infection and pattern of effects of the epidemic. Programming will remain narrowly focused as long as the research base remains limited. Once the data confirm the role of poverty amongst women as a factor in the spread of HIV infection, or the ways in which food security is affected by the epidemic, then and only then will it be feasible to determine what are the problems to be addressed and how to go about responding in ways which are effective. Some of these responses will be direct, such as nutrition programmes and scholarships for affected children. Some will be indirect, for example credit policies for women, along the lines of the Grameen Bank. UNDP has been engaged in refocusing analysis of the epidemic, in part through training, but also through capacity building for research in a number of African and other countries, with the expectation that programming will become more effective [mainstreamed].

e. There is a need for examples of effective mainstreaming if development practitioners are to respond to recommendations that this is worthwhile. So documenting examples of what works and transferring the lessons is important. Publications are important in this respect, but even more critical are opportunities for discourse; talk can be an effective instrument for change, including changes in policy and programming, and opportunities need to be found for this to occur. Amongst the more important opportunities are meetings of Res Reps in UNDP and country team-building activities at the ILO Turin Centre. But there are also much lower level opportunities for meetings and discussions at national and sub-national levels where experiences are documented and explored. An activity used by UNDP has been that of facilitated study tours where inter-disciplinary national teams [from public and private sectors] have visited a number of countries, initially to observe what is happening, and then to build on that experience back home. Modalities which can be similarly used are TCDC and TOKTEN where the intention is to

transfer south-south learning and experience so as to produce better development outcomes.

Conclusions

This note has explored some aspects of mainstreaming but in no sense is it intended to be exhaustive. It builds on some of the experience of the HIV and Development Programme of UNDP during recent years as a guide to how one might pursue the objective of mainstreaming for more effective policies and programmes. Several observations from the foregoing deserve repetition:

- * there are no blueprints for undertaking mainstreaming that will be effective
- * it is possible to avoid costly lessons by observing and internalising the experiences with mainstreaming gender
- * effective responses to the HIV epidemic require mainstreaming throughout all development activities given the structural factors central to the epidemic
- * process is crucial both for the design of how to undertake mainstreaming as well as in the implementation of programmes
- * there are many innovative approaches to mainstreaming and these need to be explored, expanded and used
- * the activities essential for mainstreaming need to be sustained over time and supported, and are not a once-for-all event.

UNDP has had much experience with mainstreaming HIV and in integrating it in a range of developmental activities. Much has been achieved both within the organization and through partnerships with others engaged in development. UNDP remains committed to the principle and practice of mainstreaming at all levels within the organization, and will continue to strengthen its capacity for more integrated responses to the HIV epidemic in all Regional Bureaux and throughout the organization. This will be achieved through the pursuit of all the strategies identified above, including training for UNDP and counterpart staff; training to consultants involved in programme design; support to Thematic Working Groups, and more specifically to the Resident Coordinator in her/his role in achieving integration of HIV in Country Programmes, and full participation of UNDP in the mainstreaming activities of UNAIDS and other partner organizations.

CAPACITY BUILDING AND THE HIV EPIDEMIC

PROGRAMME

Friday January 27 1995

Section A: 10.30 -11.00

Background Briefing on UNDP HQ, Country and Regional Activities and the HIV Epidemic in Asia, and the Current Situation with the Joint and Cosponsored UN Programme for HIV and AIDS.

Section B: 1100 - 12.30

Capacity Building and the HIV Epidemic

1. Programme Policy Framework
[Papers 1 and 2, Communities and Outsiders: and HIV and Development: The Challenges Facing the Asia and Pacific Region]
2. Strengthening National Research Capacity
[Paper 3, Enhancing Programme Development Through National Research Capacity Building]
3. Building An Enabling Environment: Legal, Ethical and Human Rights
[Paper 4, Building an Enabling Environment]
4. Working With and Through Networks; Principles and Processes
[Paper 5, Networking]
5. Language Policy
[Paper 6, UNDP HIV-Related Language Policy]
6. Working Principles; Development Practice
[Paper 7, Principles To Guide The Action Of Those Working In Response To The HIV Epidemic]
7. Capacity Building; General Principles
[Paper 8, Capacity Building: Premises and Instruments]

Section C: 12.30-1.00

Preparing a Bureau Policy Framework Paper for HIV and AIDS in the Asia and Pacific Region; A General Discussion

'Communities and Outsiders'

Notes from an address given by Elizabeth Reid at the HIDNA Network Meeting, in Sydney 25 August 1994

This address was based on a schematic outline (diagram below) for the process of social change which can be used for program development at all levels and program appraisal.

The notes below expand on the categories listed in the outline. All categories are of course interdependent and contain many sub-categories. The outline is a framework representing a particular way of looking at the issues and is not intended as a prescriptive list of things to consider.

CATALYSING CONCEPTS

Being informed - we have limited understanding of epidemic and it is changing all the time. *Association* - we must work with affected communities. Those who know the most about the epidemic. *Engagement* - we should refuse to divide the world into them and us. We are all affected; actors as well as practitioners. *Consensus building* - the epidemic is complex. Both constraints and solutions are local. A prescriptive approach is not effective. *Partnership* - we need to combine expertise and knowledge, and avoid imposition of outside agendas. Partnership takes time and requires self-confidence and self-esteem. A feature of the pandemic has been the development and enhancement of these qualities among HIV-affected groups. *Capacity building* - this is now acknowledged as central, not just to HIV issues but to all development.

INTERVENTIONS

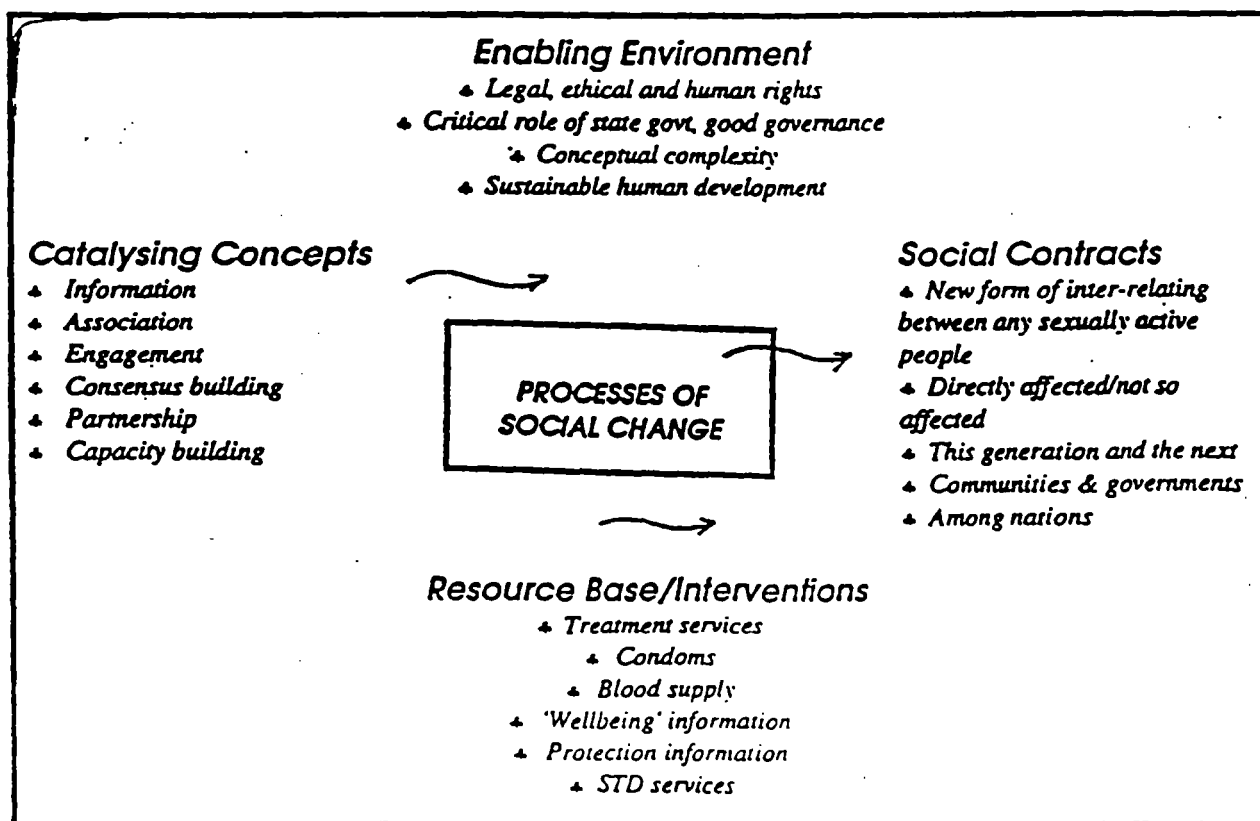
By themselves, interventions are a part of the process of impacting on HIV, not at the heart of it. They create supply, but not demand. For example, experience has shown that supplying education, pamphlets and condoms, in itself has little effect on behaviour. Interventions include: voluntary testing/counselling, condoms, treatment, blood supply, well-being information (nutrition, stress management, exercise), education/prevention campaigns.

ENABLING ENVIRONMENT

This is the environment which allows change to take place and may be between partners, within villages or at a national level. The processes which impact on this environment are catalysed by those directly affected. Issues include: *legal, ethical and human rights*; *stable government, good governance* - need a strong civil society with structured collective/communities. The role of the church is central to this issue in many countries; *conceptual complexity* (we need to acknowledge this - there are no simple solutions); *sustainable human development* - economic growth, access to education, health, employment, redistribution (Robert Chamber's paper expands on this and is available from HIDNA).

SOCIAL CONTRACTS

1. *Trust between individuals*. The need for a new form of interrelating between men and women and any sexual partners based on mutual respect and concern.



PRINCIPLES TO GUIDE THE ACTION OF THOSE WORKING IN RESPONSE TO THE HIV EPIDEMIC

The response to the HIV epidemic, to be effective, must lead to a world where those most affected, those who live their daily lives within the confines of this epidemic, must be able to speak and act for the good of their societies, without recrimination, without retaliation, without repudiation. But it must also lead to a greater understanding of and impetus towards the kind of society in which people will be able to survive this epidemic and an identification of the value system or systems which will foster this. This cannot occur in isolation from the social and economic conditions which determine the pattern and speed of its spread.

It is probable, although this must be tested in the crucible of reality, that the principles required to address this epidemic and those required to address the complex reality of the world on which it is feeding overlap.

There is a need to identify the principles which must guide and shape the actions of those working to overcome this epidemic as well as those that will enable a community to survive through the tragedy in which we are already living and which is to come.

The principles required to guide the actions of those working to assist others, as well as themselves, to respond to the epidemic, be they doctors, leaders, lawyers, researchers, development workers, counsellors, or whatever, those one might simply call the outsiders: those outside of a family, village or nation working with it could include the following.

The principle of being informed: each person engaged in or a part of the response to the epidemic needs actively and in an ongoing manner to continue the quest to understand this epidemic in all its complexity and as it unfolds and changes. This principle is a prerequisite for the conceptual and programmatic flexibility demanded by the epidemic.

The principle of association: to work within this epidemic is to work in partnership with those living with the virus. Those who do not know them as partners and confidants, who do not spend time in their company, should not represent them, speak for them, speak about them, attend conferences on the subject, be employed as consultants, receive research grants or project financing, or head national programmes. If this principle is not respected, we run the risk of setting false priorities and designing irrelevant or ineffective programmes.



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CAPACITY BUILDING: PREMISES AND INSTRUMENTS

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8. The performance of each of these functions requires that capabilities reside within identified groups of individuals and organizations, and are facilitated by the institutional, legal and policy environment. They are therefore the 'capacity of specific individuals and organizations. Effective performance of functions may also require reforms of organizational arrangements, involving the disappearance or reorganization of existing organizations and the creation of new ones. The capacity to perform functions is therefore a dynamic concept which is not linked in any rigid way to specific organizations or particular institutional arrangements.
9. A critical examination of past efforts, from a capacity building viewpoint, reveals that many operational activities have:
- failed to build capacity which was sustained;
 - failed to address central and critical national objectives/goals;
 - emphasized downstream (i.e. implementation) aspects, without adequate attention to upstream aspects, involving the capacity for national policy dialogue and debate, policy analysis and policy formulation, implementation and monitoring;
 - witnessed a rapid erosion of results by frequent staff turnover, skill and brain drain which have in turn re-created manpower shortages and imbalances at virtually all levels of responsibility and in virtually all branches, resulting in further apparent demand for donor-funded support to fill the gaps;
 - underestimated the importance of an overall supportive/enabling environment;
 - ignored the macro-level implications of specific activities, hence suffering from the fallacy of composition, i.e. micro-level rationality producing macro-level irrationality;
 - overemphasized support for government agencies and entities, which have a key role to play in the development process, but which need to be balanced by a strong civil society, including political institutions (e.g. parliaments); independent public bodies (e.g. judiciaries, electoral commissions); academic and research institutions; the media; collective economic institutions such as chambers of commerce, trade unions and cooperatives; non-governmental organizations; and community based organizations.
10. In order to overcome the deficiencies of past approaches, certain key elements need to be emphasized in all operational activities. First, and most importantly, the process of capacity building must be a national process, in which the role of

16. Not all forms of external support are necessarily geared to or conducive to national capacity building, even though individually they may be highly valued and solicited by national authorities. An example would be relief aid, which is considered humanitarian and an indispensable form of global solidarity. Even in such cases, however, there should be a concern to ensure that relief aid is not seen as totally separate from development processes, that the forms and mechanisms of relief aid do not undermine national capacity, and that where possible there is attention to the relief-to-development continuum.
17. Among the non-capacity forms of external support, some may even cause damage to morale, productivity and good governance. Examples of such forms of support from a capacity building angle are as follows:
- offer of technological equipment the relevance of which to prevailing national production methods or practices is dubious whilst their maintenance and recurrent costs are complex and high;
 - overseas study the hidden purpose of which is pursuit by the donor of a commercial or economic advantage, which is not perceptible at the outset, but which leads to large 'leakages' of able and talented people to the host country;
 - mandate-driven external support, the timing and nature of which takes no account of national agenda or national needs;
 - relief and emergency aid which responds to unpredictable events with a minimum of local involvement, participation and control;
 - the establishment of special, separate project implementation units by donors to oversee the implementation of their own projects, without regard for the sustainability of the activities or to their integration with national efforts and national implementation capacity. In some cases such special units have created problems of morale, and have reduced the pressure for public sector reform;
 - ad hoc salary supplementation by donors, which undermines attempts to reform public sector salaries, which creates large and irrational salary differentials among public sector officials and which has associated negative effects on morale.

5. On the basis of the formulation and adoption of a national strategy for capacity building, there may be a role for external resources to support the national strategy. The process described above provides the basis for external resources to be integrated with national efforts, and to become subordinated to a national programme. This is what is meant by 'the programme approach', i.e. external resources are provided in support of a national programme, and therefore respond to a nationally identified need. The most widely shared definition of a programme is "a coherent set of policies, strategies, activities and investments designed to achieve a specific time-bound national development objective or set of objectives" (ACC/CCSQ/OPS, 1992). A shift to the programme approach has been advocated by the UN General Assembly for some years, and has been adopted by the UN development system as the most effective mechanism for providing support to the development of national capacity.
6. In the past, the principal instrument through which external support was provided for capacity building was via free-standing projects, each involving "a set of planned, interrelated activities aimed at achieving defined objectives by producing specified outputs". Projects have dominated the development assistance scene in the past, have varied widely in type and scope, and in retrospect have left behind a record that has in many cases been impressive and inspiring.
7. By advocating a shift towards a programme approach, it is not the intention to abandon projects as an instrument of external support. Perhaps it is more accurate to say that it is the 'project approach' which is being abandoned. Projects will continue to be useful and relevant in many circumstances, for example those providing direct support, gap filling, policy reports and feasibility studies. The project approach, however, is now widely recognized as an ineffective approach to development cooperation. The project approach was viewed as synonymous with piecemeal, scattered, loosely coordinated, input-focused, under-resourced, poorly conceived and isolated activities without linkages to other complementary activities. Activities were often divorced from potentially complementary investment projects, divorced from the policy environment and policy circumstances needed for effectiveness, and divorced from the competitive environment such as the labour market.
8. The case for external support to be based on the programme approach is overwhelming: it requires coordination with national efforts and coherence with the macro-economic and sectoral frameworks. As has been discussed in the previous note, effective capacity building requires that specific activities be formulated within a coherent overall framework, including institutional and inter-institutional arrangements and relationships, and the overall policy environment within which the activities are taking place. It can therefore be seen that capacity building and the programme approach are fully consistent with each other.
9. Aside from the programme approach and free-standing projects, development cooperation has additional instruments which may support capacity building. One

Building An Enabling Environment:
Legal, Ethical and Human Rights

HIV, CULTURE AND THE SOCIOECONOMIC PATTERNS OF THE EPIDEMIC

Unlike many epidemic diseases in the past, HIV is not spread by mere casual contact between individuals. As is now well known, the virus is transmitted only through direct exposure to the bodily fluids of an infected person, as can occur during sexual intercourse, from sharing needles and syringes or during pregnancy from an infected woman to her child.

An understanding of the scientific basis of transmission, however, provides little insight into the social, economic and cultural factors within any society that determine the patterns of vulnerability to HIV infection. Increasingly, the global pattern of the epidemic shows that the people most likely to become infected are those who, by reason of their social or economic position, are unable to protect themselves against infection.

These underlying socioeconomic causes of vulnerability to HIV operate in many ways. In the first place, basic information about HIV and how to prevent transmission may be denied to people, particularly in developing countries, through poverty, geographic isolation and poor amenities. Even where knowledge about the epidemic is available, the ability of individuals to act on this information in order to protect themselves against infection may be seriously limited. The pattern of sexual relationships is frequently prescribed by culture, social roles and expectations and economic need. Changing these patterns in order to prevent transmission of HIV will involve addressing deeply-rooted social and cultural practices, as well as the economic factors which may underpin and reinforce them.

For women, the obstacles to avoiding the risk of HIV infection are particularly great. Their position within families and societies means they are often not free to make their own decisions about their sexual relationships or to insist upon measures, such as the use of condoms or fidelity on the part of their partner, that would reduce their risk of exposure to HIV. Cultural expectations in relation to marriage and childbirth and the absence of means of economic support outside the family unit compound the difficulties for women to avoid exposure to the virus. For these women, as for many poor or disadvantaged people of any gender or race, the main risk factors for HIV are inequality and powerlessness within their relationships and societies.

The implications of this for strategies to respond to the HIV epidemic, and particularly for legal policy, are critical. The changes that are required to prevent the spread of HIV demand changes to fundamental patterns of social and economic interaction at both the individual and the communal level. They clearly transcend what can be achieved by coercive interventions by governments. Rather, a social contract is required that can acknowledge the existence of different values and interests within any one society, but at the same time allow those differences to be bridged to the extent necessary to respond effectively to the HIV epidemic. This depends upon there being a recognition by all

- whether there are legally recognized rights of privacy or obligations of confidentiality to guard against unauthorized disclosure of a person's HIV status;
- whether a person with HIV will be permitted to continue working and will be protected against discrimination in the workplace;
- what access to education, training and health care will be available for infected people and will this be legally sanctioned or required;
- are criminal or civil sanctions available for use against people who transmit the virus to others?

In these ways, the law has an immediate and self-evident impact on the HIV epidemic. It determines rights and duties as between infected individuals and other members of the community and as between individuals and the state.

In more subtle ways, though, the law can have an equally pervasive yet indirect impact on HIV and AIDS-related policy by influencing the background or context within which the policy response to the epidemic takes place. It can be instrumental in shaping the environment for all aspects of HIV policy and, by promoting an environment of support, cooperation and collaboration - an "enabling environment" - can be used actively to give maximum effect to other HIV strategies aimed at encouraging the behaviour change necessary to prevent the spread of the virus.

Experience teaches us that reducing the stigma attaching to HIV infection, and building the self-esteem of people with or at risk of infection, create the conditions necessary for mutual trust, support and collaboration in effecting and sustaining the behaviour changes needed to stem the epidemic. Conversely, alienating people from society, making them feel they have nothing to gain by protecting themselves or others, breeds helplessness, indifference and contempt for self and others: perfect conditions for the spread of HIV.

The law can contribute to the desired "enabling environment" on both a practical and symbolic level. At the practical level, the law will determine whether people with HIV or those at risk of infection are subject to punitive measures such as compulsory testing and detention or whether they have strong, legally enforceable protection against discrimination or breach of confidentiality. In this way, it will be the test of whether HIV policies can truly be said to be based on principles of collaboration and trust. At the symbolic level, these legal measures set the tone for society's response to HIV. They make a statement about whether our response to infected people should be based on understanding and support or on rejection, and by either condoning or condemning certain forms of response, they can actively promote the attitudes that will enable policies on HIV to have the best effect.

against the virus because of the unequal position within relationships and communities, laws such as those dealing with rape within marriage and the age of marriage or sexual consent, which uphold the independent rights of women, may increase the options for women in the context of the epidemic.

While one could debate the extent to which changes of this kind can be effected through legal measures, it is nonetheless important to keep these broader considerations in mind when formulating strategies on HIV and the potential role of the law. They demonstrate that there is scope for creative approaches to HIV legal policy that go beyond the traditional ambit of infectious disease control.

The Network Approach

The main objective of the networking process is to strengthen the capacity of countries to develop consensus on appropriate ethical responses to the HIV epidemic. Networks facilitate a participatory and non-directive approach, allowing for different solutions to emerge according to local characteristics and conditions. This process should ensure that these responses are reflected in a meaningful way in people's daily lives.

A national response to the HIV epidemic must be integrated and holistic if it is to be effective and sustainable in the long term. The integration of an ethical perspective and principles of human rights is an essential part of a comprehensive national response. There is a need to bring together all the relevant parties including people living with HIV, ethicists, lawyers, health professionals, human rights and women's advocates and others, to build a consensus on effective responses to the challenges raised by the HIV epidemic.

A regional network exists to support the national networks, and to address issues of a regional nature. This network works in partnership with existing national, regional and international networks in related areas.

Networks are an important capacity-building mechanism, because they are uniquely flexible and sensitive to changing needs and situations, while strong in promoting sustainable solutions and building consensus. The initial step in the establishment of national networks is to identify and draw on existing resources to create a multi-disciplinary, non-hierarchical and flexible group of informed, engaged and courageous individuals and organizations. This group will define itself and establish priorities for its activities according to both the local characteristics of the epidemic, and the interests and capacities of the network members.

HIV and Development: The Challenges Facing the Asia and Pacific Region

These are:

- . the challenge of making the invisible visible;
- . the challenge of creating an ethic of compassion; and
- . the challenge of placing people and their communities at the centre of the response to the epidemic.

The first challenge, to make the invisible visible, is a clear imperative in this region. We must find the means to better understand and make known the speed and the surreptitious patterns of spread of the virus. Surveillance systems tell us where the virus has been but we need predictive systems that map out for us where it is likely to go. Understanding the factors which determine this will enable us to put faces to the figures, to see ourselves in its path or in its wake.

But more than just numbers and silhouettes of those affected need to be made visible. Those living within the epidemic, those at the forefront of change, must create a new language that makes more visible the new realities of life in the post-HIV era.

This is already happening in two important aspects of the epidemic. Firstly, we are beginning to develop a language of optimism: affirmations of the possibility of behaviour change, of the centrality of compassion and concern, of care and commitment. Secondly, we are developing a language of process rather than of interventions, of people as responsible actors rather than manipulable objects. It is a language of empowerment, of participation, of listening and talking, of counselling, of deciding together.

However, there is still a silence, an inarticulateness, about the dark side of the epidemic: the doubt, the trembling, the uncertainty, the distancing, the denial, the fear. We do not yet have a language that reflects the reality of living with the knowledge that one is infected or that someone one loves dearly is infected: the constant companion of mortality, the sadness, the tentativeness of desire, the longing for love, the stripping raw of self by death after death after death of partners, of children, of childhood friends, of companions.

There is another silence around a central reality of this epidemic: that it evokes a wilderness of emotional and psychological states with whose very existence we are uncomfortable, for which our vocabulary is too limited and which we are reluctant to acknowledge and express. These include hatred, anger, shame, guilt, humiliation, grief, indignity.

Enhancing Programme Development Through National Research Capacity Building.

The parameters of the discourse about development are widening. The respective roles of the state and the market, privatization, liberalization, deregulation and other market reforms, the globalization of trade, finance and knowledge and the emergence of cross-border economic zones remain in the discourse but they are increasingly embedded in or linked to concepts of human agency, of people's capabilities and aspirations, of diversity, participation and innovation (Banuri et al. 1994). Responses to the perceived exigencies of today are now understood to be inextricably linked both to the perceivers (Chambers, 1994) and to the actors of the future (UNDP 1990).

The problems inherent in approaches to development or social transformation as exercises in social or economic engineering are reshaping development thinking and practice (UN 1994a, UN 1994b). Development is now understood as sustainable if it empowers people to take charge of their own well-being, if it builds on the strengths of local knowledge and values and if an enabling environment is created at national and international levels which fosters and supports local initiatives.

These new approaches to development thinking are forcing changes in development practice: the role of outside experts or donor agencies is becoming understood to be the stimulation or facilitation of organic processes of the creation of new norms, values and practices that enable people through their organizations to gain greater control over their lives (Reid 1993). The emergence of these organic processes is a critical indicator of social change. Development is constituted by local sources of experimentation, of innovation and of diversity fostered within a supportive macro-level institutional, policy and legislative environment.

At the heart of this new form of development practice is the recognition that sources of learning must be local, that for ideas and programmes to take root within communities, they must spring from within, be based on the realities of the lived experiences and must be disseminated and defended from there. Hence the centrality in development practice of the concepts of facilitation rather than direction, of the participation of the organizations of civil society in partnership with public institutions, of consensus-building, of human and social capacity-building and of ethical practice.

An essential element of this new form of development practice becomes the support and strengthening of these local processes of social learning through participatory research initiatives and by the strengthening of national capacities for thinking and analysis and for the transformation of social learning into policy and programmes.

UNDP HIV-RELATED LANGUAGE POLICY

Language and the images it evokes shape and influence behaviour and attitudes. The words used locate the speaker with respect to others, distancing or including them, setting up relations of authority or of partnership, and affect the listeners in particular ways, empowering or disempowering, estranging or persuading, and so on. The use of language is an ethical and a programmatic issue.

UNDP has adopted the following principles to guide its HIV-related language.

Language should be inclusive and not create and reinforce a Them/Us mentality or approach.

For example, a term like "intervention" places the speaker outside of the group of people for or with whom he or she is working. Words like "control" set up a particular type of distancing relationship between the speaker and the listeners. Care should be taken with the use of the pronouns "they", "you", "them", etc.

It is better if the vocabulary used is drawn from the vocabulary of peace and human development rather than from the vocabulary of war.

For example, synonyms could be found for words like "campaign", "control", "surveillance", etc.

Descriptive terms used should be those preferred or chosen by persons described.

For example, "sex workers" is often the term preferred by those concerned rather than "prostitutes"; "people living with HIV" or "people living with AIDS" are preferred by infected persons rather than "victims".

Language should be value neutral, gender sensitive and should be empowering rather than disempowering.

Terms such as "promiscuous", "drug abuse" and all derogatory terms alienate rather than create the trust and respect required. Terms such as "victim" or "sufferer" suggest powerlessness; "haemophiliac" or "AIDS patient" identify a human being by their medical condition alone. "Injecting drug users" is used rather than "drug addicts". Terms such as "living with HIV" recognize that an infected person may continue to live well and productively for many years.