A CULTURAL APPROACH TO

HIV/AIDS PREVENTION AND CARE

UNESCO/UNAIDS RESEARCH PROJECT

UGANDA'S EXPERIENCE

COUNTRY REPORT

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Since the mid-eighties, the fight against HIV/AIDS has gradually mobilized governments, international agencies and non-governmental organizations. However, it became evident that despite massive action to inform the public about the risks, behavioural changes were not occurring as expected. The infection continued to expand rapidly and serious questions began to emerge as to the efficiency of the efforts undertaken in combating the illness. Experience has demonstrated that the HIV/AIDS epidemic is a complex, multifaceted issue that requires close cooperation and therefore multidimensional strategies.

The establishment of the Joint United Nations Programme on HIV/AIDS (UNAIDS) in 1994 initiated a new approach to the prevention and care of this disease. The first requirement stressed was the need for increased coordination between institutions. An emphasis was also made on the need to work on both prevention and treatment while considering the significant social factors involved. As a result UNAIDS was involved in several studies focusing on developing new methodological strategies with which to tackle the issue.

Following a proposal made by UNESCO's Culture Sector to the UNAIDS Programme, on taking a cultural approach to HIV/AIDS prevention and treatment for sustainable development, a joint project "A Cultural Approach to HIV/AIDS: Prevention and Care" was launched in May 1998. The goals were to stimulate thinking and discussion and reconsider existing tools with a cultural approach.

Taking a cultural approach means considering a population's characteristics - including lifestyles and beliefs - as essential references to the creation of action plans. This is indispensable if behaviour patterns are to be changed on a long-term basis, a vital condition for slowing down or for stopping the expansion of the epidemic.

In the first phase, of the project (1998-1999) nine country assessments were carried out in three regions: Sub-Saharan Africa (Angola, Malawi, South Africa, Uganda, Zimbabwe), Asia and the Pacific (Thailand and bordering countries) and the Caribbean (Cuba, Dominican Republic, Jamaica). The findings of these studies were discussed in three subregional workshops held in Cuba, Zimbabwe and Thailand, between April and June 1999. All country assessments as well as the proceedings of the workshops are published within the present Special Series of Studies and Reports of the Cultural Policies for Development Unit.

The opinions expressed in this document are the responsibility of the authors and do not necessarily reflect the official position of UNESCO

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CHAPTER 1

AN OVERVIEW OF THE AIDS EPIDEMIC IN UGANDA

1.1 Introduction

Nearly two decades since a new syndrome, the acquired immune deficiency syndrome (AIDS) was first recognised in 1981, and its aetiological agent the human immunodeficiency virus [HIV] identified in 1983, there is still no cure nor is a vaccine against the disease available. Interventions intended to bring about changes in behaviour remain the principal means of preventing further spread and counselling is the main avenue for alleviating the adverse impact of the disease.

Uganda, in common with other countries of Eastern and Central Africa, is one of the worst hit. By the end of 1997, UNAIDS estimated that between 400,000 - 500,000 Ugandans had already died of AIDS - related illnesses, out of a population of 20 million.

Currently, HIV/AIDS is the leading cause of deaths among adults aged 25 - 44 and ranks only second to malaria in the general population, (Ministry of Health). It is estimated that about 1.8 million Ugandans, or 9 per cent of the population are infected with HIV, the virus that causes AIDS.

The HIV/AIDS epidemic in Uganda has been characterised by diffusion over time, spatially and across social-demographic groups. In its initial stages, the epidemic was limited to the crescent around Lake Victoria and concentrated along the transnational highway running from Kenya through Uganda to Rwanda and the Democratic Republic of the Congo. There were also social-demographic categories such as young, single women, commercial sexual workers, long distance truck drivers, the army and urban residents which were identified as 'high risk groups'.

The available surveillance data show that HIV/AIDS is no longer clustered around a few urban sites but has spread to the remote rural areas and to all strata of society; the notion of 'high risk groups' is no longer relevant.

According to data available from HIV sentinel surveillance sites and AICs, the prevalence rates have varied from 5 per cent in most rural districts like Moyo to as high as 30 per cent at some urban sites in Kampala and the South western region which were the areas initially most affected by HIV/AIDS; one of the areas most affected in the recent past is Northern region. UNICEF data (1993) show that of the twelve districts with more than 90 AIDS cases per 100,000 residents, six are located in the Northern region; Gulu is currently ranked third to Kampala and Masaka where the epidemic was first reported. The prevalence rates are higher in the trading centres along major roads. However, basing on data generated since 1995, the trend of infection in urban and rural areas is changing . A number of urban sites have recorded a downward trend in infection rates while the trend in rural areas is either level or upward leading to a convergence in the prevalence levels. There is a similar convergence of rates between high prevalence, urban areas.

According to the 1991 - 1996 sentinel surveillance data, prevalence rates declined from 30.2 per cent in Mbarara and 13.2 in Tororo in 1992 to 15.0 and 8.2 per cent in 1996 respectively.

The age-sex pattern of HIV/AIDS prevalence has remained unchanged. HIV/AIDS infection ratesvary significantly with age and between the sexes, albeit in a predictable way. Characteristically, there are more females, sometimes 4 - 6 times more, infected at the younger age (12 - 19). Prevalence rates among males steadily rise with age and are about equal to female rates in the 25 - 30 age group and typically surpass female rates after 35 years. This pattern reflects the earlier age at sex debut for girls and in the later ages the fact that men tend to have more extensive sex networks through polygamy and extra marital relations which increase the risk of infection.

1.2 Government Policy:

Government of Uganda recognized in the very early phases of the epidemic that HIV/AIDS posed a real and serious threat to the socio-economic life and development of the country. Since 1982 when the first AIDS case was reported, the national response to the HIV/AIDS problem has been characterised by a policy of openness and the challenge has been placed at the highest level of government. For example, the Uganda AIDS Commission (UAC) has, since inception, drawn on the highest calibre of personnel for its leadership. The Government also recognizes the multi-dimensional nature of the HIV/AIDS challenge.

Government's Multi-sectoral Approach to the Control of AIDS (MACA) was born out of the recognition that the HIV/AIDS problem had causes and consequences beyond the health sector. It was realized that the epidemic affected various aspects of individual, family, community and national life and required to be addressed comprehensively. The Uganda AIDS Commission and its Secretariat were established in 1992 and specifically charged with the formulation and development of the national multi-sectoral approach.

The HIV/AIDS challenge has received a lot of attention and its programs have benefitted from support and commitment from various sources. A recent inventory of HIV/AIDS-related activities in the country revealed that there were more than 1,000 on-going projects addressing various facets of the problem. These projects are being undertaken at various levels: community, district and national. The key players include individual families, communities, local NGOs and international bilateral and international organisations.

The government policy on HIV/AIDS developed the National Operational Plan (NOP) to combat the epidemic. This plan (NOP) was based on a three-pronged strategy, namely:

- i) prevention of HIV transmission through sexual contact;
- ii) prevention of mother-to-child transmission; and
- iii) prevention of blood borne transmission

The operationalisation of these strategies was done through the following activities: IEC and behaviour change; STD/HIV Testing and Treatment; Blood-borne Transmission; Prevention of HIV through Mother to Child Transmission (MTCT)

It should be noted that each one of these activities recognised the cultural setting and was responsive to many of its tenets. Consequently, the NOP was able to make the following achievements:

- i) **IEC and Behaviour Change**: A wide range of Health care providers were trained, Training manuals were developed, regular IEC campaigns were mounted through mass media, advice for the practice of abstinence before marriage, faithfulness during marriage and condom use especially during intercourse with non-regular partners.
- ii) **STD/HIV Testing and Treatment**: Coordinating the efforts of agencies such as Delivery of Improved Services for Health (DISH), Programme for Enhancing Adolescent Reproductive Life (PEARL) training of service providers, such as Traditional Birth Attendants (TBAs), the STI project in the Ministry of Health, etc.
- (iii) **Blood Borne Transmission**: The Uganda Blood Transfusion Services has reduced blood borne transmission by:
 - < Continuing to recruit low risk blood donors;
 - < Screening blood for HIV and hepatitis virus infection;
 - < Store, distribute and supervise utilization of safe blood to hospitals; and
 - Sensitizing blood donors, medical workers and the public on the dangers of excessive use of good transfusion; and sharing of non-sterile skin piercing instruments with another person.
- (iv) Mother-to-Child: Considerable biomedical research has been undertaken and drug trials (AZT) are underway. This is being spearheaded by UNICEF, UNAIDS and the Ministry of Health.

1.3 The Cultural Component of HIV/AIDS Transmission, Prevention and Care

Culture, by definition, is a complex set of distinctive spiritual, material, intellectual and emotional features that characterize and define a society or social group. In addition to arts and letters, it encompasses ways of life, the fundamental rights of the person, value system, traditions and beliefs¹. Culture encompasses two essential elements:

- (i) it is not the possession or accomplishment of an individual, but defines a way of being together with others; it is essentially social
- (ii) it is not made up of a given range of activities, but consists of all and only those activities through which a society defines and identifies itself (UNESCO, 1997:30).

From this definition, it would therefore follow that a cultural approach to HIV/AIDS epidemic is one in which all activities undertaken as a society pertaining to prevention, treatment and care are identified for their contributions in containing the scourge. This view is consistent with a

¹ Declaration of Mexico on Cultural Policies: Preamble World Conference on Cultural Policies, Mexico, 1982.

perspective which views culture to be a focal point where a society meets in order to think about itself and determine collectively what sort of society it is and wants to be: (UNESCO 1997:31).

In the context of this study, culture, as manifested in values, norms, beliefs and practices, is a major contributor to the health - status of a population. These can be positive or negative. Anthropological examples of negative values include infanticide and the preferential treatment of sons. Equally, certain beliefs determine for what diseases to seek health-care and in what form. For example, the Baganda classify disease into three categories:

- (i) *olumbe* denoting that this is untreatable and is likely to be the cause of the victim's demise (fatalism);
- (ii) *endwadde* treatable, preferably by traditional doctors;
- (iii) *obulwadde* treatable, by both traditional and western medicine.

Under category (i) would be all those ailments for which no cure is known, including degenerative conditions associated with cancers and old age. Category (ii) subsumes most of the mental disorders, including epilepsy, which are linked to offending one's forefathers and other societal norms (e.g. having sex with a close relative). The last group includes the commonest illnesses such as malaria, fever and diarrhea for which there exist well - known cures.

A number of studies show that traditional practices such as widow inheritance, polygamy and wife sharing are factors of aetiologic significance in HIV transmission. Irresponsible sexual behaviour and alcohol consumption during funeral rites and other traditional ceremonies are common.

In 1992, a workshop to discuss the socio-cultural factors affecting the spread, treatment and caring for AIDS patients was held in Kampala, (Olowo-Freers, 1992). Among the major observations of that workshop was that there existed, in all the cultures examined, both positive and negative cultural tenets regarding the AIDS spread, treatment and caring for patients with AIDS.

It was desirable that the positive aspects be encouraged while the negative ones should be discarded.

1.4 Purpose of this Exercise

Whilst the detailed Terms of Reference are contained in Appendix 1 to this document, the purpose of this exercise was threefold:

- (i) to assess the evolution of the epidemic (HIV infection and PWA) and its cultural and societal impact in the context and perspective of sustainable development.
- (ii) to determine how and to which extent culture, features and resources of the population are being taken into consideration in the design, implementation and evaluation of HIV/AIDS interventions.

(iii) to document the success stories and innovative experiences which have been carried out to date and from which lessons could be learnt, as far as taking a cultural approach in this matter is concerned.

This study is sequel to and builds upon an earlier pilot one titled inter-linkage between Culture, Traditions and HIV/AIDS in Uganda. (Sengendo, et al 1998). The earlier study covered three districts of Mpigi, Hoima and Kumi representing, respectively, the Ganda, Nyoro and Iteso cultures. The study revealed, for each of the three cultures examined, strong evidence that the people very strongly value their traditional practices and that many of these traditions and practices have a bearing on sexual relations and therefore HIV transmission. However, the study did not provide any understanding as to why some cultural institutions such as marriage and the extended family are being eroded while others persist. Such information, when available would provide the basis for designing culturally relevant interventions to modify sexual behaviour in the combat against HIV/AIDS.

This study aims at providing in-depth information on the inter-linkages between culture and traditions and HIV/AIDS regarding its spread, treatment and care for PWAs. This is done for the family, the community and institutional levels.

1.5 Conceptual context of the problem

In Uganda, the problem of HIV./AIDS is still a challenging task. Data from sentinel sites to the AIDS Control Program of the Ministry of Health (ACP-MoH) indicates that 51,344 cases of AIDS had, by the end of December 1996, been reported.² Of the cases reported, a cumulative total of 47,555 (92.6%) and 3,789 (7.4%) were, respectively, adults aged 12 years and above, and children below 12 years. Available information on the magnitude of the AIDS epidemic in the country indicates that it is significantly depleting the most productive human resources; be it the technically skilled people trained at considerable cost or the physically healthy peasantry who are critical to the productivity of a predominantly agricultural economy. The age group 15 - 40 is greatly affected.

The epidemic is contributing to the increase in the orphan population, with 50% of the 1,197,000 orphans in Uganda estimated to be linked to AIDS. This huge figure of orphans has a serious impact on the socio-economic life of society as the phenomenon of orphanhood creates many forms of behaviours which are not necessarily consistent with the traditional ways of living. One such behaviour is the reduced coping mechanism of the family to cater for the orphans. Indeed the poverty condition in the family appears to be a serious push-factor in forcing the orphans to flee the family environment and to live on the street. Studies have indicated that many of these orphans have unresolved psychological and emotional problems and there is little society is doing to provide the needed emotional support.

² Source: <u>Uganda HIV/AIDS Surveillance Report</u>, A Report of the STD/AIDS Control Programme, Ministry of Health, March, 1997, p.1

Consequently, many of the children are adopting unguided behaviours as a result of the breakdown of the family, socialisation process which is, to a significant degree, attributable to the AIDS epidemic.

1.6 Problem Statement

The major mode of HIV infection in Uganda is heterosexual transmission, accounting for about 80% of the cases. Sexual practices, within the family institution as well as outside the family have a lot to do with the culture of society and its traditions. Heterosexual behaviour forms a major component of the problem. However the role of traditional culture and its impact on a rapidly changing society have not been well studied and documented in Uganda.

Secondly, and as already hinted, the AIDS epidemic in Uganda is significantly depleting the most productive human resources, particularly those in the 13 - 40 age group. In this age-group, the female children of 13 - 20 years and boys/young men of 16 - 35 years are particularly vulnerable. These same groups are also at the centre of a dynamic culture, and their behaviour is constantly responding to new sets of norms, values and beliefs. From this point of view, there was need to study the inter-linkages between culture/traditions and HIV/AIDS in Uganda.

1.7 Methodology

The study has been done in two major phases. The first phase concentrated on collecting data on the factors linking culture with HIV infection which was conducted during the period January - April, 1998. During this first phase, secondary sources were critically reviewed. In other words, the review and compilation of existing documents and materials related to the interlinkage between culture and HIV/AIDS prevention and control, preceded actual field work.

Abstracts were written on existing materials and a bibliography on the state of the art research reports, policy documents, and other sources was prepared.

A cross-sectional in-depth study design the used for purposes of integrating the units of analysis as participants rather than as respondents (in traditional sense). Such research design has been gainfully used in studies that deal with sensitive topics like sexuality. In the course of the cross-sectional study, descriptive analysis was also employed for the existence and variability of cultural dispositions that impact on HIV/AIDS in the study areas. Three districts were studied. These are Hoima in the Western region; Mpigi in Central Uganda; and, Kumi in Eastern Uganda. The three districts represented regional differences in cultural tendencies found in the country.

The sampling frame for the study was the first tier of the Local Council system (i.e. LC 1). Thus, through the LC1 officials, a combination of sampling procedures were utilised. The sampling design was guided by a self-weighting principle that allowed and provided for optimum efficiency within the constraints of available financial, logistical and human resources.

Stratified sampling was done on the basis of age/generation, households, and religion, to ensure maximum representation in the sample. Ethnicity was held constant for each of the three

samples. Thus, in Mpigi, the respondents were Ganda; in Hoima they were Nyoro; and in Kumi, the respondents were Iteso.

This phase has involved the collection of relevant literature on the interface between social and cultural factors and HIV/AIDS in Uganda was sourced from several resource centres whose collections are devoted to this topic. This included the AIDS line, Medline and Popline. Local materials were obtained from the University Library (East African section), the Child Health and Development Centre, among others. In addition, material was accessed through personal contact.

A partial list of the documents consulted is included as Appendix 3 to this report.

The extent of reference to cultural resources among institutions working in the area of HIV/AIDS was assessed through a review of project documents and periodic reports indicating the implementation strategies. The documentary evidence was supplemented by discussions with the key players, usually managers, at institutions visited.

The third source of information was key informants. Altogether twelve (12) key informants (all Baganda) responded to in-depth interviews. Six men and six women in the age range 40 - 65 were purposively selected for this inquiry. Equal numbers of men and women were needed so as to obtain the two gender perspectives. The age range was decided and based on its relevance to the HIV/AIDS problem vis-a-vis its position in terms of family and power relations. This age group are the principal interpreters and implementers of cultural provisions since they have power over their children and their opinion prevails over that of their parents who do not have the material resources to realise their wishes. This age group also has very diverse experience of HIV/AIDS problems: having lost peers, having lost their offspring and being still at risk alongside their own children.

The in-depth interviews focussed on four thematic areas; beliefs and practices related to sexual behaviour; the acquisition of knowledge regarding sexual matters; fertility considerations; and the provision of care for persons with AIDS. In each section information was sought on whether some well-known cultural tenets were being adhered to or not; and if not, why not. For those harmful traditions (in relation to AIDS) that had persisted, information was sought as to why this was the case.

CHAPTER 2

REVIEW OF LITERATURE: A GENDERED PERSPECTIVE

This chapter is meant to identify previous research on the problem of HIV/AIDS epidemic in Uganda. It focuses on the traditional knowledge and practices of the cultures in Uganda and their impact on the epidemic.

2.1 Vulnerability of Women to HIV Transmission

Studies on sexuality in different cultures of Uganda show that women are particularly more vulnerable to contracting HIV and other STDs, relative to men. A number of factors have been identified.

2.1.1 Physiological Vulnerability

Scientific evidence has shown that women's risk of HIV infection from unprotected sex is at least twice that of men (WHO, 1995). Semen which has high concentrations of virus, remains in the vaginal canal for a relatively longer time. Women are more exposed through the extensive surface area of mucous membrane in the vagina and on the cervix through which the virus may pass. In men, the equivalent area is much smaller, mainly the entrance of the urethra and in uncircumcised men, the delicate skin under the foreskin.

Young women are at greater risk than mature women. A teenager's vagina is not as well lined with protective cells as that of a mature woman. Her cervix may be easily eroded potentially enhancing risk of HIV/infection. The practice of forcing the girl-child into marriages sometimes at an early age of about 12 years, is not only traumatic but also physiologically devastating.

2.1.2 Age at marriage

Age is cited in literature as a major variable in HIV transmission. In the West of Uganda, among the Bakiga, girls are thought to be ready for marriage at puberty or even before (Yeld, 1973). In the North, Lugbara girls often get married at age of 13 - 14 (Middleton, 1973). In the East, Iteso girls marry at 14 - 15 and boys at 23 - 25 years. At this early age at which girls marry, their bodies are not yet fully developed. (WHO, 1997). Young girls marrying old men may end up seeking sexual satisfaction and reproductive fertility elsewhere. Among the Bakiga (Western Uganda), the older sons can bathe with their mother i.e. have sex with young wives of their elderly father as long as she is not the biological mother (Moodie et al, 1991).

2.1.3 Polygamy

While all marriages in Uganda start off by a man having a single wife, men enter into polygamous relationships for various reasons. These include failure of the first wife to have children (Ankole - Mushanga 1973), Ntozi 1986, Bunyoro-Beathie 1973). Polygamous

marriages were also a result of poor marital relationships, conflicts or when the wife was old, weak and unable to work effectively in the agricultural gardens or in milk products (Ntozi and Kabera 1991; Omongole 1983). In some cases, polygamy was a result of improved wealth economic status (Bond and Vincent, 1991; Kyewalyanga, 1976, Arya et al 1973). Studies show that there are relatively fewer formal polygamous marriages among the Baganda (Central region) partly due to the influence of education, religion (Christianity) and cash economy.

Informal polygamy also exists, in varying degrees, across Ugandan society. This is a marital practice where a man may have multiple sexual partners. The practice is more common in towns where *outside wives* are more stable than girl friends, but mean less financial commitment than full marriage (Larson, 1983). Olowo-Freers and Barton (1992:8) estimate the majority of men in the Central region (Buganda) maintain one or more extra marital lovers in long term relationships which are like concubines (Kisekka, 1973).

2.1.4 Wife-sharing:

Traditionally, a new wife among the Bahima (Nkore) was considered an addition to the family and the clan. The father of the bridegroom had a right to test where his cows have gone by having the first sexual access to the new bride (Oberg, 1938; Elam, 1974). Among the Bakiga, on many occasions a family pooled its resources to raise the bride wealth capital for obtaining a wife to one of the brothers. Sexual accessibility to the bridegroom was acceptable to the groom s father as well as his other sons. One of the outcomes was ensuring fertility even if the groom was sterile (Yeld 1973); Kubahire, 1981)

2.1.5 Marital Instability

In Ankole, divorce is reported to be rare as elders discourage it and actively try to keep marriages together (Ntozi and Kabera 1991, Elam 1973). Women who are divorced are usually remarried (Ntozi et al, 1991). Among the Bakiga marital instability and broken homes are common, currently due to the fear of contracting HIV (Van der Meeren, 1990). A woman in Kigezi who is married but leaves her marital home in distress will be forced to return to her husband. Nothing is done, however, to a man who brings in an extra woman (Brown, 1988).

Among the Baganda, divorce and marital separation are common. There is some prestige attached to formal marriage and girls are considered to *owe* their parents at least one such marriage.

people, however, consider ending a marital union which is no longer satisfactory as one of their more sensible customs (Mandeville, 1975) Baganda women easily desert men if they are dissatisfied in a relationship, even marriage; reasons include discord, neglect, or maltreatment (Southall, 1960; Mandeville, 1975; Obbo, 1991). Infertility and impotence are also complaints that can lead to marital discord and separation in Buganda (Southwold, 1973). The separations for any of these reasons are frequent enough to be a common cause of single-headed households in the region (Bennett, Saxton, and Junod, 1968). One problem for the unattached Muganda woman is a tendency among local men to expect that she is sexually available and for women in the area to label her (sexually loose (Kisekka, 1973).

2.1.6 Widow Inheritance

Upon the death of a husband in many parts of Uganda, a woman is inherited by one of the dead man's relatives, usually a brother or an older son by another wife, for example:

Acholi (Kisekka 1989), Ankole (Ntozi and Kabera, 1991), Basoga (Kisekka, 1989), Iteso, Kisekka, 1989). There is an increasing trend however that a widow makes a choice of the inheriting partner e.g. Bakiga (Kubahire, 1981), Lango (Kisekka, 1989) Japadhola (Kisekka, 1989).

2.1.7 Extramarital sex by Women

Overall, throughout most of Uganda, wives are expected to be faithful to their husbands, although the same rule does not generally apply to men. A man who sticks only to his wife may be chided by his peers for lack of sexual prowess. Traditionally, though, adultery used to be severely punished among many tribes for both men and women. However, among the Bahima, adultery was forbidden to women but not for men (Oberg, 1940). In Buganda, social norms expected married women to refrain from going outside the marriage for sex (Kisekka, 1973; McGrath et al, 1990). If they did, however, the extramarital partners were expected to provide some material assistance (McGrath et al, 1990). It has also been noted that Baganda women would sometimes have affairs if the husband was a polygamist or migratory worker gone for long times; women explained that this was done to avoid sexual deprivation (Kisekka, 1989).

2.1.8 Extramarital sex by Men

Men are more likely than women to have outside relations; up to 80% of rural women say their husbands have multiple partners (Forster, 1989). There are certain limits and variations to such activity, e.g. a Munyankole man is not supposed to have any extramarital sex when building a house, sowing some crops, or when preparing a brew (Mushanga, 1973). Moreover, his wife will begin to suspect him of outside activity if he goes for one week without demanding sex (Kisekka, 1989). During pregnancy, however, both partners were expected to abstain from outside sex (Mushanga, 1973).

In Buganda, extramarital relations are considered normal for men; a man having no outside sex may be teased about having little or no strength (Kisekka, 1973). Even adolescent school children expect that married men will have extramarital sex while married women will not do so (Kisekka, 1976).

2.2. Predisposing factors

2.2.1 Alcohol

Alcohol has several adverse effects. First, it is a pull factor for customers both men and women, who converge to the drinking places for a drink. After drinking, impairs judgement and loss of control among individuals and sexual relationships may result. Secondly, those drinking places are breeding points for multiple partner sexual relationships and even commercial sex has been closely associated with the development of the alcohol trade. Thirdly, Van der Meeren (1990)

describes a relatively common pattern of HIV -positive young Bakiga men drinking and then sexually seducing or assaulting young girls.

Among the Baganda, drinking is more common among men than women, and selling alcohol is more commonly done by women (Seeley, Malamba, et al, 1992). Drinking in this area is especially noticeable at weddings, which are preceded by all night-parties, *akasiki*, and at last funeral rites, *okwabya olumbe*, where love-making in small temporary huts ensisira has been frequently described (e.g. Ongom, Lwanga, et al, 1971; Bennett, Saxton, Mugalula-Mukibi, 1973; Olowo-Freers 1992). Sex with strangers in such ceremonies while drunk was one of the more commonly described rural occasions associated with transmission of STDs (Arya, Ongom, Tomusange, 1974).

2.2.2 Migration

Migration is another risk factor and it is precipitated by: pastoral practices, where herdsmen move seasonally with their cattle in search of good water and pasturage. Similarly men and women often migrate to urban areas for employment (Bennett, 1962). There are studies which show that women widowed by AIDS migrate to urban areas to avoid stigma or to seek economic survival. Cross border trade is another factor leading to HIV/STD infections when businessmen and women travel between countries and within countries selling or buying merchandise. By so doing, they indulge in sexual relations thereby causing a major risky group (Bond and Vincent, 1991). Traders and lorry drivers in the area had a history of multiple sexual contacts. Both men and women in trading centres along the major highways are particularly at risk for HIV/STD infections. (Serwadda et al, 1985; Bond and Vincent, 1991). Central and southern Uganda have also seen considerable numbers of migrant labourers from Tanzania, Rwanda, Burundi, and other parts of Uganda; other mobile population groups have included military, refugees, and teachers (Bond and Vincent, 1991; Seeley and Nabaitu, 1990).

2.2.3 Infertility

Infertility is known to trigger off sexual relations in search for children. Normally a woman is blamed for infertility and there are various explanations; for instance barrenness is linked with too much sex while still young (Bennett, 1965). In Buganda the commonest local explanation for barrenness is called *ekigalanga* i.e. a condition that associates barrenness with aerophagia and loss of weight (Bennett, 1965).

As a result of these fears about infertility, there is a big demand for fertility and potency medicines and treatments. In Buganda (Southwold, 1973). Sometimes the desperate searches for a cure can be quite risky; among the infertility remedies carried out by some male healers specializing in treatment barrenness is having sex with their patients.

2.2.4 Sex for Pleasure

Evidence is available to show that there is a link between sex and enjoying it. (e.g. Kisekka, 1989; Moodie et al, 1991). Forster (1989) found that sex is regarded as a game 'playing sex' is the most common local expression for sexual coitus. The Baganda sexual norms are said to emphasize mutual pleasure, foreplay, high female sensuality, and active participation by both

partners (Kisekka, 1991. Many cultures in Uganda consider more than one round penetrative vaginal sex per night is the desirable and usual practice (Kisekka, 1989). Female gential modification through labial elongation has traditionally been carried out in the Central region as a means of promoting mutual pleasure (Kisekka, 1973; Kisekka, 1989).

2.2.5 Commercial Sex

Commercial Sex (or prostitution) is used as a generic term to imply sale of sex for cash. However, the term is used for other persons usually women who may be known to engage in multiple sexual relationships even if such relationships are not for cash gains. In Ankole, for instance, a prostitute is a woman who has sex outside marriage, sells local brew, or engages in sex for gain or favours (Kisekka, 1989). It can also be used as an indication of stigma or disapproval. For example, adolescent girls may be called 'prostitutes' by older women criticizing them for wanting more than one partner. (Seeley, et al 1991).

Forster (1989) distinguishes between some of the concepts of prostitution and argues that the Baganda and Bakiga women indulge in occasional sex for exchange or receiving gifts from stable partner. However Bennett (1962) found four classes of urban prostitutes in Kampala; the Bahaya who sold sex from single rooms in certain slums areas; barmaids, a well-dressed and educated upper class prostitutes; and homosexual males who mostly catered for European clients.

2.2.6 Ritual Sex

Sex is a very intense experience; as such, it can often be linked with other important events as a way of giving those events extra meaning in people s lives. Among the Ankole in the West, there are at least 33 special occasions which are supposed to be associated with ritual sexual acts between husband and wife; these include harvesting time, building a new house, and birth of children. (Ntozi, 1990; Ntozi, Kabera, Mukiza-Gapere , et al, 1991). In Bunyoro, ritual acts to symbolize sex, and sometimes actual sex, are used to 'leave the deathl after a period of mourning, these acts are required of the widow and sometimes other male relatives and are supposed to be carried out with strangers (Beattie, 1973). Ritual sexual acts are also part of the initiation activities in the Mbandwa healing cult of the Banyoro (Beattie, 1957). During the initiation ritual, the gods are said to get quite stirred up and the initiate is in considerable ritual danger (mahano).

In Buganda, on a wedding night the girl's Ssenga (paternal aunt) was required to be present to explain, and sometimes to demonstrate sexually, proper sexual activity to the new bride (Kisekka, 1973; McGrath 1990.

Sexual acts are sometimes required as part of the rituals surrounding death and widow inheritance. Among the Sebei, the legal heir has to have sex with the widow to clean out the ashes, *erandet*, three days after the death (Goldschmidt, 1973; Muhumuza and Tajjuba, 1990).

2.3 Sexual Violence

2.3.1 Rape

Violence against women, especially rape, is a major risk factor. Women (and sometimes men) are raped both within and outside marriages. Society does not always understand the problem of marital rape. Among the Karamojong, for example, rape is not considered to be a crime at all (Laughlin, 1973). In the North, abduction which often meant rape, was said to be more common and important than adultery (Southall, 1970). The eastern Sebei frequently marry by elopement, which sometimes is actually rape (Muhumuza and Tajjuba, 1990).

In the central Buganda region, 22% of women said that they had been forced to have sex against their will at some point in their adult lives (Okongo, 1991).

2.3.2 Sex with Teachers

Sexual coercion of female students by teachers is emerging as a major catastrophe. Male teachers running for the female students and in some cases female teachers running after their male students. This is especially the result of the belief these boys are free of HIV/STDs (Onyango, 1991).

2.3.3 Child Abuse

Family based sexual abuse of young children is often denied and has very little scientific evidence. In part this is due to stigma and fear of being labeled which may have a life long impact. (Ndyakira (1992) argues that much of the intra-family incest is undetected or no legal action is taken for fear of being publicly exposed in court. In Kampala a 1991 study found that some had been forced to have sex as early as four years of age (Kaharuza, 1991) and a study in Kasangati uncovered evidence of rape among very young children, some as young as age two and three years (Ongom, et al, 1971).

2.4 Prevention

There are several ways in which the prevention of HIV infection is communicated among the Ugandan public. These include: safer sex options, blood screening, safe delivery practices, and use of sterilized equipment. The AIDS INFORMATION CENTRE (AIC) Trainers Guide uses group discussion as a major method of training its workers and other personnel from NGOs dealing with AIDS. By use of discussion groups, trainees learn methods of HIV prevention, benefits and limitations of each method and strategies.

2.4.1 Blood Screening

Blood transfusion being a major source of HIV infection, Uganda has adopted a policy of screening blood for every donor. In box 1 below, the process and cost of blood screening at the Nakasero Blood Bank is described.

Box 2.1: Cost of Preventing Secondary HIV Infections through Blood Screening in Uganda

HOW **COST-EFFECTIVE** IS **BLOOD** SCREENING IN preventing secondary HIV infections? One answer to this question can be seen in the results of the Uganda Blood Transfusion Service (UBTS) for 1993. Having established its ability to supply Kampala with clean blood in 1991, by 1993 the UBTS was reaching out to cover the entire country. That year the service transfused 20,156 patients throughout the country at an average cost of approximately \$38 per unit of blood, and an average of 1.2 units per patient, for a total budget of approximately \$929,900. Box table 4.2 breaks out the HIV prevention benefits of the service, showing that its use averted HIV infection in an estimated 1,863 surviving transfusion recipients.

But to measure the positive externalities of the program, and thus the rationale for government subsidies, we need to look beyond these primary infections to consider secondary infections. Children who are infected by transfusion are unlikely to live long enough to infect others, but some of the adults may be sufficiently young and sexually active to engage in risky sexual behavior later in their lives. Since many of these people are quite

sick, the evaluation study estimated that each of these adults would have only a 50 percent chance of infecting one other person with HIV (European Commission 1995). Thus the total number of secondary infections averted would be 415.¹ If the entire justification of the blood supply service is prevention of these secondary infections, the cost-effectiveness of the service is \$929,900 divided by 415, or \$2,240 per such infection averted. If Uganda had a sustainable blood supply system, the cost of preventing these 415 infections would have been only \$319,894, or \$771 each. This much smaller amount is still substantially larger than the cost of preventing secondary infections in other ways (see box 2.6)

¹ The authors point out that the counseling provided to blood donors may have averted additional primary infections (European Commission 1995). Any secondary infections averted through this route should be added to the 415 to compute the total positive externalities of the program.

Effectiveness of Blood Transfusion at Averting HIV Infection, Uganda, 1993

	Benefits			
Effects of blood transfusions	Children	Adults	Total	
Patients transfused	11,515	8,641	20,156	
Patients expected to die without transfusion	5,758	3,898	9,656	
Patients who died despite transfusion	3,801	2,592	6,393	
Number of deaths prevented	1,957	1,296	3,253	
Number of primary HIV infections prevented	1,033	830	1,863	
Number of secondary HIV infections prevented	0	415	415	

Source: Based on the results by the Ugandan Blood Transfusion Service as reported in Beal, Bontinck, and Fransen (1992) European Commission (1995a); and Fransen (1997), personal communication. Cited in World Bank Policy Research Report, <u>Confronting AIDS</u> Public Priorities in a Global Epidemic, Oxford University Press, 1997:189

2.4.2 People Living with HIV/AIDS going public

This method is intended for an audience of trainers who will train people living with HIV/AIDS that volunteer to *go public* and could also be used by other trainers involved in HIV/AIDS prevention training. It is primarily intended for trainers who have been under the Philly Lutaaya Initiative (PLI) to train People With AIDS (PWAs) who want *to go public*. It deals with the following topics:

HIV/AIDS situation analysis, societal interventions, behaviour change, gender issues in relation to HIV/AIDS. Its main emphasis is on the procedure a trainer can follow to involve participants in training activities using participatory methods it should be used together with the handbook which contains topics used for training people with HIV/AIDS that *go public*. This method is culturally accepted as an effective way for communicating to the public through the courage of an infected person testifying his or her experiences in order to help others to avoid the experiences.

2.5 Approaches to care of people with AIDS

Health care for persons with AIDS has three main categories. The first category is referred to as Palliative Care (PC) which is meant to relieve symptoms such as headache, pain, diarrhoea, shortness of breath, scaling of skin rash, itching skin rash, cough, fever and nausea,

The second category is prevention and treatment of opportunistic illnesses (OIs); These include Tuberculosis, Pneumocystis carinii pneumonia, Toxoplasmosis, oral thrush, Pneumonia septicemia, fungal diseases (Cryptococcosis) including cryptococcal meningitis and Herpes simplex virus. The third category is the antiretroviral treatments (ARV) which attempt to combat HIV itself. (World Bank, 1997: pg. 174 - 183). This treatment currently involves use of a combination of three drugs which, if taken properly, reduce the levels of HIV in patient's blood below the ability of laboratory tests to detect it. Unfortunately these drugs are expensive and complex to administer, their long-term benefits are uncertain, and their efficacy varies greatly from one individual to another. These drugs are categorised as;

Nucleoside RT inhibitors	Daily Dose (mg)	Daily or unit cost	
Zidovudine (AZT)	500	2.738	
Didanosine (ddl)	400	2.099	
Zalcitabine (ddC)	2.25	2.486	
Stavudine (d4T)	80	2,900	
Lamivudine (3TC)	300	2.690	
<u>Group 2</u>			
Protease inhibitors			
Saquinavir (SQV)	1,800	6,820	
Ritonavir (RTV	1,200	8,010	
Indinavir (IDV)	2,400	4,320	

It should be noted that the triple-drug therapy consists of two of the first group of drugs in Table 1 plus one of second group plus monitoring. Drugs are given daily. Which three drugs should be combined is a matter of current research and probably varies by patient. For example, the triple drug may be combined as AZT, ddI, and IDV or AZT, ddI, and RTV. World Bank (Confronting AIDS, 1997:180)

2.6 UNAIDS Drug Access Initiative

The advancement in medical sciences which has resulted into the Triple Antiretroviral Therapy has led UNAIDS to make strategies on how the drugs can be made accessible to developing countries.

A pilot scheme has been developed in which four countries are participating in the Drug Access Initiative. These are Uganda, Cot e D Ivoire, Vietnam and Chile. Accordingly, UNAIDS has spearheaded the HIV Drug Access Initiative in Uganda.

This is the result of a series of meetings UNAIDS held in Geneva in 1997 with pharmaceutical companies to iron out issues of feasibility and implications of the initiative, the strategies to be used in the pilot phase as well as issues of sustainability.

With UNAIDS support, the Uganda Government has established a 14-Member Drug Access Initiative Advisory Board. Among other responsibilities, the Advisory Board selects the medical Institutions to participate in the drug distribution system under three main categories: Category A are referral Centres; Category B are follow up clinics, and category C are Primary Health Care Centres. The Board also set up the criteria for the selection of patients who are benefitting from the initiative; the development of protocols for management and treatment of opportunistic infections as well as management and treatment of patients using antiretroviral drugs; supervision of the management of the Non-Profit Making Company (Medical Access (Uganda) Ltd, which is managing the procurement and distribution of the drugs.

Through the STI project the government of Uganda is using public funds for drugs targeting opportunistic infections and STDs and has provided the framework for a rational prescription and use of antiretrovirals. Clinical management guidelines have been established.

2.7 In-patient Care

Three alternative inpatient care usually available for AIDS care. These are: outpatient AIDS clinics, hospices care (residential low technology care for the terminally ill) and home-based care. Studies relating to the cost of each one of these care are scarce. However, evidence from Zambia shows that community-based care programmes were more effective and much

less expensive than hospital-based programmes (Chela and others, 1994); Martin, Van Praag and Msiska, 1996). The AIDS Information Centre Manual identifies six major areas for care and management for people affected by HIV/AIDS. These are:

- (i) Effects of HIV/AIDS on self, family and community.
- (ii) Definition of care.
- (iii) Definition of management of PWAs and other affected by HIV /AIDS
- (iv) Factors that influence how to care for people with AIDS/people affected by HIV/AIDS.
- (v) What constitutes caring (medical and non medical).
- (vi) What constitutes managing HIV/AIDS related situations.

The training puts emphasis on the following five areas:

- (i) Impact of HIV/AIDS on person, family and community
- (ii) Issues relating to crisis, adjustment and coping stages in HIV infection
- (iii) Personal experiences on what helps them to overcome the crisis and adjust to coping
- (iv) Psychological, medical and social support mechanisms
- (v) Types of care and support in terms of treatment, material and psycho-social support.

2.8 Impact of HIV/AIDS on the family

The capacity of the family and the community as a whole to care to AIDS patients is influenced greatly by the income levels and the social networking. The fact that AIDS kills the most productive age group 20 - 50 years, it follows that the disease depletes the most productive members of the family. In some of the cases these are the people who are expected to provide care services such as finance, food and housing.

The impact of AIDS on the family is to rob the family of the income support and leave behind large number of dependents (children and the elderly) who become more vulnerable.

Previous studies have been cited to show that people in high income groups are more likely to attract more prospective sexual partners and they will also likely to have more money than a person with low income to compensate sexual partners. Hence, the rich have tended to be more at risk than the poor (World Bank 1997: 207). Similarly, whereas it is expected that the educated will be more knowledgeable about HIV transmission, unfortunately they have ended up being more at risk of HIV infection given the possibility that the educated are also in high income groups.

Studies have also established that the death of a prime age adult is not only a tragedy to the household but it has a long term impact on the survivors in several ways.

First, the psychological and emotional stress and trauma which the survivors have experienced, has largely remained unattended to. In the Ugandan context, there is evidence that in most of our communities, there are no psycho- treatment and counselling centres specifically established to address this need (Sengendo and Nambi, 1997).

Secondly, AIDS imposes very high medical costs prior to death as well as high costs for the funeral. In the Ugandan cultural context, the family must also find money to finance the funeral rites, which in most cases, cannot easily be afforded. All of these factors combine to make the impact of AIDS on the family to be devastating.

Thirdly, with the onset of the HIV/AIDS epidemic women's roles as caretakers and providers have had to be adapted drastically for personal and family support. It is the woman who will take care of a sick husband until he dies. A sick woman may be moved back to her natal home so that her old mother can take care of her. Sometimes, when a woman is sick, a sister or daughter will move to her home to take care of her. When a woman survives her husband who has died of AIDS she becomes fully responsible for her family. In some places she is shunned and will therefore move away to where people do not know her.

She may even remarry in order to support herself and her children or she might exchange sex for money and other favours, especially if she has little education or occupational skills, (Van der Meeren, 1990).

Rural people often deny AIDS and associate illnesses to be a result of witchcraft. It is expected that family and relatives will give care. However, in instances where AIDS is admitted, it is normally associated with promiscuity, it is therefore the person who infected the patient should give care. If it is the woman who has fallen sick, it is automatically assumed that it is the man

who infected her and should be the one to provide care and support. Similarly, if it is a man who is sick, the conclusion is that it is his wife who infected him and therefore should provide nursing care. If a patient is believed to have been involved in multiple sexual partners, the general belief is that he or she should afford the costs of medical care and treatment, (Ankrah, et al 1989: 116).

The greater percentage of people anticipate that the family and relatives will provide the necessary physical care. In suggesting that the patient meets the financial costs of treatment, the people show awareness that some AIDS sufferers are not poor, to the contrary, included among the patients are businessmen and businesswomen, the educated professionals, civil servants and others with medium to high incomes.

CHAPTER 3

INSTITUTIONS OFFERING CARE SERVICES: POLICIES AND PROGRAMS

3.1 Introduction

The Uganda AIDS Commission (UAC) was set up in 1992 specifically to foster the implementation of the government's Multi-Sectoral Approach to the Control of AIDS (MACA). This policy was born out of the recognition that the HIV/AIDS problem had causes and consequences beyond the health sector. It was realized that the epidemic affected various aspects of individual, family, community and national life that required to be addressed comprehensively. The document articulating the multi-sectoral approach to the control of HIV/AIDS was concluded in February 1993 and the Commission has since been responsible for overseeing its realisation. Subsequently, a National Operational Plan for HIV/AIDS/STD Prevention, Care and Support 1994 - 1998, was drawn up to operationalize the multi-sectoral approach. This was succeeded by The National Strategic Framework for HIV/AIDS Activities in Uganda (1998-2002) which provides the guidelines and sets out national priorities for the design of interventions in the prevention of AIDS spread and alleviating its adverse effects.

As part of its coordinating function UAC periodically prepares an inventory of agencies with HIV/AIDS related activities in Uganda. The inventory classifies agencies according to location, nature of intervention, target group and the administrative level of its operations (i.e. national, district or community).

Over 1,020 agencies were reportedly engaged in HIV/AIDS control activities in Uganda during 1997. About one in three agencies (32%) were operating at district level. Other levels of operation were county (23%), sub-district (16%), national (21%), regional, a number of districts (7%). About 6% of the agencies were operating at international level.

Awareness creation, sensitization and education is the main form of intervention, reported by 14.9% of the agencies. Patient care and management was reported as the principal intervention by fewer agencies (154) than orphan care and support (183). Women issues were the focus of 156 agencies compared with 73 for men's issues. Culture, traditional health practices and support to clans were mentioned by a total of 208 agencies.

A few agencies were selected for detailed study. These were selected on the basis of their intervention (prevention, treatment and care) and convenience. Owing to time constraints, the sample was limited to Kampala based agencies which the Team could visit and no grassroots organisations were included. The following analysis is based on a review of project documents supplied by the management of the various institutions and the discussions held with personnel contacted. In addition, the Consultants drew upon their first hand information about the HIV/AIDS problem in the country and the institutions in question.

3.2 International Agencies

3.2.1 UNDP Strategy for Cooperation in HIV/AIDS and Development Programme

The UNDP HIV/AIDS Strategy 1993 -1996 was designed within the framework of the national strategy which addressed two key areas;

- (i) Prevention of the spread of HIV
- (ii) Coping with the epidemic's existing consequences.

Prevention

With respect to prevention, there is a focus on vertical transmission, non-school going youths, young adults and blood donors. The policies aim to promote safe medical practice, control of other STDs, the role of religious organizations, blood testing and multi-disciplinary research into prevention.

Coping with the epidemic

Regarding coping with the epidemic, there is a focus on treatment of HIV-related diseases; confidentiality for people with HIV/AIDS; counseling; humanistic acceptance, support, care and treatment of people with HIV/AIDS; support for careers; and the socio-economic impact of the epidemic.

Within its mandate, the UNDP Strategy was primarily designed to provide support to the ongoing efforts to control the epidemic by both government and international agencies. For example, USAID, GTZ, DANIDA, EEC, UNFPA, UNICEF, WHO, WORLD BANK.

3.3 Intervention Policy

The UNDP Intervention Policy was therefore directed to multidimensional activities which build capacity. The overall objectives of capacity building under conditions of high sero-prevalence were:

(i). To improve the functioning of existing institutions through improving their efficiency in resource use.

(ii). To generate new insights and skills in understanding the challenges posed by the epidemic.

- (iii). To induce and assist innovative approaches and organizational developments, both in the public and private sectors.
- (iv). To replicate those approaches and institutional structures which are successfully meeting the existing challenges in other institutions and areas of the country.

The strategy for the prevention of HIV Transmission was focussed on the following areas:

(i) Increase the awareness of HIV/AIDS which was still very low in some areas such as Lira, Apac in which UNDP agreed to assist government and other agencies to identify which regions need more IEC and which programmes would be appropriate. (ii) While there was evidence that behaviour was changing, it was very slow. Therefore in efforts to promote behavioural change, UNDP focused its attention to supporting NGOs and other agencies that were working on the social cultural factors contributing to HIV risk.

- (iii) UNDP undertook to support programmes which addressed the question of how women can protect themselves. Therefore in this context, UNDP supported activities in social, cultural and economic conditions which predispose females to HIV infection at a younger age than males. Research was also needed to address not just behavioural change but also formation of behaviours which are specifically risky to women.
- (iv) UNDP undertook to support efforts to prevent HIV prevalence among the military personnel, prisoners, and refugees which are particularly vulnerable groups to HIV infection.

3.4 Economic and Social Impact

UNDPs efforts in capacity building were also directed at mitigating the economic and social impact. These included support to the following projects:

- Micro Projects which targeted groups and household groups, and communities which were considered most vulnerable.
- (ii) Sectoral interventions in agriculture, health and education.

The strongest cultural pillar within the UNDP strategy was based on the involvement and participation of the community in monitoring and evaluation regarding impact, social responses and methods which were used to generate improvement in the levels of epidemic. It is this aspect that supported other initiative pillars such as Community-base care, support to orphans and other vulnerable groups, community development and organizational structures such as local governments, the Uganda AIDS Commission, Ministry of Finance and Economic Development, Line Ministries, and several Non-governmental Organizations (NGOs).

3.5 UNICEF/Ministry of Education and Sports (MOE&S):Life Skills Model

The Life Skills Model uses a large variety of methods to teach children certain skills needed in behavioral change. These skills are needed by an individual to operate effectively in society in an active and constructive way (Edward de Bono). However according to TACADE, United Kingdom) personal and social skills are required. The model was developed in Uganda as a result of the gaps identified in the 1990-1995 Basic Science and Health programme. Despite this programme, behaviour did not change towards the promotion of health living. The missing link between knowledge in Basic Sciences and Health Education and positive change was identified as the practical Life Skills. Hence the Government of Uganda and UNICEF, launched the Life Skills Initiative.

The following Life Skills were selected, based on a baseline study report on the level and type of skills among Uganda's primary school children (See Appendix II for details).

The Baseline Study (1996) investigated the following Life Skills: Assertiveness (ASD), Coping with Emotions(CE), Friendship Formation (FF), Interpersonal Relationship (IR), Negotiations(NG), Non-violence Conflict Resolution (CR), Creative Thinking (CT), Peer Resistance (PR), Self Awareness (SA), Critical Thinking (CRT), Decision Making (DM), Problem Solving (PS), Effective Communication (EC), Coping With Stress CS) and Empathy (EM). These terms are explained in detail in Annex 1 to this chapter.

3.5.1 Self Report Techniques

Two instruments were developed for self reports by the pupils namely;

- (i) The Pupils'Questionnaire
- (ii) The Pupils' Focus Group Discussion.(FGD)

These instruments, particularly the FGD fell within the cultural context of society in which a small group of people at community or all family levels discuss and make in-depth understanding of a phenomenon.

3.5.2 Pupil's Questionnaire

In the Pupils' Questionnaire, a Likert type rating scale was used (Ministry of Education and Culture, Zimbabwe, 1993, 1994, WHO, 1994). Each child's choice of response to an item was to reflect how the child perceived of himself/herself. This was on a 5 point scale and the pupil would start by considering his/her position as to whether it was negative, neutral or positive with respect to the statement. If it was negative or positive, was it "very much" or just "much". Hence, for the five responses, the choices were to mean;

5=strongly agree4=agree3=partly agree2=disagree1=strongly disagree

The means of the pupils' rating of themselves are shown in table 3.1 below:

Life Skills		Mean Ratings	
	All	Female	Male
Conflict Resolution	3.6	3.6	3.6
Friendship Formation	3.4	3.4	3.4
Peer Resistance	3.4	3.5	3.4
Assertiveness	3.4	3.5	3.4
Decision Making	3.9	4.0	3.9
Coping with Stress	3.3.	3.3.	3.3.
Self Awareness	3.5	3.6	3.5
Empathy	3.4	3.5	3.4
Problem Solving	3.4	3.5	3.4
Critical Thinking	3.2	3.3	3.2
Interpersonal Relationship	3.8	3.9	3.7
Creative Thinking	2.9	2.9	2.9
Effective Communication	3.6	3.7	3.5
Coping with Emotion	3.4	3.4	3.4
Negotiations	3.4	3.5	3.4
Mean	3.4	3.5	3.4

Table 3.1 Distribution of Self Mean Ratings of Male and Female Pupils' Behaviours into Life Skills

Source: "The Level of Life Skills of Uganda's Primary School Children", A Baseline Study Report - Ministry of Education / UNICEF, October, 1996; pg 25. The following ranges were adopted for interpreting the mean skill levels of the pupils:

1.0 to 1.4very low1.5 to 2.4low2.5 to 3.4moderate3.5 to 4.4high4.5 to 5.0very high

3.5.3 Pupils' Focus Group Discussion

This was an attempt to assess skill levels of the pupils during the group discussion, by listening to their arguments and watching their physical and emotional expressions. As a topic was being discussed, each researcher made notes of what each child was saying and the way he / she was behaving with a view to relating behaviour and the verbal expressions to the level of Life Skills.

For each skill a researcher would score each pupil on a five point scale. The scores meant that on the basis of the arguments and the facial, bodily, etc, expressions of the pupil during the group discussion:

5 = The pupil was excellent: He/she was an exemplary model other children could emulate for the development of that skill. The responses and behaviours convinced the researcher that the skill was well developed and could be classified as very high.

4 = The pupil was good: There was very little improvement required on the skill as the level was high.

3 = Behaviours representing the skill were exhibited, but they were not developed sufficiently. The signal was weak, but could still be received. The skill level was moderate.

2 = The skill was faintly exhibited. The level of the skill was low.

1 = The skill was hardly displayed. Behaviours reflected the skill were mostly avoided. Developing the skill would mean nearly starting from zero as the skill level is very low.

The results are given in table 3.2 below:

Skills		Pupi	ils	F	Resear	<u>ch</u>]	Feach	ers
	<u>A</u>	<u>F</u>	<u>M</u>	<u>A</u>	<u>F</u>	<u>M</u>	<u>A</u>	<u>F</u>	<u>M</u>
Conflict Resolution	3.6	3.5	3.7	2.4	2.5	2.5	3.0	3.1	3.0
Friendship Formation	3.4	3.4	3.4	2.7	2.8	2.7	3.4	3.7	3.2
Peer Resistance	3.4	3.5	3.4	3.0	3.1	3.0	3.2	3.4	3.1
Assertiveness	3.5	3.6	3.5	2.6	2.6	2.6	3.1	3.1	3.1
Decision Making	3.7	3.8	3.6	2.7	2.8	2.7	3.0	3.1	3.0
Coping with Stress	3.3	3.3	3.4	2.4	2.4	2.4	3.1	3.2	3.0
Self Awareness	3.5	3.4	3.6	2.6	2.6	2.6	3.2	3.2	3.2
Empathy	3.4	3.5	3.4	2.7	2.8	2.7	3.3	3.4	3.3
Problem Solving	3.4	3.3	3.4	2.9	3.0	2.8	3.1	3.1	3.0
Critical Thinking	3.3	3.3	3.3	2.5	2.4	2.5	3.1	3.2	3.1
Interpersonal	3.9	4.1	3.8	2.7	2.8	2.6	3.4	3.5	3.3
Relationship									
Creative Thinking	2.9	3.0	2.9	2.0	2.1	1.9	3.1	3.1	3.0
Effective communication	3.6	3.6	3.6	2.9	3.0	2.9	3.3	3.4	3.3
Coping with Emotions	3.5	3.4	3.5	2.5	2.6	2.5	2.9	3.1	2.8
Negotiations	3.5	3.5	3.4	2.3	2.5	2.0	3.0	3.1	2.9
Mean	3.5	3.5	3.5	2.6	2.6	2.6	3.1	3.2	3.1
Key: $A = All$, $F = Female$;	M :	= Mal	e	1	1	1	1	1	<u> </u>

Table 3.2: Rating of Skills of Pupils in Focussed Group Discussion

<u>Source</u>: "The Level of Life Skills of Uganda's Primary School Children" A Baseline Study Report - Ministry of Education / UNICEF, October, 1996; pg 34 <u>Note:</u> The Mean score for Pupils self rating of their life skills was at high 3.5 while the researchers, and the teachers mean rating for life skills of these pupils was moderate (2.6 and 3.1, respectively). Pupils rated themselves high on Interpersonal Relationship, followed by Decision Making and then Effective Communication. On the other hand, researchers rated pupils moderate on Peer Resistance, Decision Making, Assertiveness, and Self Awareness.

3.5.4 Reports by Other People

i) Rating by Teachers

The teachers who participated in the group discussion were assisted by the researchers to rate each of the pupils who participated in the Pupils Group Discussion. The rating was done on a five point scale as described.

ii) Rating by Headteachers

The last item on instrument number one asked the headteachers to rate the pupils on a number of attributes, including Life Skills, No technical terms were used in describing Life Skills. These were based on the following three scales:

3 = the pupils are high on the skill. The Headteacher feels there is very little left that could be done to improve on their skill.

2 = the pupil body frequently displays the skill, but not to a satisfactorily level. Some effort is needed to raise the level of the skill from moderate to high.

1 = there is absence or infrequent display of the skill. A lot of effort would be needed to develop the skill from this low level to high.

The results are presented in Table 3.3.

Life Skills		Mean Ratings			
Life Skills	All	Urban	Rural		
Conflict Resolution	-	-	-		
Friendship Formation	4.2	4.2	4.2		
Peer Resistance	3.3	3.3	3.3		
Assertiveness	3.0	3.0	3.2		
Decision Making	2.7	2.7	2.8		
Coping with Stress	3.3	3.3	3.2		
Self Awareness	2.7	2.8	2.6		
Empathy	3.7	3.8	3.5		
Problem Solving	3.2	3.0	3.4		
Critical Thinking	2.2	2.2	2.2		
Interpersonal Relationship	3.5	3.3	3.8		
Creative Thinking	2.8	2.8	2.8		
Effective Communication	3.4	3.1	3.4		
Coping with Emotion	3.7	4.0	3.2		
Negotiation	-	-	-		
Mean	3.2	3.2	3.2		

 Table 3.3: <u>Distribution of Headteacher Mean Ratings of Urban and Rural Pupils</u>

 According to Life Skills

Source: "The Level of Life Skills of Uganda's Primary School Children" A Baseline Study Report - Ministry of Education / UNICEF, October, 1996; pg 3.

3.5.5 Rating by Community Representatives

The community representatives were asked to rate the pupils on a number of attributes. Their rating was based on a three point scale and considering the entire pupil body as the Headteachers

had done. The community representatives discussed their rating on each skill until consensus was reached. The results are presented in Table 3.4 below.

Life Skills			Mean Rati	ngs		
	Pupils *	HeadTeachers **	Community **	Researchers ***	Teachers ***	Mean
Conflict Resolution	3.6	-	3.1	2.4	3.0	3.0
Friendship Formation	3.4	4.2	-	2.7	3.4	3.4
Peer Resistance	3.4	3.3	3.0	3.0	3.2	3.2
Assertiveness	3.4	3.0	3.4	2.6	2.1	2.1
Decision Making	3.9	2.7	3.6	2.7	3.0	3.2
Coping with Stress	3.3	3.3	-	2.4	3.1	3.0
Self Awareness	3.5	2.7	3.4	2.6	3.2	2.1
Empathy	3.4	3.7	-	2.7	3.3	3.3
Problem Solving	3.4	3.2	3.7	2.9	3.1	3.3
Critical Thinking	3.2	2.2	3.2	2.5	3.1	2.8
Inter Personal Relationship	3.8	3.5	4.8	2.7	3.4	3.6
Creative Thinking	2.9	2.8	4.1	2.0	3.1	3.0
Effective Communications	3.6	3.4	4.3	2.9	3.3	3.5
Coping with Emotion	3.4	3.7	3.8	2.5	2.9	3.3
Negotiation	3.4	-	-	2.3	3.0	2.9
Mean	3.4	3.2	3.7	2.6	3.1	3.2

Table 3.4: Distribution of Pupils' Mean Rating by Self, Headteacher, Community Representatives, Teachers and Researchers Into Life Skills

Source	:	"The Level of Life Skills of Uganda's Primary School Children"
A Baseline Study Report - Ministry of Education / UNICEF, October, 1996; pg 39		
Key:	*	All the pupils to whom the questionnaire was administered.
	**	All the pupils in the schools sampled
	***	the pupils in the focus group discussion.

It may be noted that the pupils rated the level of their Life Skills as moderate (3.4) which was at an equivalent level by the Headteachers (3.2) and Teachers (3.1). It was only the community representative who judged the level of life skills of the pupils to be high (3.7).

Overall, pupils are high on Interpersonal relationships (3.6) and Effective Communication (3.5). The weakest skills were Critical Thinking, Negotiations, Conflict Resolution, which fell below the Mean (3.2).

Females tended to have a more positive view of themselves than males particularly on Peer Resistance, Assertiveness, Empathy, Problem Solving and Negotiation. Hence parental contention that girls are less assertive than boys because they are shy and are trained to be respectful may not represent the way the girls feel about themselves. (The Level of Life Skills of Uganda s Primary School Children) October, 1996

3.5.6 Direct Observation of Behaviour

The effort here involved observing behaviours of the pupils and teachers directly in the classroom and during break time. The target was to study the way in which teacher passes on or reinforces the development of Life Skills in the pupils as well as how pupils encourage the development of Life Skills among themselves. This observation skill is deeply embedded in the cultures where parents and other elders observe behavioural patterns of the young people and make decisions on how such patterns can be changed in accordance with value system of society.

3.6 UNICEF/Ministry of Health (MOH): Health Education Network Model

This model was developed by the Ministry of Health with the assistance of UNICEF and it is detailed with Facilitators Training Manual, 1998. The approach recognizes the cultural value of individual and group discussions and utilisation of locally available materials and case studies for illustrating new points to the target audience. The approach also dwells on the audience's participation and involvement in identifying health issues and in offering explanations for community based health problems. Hence through participation, the audience interpretes what health is from the local point of view and what it means for the community and individuals to experience absence of pain and discomfort.

The manual provides guidance on the use of environmental factors that are important to the possession of diseases and stresses the role of individuals and family circles for the responsibility they shoulder for their own health through their life styles. However, the manual also offers guidance on how the community is helped to understand health determinants that are outside individual/family control mechanisms e.g. congenital/hereditary conditions.

i) Health Education as a Learning Process

The model shows the relationships between social, cultural, political and environmental factors which influence the health status of society. It also stresses that health education is a continuous study of peoples behaviour most of which is within the control of the individuals themselves. This therefore makes health education a learning process that facilitates people to make decisions for their own situation.

ii) Principles of Health Education

In imparting knowledge to the audience about principles of health education, the manual deals with the cultural values of an orderly society in which there is accountability in its management. Within this principle, the manual guides health workers on the principles related to health education emphasizing mutual learning, by doing rather than teaching; including basic knowledge, skills, experiences, attitudes and ideas on health. Additionally, the guide offers skills for motivating the community to participate and get involved in the achievement of their health.

iii) Strategic Thinking

The manual offers skills in how our community should strategically think about its health and how it should make strategic planning and implementation on activities designed to improve the quality of life in the community. These strategies focus on existing community organisations such as schools, churches, clubs, cooperatives etc and they also stress the importance of community participation and involvement. They also show how capacity can be created at household level to save life for instance by demonstrating the mixing of Oral Rehydration Salts (O.R.S.) or simple first aid skills.

3.7 Non Governmental Organizations (NGOs)

3.7.1 The Delivery of Improved Services for Health (DISH): Family Planning Model

Sengendo and Iga (1997) described a family planning model used in Masaka district to effect the increased acceptability and accessibility of family planning methods. The problem they addressed was that only 8% of married women in reproductive age used family planning methods in Uganda. In Kampala the contraceptive prevalence rate was 25% while the knowledge about modern methods was almost 100% and the reason for non use were not fully understood. But among those women who did not want to become pregnant, about 20% stated that they did not use modern family planning methods because they feared health problems, side effects, lack of information on the location of services or did not get support from their husbands.

The 'Plan Today, Enjoy Tomorrow Family Planning' Campaign was implemented in 10 districts of Uganda through the Delivery of Improved Services for Health (DISH) Project. The project aimed to improve the quality of reproductive health services, behaviour, knowledge and attitudes of the people in the areas of family planning, human immunodeficiency virus (HIV)/acquired immune deficiency syndrome (AIDS) prevention, sexually-transmitted diseases (STDs) prevention and treatment and maternal and child health. The project involved health educators

from the 10 districts to design the message and media strategy for family planning campaign for rural men and women. The group decided to focus primarily on married women 18 - 35 years old who did not use modern family planning methods and did not wish to have another pregnancy immediately. The secondary audience were the husbands of these women.

All campaign activities and materials carried the promise that if couples use the modern family planning methods, they would have greater peace of mind. The campaign slogan was Plan Today, Enjoy Tomorrow'. The main campaign messages were:

< The modern family planning methods are safe.

< Modern family planning methods allow couples to have children when they choose to. This gives couples more time to care for their children, to work and to relax in accordance their respective cultural obligations.

< Modern family planning users are happy with their decisions to use modern methods. They are healthy, happy and recommend the methods to others.

The following factors made unique contributions to the success of the campaign:

< Active involvement of the target audience in research and implementation.

< Well-defined and consistent campaign theme and specific messages.

< Strong publicity campaign using posters, radio and interpersonal communication.

< Support and active participation from DISH and the Ministry of Health.

< Formation of District Action Committees (DAC) to be in charge of the campaign made district to feel ownership of the campaign.

< Community participation.

Another cultural activity utilised was the Market Day Fairs. Market days usually attract huge crowds of over 10,000 persons. The campaign utilised them by organising stalls for information, counselling, drama and video shows, and selling condom and pills. This avenue was deemed effective owing to the following considerations:

< Market days in particular; gave the campaign an opportunity to reach the primary audience (women 18 - 35 years) who were often thought to be busy and isolated in their homes and the secondary audience, i.e. the husbands.

< Family planning messages reached homes which health educators could not ordinarily reach.

< The audience was ready made, thus, less time and money were spent to mobilize the audience. The cost per person was low while the audience reached 500 per market day.

- < There was immediate feedback from the audience and issues were clarified immediately.
- The friendly, relaxed market environment gave the women opportunity to discuss or talk
 to the men about reproductive health issues and family planning in particular.

The evaluation of this activity showed that there was behavioural change based on the following indicators:

- < Increase in contraceptive prevalence rate in the campaign areas
- < Increase in number of new clients in the health facilities.
- < Women are able to avail of family planning services.
- < Women are able to discuss family planning issues and concerns with their husbands.

3.7.2 DISH Safer sex campaign for the youth in Uganda

Gamurorwa, et. al, 1998 describe how The Safer Sex Campaign has been implemented through the Delivery of Improved Services for Health (DISH) Project, a USAID-funded project that works in 10 districts in Uganda. It is a reproductive health project that aims to improve the quality of reproductive health services, behaviour, knowledge and attitudes in the areas of transmitted diseases (STDs) prevention and treatment and maternal and child health. The District Health Educators implement the IEC component of the project at the district level, with technical assistance from IEC coordinators based in Kampala.

In 1994, when the DISH project started in Uganda, youths aged 15-19 years had the highest risk of becoming infected among the age groups. This prompted a review of research, focus groups and in-depth interviews with youths to determine some of the factors contributing to infection. They held very fatalistic attitudes, even though they knew that abstinence and monogamy could prevent HIV infection.

Few young people accepted condoms as an effective or acceptable way of avoiding infection with HIV. Many of them admitted to being sexually active. Most had more than one sexual partner and almost no one had ever discussed how to prevent HIV infection with their partners. In accordance with our cultures, most young men experienced a lot of pressure from their peers and parents to prove their manhood early during adolescence. Many believed that abstinence could harm them physically and could affect their ability to perform sexually in the future. The strategy used was focused primarily on unmarried men 15 - 19 years old in 10 project districts and secondarily to their potential sexual partners, 12 - 19 years old unmarried women. These women reasoned that the men usually initiated sexual advances and that the men also had more control over condom use.

The prevention messages were designed according to the following themes:

< Resist peer pressure by making your own decision about how you will protect yourself from HIV infection.

- < Abstinence will not hurt you and abstain from sex until you find a life-long partner.
- < Use condoms every time you have sex.

In addition to these messages, the campaign used a combination of mass media activities including print materials, radio programs and spots, music contest (Hits for Hope) and quizzes. In addition to these, there were drama competitions and video shows, bicycle rallies.

Impact of the campaign on the Youth

The project made a follow up survey in October 1996 and the findings showed that the campaign was very successful in reaching the youth and influencing behaviour change. For example:

Youth participation in the campaigns was very high: More than 90% of the youth surveyed had been exposed to at least one of the campaign media; on average, respondents had been exposed to five or six of the media.

< More than three-fourths of the respondents stated that the campaign messages had influenced them to change their sexual behaviour in some way.

< The majority claimed to have decided to abstain from sex and many began using condoms.

- < The proportion of respondents who were sexually active remained stable at around 50%.
- < Radio was most effective but more so in areas with local activities.
- < Experience with Safer Sex or AIDS Campaign showed that radio is an important medium for safer sex messages.

The cultural factors which contributed to the success of the campaign were:

- < active involvement of the intended audience in research and implementation.
- < well-defined and consistent campaign themes and messages;
- < support, advocacy and active participation of local leaders at the grassroots level;
- < strong and effective publicity campaign using posters, radio and interpersonal communication;
- < participatory distribution of campaign materials to target groups at the grassroots level;

< networking with other organizations and professionals to form Action Committees at district levels to make the campaign activities happen;

< process-led and participatory research campaign.

3.8 AIDS Information Centre (AIC)

The AIDS Information Centre was established in 1990 by a consortium of government, nongovernmental organisations (NGOs) and donors in response to the growing demand for HIV testing services. Prior to its establishment some HIV testing was being provided in certain settings without consent or counselling. Moreover, AIDS service organizations were not able to provide HIV testing to persons requesting AIDS care and support.

AIC's strategy for providing voluntary counselling and testing for HIV consists of six basic elements. First, AIC has trained personnel as HIV counsellors, laboratory technicians, data analysts, trainers and managers.

Secondly, they have developed protocols for both counselling and testing. Thirdly, support services have been established (<u>with collaborating agencies</u>) to provide long term care for those testing positive and post-test clubs to ensure long term behaviour change. The principle of voluntary counselling and testing (VCT) is being popularised through community mobilisation to increase acceptance and demand for it and the mass media is being used to educate the public about the benefits of VCT.

The major benefits of VCT for those testing negative include encouraging behaviour change based on HIV test results, making informed decisions regarding marriage and pregnancy and reduction of fear and anxiety. VCT also provides the opportunity for STD detection and treatment. For those testing positive, they benefit from early and better management of opportunistic infections and other STDs. They may also be referred for AIDS care and support. In addition they are screened for TB and preventive therapy may be provided.

VCT faces a number of challenges in the future. Foremost among these is obtaining negative outcomes for a client who is in fact HIV positive as a result of a technical error, (Downing et. al, 1998:386). This may erode the public trust in these services. The second challenge is the presence of discordant couples (about 11%) which are hard to explain. These are also clients concerns about breast-feeding, mother to child transmission and access to HIV drugs which need to be addressed. Increasing the availability of VCT in rural areas and the integration of services for STIs, family planning and TB are additional challenges.

Although the project documents do not mention specific cultural tenets to be addressed, counsellors are trained and are expected to adopt their skills to the various cultural settings. The training manual has a chapter on ethics and attitudes where the role of culture is emphasized.

For instance, the counsellors are alerted to variations that exist in intra-couple communication in the various cultures and the possibility of culturally determined constructs such as widow inheritance and wife sharing. It should be recognized that it is the individual clients as

custodians of culture who play out their cultural beliefs during contact with a trained counsellor. It is then the duty of a good counsellor to be sensitive to these cultural beliefs and practices and there is considerable latitude within the project design to accommodate cultural diversity.

Implementation of the project depends heavily on the clients' willingness to come forward for counselling and testing. Clearly, this is an individual decision and is reached through an evaluation of the services in light of the perceived benefits weighed against losses such as intrusion into one's private life, in the context of the client's background. The success of the VCT program, including the introduction of cost sharing in 1994, is evidence of support; more than 300,000 clients had been tested by the end of 1996.

3.9 Traditional Healers and Modern Practitioners Together Against AIDS (THETA):

The Traditional Healers and Modern Practitioners Together against AIDS (THETA) started in 1992 to study the effectiveness of local herbal treatment for selected AIDS related symptoms such as herpes zoster and chronic diarrhoea. The study revealed that traditional herbal treatment was superior to modern drugs in the treatment of herpes zoster; there was no discernible difference regarding chronic diarrhoea.

As a result of this observation and other considerations, it was decided to form an organisation that would link traditional herbalists with modern practitioners.

THETA recognizes that traditional healers have a role to play in the provision of health services; including the control of AIDS. They are generally respected in society and in some areas they are looked upon as cultural leaders and this places them in a good position to influence behaviour. Traditional healers are self reliant and would not depend on project funds for their survival and herbs often offer a cheaper alternative to modern drugs. However, traditional healers also manifest negative traits such as the sexual exploitation of female clients and quackery. They also remain suspicious and do not readily reveal the content of their concoctions.

Traditional healers undergo training upon recruitment into the THETA AIDS - project. This training aims at empowering them with the skills necessary to act as community educators, counsellors and condom distributors. In addition, the training aims at pointing out the harmful practices commonly committed by the traditional healers. The training is spread over 18 months to allow the traditional healers carry out their other duties simulatenously. A slower pace of instruction is also preferred for adult learners.

Following training, THETA provides continuous supervision to the traditional healers. The program started in Kampala but has been extended to six (6) other districts over time. Kiboga, Soroti, Mbarara, Mukono, Kamuli and Hoima. Supervision takes the form of monthly meetings through which their knowledge is refreshed and emerging issues discussed.

This program is a good example of using culturally relevant institutions in the combat against HIV/AIDS. Traditional healers provide a wide spectrum of services including education, counselling and treatment of opportunistic infections. They are respected in the communities they work in and are fairly knowledgeable about health matters.

3.10 NSAMBYA Integrated AIDS Services

The broad objective of this project is to alleviate the adverse effects of HIV/AIDS among those already sick with AIDS and their dependants. This project provides medical and nursing care to the AIDS patients in their homes and at referral clinics. In addition to counselling services, to those who are HIV positive, sick with AIDS and other family members, the project also provides spiritual and pastoral care to PWAs and the affected family members. Health education and basic nursing skills are offered to members of the family together with protective materials. Additional supportive help to families with AIDS patients is provided through income generating activities (IGAs). The project also supplements the diet of the patients and their families and assists with legal advice to clients.

The operational process for this project starts from a patient being referred from either the AIDS Information Centre or any outlet that is capable of confirming seropositive status. The first contact with the program is usually through the Mobile Home Care Services. In case of serious illness the patient is referred to an in-patient unit for confinement; sometimes they are advised to attend a special care AIDS clinic.

This project has extensive contacts with other AIDS support groups and community programs which complement its work. The community is consulted and is deeply involved in the implementation of the project. Patients are seen earlier than would be the case if they had to travel to a facility as an initial step. Staying with the rest of the family during care and treatment is believed to have psychosocial benefits, it also allows the patient to do some work however minimal.

Among the lessons learnt in this project is the fact that government and community support are essential for implementing a successful program for AIDS patient care.

It also became apparent that medical and nursing care constitute only a small part of the total care needed once AIDS enters the family. Pain relief is a very important aspect of care for AIDS patients. Equally important is the role of the community and the presence, attitudes, approach of the personnel involved and friends.

3.11 The AIDS Support Organization (TASO)

TASO was created in 1987 by Ugandans to provide psychological support to people living with AIDS. The organization was founded to contribute to the process of restoring hope and improving the quality of life of people and communities affected by HIV/AIDS. By 1994, TASO had expanded to seven districts of Uganda and was providing counselling , medical care and social support to a cumulative number of 22,795 people with HIV/AIDS and their families. In addition to providing a care package, TASO also offers training in counselling, provides material support to clients and their families, and supports community efforts in responding to the AIDS epidemic.

TASO is extremely exemplary in using the cultural approach to the problem of HIV/AIDS. The social and psychological support provided by the organization has a very high component of peoples participation. All the stakeholders, the clients, community, and staff contribute to the design, planning and implementation of the programme activities. The participatory approach enables the stakeholders to get a sense of ownership, to build capacity and to define concepts and methods related to living with HIV/AIDS and to involve the people in the evaluation process.

i) Counselling Services

The TASO methodologies empower people to cope with the problem. However, this means that those infected and affected must accept of being HIV positive and having a positive attitude towards the prospect of a shortened life expectancy. This way, counselling helps clients to cope with the infection.

Counsellors and clients discuss topics related to coping mechanisms. The end result is a very high level of acceptance by the affected persons, their families and communities.

ii) Medical and Home Care Support Services

In this endeavour, TASO provides treatment for opportunistic infections. Care comprises of medical treatment, counselling and nursing care. The evaluation exercise of 1993-94 revealed that twelve of the fourteen Focus Group Discussions were satisfied with TASO medical services. The majority of the clients sought early medical treatment, i.e. within two weeks of onset of symptoms.

iii) Social Support Services

Essentially, this involves the PWAs and their families receiving material support (food clothing medicines , day care center activities for people With AIDS (PWAs), Income Generating Activities (IGAs), and support to needy children in school sponsorship programmes. These services are well intentioned but they are sometimes affected by lack of funds.

3.12 Family Planning Association of Uganda (FPAU)

The Family Planning Association of Uganda (FPAU) is a national-grassroot, voluntary, not for profit, non-governmental organisation. An IPPF affiliate, FPAU is a non-discriminatory, non-political and pioneer family planning organisation in Uganda.

FPAU believes that knowledge of sexual and reproductive health and access to services is a fundamental human right. The Association is committed to the promotion of free, informed and responsible sexual and reproductive health decisions for the eligible population.

Through information, education, advocacy and services, the Association endeavours to address the unmet needs and demand for sexual and reproductive health care for individuals and couples including adolescents and identifiable under-served groups in collaboration with other agencies.

FPAU s sexual and reproductive health services include, inter-alia, HIV/AIDS counselling. STI management and treatment of minor ailments in FPAU clinics; cervical cancer screening services in all clinics; information, counselling and referral services for infertility cases.

Increased and improved accessibility and quality service to the undeserved communities include: services through Community Based Distribution (CBD) sites; sexual and reproductive health outreach services; recruitment and training for Community Based Distribution Agents (CBDAs).

3.13 The Agricultural Approach to Family Planning

Bamutiire (1997) used an agricultural approach to promote family planning and contraceptive technology communication in rural Uganda. In Uganda banana cultivation is based on many traditional beliefs and practices one of which is the belief that a well kept banana plantation weed free, properly mulched, with limited suckers would give bigger banana bunches compared to a plantation where suckers are not pruned.

This analogy was used to illustrate the difficulties experienced by an unplanned family with many children who put strain to the physical, emotional and financial resources of the family, consequently leading to poorer quality of life. The project therefore addressed the communication problem of rural farmers who had no access to media and cannot conceptualize the functions of modern family planning devices and terminology.

Because the approach uses simple agricultural concepts that are familiar to farmers, it catches their imagination easily. Agriculture analogies were used to reflect the experiences of unplanned families. One of them in Luganda language is that *ekita ekitava kusengejero, ye wankindo* which is translated to mean that a beer gourd which is continuously used without a break ends up with cracks and stitches. Similarly, a woman who continuously produces children without a break will end up with her uterus often ruptured and stitched.

3.14 Uganda Virus Research Institute (UVRI)

This facility was established more than sixty (60) years ago. Its activities initially centred on yellow fever epidemiology and investigated the extent of spread of yellow fever virus from West Africa eastwards. Its mandate has evolved over time and UVRI is currently concerned with carrying out scientific investigations on major communicable diseases (especially viral diseases) of public health importance. A major part of Institute's research effort is constituted by studies of STD control for AIDS prevention and the population dynamics of HIV - 1 transmission. Although the main thrust of the research at the Institute is bio-medical, there has been considerable investigation of socio-cultural factors affecting the spread of HIV/AIDS.

CHAPTER 4

CHANGES IN TRADITIONAL BELIEFS AND PRACTICES

The thrust of the inquiry was to ask each key informant about known tenets of Ganda culture (norms, values, beliefs and practices) closely associated with sexual behaviour and ascertain to what extent these have been modified over time and explore the implications of these changes for HIV spread and care for AIDS patients. Interaction with the key informants was organized around four themes:

- (i) multiple sexual partners (either concurrently or serially)
- (ii) acquisition of knowledge about sex (sources, quality of information)
- (iii) fertility preferences (in terms of numbers, sex of offspring)
- (iv) care for persons with AIDS (who is involved)

4.1 **Polygamous Marriages**

Respondents were asked to compare the prevalence of polygamy in the past with the contemporary situation. The overwhelming response was that nothing had changed in terms of numbers – 'men are inherently polygamous and it is their 'normal' state to have more than one wife'. In their view, a man cannot be satisfied with one wife. What has changed is that these days they are kept in separate residences and are sometimes unknown to each other. Co-wives often learn of each others' existence at the death of the husband when the will mentions children unknown to them. The respondents view absolute monogamy (one wife, one husband; no boy/girl friend) as very rare and would be an aberration for a man not to have one 'outside'. Even where no overt action has been taken by the man to become polygamous, the belief is that there is potential for this to happen when he 'decides' or 'gets a chance'. For other monogamous unions, the evidence has not been found, that is, no child has been born or declared from this out-of-wedlock arrangement.

These findings are in agreement with the earlier study (Sengendo et al 1998:45) which found that among the Baganda of Mpigi district only 44.4% disapproved the practice of marrying more than one wife. Essentially, this data shows that the majority of respondents in Mpigi district (56%) still cherish the practice of polygamous marriages. Similarly while this study found that 54% of the respondents disapprove the practice in Hoima. Among the Nyoro culture of Hoima district and the Iteso of Kumi district those who disapproved the practice of formalised polygamous marriage constituted 54% respectively. This is a reasonably significant trend. However, considering the epidemic and the risks of HIV infection associated with multiple sexual partners, the remaining 46% of the respondents in Hoima and Kumi districts who still favour polygamous marriage can have a negative impact on the campaign against the epidemic.

4.2 Multiple Sex partners:

Multiple sexual partner arrangements take several forms representing varying degrees of attachment and can be altered over time. A monogamous husband who has a child from a previous affair considers that the mother of his child as potentially available, especially if she remains unmarried. Monogamous husbands who contribute to rent for a room or house for a

'girlfriend' consider her a wife although she may be unknown to the co-wife at home. There are also overt forms of polygamy where a husband has two or more homes or rented. Co-residence of several wives has become rare.

4.1 Police Officer Invites Girl, Wife Nabs Them

There was drama at Jinja Road Police Station when a wife of a Police Officer nabbed her husband with a lover in bed. The wife had come to check on her husband to confirm if he would be coming upcountry for Christmas. This was on December, 23, 1998. Ironically, the officer who resides in the posh flats of the barracks, is reported to have grabbed his wife's bag, locked it in the house before giving her marching orders. The situation, however, worsened when he came out with his lover and was heckled by children who had come to welcome his children who had come with their mother from the village. The children of other officer swho also reside at the barracks started chanting *malaya* (prostitute) as the officer left the flat with his *kyana* (lover). They later boarded a pick-up truck which had conveniently been parked in the compound. The Police Officer stayed away until after Christmas. He immediately left for the village to join his disappointed wife.

Source: The New Vision Newspaper, Saturday January 16, 1999 pg.6

Respondents indicated that the preferred status is to appear monogamous in public; it is embarrassing to be seen 'parading' with different wives at every occasion. Monogamy is accepted in church and is good for public relations. Economic considerations are also a factor: it is difficult to cater for several women fully and some men deliberately withdraw from extramarital relations because of this. One informant mentioned the hit and run strategy; where a man gets a child out-of-wedlock, looks after the mother and child until the child is weaned and takes the child into his home and severs relations with its mother.

The most serious challenge in this behaviour goes far beyond knowing whether or not individuals engage in extra marital sex or in multiple sexual relationships. The most serious challenge is knowing why these behaviours persist in spite of the vast knowledge and awareness associated with HIV transmission. In the earlier study (Sengendo et al, 1998:46) ten reasons were given for multiple sexual relationships/extra marital. These included:

- Lack of sexual satisfaction with a regular partner. This was attributed to different types of physiological and psychological incompatibility. Respondents unacceptable differences due body fluids, body odour, sexual organs (too small, too wide, too short, too narrow, etc).
- < Unfaithfulness on the part of either partner.
- < Conflicts between partners.
- < Alcoholism
- < Impotence (even if partial)
- < Infertility which culturally is blamed on the woman.
- < Lust for too much sex which behaviour is mostly attributed to men.
- < If partner migrates for employment, land acquisition, etc.
- < Seeking another sex for a child.

- < Seeking material gain (from sugar daddies, sugar mummies, or escape from poverty).
 - < Peer influence, particularly among the young people
 - < Curiosity. It was alleged that sex satisfies human and psychological needs.

The main conclusion of this discussion is that although overt polygamy is declining, in fact little has changed in terms of number of sexual partners. Having multiple sexual partners is deeply rooted and is still accepted as the norm, by both men and women.

4.3 Age at first sexual contact

A question was asked as to whether children, especially girls, were being involved in sexual intercourse at a later or earlier age these days compared with the past. The reasons for any change were also probed.

Most responses did not point to a change in the age at the first sexual contact per se (either upwards or downwards). Rather, the key informants stated that the circumstances had changed enormously; there was less supervision and hardly any sanctions against pre-marital sex these days. Sanctions like *amawemukirano* where pre-marital pregnancy was punished by ostracizing the girl - living and eating alone - are no longer being practiced. Nor is sleeping with several men during pregnancy currently being sanctioned. Rape and the phenomenon of 'sugar daddies' have also become common forms of sexual initiation.

In the past, a paternal aunt 'ssenga' would be identified for a girl before she commenced having menstrual periods. Usually, this was an exemplary aunt, in a stable marriage and in whom the couple (father and mother of daughter) had trust and confidence. Virginity on the wedding night was prized and rewarded. These arrangements together with the value attached to virginity have collapsed.

These days there are a lot of distractions in terms of videos, discos and immoral characters. Living arrangements also present a problem and children living in tenements 'emizigo' see 'nakedness' very early. 'A young girl of about 2 years will say that so and so has beads like her mothers' - these are worn in the waist! Sugar daddies take on small children because they are cheap; their immediate demands do not include rent. There is also the prevalent view that young girls are less likely to be infected with HIV/AIDS.

Yet, if this view is held by many it could well engender the spread of the disease.

4.4 Widow inheritance:

This practice is declining. Originally, the purpose was for the family of the late husband control the property of the deceased. The word for widow 'Namwandu' is derived from 'endu' meaning property and 'Namwandu' was in charge of that property. It appears it was never a rule nor widespread. Respondents suggested it was an arrangement for the widow (usually one even if the late husband were polygamous) to continue enjoying the property jointly accumulated with her husband.

Several reasons were offered for the abandonment of the practice of widow inheritance. First, these days many women have extramarital affairs, they would have ready alternatives upon the death of their husbands. Second, the widows have means of expressing preference among the surviving brothers for example, by inviting them to join hands in business, taking kids to school etc - they eventually become sexually involved. Third, this practice is dying out because of fear of AIDS since the symptoms are pretty obvious.

4.5 Last funeral rites:

This practice has been modified over the recent past. The traditional form involved drumming, beer drinking and took place at night. Usually, relatives would start gathering on Wednesday to make final arrangements and building huts in which to spend the Friday night. The rites were carried out on Friday night culminating in the announcement and introduction of the heir on Saturday morning followed by a luncheon *okugabula*.

The main changes stem from financial considerations and the involvement of the religious institutions (particularly Christian churches). Organizers find it difficult to fund a three-day binge: food is scarce, beer is expensive and the relatives themselves do not have the time. As a result, it is common these days to hear over radio that 'there will be no sleeping arrangements made for the occasion'. While there may be a few relatives staying to put on the final touches, the compound would be brightly lit, no huts would be put up and this lack of darkness would 'bring about shyness'.

Church services are increasingly becoming the accepted way for conducting last funeral rites: instead of being offered a spear as a symbol of the duty of defending the family, the heir is increasingly being given a bible. Where the two ceremonies are being carried out concurrently, the church frowns on 'acts of immorality' and they are discouraged.

4.6 Twin rites:

Some of the key informants were not sure what used to go on at twin rites because they had never witnessed them. Those who had knowledge of these ceremonies indicated that it had undergone tremendous change.

Owing to its traditional nature and obscenity, it appears that the church early on singled out this ceremony for opposition. In its original form it involved a staged fight between the mother of the twins (Nalongo's) and the father (Ssalongo's) side - *okumenya olukanda*) leading to possible bruises; stepping in cooked food is also not practiced these days so is the shouting of obscenities.

The church has taken over this ceremony and the twin children are simply taken for a baptismal service usually followed by a luncheon.

4.7 **Pre-wedding night** (*Akasiki*)

Akasiki has maintained its essential features: it is dominated by young adults, there is music and beer. However, we were told that there is less darkness these days, viewed as a catalyst for immoral acts. One key informant stated *Ekizikiza kiyamba mumizi* - 'darkness favours the hungry'.

Again, financial considerations and church involvement have led to the slight modification of this occasion. There is a trend toward catering for guests only instead of a 'free'for'all' party. It is also often a bottle party, the host only providing the music. In addition, a church service is often seen as incompatible with acts of immorality and the host will endeavour to limit the number of guests.

4.8 Taboos

Taboos regarding sexual relations are still being felt very strongly. One is not expected to marry first cousins, from either side. Nor is one allowed to have sexual intercourse with members of one's clan (totem) or one's mothers' members. However, there are several names that are not identified with any clan - Musoke, Mukasa - which are leading to confusion. Socio-economic development and technological changes have led to the growing cash economy, increased and sophisticated means of production, employment opportunities, education, etc which combine to trigger off population movements including individual and group migration. As a result of these factors, families and clans are separated and many do not know even their close relatives.

4.9 Acquisition of Knowledge:

The traditional way for girls to acquire knowledge was to be ceded to the home of her paternal aunt (Ssenga) for a period of time preferably preceding her menarche. Among the roles for the paternal aunt was to initiate the elongation of the labia (*okusika enfuli*).

Box 4.2 The Baganda and the Practice of Elongating Labia Minora Among Adolescent Girls

In traditional Buganda, a girl at reaching the age between 10-15, would be required to be taught by her paternal aunt to elongate her labia minora (enfuli) or okukyalira ensiko, in Luganda. A woman who did not elongate the labia minora, is traditionally despised and regarded as having a

pit (*kiwowongole; kifufunkuli, funkuli muwompogoma*). If a bride was found not to have elongated her labia minora, she would be returned to her parents, with disgrace. The elongated labia minora serves the advantage of stimulating the man, and they are particularly exciting to the woman as part of the foreplay. In bed, the man would request the woman to be allowed to touch her labia minora. On being allowed, the man would very gently stroke them, making sure that no pain what soever is caused in the process.

Source: Sengendo, et. al, 1998:31

This study found that this practice has been altered over time and the aunts no longer perform this role. Several reasons were cited for this change. The first is that these days aunts and daughters are physically separated by long distances and it is expensive for them to meet. Spending a lot of time in schools, especially boarding schools, also deprived aunts the opportunity to perform this role. Thirdly, it is common for the gap in material possessions between families to preclude the daughter visiting her aunt. Fourthly, intermarriages have dampened the practice. Usually, the mother, who together with her daughter chooses a paternal aunt, starts the practice. Men are not involved in this transaction but it is necessary that the paternal aunt and the mother are both Ganda for this to occur. When asked whether the practice of labia elongation should be kept, we were informed by most informants that it was important to do so. The main reason was that it led to greater sexual satisfaction and ensured that a woman *kept her home* - i.e. man. They were categorical that the procedure made sex more pleasurable.

Peers, both in the neighborhood and in schools were replacing the paternal aunts as the source of information about sexuality. However, there were fears that some of the information obtained this way was improper and immoral. This included information on how to avoid pregnancies (correct or wrong), how to deceive men and fight authority. Although schools were acknowledged as providers of information on sexuality their approach was viewed as western *kizungu* and omitted some essential parts.

Schools do not deal with personal cleanliness using herbs, for example. There was also a problem of cases of two *generations of ignorance* where both the teacher and pupil had no knowledge of traditional practices regarding sexuality.

The general view is that the mass media is doing a bad job and is not constructive. Videos, films convey negative messages that link sex with brutality, drugs and crime. Key informants were of the view that the mass media does not target any particular audience and the messages end up being inappropriate for many.

4.10 Fertility considerations and HIV/AIDS:

The desire to have children is still strong. In the earlier study, Sengendo et al, 1998:42 found that over 90% of the respondents value producing their own children. *Children make a home and without them, there is no home*. FGD Kumi district. However, in contemporary times a small number 2 - 4 is now preferred. Respondents cited financial constraints - ability to feed, cloths, pay school fees - as the main reason for this trend. However, having at least one child of either sex is strongly preferred. Our respondents saw separate roles for sons and daughters and therefore the need to have both. Sons would be heirs to their fathers and carry on the (patrilineal) line while daughters were viewed as better nurses for the elderly parents. *Sons have no time for their homes and their parents*.

There exist traditional treatments for infertility, most of them relating to female infertility. Infertility is normally blamed on the woman and the man is advised to try elsewhere. Although rare these days, a woman who reaches menopause without bearing a child for her husband would encourage him to marry a younger woman; some would go as far as bringing in their nieces (daughters of her brother). We were also told that there is subtle acquiescence to infidelity for an infertile couple. One key informant stated that *there are no infertile individuals, it is only blood which is incompatible.* This belief abets infidelity and may be a vehicle for HIV/AIDS transmission.

Contraception is traditionally referred to as *okwesiba* i.e. tie oneself. It appears that there are several variations to this. Some tie a thread around the waist or put herbs in the waist hem of the petticoat. Others take the first menstrual blood of their daughters and *lock her up until she is ready*. Another variant is to drink a concoction of herbs. The key informants also recognized abstinence and extensive breast-feeding as traditional means of preventing pregnancy.

Increasingly, modern contraceptive methods are being preferred since they are more readily available. These include pills, injectables, coil and foaming tablets. The key informants stated that it was difficult to find a traditional healer who knew how to prevent pregnancy.

4.11 Care for People Living With AIDS (PWA)

Who cares for a person with AIDS depends on a number of factors including marital status, whether or not the spouse is sick too, and how severe the sickness of the patient in question.

For sick married women, the husbands would look after them up to a point when it becomes necessary to bathe them and change clothes for them, they would be asked to draw in the women's relatives to look after her. Married men would on the other hand be looked after by their wives except if they too fell sick. If the wife fell sick she would draw in her relatives to look after her and her husband.

Single men or women with AIDS are invariably looked after by their mothers, if still alive. Otherwise brothers and sisters assist them. It was reported that as a rule these receive help very late in the day. Since no one listens in to their daily complaints, the disease progresses without notice or the necessary care.

CHAPTER 5

OBSERVATIONS AND RECOMMENDATIONS

5.1 This is a new approach to the process of conceptualizing and understanding national development. Unfortunately the study has not found evidence that the approach is consciously embedded in the government and non-governmental documents (policies and plans) which were reviewed. Unlike the social development and the Human Development models, the Cultural approach to development has a fuzzy definition, without well defined indicators which agencies and institutions can use for planning, implementation, and monitoring and evaluation. Consequently, there is no evidence that institutions have made conscious effort to incorporate the approach in the policy formulation and planning process. The evidence we have traced is that the institutions have utilized the participatory model which focuses on the bottom - up approach in decision making processes, as well as the participatory appraisal methods (RRA/PRA. In the process, the cultural approach is incorporated, rather accidentally, but not by design.

Control Con

5.2 There is some literature on the interlinkage between culture and HIV/AIDS. Most of these studies, however are too general to provide in-depth understanding of the factors precipitating risky behaviours, those factors that should be targeted in the prevention campaign e.g. (IEC), treatment or in-patient care.

There are studies on risky behaviours, for example, but they do not analyze and provide knowledge as to why an individual should take risks in activities which can lead to death and or total eradication of a family.

There is evidence of rationality in behaviour. There are also models in behaviour modification. There is, however, a serious dearth of knowledge in factors (social, cultural etc) which influence behaviour formation and ultimately which can lead institutions to design more effective skills and techniques for HIV/AIDS control.

< Cultural specific studies on sexual behaviour formation should be undertaken to provide a deeper understanding on the effect of cultural tenets on HIV/AIDS spread, treatment and care.

5.3 There is evidence that women, are particularly at risk and that these risks start early in their lives (e.g. child abuse) and persist to the end of their life cycle (e.g. rape, domestic violence,

widow inheritance, etc). Studies on culture have artificially identified some aspects of culture. As already pointed out, the women in general, and young women in particular, are extremely vulnerable to exploitation and ultimately HIV infection. Unfortunately the bulk of the institutions which have preventive and treatment programs do not specifically address the needs of women such as treatment of trauma and conflict management. The life skills for youth are well focussed. The major shortcoming they have is that these skills are primarily addressed to school going youth through programmes such as School Health Education Project (SHEP) and the Basic Education, Child Care and Adolescent Development Intervention (BECCAD). The needs of the out-of-school youth largely remain unattended.

Institutions should focus their attention to the especially vulnerable groups with IEC material specifically targeted to them. In addition, there is need to isolate different cultural identities and address their particular needs.

5.4 Research institutions which have the capacity to operationalize the cultural approach are few. Currently, Makerere University, Faculty of Social Sciences, has spearheaded the initiative to incorporate the cultural approach to development into its curricula.

< However, there is need to expand the initiative to cover institutions such as Makerere Institute of Social Research (MISR), the Institute of Statistics and Applied Economics (ISAE), Institute of Public Health, Child Health and Development Centre, Mbarara University of Science and Technology as well as Nkozi University.

5.5 There is evidence that the HIV prevalence is reducing and it is currently around 8% in sentinel sites. There are also reports that the national poverty level has dropped from 55% of the population to 45%. It is unknown whether there is any association between HIV prevalence rate and poverty so as for both of them to be changed in the same direction. The underlying factors and the manner in which they are associated remain unknown.

< There is need to establish whether the two phenomena are causally related and if so, the mechanism through which they are linked.

5.6 The discrepancy between HIV/AIDS awareness and the actual behaviours which seem to promote HIV transmission is amazingly high. Behaviour seems to be changing only in the direction of increased condom use, which is an urban based trend. Extra marital sex as well as polygamy (overt and/or disguised) remain rampant. The reasons mentioned in this and earlier studies, and the needs of the partners are not addressed in the existing intervention (e.g. conflicts impotence, infertility, etc). This area has cultural implications and should be explored and programs developed to address the unmet needs of individuals and couples.

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APPENDIX I

Specific Terms of Reference

Taking a cultural approach to HIV/AIDS prevention and treatment for sustainable development.

Institutional Assessment

In the framework and along the lines of the UNESCO/UNAIDS project on "Cultural Approach to HIV/AIDS prevention and Care", the contractor shall carry out an assessment of:

- The evolution of the epidemic (HIV infection and PWA) and its cultural and societal impact in the context and perspective of sustainable development.
- The present situation in AIDS prevention, detection and treatment, in which international cooperation institutions, national institutions and NGOs are involved, with special emphasis on how and to which extent they are taking into consideration cultural features and resources of the population into their programmes, plans and projects, more specifically through IEC activities, and are evaluating their own professional and institutional cultures.
- The success stories and innovative experiences which have been carried out to date and from which lessons could be learnt, as far as taking a cultural approach in this matter is concerned.

To this effect, the Contractor shall:

- Use the following information and literature for his assessment work; project documents, programmes and evaluation reports of international institutions (UN system, other NGOs, bilateral cooperation institutions, national institutions, NGOs, Universities, research institutions).
- As a complement to this documentary research he/she shall carry out interviews with people in charge at the various levels: international cooperation (theme groups), national institutions (National Committees, specialized centres and resource persons.

In this work he will use the methodological proposals made in the Planning Manual A Cultural Approach to Development, more specifically in Chapter III: Projects and Programs and Chapter IV: Role of the Development Institutions.

The assessment report about 50 pages long, shall be completed by December 20th, 1998. A list of contacted and interviewed persons and personalities, as well as a list of consulted documents and literature, shall be appended to the report.

During all his work period, the Contractor shall keep in contact with the researcher or researching team working on the in-depth investigation, in order to inform and receive information from them in a cross-fertilizing perspective.

APPENDIX II

Definitions of Life Skills Concepts

(i) Skills of knowing and living with oneself: 3

These include:

a) Self Awareness:

On which young people need to know and understand themselves first, their potential, their feelings and emotions, their position in life and in society and their strengths and weaknesses. They need too to have a clear sense of their own identity, where they come from, and the culture into which they have been born and which has shaped them.

b) Self esteem

Self awareness leads to self esteem as people become aware of their own capabilities and place in their community. It has been described as an *awareness of the good in oneself*. It refers to how an individual feels about such personal aspects as appearance, abilities and behaviour and grows on the basis of their experiences of being competent and successful in what they attempt. However, self-esteem is strongly influenced by an individual's relationships with others, including significant adults, such as parents, family members and teachers, and one's peers.

c) Assertiveness

Assertiveness means knowing what you want and why and being able to take the necessary steps to achieve what you want within specific contexts. It can cover a wide variety of different situations, from a girl rejecting the sexual advances of a fellow student or older man to children convincing their parents that they need to continue with their education, to adolescents taking the lead in bringing people together for some beneficial act in the community such as protecting or developing the environment.

d) Coping with Emotion

Emotions, such as fear, love, anger, shyness, disgust, the desire to be accepted etc are subjective and usually impulsive responses to a situation. That is why they can be very unpredictable and often lead to actions which are not based on logical reasoning. Emotions are strong reflections of what we are. Thus, identifying and then coping with emotions implies that people can recognise their emotions and the reasons for them and make decisions which take account of but are not overly influenced by them.

³ Source: <u>Life Skills for Young Ugandans: Secondary Teachers= Training Manual</u>, 1997: Republic of Uganda/UNICEF.

e) Coping with Stress

Stress is an inevitable part of life. Family problems, broken relationships, examination pressures, the death of a friend or family member are all examples of situations that cause stress in people's lives. However, stress can be a destructive force in an individual's life if it gets too big to handle.

Therefore, as with emotions, young people need to be able to recognise stress, its causes and effects and know how to deal with it.

(*ii*) The skills of knowing and living with others

a) Interpersonal Relationships

Relationships are the essence of life. Relationships also come in different shapes and sizes. As children grow up, they have to develop relationships with:

- < significant adults in their lives such as parents, relatives, neighbours, teachers etc.,
- < peers in and out of school
- < people they meet in life, friends of their parents, the local leaders, shopkeepers etc. Not everybody can be one's friend but children need to know how to react appropriately in

each relationship so that they can develop to their maximum potential in their own environment.

b) <u>Friendship Formation</u>

At the level of peers, this is one of the most important aspects of interpersonal relationships. An individual needs friends to share life with, activities, hopes, fears and ambitions. However, young people should be able to recognise and, if necessary, resist friendships that can lead them into dangerous or unnecessary risk taking behaviour such as taking alcohol or other drugs, stealing and dangerous sexual behaviours.

e) Empathy

Showing empathy involves putting oneself in other peoples' shoes, particularly when they are faced by serious problems caused by circumstances or their own actions. It means understanding and internalising other people's circumstances and finding ways to lessen the burden by sharing with them rather than condemning or looking down on them for whatever reason. Thus empathy also means supporting the person so that they can make their own decisions and stand on their own feet as soon as possible.

f) Peer Resistance

Peer resistance means standing up for one's values and beliefs in the face of conflicting ideas or practices from peers, friends, or colleagues. One needs to desist from doing things that one believes to be wrong and be able to defend one's decision even if the suggestions or influences are coming from very close friends. With young people in particular, the pressure to be like other group members is great. Thus, if the group is turning to negative influences and habits, peer resistance is a very important skill.

g) Negotiation

Negotiations involve assertiveness, empathy and interpersonal relations and also the ability to compromise on issues without compromising one's principles. It involves being able to cope with potentially threatening or risky situations in interpersonal relations, including peer pressure, state one's own position and build mutual understanding.

h) Non-violent Conflict Resolution

This is connected to interpersonal relations, negotiating skills and coping with emotions and stress mechanisms. While conflicts are unavoidable and sometimes necessary but the skill of non-violent conflict resolution ensures that such conflicts do not become destructive.

i) Effective Communication

Includes listening skills and understanding how others are communicating as well as realising how one communicates in different ways. It is a two way process between the sender of the message and the receiver and both sides must understand the message in order for the communication process to take place.

iii) Skills of making effective decisions

a) Critical Thinking

Young people are confronted by contradictory issues, that messages, expectations and demands from parents, peers, teachers, the media, religious leaders, advertisements, etc. These interact with their own aspirations and ambitions. The young people therefore need to be able to analyze critically the environment in which they live and the multiple messages that bombard them.

b) Creative Thinking

This skill recognizes that in life there are various ways of doing things. Therefore, coming up with new ways of doing things, including new ideas, arrangements or organisations is part of creative thinking. This skill is extremely important in a changing world.

c) Decision Making

An individual is frequently confronted with serious decisions in regard to relationships, future life etc. There are frequently conflicting demands all of which cannot be met at the same time. One must make a choice but demands all of which cannot be met at the same time. One must make a choice but at the same time one must be aware of the possible consequences of one's choice. Thus it is important to weigh the consequences before making a decision and have a framework for working through these choices and decisions.

d) Problem Solving

Problem solving is related to decision making and needs many of the same skills. It is only through practice in making decisions and solving problems that children and adolescents can build the skills necessary to make the best choices in whatever situation they are confronted with.

APPENDIX III

Documents Consulted

Ankrah, E.M., Lubega, M.; Nkumbi, S (1989) "The family and care-giving in Uganda" (W.G.P.32) In: Abstracts of the V International Conference on AIDS: the Scientific and Social Challenge; Montreal, June 4-9, 1989; IDRC.

Arya, O.P.; Ongom, V.L.; and Tomusange, L.T. (1974), "The Role of the rural health centre in the control of venereal diseases in Uganda", <u>East African Medical Journal</u>

Bamutiire E.K. (1997), "Agricultural Approach to Family Planning: The Uganda Experience", in: International Institute of rural Reconstruction (IIRR): <u>Reproductive Health and</u> <u>Communication at the Grassroots,</u>; <u>Experiences from Africa and Asia</u>, pg 153-156.

Beattie, J.H.M. (1957) "Initiation into the Chwezi spirit possession cult in Bunyoro <u>Africa</u> <u>Studies</u> 16(2): 150-61

Beattie, J.H.M., "The Nyoro of Western Uganda". In Molnos, ed cit, 1973.

Bennett, F.K. (1962) "The social determinants of gonorrhea in an east African town", <u>East</u> <u>African Medical Journal</u> 39(6):333-42.

Bennett, F.J.; Saxton, G.A. and Mugalula-Mukiibi (1973) "Kasangati: the background to a health centre", <u>Nkanga</u> 7:15-31

Bennett, F.J. (1965) "The social, cultural and emotional aspects of sterility in women in Buganda" Fertility and Sterility 16(2):243-51.

Bond G.C. and Vincent J, "Living on the Edge: structural adjustment in the context of AIDS" in Hansen, H.B. and Twaddle, M (eds); Changing Uganda, The Dilemmas of Structural Adjustment and Revolutionary Change, London, James Currey, 1991.

Brown, W. "Marriage, divorce and inheritance: movement for legislative reform", The Uganda Council of Women, 1988.

Chela, C.M., et al, 1994 "Cost and Impact of Home-based Care for People Living with HIV/AIDS in Zambia", Unpublished Report. World Health Organization, Global Programme on AIDS, Geneva.

Downing G. Robert et. al, "Optimizing the Delivery of HIV Counselling and Testing Services: The Uganda Experience Using Rapid HIV Antibody Test Algorithm", <u>Journal of Acquired</u> <u>Immune Deficiency Syndromes and Human Retrovirology</u>, 18:384-388, Lippincott-Raven Publishers, Philadelphia. Edward de Bono, in <u>Life Skills for Young Ugandans; Secondary Teachers' Training Manual</u>, Republic of Uganda/UNICEF, (1997/1998)

Elam, E. <u>The Social and Sexual roles of Hima Women</u>, Manchester: Manchester University Press, 1973.

Forster, S.J. and Furley, K.E. (1989), "1988 public awareness survey on AIDS and condoms in Uganda: <u>AIDS</u>", 3(3):153-6.

Gamurorwa, A.B., Lettenmaier C.L. and Nan Lewicky, (1997), "HIV/AIDS Prevention", in: International Institute of Rural Reconstruction (IIRR); <u>Reproductive Health and Communication at the Grassroots</u>,; Experiences from Africa and Asia, pgs 59 -64.

Goldschmidt, W (1973), "Guilt and pollution in Sebei mortuary rituals", Ethos 1:75-105.

Hamburg, B.A. (1990). "Life Skills Training: preventive interventions for young adolescents". Washington D.C.

Kaharuza, F. (1991) "The knowledge, attitudes and practices of contraception and sexuality of adolescents of Kampala, Uganda", Dissertation, submitted for M. Med., Obstetrics/Gynecology, Makerere.

Kisekka, M.N. (1991) "Socio-cultural beliefs and practices related to condom acceptability among Hausa in Nigeria and Baganda in Uganda" WHO, Special Programme of Research, Development and Research Training in Human Reproduction.

Kisekka, M.N (1989), "Langi - Lira district In: Standing, H and Kisekka, M.N.; <u>Sexual</u> <u>Behaviour in sub-Saharan Africa: a review and annotated bibliography</u>", Overseas Development Administration.

Kisekka, M.N. (1989), "Japadhola - Tororo district", in: Standing, H and Kisekka, M.N.; op. cit, 1989).

Kisekka, M.N. "Heterosexual relationships in Uganda", PhD Dissertation, University of Missouri, 1973.

Kisekka, M.N. (1989), "Ankole - Bushenyi district", op. cit.

Kisekka, M.N. (1989), "Baganda - Kampala and Mukono", op cit.

Kubahire, N.B., "Continuity and Change in Kiga marriage - An Analysis of Structural Change in Kiga Marriage", BA (SWASA) Thesis, Makerere University library, (Africana), 1981.

Larson, A., "The Social Context of HIV transmission in Africa; a review of the historical and cultural bases of East and Central African Sexual relations", Review of Infectious Diseases, 11(5): 716-31.

Life Skills Workshop, UNICEF/Bangladesh (1993).

Mandeville, E. (1979), "Poverty, work and the financing of single women in Kampala", <u>Africa</u> 49(1):42-52.

McGrath J.; (1990) Rwabukwali, C.; Schumann, D "Cultural determinants of sexual risk behaviour for AIDS among Baganda women". Paper presented at American Anthropological Association Meetings, Washington.

Middleton, F.K. The Lugbara of North - Western Uganda, in Molonos, ed cit, 1973.

Ministry of Higher Education, Zimbabwe/UNICEF (1994). "Knowledge and attitudes on STD/HIVAIDS of College students in Zimbabwe". Report of a baseline study carried out in teacher training and technical colleges before the start of the general course in AIDS education.

Ministry of Education and Culture, Zimbabwe/UNICEF (1993) 'What grade 7 pupils know about and think about AIDS'. Report of baseline study carried out in primary schools in Matebeleland South and Mashonaland East before the start of the National AIDS Action Programme for Schools.

Ministry of Education and Culture, Zimbabwe/UNICEF (1993). 'Primary school teachers knowledge and understanding of AIDS'. Report of a baseline study carried out in primary schools in Matebeleland South and Mashonaland East before the start of the National AIDS Action Programme for Schools.

Moodie, R ; Katahoire et al (1991) "An evaluation study of Uganda AIDS Control Programme's Information Education and Communication Activities", WHO, ACP/MoH.

Molnos, A, <u>Attitudes Toward Family Planning in East Africa: An investigation in Schools</u> <u>around Lake Victoria and in Nairobi</u>, Weltforum Verlag: Munchen, 1968.

Muhumuza, C., Tajjuba, P. (1990), "A report on Kapchorwa district AIDS mobilisation workshop 27 Jan - 15 Feb, 1990" Health Education Division, AIDS Control Programme.

Mushanga, M.T., "The Nkole of South Western Uganda" in Molnos op. cit, 1973.

Ntozi, J.P.M.; Kabera, et al (1991), "Some determinants of fertility among Banyankole: Findings of the Ankole fertility survey", ISAE, Makerere.

Ntozi J.P.M. and Kabera J.B., (1991), "Family Planning in rural Uganda: Knowledge and use of modern and traditional methods in Ankole", Studies in Family Planning, 22(2):116-23

Ntozi J.P.M., et al, "Some Aspects of the determinants of fertility in Ankole, Uganda: Findings of the elders Survey", IDRC, 1986.

Obbo, C, (1988): "Facilitator of Women's Educational Opportunities", In: Romero, R.W. (Ed); Life Histories of African Women Ashfield Press.

Oberg, K. (1949), "Analysis of the Bahima mmarriageceremony", Africa 19(2): 107-20

Oberg, K. (1938), "Kinship Organization of the Banyankole", Africa, 11 (2): 129-59.

Olowo-Freers, B. (1992), "Socio-Cultural aspects of sexual behavioural practices and transmission of HIV/AIDS in Uganda", UNICEF.

Olowo-Freers Bernadette P.A. and Barton G.Thomas,1992 <u>In Pursuit of Fulfilment</u>: <u>Studies of</u> <u>Cultural Diversity and Sexual Behaviour in Uganda</u>

Omongole, O.O., "High polygamous tendencies among the Iteso", Thesis submitted for BA (Social Work and Social Administration) Makerere University, (Africana) 1983.

Ongom, V.L.; Lwanga et al (1971), "Social background to venereal disease at Kasangati", <u>East</u> <u>African Medical Journal</u> 48(8):366-71.

Onyango, K. (1991), "Teacher gets 12 years", <u>New Vision</u> Friday, Nov.1.

Seeley, J.A. et al (19912), "Socio-economic status, gender, and risk of HIV-1 infection in a rural community in south west Uganda", Unpublished Manuscript, submitted for publication, MRC.

Sengendo J.R. and Yiga D., (1997), "Family Planning Campaign, The Case in Masaka District, Uganda", in: International Institute of rural Reconstruction (IIRR): <u>Reproductive Health and</u> <u>Communication at the Grassroots</u>,; Experiences from Africa and Asia, pgs 119 - 124.

Sengendo J., et. al (1998) "Inter-linkage between Culture, Traditions and HIV/AIDS in Uganda A Research Report on the Districts of Mpigi, Hoima and Kumi", submitted to THE UNAIDS - UGANDA THEME GROUP.

Sengendo J and Nambi J (1997), "The Psychological Effect of Orphanhood: a Study of orphans in Rakai District", <u>Health Transition Review</u>, Supplement to Vol 7, 1997, pg 105-124. Serwadda D., et al, (1985) Slim disease: a new disease in Uganda and its association with HTLV-III infection, <u>Lancet</u> ii.849-52.

Southall, A.W. (1960), "On chastity in Africa", Uganda Journal 24(2):207-16.

Southwold, M (1973),"The Baganda of central Uganda",In: Molnos, A.; <u>Cultural source</u> materials for population planning in East Africa East African Institute of African Studies.

TACADE, "Skills for the Primary School Child: Part 2 Cross cultural Themes", in <u>Life Skills for</u> <u>Young Ugandans; Secondary Teachers' Training Manual</u>, Republic of Uganda/UNICEF, (1997/1998)

TACADE, "Energizers, Ice Breakers and Warm-Ups: in Life Skills for Young Ugandans"; <u>Secondary Teachers' Training Manual</u>, Republic of Uganda/UNICEF, (1997/1998)

TACADE, "Skills for the Primary School Child: part 1 Foundation Programme", in Life Skills for <u>Young Ugandans</u>; <u>Secondary Teachers' Training Manual</u>, Republic of Uganda/UNICEF, (1997/1998)

The New Vision daily newspaper Kampala - Uganda.

UNESCO, 1997, <u>A Cultural Approach to Development</u>, World Decade for Cultural Development CLT/DEC/CD.

UNESCO, 1997, <u>Culture, Gender & Development for Eastern & Southern African English</u> <u>Speaking countries</u>, World Decade for Cultural Development.

Van Praag, et al 1996, "Can HIV/AIDS Care initiatives Be Part of Integrated Care? Lessons from Developing Countries", Abstract Th.B.400. Paper presented at the Eleventh International Conference on AIDS, Vancouver, B.C., Canada. July 7-12. World Health Organization, Geneva.

Van der Meeren, R. (Yeld), "AIDS education for behaviour change: preliminary research findings among the Bakiga of Kabale and Rukungiri districts", UNICEF, unpublished Draft report.

World Bank Policy Research Report, <u>Confronting AIDS, Public Priorities in a Global Epidemic.</u>, Oxford University Press, 1997.

World Health Organization/UNESCO. (1994). School Health Education to prevent AIDS and STD: handbook for curriculum planners.

Yeld, R.V. The Kiga of South-Western Uganda:"Traditional beliefs influencing levels of fertility" In Molnos, A, (ed) <u>Cultural Source Materials for Population Planning in East Africa</u>, Nairobi, Institute of African Studies, University of Nairobi, 1973.