FOCUS GROUP DISCUSSION ON SOCIAL CULTURAL FACTORS IMPACTING ON HIV/AIDS IN UGANDA

FINAL REPORT

Prepared by:

Delius Asiimwe
Richard Kibombo
Stella Neema
Makerere Institute of Social Research (MISR)

for

Ministry of Finance, Planning and Economic Development/UNDP

KAMPALA - UGANDA

June 2003
# TABLE OF CONTENTS

**ACKNOWLEDGEMENT** ............................................................................................................. III  
**TABLES AND FIGURES** ........................................................................................................... IV  
**LIST OF ABBREVIATION** ......................................................................................................... V  
**EXECUTIVE SUMMARY** .......................................................................................................... VI  

## 1.0 BACKGROUND TO THE STUDY ......................................................................................... 1  
### 1.1 CONTEXT ........................................................................................................................... 1  
### 1.2 STATUS OF THE HIV/AIDS EPIDEMIC ........................................................................... 1  
### 1.3 STUDY OBJECTIVES ......................................................................................................... 2  
### 1.4 METHODOLOGY .............................................................................................................. 3  
#### 1.4.1 Study Design ................................................................................................................ 3  
#### 1.4.2 Sample Selection .......................................................................................................... 3  
#### 1.4.3 Data Collection ............................................................................................................ 4  
### 1.5 ORGANISATION OF STUDY ............................................................................................ 6  
#### 1.5.1 Study execution and implementation Modalities ......................................................... 6  
#### 1.5.2 Research Process ........................................................................................................ 6  
#### 1.5.3 Training of Research Team ......................................................................................... 6  
#### 1.5.4 Pre-test ....................................................................................................................... 7  
#### 1.5.5 Execution of the Field Work ....................................................................................... 7  
#### 1.5.6 Data Processing .......................................................................................................... 7  
#### 1.5.7 Response Rates ......................................................................................................... 7  
### 1.6 STRUCTURE OF THE REPORT ......................................................................................... 8  

## 2.0 REVIEW OF MODELS/THEORIES OF BEHAVIOUR CHANGE. ......................... 9  
### 2.1 REVIEW PROCESS ......................................................................................................... 9  
### 2.2 ASSESSMENT OF MODELS/THEORIES ....................................................................... 13  

## 3.0 VERIFICATION OF THE ‘CAUTIOUS SHIFT’ MODEL .................................................. 16  
### 3.1 INTEGRATED BEHAVIOUR CHANGE FRAMEWORK ................................................... 18  

## 4.0 KNOWLEDGE, ATTITUDES AND PERCEPTIONS OF HIV/AIDS ...................... 20  
### 4.1 COMMUNITY KNOWLEDGE AND SOURCES OF INFORMATION ON HIV/AIDS . 20  
### 4.2 COMMUNITY PERCEPTIONS OF HIV/AIDS ................................................................. 23  
#### 4.2.1 Perceived Benefits to Behaviour Change ................................................................. 23  
#### 4.2.2 Perceived Threats/Vulnerability ............................................................................... 23  
### 4.3 PERCEIVED BARRIERS TO BEHAVIOUR CHANGE ..................................................... 24  
### 4.4 PERCEIVED HIV PREVALENCE .................................................................................... 28  
#### 4.4.1 Perceived categories of people most affected ............................................................ 30  
### 4.5 HIV/AIDS-RELATED PROBLEMS IN THE COMMUNITY ............................................ 31  

## 5.0 CULTURAL NORMS, SOCIAL PRACTICES AND HIV/AIDS ............................. 36  
### 5.1 COMMUNITY SOCIAL PRACTICES AND THEIR IMPACT ON HIV/AIDS .............. 36  
#### 5.1.1 Alcohol and drug abuse ............................................................................................ 36  
#### 5.1.2 Discos and Traditional Dances ................................................................................. 37  
#### 5.1.3 Video shows, Films and Drama ............................................................................... 38  
#### 5.1.4 Games and Sports .................................................................................................... 38  
#### 5.1.5 Peer Influence ........................................................................................................... 39  
#### 5.1.6 Market days .............................................................................................................. 39  
#### 5.1.7 Worshipping ............................................................................................................. 39
5.2 CULTURAL NORMS AND PRACTICES AND HIV/AIDS.......................................................40
  5.2.1 Traditional Ceremonies...........................................................................................41
    5.2.1.1 Circumcision .................................................................................................41
    5.2.1.2 Marriage Ceremonies .....................................................................................41
    5.2.1.3 Other Traditional Ceremonies .......................................................................43
  5.2.2 Traditional Rituals ..................................................................................................43
    5.2.2.1 Funeral Rites ...................................................................................................43
    5.2.2.2 Other Traditional Rituals ................................................................................44
  5.2.3 Traditional Healing ...............................................................................................44
  5.2.4 Widow inheritance ...............................................................................................45
  5.2.5 Other Cultural Norms and Practices ......................................................................46

6.0 COMMUNITY STRATEGIES IN RESPONDING TO HIV/AIDS...............................50
  6.1 DISTRICTS RESPONSE .............................................................................................50
  6.2 COMMUNITY RESPONSE ........................................................................................52
  6.3 INDIVIDUAL RESPONSE............................................................................................53
    6.3.1 Strategies Adopted by Adults...............................................................................53
    6.3.2 Strategies by Youths ............................................................................................56
  6.4 HIV/AIDS SERVICES AVAILABLE TO COMMUNITIES ............................................58
    6.4.1 Adequacy of available HIV/AIDS services........................................................59
    6.4.2 Impact of available Services on HIV/AIDS related Behaviour............................60

7.0 CHANGES IN HIV/AIDS RELATED BEHAVIOUR .................................................64
  7.1 CHANGES THAT HAVE OCCURRED IN HIV-RELATED BEHAVIOUR......................64

8.0 CONCLUSIONS ..........................................................................................................69
  8.1 THE INTEGRATED BEHAVIOUR CHANGE FRAMEWORK...........................................69
  8.2 COMMUNITY KNOWLEDGE, ATTITUDES AND PERCEPTION OF HIV/AIDS .............69
  8.3 CULTURAL NORMS, SOCIAL PRACTICES AND HIV/AIDS .......................................70
  8.4 COMMUNITY STRATEGIES IN RESPONDING TO HIV/AIDS ....................................71
  8.5 CHANGES IN HIV/AIDS RELATED BEHAVIOUR .....................................................71

9.0 RECOMMENDATIONS ...............................................................................................72

REFERENCES.......................................................................................................................74
Acknowledgement

This study benefited from inputs and suggestions of numerous people. Special thanks go to Ministry of Finance and Economic Planning (MOFEP) with support from UNDP for the confidence vested in MISR to undertake this important task. The overall guidance and oversight provided by the Advisory Committee consisting of key stakeholders from Government, Parliament of Uganda, NGOs, Private sector and Civil Society is similarly acknowledged. We are also thankful to Dr. Larry Adupa, Mr. Emmanuel Pinto and Mr. Sam Ibanda who provided comments and suggestions that greatly shaped the outcome of this report.

Special thanks go to the respondents in the communities and local government staff of Nebbi, Soroti, Lira, Mbarara, Mukono and Mbale who freely shared their ideas and experiences that have been used in the preparation of this report. Their contribution was very important and without it, we would never have been able to achieve our objectives.

Last but not least, we wish to acknowledge the collective efforts of the administrative and support staff of Makerere Institute of Social Research (MISR) that facilitated the study and preparation of this report.
Tables and Figures

TABLES

Table 1.1 District and Sub-counties selected for the study ........................................... 4
Table 1.2 Summary of FGDs conducted in each study district ................................. 5
Table 1.3 Summary of KIIs conducted in each study district .................................. 5
Table 2.1 Description and Application of selected models/theories .......................... 10
Table 4.1 Sources of HIV/AIDS Information to the communities ............................. 21
Table 4.2 Perceptions on HIV/AIDS prevalence in the study districts ....................... 30
Table 4.3 Categories of people considered most affected by HIV/AIDS .................... 31
Table 4.4 Categorisation of HIV/AIDS related problems by district ....................... 34
Table 5.1 Social Cultural Factors positively impacting on HIV/AIDS ....................... 48
Table 6.1 Available HIV/AIDS services to the communities .................................... 59
Table 6.2 Impact of services on HIV/AIDS related behaviour .................................. 61
Table 7.1 Changes in HIV/AIDS related behaviour .................................................. 66

FIGURES

Figure 1: The Integrated Behaviour Change Framework ....................................... 18
Figure 2: Major Factors Motivating people to change behaviours ......................... 24
Figure 3: Major Barriers to HIV/AIDS related behaviour change ......................... 25
Figure 4: Behaviour changes most significant in HIV/AIDS risk reduction ............. 67
**List of abbreviation**

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AIC</td>
<td>AIDS Information Centre</td>
</tr>
<tr>
<td>AIDS</td>
<td>Acquired Immunodeficiency Syndrome</td>
</tr>
<tr>
<td>AIM</td>
<td>AIDS Integrated Model Program</td>
</tr>
<tr>
<td>ARVs</td>
<td>Anti Retro-Virals</td>
</tr>
<tr>
<td>ASRH</td>
<td>Adolescent Sexual Reproductive Health</td>
</tr>
<tr>
<td>CBDA</td>
<td>Community Based Distribution Agent</td>
</tr>
<tr>
<td>CBO</td>
<td>Community Based Organisation</td>
</tr>
<tr>
<td>DAT</td>
<td>District AIDS Task Force</td>
</tr>
<tr>
<td>DDHS</td>
<td>District Director of Health Services</td>
</tr>
<tr>
<td>DHAC</td>
<td>District HIV/AIDS Committee</td>
</tr>
<tr>
<td>FGD</td>
<td>Focus Group Discussion</td>
</tr>
<tr>
<td>GDP</td>
<td>Gross Domestic Product</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
</tr>
<tr>
<td>IEC</td>
<td>Information, Education, Communication</td>
</tr>
<tr>
<td>IGAs</td>
<td>Income Generating Activities</td>
</tr>
<tr>
<td>IMF</td>
<td>International Monetary Fund</td>
</tr>
<tr>
<td>KII</td>
<td>Key Informal Interview</td>
</tr>
<tr>
<td>LC</td>
<td>Local Council</td>
</tr>
<tr>
<td>MOFPED</td>
<td>Ministry of Finance Planning and Economic Development</td>
</tr>
<tr>
<td>MOH</td>
<td>Ministry of Health</td>
</tr>
<tr>
<td>NGO</td>
<td>Non-governmental Organisation</td>
</tr>
<tr>
<td>PLWHA</td>
<td>Person Living with HIV/AIDS</td>
</tr>
<tr>
<td>PMTCT</td>
<td>Prevention of Mother to Child Transmission</td>
</tr>
<tr>
<td>STI</td>
<td>Sexually Transmitted Infection</td>
</tr>
<tr>
<td>TAP</td>
<td>Teso AIDS Project</td>
</tr>
<tr>
<td>TASO</td>
<td>The AIDS Support Organisation</td>
</tr>
<tr>
<td>UAC</td>
<td>Uganda AIDS Commission</td>
</tr>
<tr>
<td>UDHS</td>
<td>Uganda Demographic and Health Survey</td>
</tr>
<tr>
<td>UNAIDS</td>
<td>United Nations Program on HIV/AIDS</td>
</tr>
<tr>
<td>UNDP</td>
<td>United Nations Development Programme</td>
</tr>
<tr>
<td>UNICEF</td>
<td>United Nations Children Fund</td>
</tr>
<tr>
<td>USAID</td>
<td>United States Agency for International Development</td>
</tr>
<tr>
<td>VCT</td>
<td>Voluntary Counselling and Testing</td>
</tr>
</tbody>
</table>
Executive Summary

Uganda is one of the countries in Sub-Saharan Africa worst hit by HIV/AIDS, but at the same time among the few nations that have successfully stemmed the escalation of the epidemic. HIV prevalence among the adult sexually active population is estimated to have dropped from 18% in 1992 to 5% in 2001. Consequently Uganda is internationally considered a leader in responding to HIV/AIDS and many countries are keen to learn the approaches that have been used and where possible replicate them. The early political commitment spearheaded by President Museveni provided ground for mobilizing communities against HIV/AIDS, harnessing donor support and the efforts of government and civil society. These, together with the multi-sectoral approach, are some of the factors commonly cited to be behind Uganda’s success. However, it is noted that these same approaches have been applied by some other countries in Africa, but have not resulted into similar success as seen in Uganda. It is therefore believed that only country and context specific factors such as cultural norms and social patterns of people and communities could have played significant roles in Uganda’s success.

It is against this background that the Ministry of Finance, Planning and Economic development supported by UNDP launched this study. The primary objective of the study was to establish the social and cultural factors that have impacted on HIV/AIDS in Uganda and, in particular, their role in enhancing behaviour change. The study was two fold: First it sought to verify the “Cautious Shift” Model in terms of its relevance to the HIV/AIDS context in Uganda purposely to establish whether the model provided a viable theoretical framework for explaining HIV/AIDS interventions in Uganda. The second was an empirical study using data collection methods of Focus Group Discussions and Key Informant Interviews to establish the extent to which social cultural factors contribute to reduction in HIV/AIDS. The study was carried out in six districts of Uganda, selected on the basis of regional and ethnic representativeness (see Map of Uganda).

Following a comprehensive search and review of the literature by the internationally accredited HIV/AIDS researchers and behavioural scientists, it was established that the “Cautious Shift” Model did not exist as a behaviour change model, but rather a theoretical framework developed to explain HIV/AIDS behaviour change that has occurred in Uganda. Notwithstanding, the framework was analysed in detail but still found incomplete and inappropriate to the HIV/AIDS context in Uganda. Consequently, a new “Integrated Behaviour Change Framework” was developed, building on the merits of the Health Belief and Planned Change models.

The Integrated Behaviour Change Framework, discerns a complex interrelationship between the individual and contextual factors through which behaviour change is achieved and maintained. In this inter-relationship, the precursor to behaviour change is perception, which is itself a product of an individual’s socio-demographic characteristics and his/her immediate environment. With the help of cues to action, the individual’s perception is transformed into action, which, when supported by the requisite infrastructure, is consolidated and maintained as a desired form of behaviour. The framework therefore provides a retrospective theoretical grounding of HIV/AIDS interventions in Uganda and possible springboard for future planning and replication of similar interventions. The framework also formed a basis for the design and implementation of the study.

The findings from the empirical study indicate that there was a strong link between information, awareness, knowledge, perception and behaviour change. For example, although knowledge of HIV/AIDS (measured by people’s knowledge of how HIV is transmitted and how it can be prevented) was found to be near universal, big gaps were noted, especially in areas where access to information was limited.
In some remote rural areas, HIV transmission is still associated with witchcraft and some people believed that HIV/AIDS is unavoidable. In extreme cases, some rural women reported that they have even never seen a condom.

Information was reported to be accessible to communities through a number of channels including radio, newspapers, workshops, posters, churches/mosques, and institutions. Radio was reported to be the major source of information, especially with the increase in private FM stations that broadcast in local languages. There was general appreciation that this has increased people’s knowledge on HIV/AIDS, consequently improving people’s risk perception, knowledge of where to seek services and being updated on new interventions such as PMTCT.

There was also universal willingness and determination to change behaviour especially among adolescents and women. Factors reported to be prompting people to change behaviour included the desire to live long and fulfil life long plans and fear of consequences deriving from HIV infection such as long and agonizing illness, stigmatisation and the high cost of drugs such as Anti Retro-Vilas (ARVs). Personal experiences with HIV/AIDS such as loss and burial of close relatives and friends were also reported to be a critical factor influencing people to avoid infection.

Despite the reported zeal to change behaviour, communities also perceived significant contextual barriers to behaviour change. Most prominent of these was poverty that impacts negatively on people’s efforts to change behaviour. Women, particularly single mothers and youth out of school, are severely affected by poverty that increases their vulnerability to HIV/AIDS. Poverty was also reported to be limiting access to information and services. Alcoholism was reported to be a major limitation to behaviour change, as it deters people’s efforts to abstain, remain faithful to their partners or correctly and consistently use condoms. Other barriers included illiteracy, especially inability to read and interpret HIV/AIDS messages, negative peer pressure and cultural inclinations that perpetuate gender inequalities and failure of parents to address sexual issues with their children.

The sprawling orphan crisis was the most commonly reported problem as a result of HIV/AIDS affecting families and communities. The increased number of orphans lacking access to basic needs like shelter, food, health and education poses a potential future challenge for Uganda. As these children grow in such a harsh environment, communities must be prepared to pay heavily through crime and lawlessness that will emerge as a consequence. HIV/AIDS was reported to exacerbate poverty through spending family resources on care, loss of jobs by breadwinners and family members devoting productive time to support and care for the sick.

Social and cultural factors were said to have significant impact on HIV/AIDS related behaviour. Discos, traditional dances, films, wedding parties, religious gatherings, games, sports and alcoholism were reported to be the main social factors impacting on HIV/AIDS. Circumcision, early marriages, widow inheritance, twin ceremonies, appeasement of spirits, cleansing ceremonies as well as funeral rites and traditional rituals were some of the cultural factors mentioned. It was reported that all social and cultural ceremonies gather many people in a celebrative atmosphere and with the drinking, dancing and the resultant excitement; the risk for casual sex becomes high. Though salvation was widely reported as a coping strategy for many people infected with HIV/AIDS, some religious functions particularly night prayers were also reported to increase risk for casual and unprotected sex as they gather many people some with intentions of having sex.
Interestingly, it was noted that some of the social and cultural factors reported to be enhancing HIV transmission were at the same time contributing to reduction of the risk of HIV transmission. For example, marriage ceremonies, religious gatherings and funerals were reported to be major avenues for intensive HIV/AIDS education. Cultural norms such as preservation of virginity until marriage, culturally arranged marriages and the paternal aunt institution promote abstinence and mutual faithfulness.

Districts local governments were found to be the nucleus of HIV/AIDS services, providing leadership and oversight to community level initiatives. The districts were also found to be playing a big role in HIV/AIDS service provision, but mainly focusing on those that are facility based such as treatment of opportunistic infections, VCT and PMTCT. The role of districts was considered crucial in providing technical guidance, mobilizing resources and coordinating interventions. And support of development partners such as UNDP, USAID and other local and international NGOs. New institutional structures such as the District AIDS Task force (DAT) and the District HIV/AIDS Committee (DHAC) have been formed to enhance coordination of the multi-sectoral approach and resource mobilisation. However, human and financial resource constraints still hamper districts efforts in performing such roles.

Communities have initiated various strategies to respond to HIV/AIDS. HIV/AIDS information is shared at community gatherings such as village meetings, burials and other functions. As the challenges of HIV/AIDS increase and household resilience weaken, the community has responded by making care and support of those affected by HIV/AIDS a shared responsibility. Community organised support groups have evolved that offer mutual support in times of illness and death. Community level efforts also have been made to safeguard youth from HIV/AIDS through counselling and education. Local leaders in some communities have enacted village level bylaws against risky behaviour such as loitering at night, regulating hours for night events and enforcement of laws against rape and defilement. Other important strategies include increased the role of PLWHA in HIV/AIDS education, parents’ protection of their children from risks and equipping the youth with livelihood skills to support them avoid risky behaviour. Life skills mentioned by adolescents and youth were noted to be significant in helping them to minimise their vulnerability. Some of these critical skills include ability to resist sexual demands, insistence on condom use, desire to live, avoidance of risky peer groups and financial independence.

Though some of the services were reported to be available in some communities, in rural areas, access varied, ranging from poor to no access at all. PMTCT in particular was widely unknown in most communities covered by the study. Poverty and lack of supportive services such as VCT, care and support, print and electronic media and reliable condom outlets that critical to behaviour change and sustenance remain the major limitations especially for the youth to sustain behaviour change.

The study revealed that a number of significant changes have occurred at both the individual and community level with regard to HIV/AIDS related behaviour. Cultural and social ceremonies that increase the risk of HIV transmission have largely been abandoned or modified. HIV/AIDS related stigma has drastically reduced and there was increased information sharing on HIV/AIDS among community members and between parents and children. HIV/AIDS was regarded a community problem and there was a developed culture of mutual care and support in the face of HIV/AIDS. Parents were increasingly coming up to openly discuss sex and HIV/AIDS with their adolescent children in order to prevent them from getting into compromising situations.

With regard to sexual behaviour change, there was general consensus that condom use was the major behaviour change contributing to reduction in HIV transmission. Others were mutual faithfulness/reduction in number of sexual partners and abstinence.
However, abstinence was largely seen to be unsustainable and faithfulness to sexual partner was mostly being practiced by women. Condom use was more prevalent among adolescents in urban areas as cost, availability, unreliability and inappropriate distribution mechanisms hindered condom use in rural areas. Use or non-use of a condom has also remained more of a male domain.

In conclusion, the study established that communities in Uganda are still bound by their cultural, social and religious beliefs, which are passed on to generations and continuously renewed through performance of rituals and rites. Although some of these rituals and rites increase risk of HIV infection, it is the activities associated with them such as alcohol and dancing that makes them risky. Effective preventive strategies still remain those that are culturally and socially sensitive. Therefore these practices need to be made safe through appropriate interventions and to consolidate the social factors, cultural norms and practices that are found to be useful in promoting desired behaviour.

Faced with a lethal epidemic and inadequate institutional services, communities initiated several coping and survival strategies to fight HIV/AIDS. However, contextual factors such as poverty, illiteracy, inequitable distribution of services and gender inequalities encumber communities to adopt and continuously practice protective behaviour. For instance, women who are faithful to their husbands may still get infected because they are not in position to negotiate for safe sex even when they know their husbands engage in risky sexual practices. Similarly, adolescents and youths who would have wished to get married after an HIV test are unable to do so because VCT services are not easily accessible. To consolidate the gains made so far, Uganda will need to address HIV/AIDS simultaneously with poverty and gender issues.

Despite the universal awareness and high level of knowledge of HIV/AIDS, misconceptions about HIV/AIDS still persist especially in the rural areas where information and other services are inadequate. These misconceptions continue to distort people’s perceptions of the HIV/AIDS problem and consequently hamper behaviour change. There is therefore need for specific and targeted interventions to tackle such misconceptions using a variety of approaches especially through effective means that is easily accessible by a big cross section of the population.
SOCIAL CULTURAL FACTORS IMPACTING ON HIV/AIDS IN UGANDA
STUDY DISTRICTS.

Legend
- International boundary
- District boundary
- Study Districts

AFRICA
Uganda

SUDAN

NEBBI

CONGO (DEM. REP.)

KENYA

TANZANIA

International boundary
District boundary
Study Districts

Legend

0 60 120
km
1.0 BACKGROUND TO THE STUDY

1.1 Context

Up to the early 1970s, Uganda had one of the most vibrant economies in Africa with a well-developed export sector based on agricultural products as well as minerals. Its export earnings were more than sufficient to finance imports, leading to a growing balance of payments surplus. The industrial sector was also growing fast, with the textile, sugar and leather industries adequately meeting the domestic market demand. The country’s health infrastructure was admirable, pioneering some of the health initiatives in the region (Vision 2025:1998). All these gains were later wiped out through a combination of poor governance and consequent civil strife, inappropriate monetary policies and sustained decline in world prices for coffee. By 1985, Uganda was among the ten poorest countries in the world.

In 1986, when the current National Resistance Movement government came to power, it launched a comprehensive recovery programme. Major policy landmarks in this process include rationalization of public expenditure, divesture of government interests in parastatal organizations, liberalization of the economy, macro-economic stabilization, regulation of inflation, expanding foreign investment and introduction of participatory governance through decentralization. As a result, Uganda has recorded impressive economic gains. The country has achieved a consistent average GDP growth rate of 6.5% per annum over the last five years, GDP per capita has risen to US$330 and the proportion of people living in absolute poverty has dropped from 56% in 1992/93 to 35% in 1990/2000. Civil and political awareness has greatly improved, leading to greater interest and involvement of the people in development programs, although the participation of women in decision making remains significantly low (MOFEP: 2001).

Despite the gains at the macro-economic level, there is widespread intrinsic poverty at the micro-economic level, especially in rural areas. The country’s health indicators also remain among the worst in Sub-Saharan Africa. For instance, infant mortality rate is 89/1000 and maternal mortality ratio is 505/100,000. Only 37% of eligible children complete a full immunization cycle, and 39% of children under 5 years are stunted while 4% are chronically wasted (UDHS: 2000/2001). HIV prevalence, though reported to be declining, remains significantly high at 6.5% among women in reproductive age groups (MOH: 2001).

1.2 Status of the HIV/AIDS Epidemic

HIV/AIDS was first identified in Rakai district in Southern Uganda in 1982 and by 1985 the disease has reached epidemic levels. It is estimated that by December 2001, 947,552 deaths had been caused by AIDS. Currently 1,050,055 people are said to be living with HIV/AIDS of whom 51% are women, 39% men and 10% are children below 15 years (MOH, 2002). HIV/AIDS is now the leading cause of morbidity and mortality, especially among people aged 15 to 49 years. It is also estimated that up to 1 million children in Uganda had lost either one or both parents to the disease. (UNAIDS 2002) As a result, the traditional African extended family system that used to take care of orphans has been severely over-stretched thereby exposing orphans to varied forms of vulnerability.
Uganda has since 1986 adopted an open and candid response to the epidemic. In 1991, a multi-sectoral approach that involved the entire society was adopted to address prevention and control of HIV/AIDS as well as management of all perceived consequences of the epidemic. This approach has provided ground for innovation resulting into a plethora of interventions in prevention, care, support and mitigation championed by government institutions, local and international NGOs, faith based organizations and the donor community.

These interventions have jointly helped to slow down the epidemic, and once known as the epicentre of HIV/AIDS, Uganda is now emerging as an international success story. MOH surveillance report 2002 indicated a decline in the weighted overall antenatal prevalence of 6.5% in 2001 from 18% in 1992. More significant declines were noted in urban sites where the weighted average dropped from 10.9% in 1999 to 8.8% in 2001, compared to declines of 4.3% to 4.2% in rural sites over the same period. HIV prevalence among the total adult population is currently estimated at 5%, down from 8.3% in 1999. HIV prevalence has also declined among high risk and vulnerable groups such as youth and people with sexually transmitted diseases. Among the youth aged 15-24 years, prevalence declined from 29% in 1992 to about 10% in 2001 for females and from about 10% to less than 4% for males. Among STD patients at Mulago Hospital, prevalence declined from 44.2% in 1989 to 23.7% in 2001.

The decline in HIV prevalence in Uganda has been attributed to many factors such as high political commitment, multi-sectoral approach, donor support, impact of HIV/AIDS on individuals and families and high levels of awareness. However, there are similar high HIV prevalence countries in Sub-Saharan Africa that have had similar interventions but have not realised significant decline in prevalence.

Since HIV/AIDS has no known cure yet, behaviour change has been fronted as the most likely scientific basis for the reduction in HIV prevalence not only in Uganda but also elsewhere in the world. Indeed, individual behaviour change is outlined as one of the primary goals in the National Strategic Framework for HIV/AIDS activities in Uganda (UAC: 2000). In targeting behaviour change, emphasis has been put on changing those factors that impact significantly on an individual’s sexual behaviour. However, in the context of Uganda, there is neither any theoretical basis nor empirical data to clearly explain the changes in HIV/AIDS related behaviour.

This study sought to establish the relevance of the ‘Cautious Shift’ Model in explaining the HIV/AIDS response in Uganda and using a viable model assesses the social and cultural factors impacting on HIV/AIDS.

1.3 Study Objectives

The main objective of the study was to establish the social and cultural factors that have impacted on HIV/AIDS in Uganda and in particular their role in enhancing behaviour change.
The Specific objectives were:

- To verify the relevance of the “Cautious Shift” Model to the HIV/AIDS context in Uganda.
- To describe and understand the social and cultural environment and strategies that contributed to behavioural change in Uganda.
- To document community based strategies that have been used to bring about behaviour change.
- To assess community knowledge, perception, attitudes and behavioural practices of HIV/AIDS.
- To identify and document current practices and life skills among the youth in the context of HIV/AIDS.
- Establish the major socio-cultural determinants underpinning behavioural changes in the context of HIV/AIDS in Uganda.

1.4 Methodology

1.4.1 Study Design

The study was two fold: First was a detailed assessment of the ‘Cautious Shift’ Model with the purpose of verifying its relevance to the HIV/AIDS context in Uganda. This entailed a review of a number of behaviour change models, theories and constructs in order to obtain an objective view of the ‘Cautious Shift’ Model. The outcome of the appraisal and review of various Behavioural Change Models/Theories was the development of Integrated Behaviour Change Framework that was to be used to explain the HIV/AIDS response in Uganda. Further more the Integrated Behaviour Change Framework variables provided a basis for the development of topics for discussion and questions for the study.

Second was an empirical study intended to generate information on the social and cultural factors impacting on HIV/AIDS in Uganda. This was a national study covering all geographical regions of Uganda. The target population was the most sexually active population in the age range 15-49 years, across all socio-economic and demographic characteristics. Two age cohorts of 15 – 24 and 25 – 49 years were selected to include sexually active adolescents and adults.

1.4.2 Sample Selection

To ensure national representativeness, the country was divided into six regional groupings, which are internally fairly homogeneous in terms of their social and cultural characteristics. These regional groupings include Western, Northern, Eastern, Central, Mid Eastern and North Western. The districts within these groupings constituted the sampling frame for each stratum. With the time and financial resources available, the study was carried out in one purposively selected district from each of the six regional groupings to give a total of six study districts. Some of the factors considered in the selection of the districts in each stratum included population size, security concerns, accessibility, social and cultural representation.
The other important factor was uniqueness of some districts with regard to existence of social cultural practices such as circumcision and widow inheritance that were deemed to impact significantly on HIV/AIDS. Within each selected district two sub-counties, one rural and one urban, were also purposively selected as study sites giving a total of 12 Sub-counties in which the study was based (see Table 1.1 below).

### Table 1.1: Districts and Sub-Counties Selected for the Study

<table>
<thead>
<tr>
<th>Region</th>
<th>District</th>
<th>Sub-counties</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Rural</td>
</tr>
<tr>
<td>Western</td>
<td>Mbarara</td>
<td>Bugamba</td>
</tr>
<tr>
<td>North Western</td>
<td>Nebbi</td>
<td>Parombo</td>
</tr>
<tr>
<td>Central</td>
<td>Mukono</td>
<td>Nabbaale</td>
</tr>
<tr>
<td>Mid-Eastern</td>
<td>Mbale</td>
<td>Bukhiende</td>
</tr>
<tr>
<td>Eastern</td>
<td>Soroti</td>
<td>Atiira</td>
</tr>
<tr>
<td>Northern</td>
<td>Lira</td>
<td>Amach</td>
</tr>
</tbody>
</table>

In each of the selected sub-counties/Division, four parishes were randomly selected, in which four Focus Group Discussions were held in each parish, two with males and two with females in the age cohorts of 15-24 and 25-49 years. Participants in each Focus Group Discussion were identified with the help of community mobilisers. A total of 192 Focus Group Discussions were conducted in the six selected districts

In each district, 12 Key Informant Interviews were conducted with the people in mandated positions; resource persons and service providers at the district and sub-county level, giving a total of 72 Key Informant Interviews in the six districts.

### 1.4.3 Data Collection

The data for this study was collected using three main methods, namely: Focus Group Discussions (FGDs); Key Informant Interviews (KII); and Document Review. The first two methods of data collection were used to collect qualitative data from communities and local leaders, resource persons as well as service providers, respectively. The latter was used to collect relevant and related information from other studies and reports to verify the “Cautious Shift Model” and supplement the empirical data from the field.

#### Focus Group Discussions

Focus Group Discussions (FGDs) were conducted in two villages in each parish with purposively selected groups of adolescents and adults. For the two villages selected in each study parish, 2 adolescent FGDs (one for girls and one for boys) were conducted in one village and 2 FGDs for the adults (one for men and one for women) in the second village. Thus, a total of 4 FGDs were conducted in each parish, giving a total of 16 FGDs per study sub-county and 32 FGDs per study district. The FGDs were used to collect detailed and spontaneous information on issues pertinent to HIV/AIDS in the community such as knowledge of HIV/AIDS, gender dynamics, social cultural factors impacting on HIV/AIDS and general community perceptions, roles and strategies in the fight against HIV/AIDS (Table 1.2).
Table 1.2: Summary of FGDs conducted in each of the Study districts.

<table>
<thead>
<tr>
<th>Level</th>
<th>Type and Number of FGDs conducted</th>
</tr>
</thead>
<tbody>
<tr>
<td>District</td>
<td>32 FGDs (16 FGDs for adolescents and 16 FGDs for adults)</td>
</tr>
<tr>
<td>Sub-county</td>
<td>16 FGDs (8 FGDs for adolescents and 8 FGDs for adults)</td>
</tr>
<tr>
<td>Parish</td>
<td>4 FGDs (2 FGDs for adolescents and 2 FGDs for adults)</td>
</tr>
<tr>
<td>Village</td>
<td>1 FGD for 15 – 24 yr females 1 FGD for 15 – 24 yr males conducted in the 1st selected village in each parish</td>
</tr>
<tr>
<td></td>
<td>1 FGD for 25 – 49 yr females 1 FGD for 25 – 49 yr males conducted in the 2nd selected village in each parish</td>
</tr>
</tbody>
</table>

Key Informant Interviews

In each of the selected districts, Key Informant Interviews were held with three district officials whose responsibilities had a bearing on HIV/AIDS. They included: the Officer in charge of Sexual and Reproductive Health, HIV/AIDS Focal Point Person, and the Community Development Officer. Interviews with these officials focused on policy and program issues to gain insight into the holistic HIV/AIDS situation in the district and the perspectives with regard to the on-going and future interventions.

At sub-county level, similar interviews were conducted with LCIII Chairman and in his absence the Secretary for Health, and a Health Assistant. The interviews were intended to generate information on the leaders’ perceptions of the gravity of the HIV/AIDS problem in the communities, assess current and planned interventions and new strategies for responding to the epidemic.

At community level, Key Informant Interviews were held with a Traditional Healer, Traditional Birth Attendant, Community Health Worker, Secondary School teacher trained in adolescent health services, Person Living with HIV/AIDS (PLWHA), heads of HIV/AIDS service CBO and NGO operating in the community. These respondents were viewed as people who were in constant touch with the community and therefore widely knowledgeable about the community dynamics. Interviews with them helped in generating information on what people perceived to be the factors influencing transmission/prevention of HIV; the HIV/AIDS related problems in the community and the strategies adopted to respond to the epidemic.

Table 1.3: Summary of KIIIs conducted in each of the Study Districts.

<table>
<thead>
<tr>
<th>Level</th>
<th>Key Informant Interview held</th>
</tr>
</thead>
</table>
| District | In-charge Sexual and Reproductive Health  
District HIV/AIDS Focal Officer/District Health Educator  
Community Development Officer |
| Sub-county | LCIII Chairperson/Secretary for Health  
Health Assistant  
Head of an HIV/AIDS service NGO  
Head of an HIV/AIDS service CBO  
Community-based health worker  
Teacher involved or trained in adolescent health issues |
| Community | Person living with HIV/AIDS  
Traditional birth attendant  
Traditional healer involved in HIV/AIDS related activities |
Document Review

The study involved extensive literature review, ranging from varied publications on Behaviour Change Theories and Models to current relevant documents on HIV/AIDS and the various responses within and outside Uganda. The review of Behavioural Models/Theories was done to assess the relevance of the “Cautious Shift Model” to the HIV/AIDS context in Uganda.

Other policy and strategic documents especially from the districts, Ministry of Health, Education and Sports and Uganda AIDS Commission were also reviewed. The document review helped in obtaining a clear and wider understanding of the dynamics of HIV/AIDS epidemic in Uganda. It was also useful in collecting relevant and related information from survey reports that supplemented the empirical findings of the study.

1.5 Organisation of Study

1.5.1 Study execution and implementation Modalities

The study was commissioned by Ministry of Finance, Planning and Economic Development supported by UNDP and implemented by Makerere Institute of Social Research (MISR). An advisory committee consisting of key stakeholders from government, Parliament of Uganda, NGOs, private sector and civil society guided the implementation of the study.

1.5.2 Research Process

The study began with literature review to verify the ‘Cautious Shift’ Model as was required by Terms of Reference. The review necessitated looking at other Behaviour Change Models in order to get a comparative picture and also develop a rational basis for determining the relevance of the ‘Cautious Shift’ Model to the HIV/AIDS context in Uganda. This initial process helped the team to develop an Integrated Behaviour Change framework considered appropriate to Uganda’s response. Thereafter data collection instruments were developed using the variables of this framework and in line with the Terms of Reference.

1.5.3 Training of Research Team

The training included orientation of the team to data collection techniques as well as exposure to facts and dynamics of HIV/AIDS in Uganda. In general, the training covered basic concepts of research, objectives of the study, techniques of interviewing, problem solving during the interviews and recording of responses.

Others training issues were: the interviewer’s role; and identification and selection of respondents. In addition Fact Sheets about HIV/AIDS/STIs, commonly used terms in HIV/AIDS were used during the training to acquaint the team with accurate knowledge on issues they were to discuss with the participants and informants.
1.5.4 Pre-test

The FGD and KII data collection instruments were pre-tested in a purposively selected district of Wakiso to determine their appropriateness in collecting the desired data. This exercise was used to test the clarity, suitability as well as logical flow of questions. The instruments were then refined on the basis of issues raised and noted during the exercise. The pre-test helped to adapt the tools to the study objectives and improve on the data collection techniques of the research team. Following the pre-test and subsequent revisions, the tools were translated into local languages of Runyankole, Luganda, Lumasaba, Luo, Alur and Ateso.

1.5.5 Execution of the Field Work

Each district had a team of four field researchers to conduct FGDs and KIIs. At the end of each day, the teams would report their day’s activities to one of their colleagues who worked as a Supervisor.

The Team Leader and Principal Investigators from MISR made follow up and support visits especially in the first week to ensure that accurate data was being collected and recorded and that there was adequate participation of the target respondents. Actual data collection lasted 15 days from December 8 to December 22, 2002.

1.5.6 Data Processing

Data was returned to MISR offices in Kampala for processing. The Principal Investigators crosschecked all the data turned in for completeness and accuracy. Content Analysis was used to analyse qualitative data on the basis of emerging themes and sub-themes on HIV/AIDS within the context of the study framework and the Terms of Reference.

Trend analysis of all the Focus Group Discussions and Key Informant Interviews for each topic was then done. This analysis was useful in identifying the major issues for each of the study themes and sub-themes. It also facilitated comparisons and contrasts of participants’ views within and among the different districts by gender, location and age.

1.5.7 Response Rates

A total of 192 FGDs and 72 Key Informant Interviews had been planned. All the Participants and Informants targeted by the study were reached and interviewed with few exceptions. In one district the HIV/AIDS Focal Person had not been yet appointed, this being a new responsibility within the district structure. In this case, the targeted Informant was substituted with the District Health Educator who was the in-charge of HIV/AIDS activities in the district.

In another district, where the Community Development Officer was new, the District Health Educator was available during the interview to provide the required information since he had been the caretaker of the office.
1.6 Structure of the Report

The report is presented in nine chapters.

**Chapter One** presents the background, study objectives, study design and methodology.

**Chapter Two** presents the literature review of behaviour change models and theories in terms of their definition and features, application, appropriateness and limitations to HIV/AIDS context in Uganda.

**Chapter Three** discusses the relevance of the Cautious shift model in the HIV/AIDS context in Uganda. The chapter also presents the Integrated Behaviour Change Framework that was developed on the basis of the in-depth review of six models and theories commonly used in behaviour interventions.

**Chapter Four** presents findings on the knowledge, attitudes and perceptions and the role they have played in influencing HIV/AIDS behaviour in communities.

**Chapter Five** presents community cultural norms and social patterns and practices and discusses its impact on HIV/AIDS related behaviour change. The chapter presents in a bi-dimensional manner, factors inherent in the community cultural and social context that facilitate HIV transmission and those that enhance reduction in HIV incidence.

**Chapter Six** presents findings on community involvement and strategies adopted to respond to HIV/AIDS. The chapter further discusses the role of community initiatives, support from other partners and HIV/AIDS services in influencing change in HIV/AIDS related behaviour.

**Chapter Seven** presents the changes in HIV/AIDS related behaviour that has occurred in the communities and the significance of those changes in the reduction of the spread of HIV.

**Chapter Eight** presents the Study Conclusions

**Chapter Nine** presents Study Recommendations
2.0 REVIEW OF MODELS/THEORIES OF BEHAVIOUR CHANGE.

Models are theoretical constructs used to represent reality. Theories are useful to researchers and development partners in understanding and explaining success or failure of interventions.

Models for behaviour change focus on the individual, the social, and on structural and environmental factors. Those based on the individual’s psychological process examine attitudes and beliefs and how individuals change their behaviour. Social theories see individual behaviour embedded in their social and cultural context.

2.1 Review Process

The Terms of Reference required an assessment of the relevance of the ‘Cautious Shift’ Model to the HIV/AIDS response in Uganda. The ‘Cautious Shift’ Model was reviewed alongside a number of behaviour change models, with the aim of establishing similarities, differences and gaps within them. It was envisaged this assessment would help to make an informed judgement on the suitability of the ‘Cautious Shift’ Model in relation to other models in the context of HIV/AIDS response in Uganda.

The models and theories reviewed included: Health Belief Model; Planned Behaviour Change Model; Social Cognitive/Learning Theory; Theory of Reasoned Action; Stages of Change Model; AIDS Risk Reduction Model; Diffusion of Innovation Theory; Social Influence/Inoculation Model; Social Network Theory; Theory of Gender and Power; Theory of Individual and Social Change/Empowerment; Social-Ecological Model for Health Promotion and Perception of Risk Construct.

The Stages of Change; Social Cognitive/Learning; Reasoned Action; Health Belief; Planned Behavioural Change; and AIDS Risk Reduction models were selected for in-depth review. These models/theories were selected for further review because they are commonly used in behavioural interventions and they also focus on an individual who is an entry point for all HIV/AIDS interventions in targeting behavioural change. In addition, some of these models and theories have been applied in studying HIV/AIDS related behaviour. Table 2.1 gives a summary of the six models that were reviewed. The review of each model/theory covered description, application, appropriateness and limitations to the Ugandan HIV/AIDS context.
Table 2.1: Description and Application of the Selected Models/Theories.

<table>
<thead>
<tr>
<th>Model/Theory</th>
<th>Definition &amp; Features</th>
<th>Application</th>
<th>Appropriateness to Uganda HIV/AIDS context</th>
<th>Limitations</th>
</tr>
</thead>
</table>
| **The Stages of Change Model**  | Attempts to explain why people do not easily change their behaviour, even when they are knowledgeable or even directly affected by a condition. Views behaviour change as a process flowing through five stages, namely:  
  - Pre-contemplation  
  - Contemplation  
  - Preparation  
  - Action  
  - Maintenance | Applied mainly in the USA among women drug users and commercial sex workers. Widely used in smoking cessation, mammography screening and weight control. Applied by the Centre for Disease Control and Prevention (CDC) for HIV/AIDS Counselling and Testing and STD control programs. | Relevant to the Ugandan voluntary HIV/AIDS counselling and testing services, where the mode of counselling to be given is tailored to the stage in the acceptance or coping process the individual is in. | Staged change of behaviour may not be very relevant in epidemic situations like HIV/AIDS where behavioural change needs immediate adoption. Silent about environmental factors that support or impede behaviour change of an individual. Considers human behaviour to function in a linear fashion only. More of an intervention tool at a particular point in the change process than human behaviour construct. |
| **Planned Behaviour Change Model** | Behaviour change results from three considerations:  
  - Perception/belief about the outcomes of a particular action or behaviour and how individuals evaluate these outcomes  
  - Perception/belief about what the significant others expect of an individual’s new behaviour and how the individual is committed to comply with these expectations  
  - Perception/belief about the availability of an enabling environment to support or inhibit the behaviour and the extent to which one judges the power of these environmental factors. | Used to promote condom use among seropositive gay men in Canada. | Appropriate to HIV/AIDS education programs and other community-based programs that seek to raise people’s self risk perception through seminars, media and open drama, songs and personal testimonies by people living with HIV/AIDS. | Assumes rational behaviour. Influence of others may not be so significant particularly in urban areas where individualism is a norm. |
<table>
<thead>
<tr>
<th>Model/Theory</th>
<th>Definition &amp; Features</th>
<th>Application</th>
<th>Appropriateness to Uganda HIV/AIDS Context</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Cognitive/Learning Theory</td>
<td>Stipulates that human behaviour is an interaction between cognitive, behavioural and environmental determinants. The model is premised on: Self-efficacy - the belief in individual ability to implement the necessary behaviour. Outcome expectancies - the belief about outcomes.</td>
<td>Used among African American adolescents in an intervention on outcome expectancies about condom use and self-efficacy training. Used among American heterosexual women in an intervention on skills training and strategies to modify perceived peer or partner normative beliefs about risk taking. Used in an intervention to improve self-efficacy and condom use among American heterosexual men and youths.</td>
<td>Relevant to interventions that emphasize self-efficacy, and outcome expectations to promote sexual and reproductive health among the youth. Relevant to Uganda because risk perception is antecedent to behaviour change.</td>
<td>-</td>
</tr>
<tr>
<td>The AIDS Risk Reduction Model (ARRM)</td>
<td>Identifies three stages that an individual passes through in the reduction of risks associated with HIV transmission: Behaviour Labelling - recognition and labelling of one’s behaviour as highly risk. Commitment to Change - making a commitment to reduce high-risk sexual contacts and to increase low risk activities. Taking Action - information seeking, obtaining remedies, enacting solutions.</td>
<td>Used in the USA in a variety of populations including people attending HIV testing clinics, gay and bisexual men, unmarried white, black and Hispanic heterosexual and adolescent females attending family planning centres.</td>
<td>Relevant to interventions that seek to raise risk perception. Could also apply on youth peer-supported interventions.</td>
<td>The model focuses on an individual and disregards the partner factors and other socio-cultural issues that influence an individual’s behavior choices and ability to take action.</td>
</tr>
<tr>
<td>Model/Theory</td>
<td>Definition &amp; Features</td>
<td>Application</td>
<td>Appropriateness to Uganda HIV/AIDS Context</td>
<td>Limitations</td>
</tr>
<tr>
<td>------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Theory of Reasone Action</td>
<td>Asserts that intentions are the best predictors of people’s actions/behaviours. Intention to perform a certain behaviour/action is determined by two things: <em>Attitude</em> towards the behaviour - judgement of whether or not the behaviour is a good thing to do. <em>Subjective norms</em> - judgement of other people’s opinions about behaviour and his/her willingness to comply with those opinions.</td>
<td>Used in USA to explain several health related behaviours such as smoking, drinking, contraceptive use, and breast-feeding, and in Zimbabwe, on condom use.</td>
<td>Relevant to HIV/AIDS interventions in Uganda, especially those that seek to raise risk perception.</td>
<td>The role of prior experience with the behaviour is not considered. Assumes that people always weigh the perceived benefits/costs and behave accordingly. Focuses on the individual and does not consider environmental and structural factors.</td>
</tr>
</tbody>
</table>
| The Health Belief Model (HBM)            | Grounded in six key beliefs which an individual must hold in order to change behaviour.  
  - *Perceived Threat* - subjective perception of the risk of contracting a health condition.  
  - *Perceived Severity* - perceived seriousness of contracting the health condition.  
  - *Perceived Benefits* - Perceived benefits/effectiveness of the strategies designed to reduce the threat of the disease.  
  - *Perceived Barriers* - potential negative consequences of taking particular health actions including physical psychological and financial demands.  
  - *Cues to Action* - Events, either bodily (e.g. physical symptoms of a disease) or environmental (e.g. media publicity) that motivate people to take action.  
  - *Self-Efficacy* - The belief in being able to successfully execute the behaviour change required. | Used in USA, in studies that attempt to explain and predict individual participation in programs for Influenza inoculations, high blood pressure screening, smoking cessation, seatbelt usage, nutrition, breast self examination, and to gain better understanding of sexual risk behaviours in the advent of HIV/AIDS. | Relevant to HIV/AIDS in Uganda as it incorporates most of the aspects that are key in behaviour change and have been the major focus of HIV/AIDS interventions in Uganda. | Does not take into consideration environmental and economic factors that may influence health behaviours. Does not consider the influence of social norms and peer influence. |
2.2 **Assessment of Models/Theories**

From each of the six models, underlying variables were gleaned and then reviewed based on their coverage of individual, community (family, peers, associates), structural (infrastructure, formal institutions, civil society organisations) and environmental aspects (policy, socio-economic, cultural context). This was done because behaviour change results from the positive interaction among these factors. In addition, the Multi-Sectoral Approach to AIDS prevention which guides the HIV/AIDS response in Uganda, addresses itself to all these aspects.

**Stages of Change Model**

The model has five stages each with key and presumed variables. The first is the pre-contemplation stage where the individual, consciously or not, lives with a problem. Presumably the individual later gets information about the problem from either the community (peers, friends, family members) or institutions within the community (voluntary organizations and their agents, government institutions and community based organizations) or both. With information, the individual gets into the contemplation stage where he/she becomes aware of the problem and considers changing behaviour. When the individual becomes aware of the problem and with presumed sustainable source of information from either the community or the available structural systems, he/she enters the preparation stage and takes proactive steps to change the behaviour. The key variables at preparation stage are community support and accessible and sustainable sources of the required inputs. From the preparation stage, the individual enters the action and maintenance stage where he/she adopts a new form of behaviour. The variables of community support and access to inputs remain critical for sustaining the new behaviour and avoiding relapse.

**Planned Behaviour Change Model**

The model is premised on three major attributes: perception/belief in the outcomes of a particular action or behaviour and how an individual evaluates these outcomes; perception/belief in what others expect of an individual and how the individual is committed to comply with these expectations; and perception/belief in the availability of an enabling environment to support the behaviour and the extent to which one judges the power of these environmental factors. These three combine to form an attitude and if the attitude is positive, then there is positive behaviour change.

At the individual level, there are three variables, namely: knowledge and belief in designed strategies; influence of others (peers, friends, relatives and close associates) and commitment to comply with others’ expectations. There are also other variables presumed necessary and supportive of behaviour change at community, structural and environmental levels. These include source of information, supportive community, social norms, existence of structures that enhance access to inputs and designed strategies and policies that promote desired behaviour.
Social Cognitive/Learning Theory

The model is grounded on two attributes, namely; belief in one’s ability to implement the desired behaviour and outcome expectancies from the new behaviour. At the individual level, the key variables are self-efficacy and beliefs about the outcomes of the new behaviour. The model also states that new behaviour is learned either by modelling behaviour of others or by direct experience and access to sustainable source of information are both important variables at community level. Supportive cultural values and government policies, and sustainable source of information are presumed to be environmental and structural variables respectively necessary for behaviour change.

AIDS Risk Reduction Model

This model provides a framework for explaining and predicting behaviour change of individuals regarding the reduction of risk of HIV/AIDS transmission. The model identifies three stages through which an individual passes to reduce risk. These are: behaviour labelling (recognition and labelling of an individual’s own behaviour as high risk), commitment to change (self determination to reduce high-risk and increase low risk activities), and taking action that involves information seeking, obtaining remedies and enacting solutions. The model also considers other internal and external factors that may motivate individual movement across the stages e.g. education campaigns, images of people affected by HIV/AIDS and informal support groups.

At the individual level, variables include: recognition of own behaviour as risky, perception of enjoyment, determination to change (self-efficacy), evasive emotions, information seeking, obtaining remedies, enacting solutions and ability to communicate verbally with sexual partners.

At community level, social networks, informal/self-help, sexual partner beliefs/behaviour and social support were variables identified to be critical to the formation and sustenance of behaviour. At the structural level, the variables are formal help (supportive organisations) and accessibility to supplies.

Theory of Reasoned Action

This model is premised on two attributes, namely; an individual’s attitude towards a new behaviour; and the subjective norms. At the individual level, the variables discerned from this model are beliefs about the new behaviour; perceived benefits from adopting the behaviour (value judgement); judgement of other people’s perception about the behaviour; and willingness to comply with their thinking. Sustainable source of information is presumed necessary to enhance behaviour change.

Health Belief Model

The Health Belief Model is grounded in six key beliefs namely; perceived threat or vulnerability to a health condition; perceived severity of the condition; perceived benefits/effectiveness of the strategies designed to reduce the threat of the condition; perceived barriers; cues to action, that is, events either bodily or environmental aspects that motivate people to take action; self-efficacy and others that indirectly influence the related health behaviour.
Several variables were discerned from each of the six attributes of the model. At the individual level susceptibility and severity were identified as variables of perceived threats. For one to perceive a threat from the health condition, it is presumed that the individual is aware of its existence either from the community or the existing structures.

With regard to perceived beliefs, the variable is the individual’s belief in the efficacy of the advised actions to reduce risk of the health condition to which the individual feels vulnerable. The advised actions or strategies are crafted either by the community or the existing structures.

The perceived barriers are social/psychological, relating to one’s perception of what others especially peers may think. The other is financial, relating to the perceived cost of inputs required to sustain the new behaviour. It is also presumed that cultural factors may be barriers to behaviour change if the new behaviour is not aligned with them.

Variables relating to Cues to Action were strategies to activate readiness and events that motivate people to take action. The individual’s readiness to take action variable was identified from the attribute of self-efficacy. For the attribute of “Others”, the variables include: age, education, marital status, gender, ethnicity, personal traits, social class and social pressure.
3.0 VERIFICATION OF THE ‘CAUTIOUS SHIFT’ MODEL

After reviewing relevant literature by leading HIV/AIDS researchers and behavioural scientists, it was established that there was no behaviour change model called ‘Cautious Shift’. This was only found to be a proposal to develop a theoretical framework to explain behaviour change in the context of HIV/AIDS in Uganda. Indeed a close look at the proposal revealed that the principles and tenets of the ‘Cautious Shift’ Framework as outlined were derived from the Planned Behaviour Change model. Even then, the ‘Cautious Shift’ Framework as presented had several deficiencies. It did not address the limitations of the Planned Behaviour Change Model such as the influence of socio-demographic characteristics of an individual in the behavioural change process. The other is that the role of events such as death of close associates from HIV/AIDS, influence of friends and peers and HIV/AIDS IEC messages that motivate an individual to change behaviour is absent. Finally, the Framework itself is incomplete because it merely looks at positive intentions towards behaviour as the ultimate goal and not behaviour change.

The review showed that there are commonalities across the selected models as reflected by the identified key and presumed variables. For instance, although each model/theory is built on different assumptions, they all state that behaviour change occurs with changes in attitudes, beliefs, intentions and outcome expectations. Secondly all the models focus on the individual and the majority do not consider the interaction of social, cultural, and environmental issues with individual attributes. These common variables were then reviewed as presented below, to enable the selection of a model(s) that best fits Uganda’s HIV/AIDS context.

**Source of information:** Individual awareness of the undesired health condition and its potential impact on one’s health was the antecedent to behaviour change. The awareness is presumed to stem from a source of information, which could be from the community (family members, friends, peers and associates) or from structures within the community (civil society organizations, NGOs, mass media).

**Individual determination/self-efficacy:** The individual’s belief that he/she has the ability and power to change behaviour is critical to any change process.

**Perception:** Behaviour change was noted in many models to be driven by the individuals’ perception of the likely benefits, risks, barriers, opportunity costs, financial costs, effectiveness of the available strategies to address the problem and other people’s feelings. If all these factors are perceived to be supportive, the motivation to change behaviour is high and vice versa.

**Past Experience:** Prior experience with the condition or knowledge of the impact of the condition on close friends or relatives is a strong motivation to change behaviour.

**Community Support:** Community support was variably used to refer to peer support and compliance with existing social norms. If a new behaviour is perceived to be in conformity with the social norms and is supported by peers, family members and friends, the possibility of adopting it is high.

1 Cautious Shift Proposal for the Uganda Human Development Report, 05 December 2001
**Sustainable source of information:** An accessible and sustainable source of information is required to sustain the change process by supplying new information on the desired behaviour and prevent relapse.

**Access to inputs:** Some new behaviour require specific inputs to support them. For instance if one ever stops drinking, there must be alternative facilities for recreation, which are affordable and accessible.

**Structural Systems:** These are structures that are required to support people in the change process by enhancing easy delivery of inputs, designing user-friendly coping strategies and supplying information. These include formal organizations, government structures, service delivery points, social networks and civil society organizations.

**Policies:** Enabling policies are critical in providing a framework and a supportive environment for behaviour change. Though this variable was not prominently covered in most of the models, it is very critical in supporting the behaviour change process.

Further review of the six models commonly used in behavioural interventions showed that no model singularly explains the behaviour change that has occurred in Uganda with respect to HIV/AIDS. Their focus was limited to the individual and most did not consider the important role played by the contextual factors such as environment and infrastructure. This is contrary to Uganda’s multi-dimensional response to HIV/AIDS that simultaneously target individuals and their social cultural contexts at the same time promoting an appropriate policy environment to support the interventions.

Consequently, socio-demographic characteristics, perceptions, environment, cues to action and infrastructure were found major components of Uganda’s HIV/AIDS response. These components were found to occur prominently in the Health Belief and Planned Behaviour Change models and were put together to develop the “Integrated Behaviour Change” Framework (Figure 1).
3.1 Integrated Behaviour Change Framework

The Framework recognises that socio-demographic characteristics of an individual is the basis for any desirable behaviour. Two or more of the socio-demographic characteristics such as age and education may combine to influence one’s beliefs and attitudes towards a particular behaviour. An individual’s beliefs and attitudes together form a perception towards a specific behaviour.

Perception is an individual’s judgement of the consequences/outcomes of adopting (expectations) or not adopting (threats) the desired behaviour. While consideration of the potential personal threats posed by a maladaptive response is mediated by a balance between reward accompanying the behaviour and the perceived vulnerability to the threat.

On the other hand, an adaptive response is mediated by balancing the response efficacy (perceived likelihood that the action will reduce the threat) and self-efficacy (belief that an individual can complete an adaptive response) with the response cost (barriers or inconveniences) of completing the adaptive response.
The Framework envisions that environmental and personal variables combine to further influence the kind of perception an individual is likely to form regarding the behaviour. The national policies, strategies, social norms and socio-economic factors form a set of independent or antecedent variables that influence beliefs and attitudes of an individual in forming a perception towards a specific behaviour.

For perceptions to be translated into adoption of a new behaviour, certain events that motivate an individual to take action have to take place. Such events may include death of a close relative or personal influence from relatives, friends and peers. These events that motivate people to change behaviour are collectively called ‘cues to action’. The availability and accessibility of supportive institutions, social networks, service delivery points and inputs, collectively called ‘infrastructure’, is critical in the adoption and sustenance of the new behaviour.

The Integrated Behaviour Change Framework, discerns a complex interrelationship between the individual and contextual factors through which behaviour change is achieved and maintained. In this inter-relationship, the precursor to behaviour change is perception, which is itself a product of an individual’s socio-demographic characteristics and his/her immediate environment. With the help of cues to action, the individual’s perception is transformed into action, which, when supported by the requisite infrastructure, is consolidated and maintained as a desired form of behaviour.

This framework provides a retrospective theoretical grounding of HIV/AIDS interventions in Uganda and possible springboard for future planning and replication of similar interventions. Further the Integrated Behaviour Change framework provided the context within which the study on Focus Group Discussions on the Social Cultural factors impacting on HIV/AIDS in Uganda was undertaken.
4.0 KNOWLEDGE, ATTITUDES AND PERCEPTIONS OF HIV/AIDS

Ideally, knowledge, attitudes and perceptions are believed to greatly influence behaviour patterns and practices of an individual. In the Integrated Behaviour Change Framework, it was discerned that the precursor to behaviour change is perception, which is itself a product of the interaction between an individual and his/her immediate environment. The basis of perception is attitudes that arise mainly from one’s exposure to information (knowledge) about a phenomenon. An individual’s consideration of the potential personal threats posed by the undesired behaviour vis-à-vis the potential rewards that accompany the desired behaviour greatly influence one’s ultimate decision to change behaviour.

This chapter presents primary findings on the role knowledge, attitudes and perceptions have played in influencing HIV/AIDS behaviour in communities. The findings also offer insight into the appropriateness of the Integrated Behaviour Framework and the extent to which these variables are key in influencing behaviour.

4.1 Community Knowledge and sources of information on HIV/AIDS

This section presents findings on community knowledge of HIV/AIDS. During the Focus Group Discussions, participants were asked whether they knew a disease called AIDS, how it is spread and prevented. In addition they were asked the avenues through which they receive HIV/AIDS-related information and its impact on the spread of HIV/AIDS.

Knowledge on HIV/AIDS was mainly expressed in terms of transmission and prevention. The main ways through which HIV/AIDS was said to be transmitted included sexual intercourse with an infected person; sharing of sharp instruments such as razor blades with those infected; being transfused with infected blood or getting into contact with infected blood, say through accidents and from an infected mother to her baby.

HIV/AIDS preventive measures commonly mentioned in most Focus Group Discussions (FGDs) and Key informant interviews (KII) in all the districts were Condom use; Being faithful to sexual partners for both married and unmarried; Abstaining from sex for those who are young; non-sharing of sharp instruments; using sterilised equipment; and blood testing for HIV. Others were the using of protective wear while nursing the infected, giving birth in a hospital, avoiding inheritance of HIV infected widows, avoiding alcohol, avoiding bad peer groups and becoming saved and remaining committed to God.

These findings show a near universal understanding of HIV/AIDS across the social demographic characteristics of sex (female and male), age cohorts (adolescents and adults) and residence (urban and rural) in communities. In some FGDs, some participants, especially in urban areas had accurate knowledge on the virus as the cause of HIV/AIDS. This was found to be consistent with findings from other related studies (GOU/UNFPA, 2002), (UDHS, 2000/01).

Knowledge on HIV/AIDS was reported to have increased as a result of information available to the community from a number of sources. These include radio, newspapers, posters, educative video/film shows, seminars and workshops, churches and mosques, health centres, and youth centres as presented in Table 4.1.
The other sources of information included community health workers, Persons Living With HIV/AIDS (PLWHA), and religious gatherings in churches and mosques. Adolescents and youths also accessed information through youth centres most of which are located in urban areas.

Table 4.1: Sources of HIV/AIDS Information to the Communities

<table>
<thead>
<tr>
<th>District</th>
<th>Radio</th>
<th>Print Media</th>
<th>Seminars</th>
<th>Video/films and drama</th>
<th>Churches and Mosques</th>
<th>Health Units</th>
<th>Testimonies of PLWHA</th>
<th>Peer/Parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mbarara</td>
<td>32</td>
<td>24</td>
<td>19</td>
<td>8</td>
<td>14</td>
<td>9</td>
<td>13</td>
<td>13</td>
</tr>
<tr>
<td>Mukono</td>
<td>32</td>
<td>22</td>
<td>24</td>
<td>23</td>
<td>10</td>
<td>14</td>
<td>12</td>
<td>9</td>
</tr>
<tr>
<td>Mbale</td>
<td>32</td>
<td>23</td>
<td>21</td>
<td>19</td>
<td>7</td>
<td>9</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Nebbi</td>
<td>27</td>
<td>11</td>
<td>7</td>
<td>20</td>
<td>9</td>
<td>18</td>
<td>-</td>
<td>6</td>
</tr>
<tr>
<td>Lira</td>
<td>32</td>
<td>19</td>
<td>8</td>
<td>15</td>
<td>19</td>
<td>11</td>
<td>18</td>
<td>9</td>
</tr>
<tr>
<td>Soroti</td>
<td>31</td>
<td>27</td>
<td>9</td>
<td>18</td>
<td>14</td>
<td>13</td>
<td>4</td>
<td>16</td>
</tr>
</tbody>
</table>

Frequencies

Note: Each score represents an FGD where a particular response was given in each of the 32 FGDs per district.

Source: Focus Group Discussions with communities, 2002

Radio was reported in nearly all FGDs as the main source of information on HIV/AIDS, accessible to many as a result of increased coverage through Radio Uganda and the various private FM stations spread all over the country.

“On Radio Paidha and Radio Uganda, the teaching is on protecting ourselves from slim (AIDS). They tell us not to sleep with other girls anyhow and also to use condoms. They also teach us to only have sex with our wives and also that we go to test our blood for slim. Because they repeat it so much it brings fear in us and this makes us to use condoms when we are having sex”. (FGD, Men (rural), Nebbi District)

Radio was reported to have helped demystify sex through open discussions on sexual issues in addition to providing a forum for sharing personal experiences by those infected thus helping in reducing stigma.

“The radio informs us how to avoid getting HIV/AIDS and how to have our blood tested before marriage or before having sex with a girl. This information has increased our knowledge and we are waiting for a blood testing centre to be built in Paidha”. (FGD, Men (urban), Nebbi District)

“Long ago when you would hear that one is infected you would fear to talk to her or to shake hands. If she used a plate you would not eat from the plate or even wash it. But now we have come to appreciate these peoples status and they are part of us. We don’t stigmatize them. So the attitude has changed.” (FGD, Girls (urban), Mbarara District)

Print media including Vernacular and English newspapers, Information Education and communication (IEC) materials and other newsprints were reported to be another prominent source of information in HIV/AIDS. Straight Talk, Teacher Talk and Young Talk newspaper pullouts published and supplied by Straight Talk Foundation target in-school children, adolescents and teachers on matters of adolescent sexual and reproductive health (ASRH).
However, access to the print media in the rural areas was found to be quite limited mainly because, circulation is poor and the purchasing power of the rural population is low. For example, among the rural communities, Straight Talk, Teacher Talk and Young Talk Newspaper pullouts were mentioned only in Nebbi and Soroti as information sources for children, adolescents and teachers.

“We also receive it from Young Talk. My first time reading it was Thursday this week and the question which was very interesting was that can kissing also infect, and the answer was yes.” (FGD, Girls (rural), Nebbi District)

“At school, the teachers teach us about how AIDS infects people and how it can spread so fast, we also learn about the signs of this disease and how it makes people sick. We also know that it has no medicine to cure it. For me, it has helped me have a great deal of knowledge on AIDS. We, who are in school are abstaining from sex, we are waiting until we grow up enough to use condoms or wait for marriage.” (FGD, Boys (rural), Nebbi District)

NGOs such as AIDS Information Centre (AIC) and TASO were reported to conduct seminars on HIV/AIDS in the districts where they operate. In addition staff of these organizations visit and sensitise adolescents in schools. Again this source of information was more accessed in urban than rural areas.

“AIDS Information Centre staff visit us sometimes and tell us about AIDS.” (FGD, Boys (urban), Mbarara District)

Despite the high knowledge of HIV/AIDS demonstrated in the discussions, some people still held misconceptions about HIV/AIDS, its transmission and how it can be prevented. Some participants reported that the avenue through which HIV is transmitted (sexual intercourse) is something unavoidable and hence they had nothing to do about it. There were also beliefs especially among people in rural areas that HIV/AIDS is caused by witchcraft, and this was noted to greatly influence the options for care and support for those infected.

Others believe that people who are circumcised have little chances of getting infected with HIV/AIDS. There were also serious misconceptions about the effectiveness of a condom as a means of prevention. The misconceptions about HIV/AIDS were more pronounced in rural than urban areas.

“The major cause of AIDS is this medicine they inject into children during immunization. These whites who give us drugs, aren’t these the drugs that cause AIDS? This drug called Vitamin A, which is red, it contains AIDS. You people should follow these children who have been immunized, they will die of AIDS” (FGD, Men (rural), Mbarara District)

Although information was reported to increase community knowledge on HIV/AIDS, the most prominent sources such as radio, print media and seminars were not widely accessible, to most communities especially those in rural areas. In addition, communities reported problems with regard to targeting the right information to the right audience. It was noted that access of the youth to information targeted at adults and vice versa creates perceptual problems and in extreme cases youth have been denied access to radios and newspapers for this reason.
4.2 Community Perceptions of HIV/AIDS

This section presents findings on community perception of HIV/AIDS. Key Informants and participants in Focus Group Discussions were asked what they perceived to be the major benefits and barriers to behaviour change, the impact of the epidemic on the communities and families. Participants were also asked their perceptions on the prevalence of HIV and categories of people most affected by HIV/AIDS.

4.2.1 Perceived Benefits to Behaviour Change

Participants reported that the desire to live a long and prosperous life fear and pursuing their life long the development plans as major factors motivating people to avoid behaviours that would put them at risk of getting infected with HIV. Others, particularly youths, were reportedly motivated by the desire to achieve their future ambitions such as complete their studies, raising families, building houses and taking care of their parents in reciprocation of the love and care that parents gave them. Thus, self-worth, personal future ambitions and goals were seen to be key factors and considerations driving people to avoid indulging in risky behaviour.

4.2.2 Perceived Threats/Vulnerability

In all Focus Group Discussions, participants reported that they felt threatened and vulnerable to HIV infection. They expressed fear of the consequences of HIV infection such as long sickness and painful death, fear to die and leave children to grow up as orphans (family responsibilities), fear to die and leave friends and property. They also fear stigmatisation and rejection and the high cost of drugs as very few people can afford the available Anti Retro Viral drugs. Women particularly felt more vulnerable to infection given the fact that the majority were dependent on men and had limited bargaining power in sexual matters.

“People fear to die. The fact that there is no hope for a cure scares people. We fear to leave our families, the children and our wealth. Some of us have parents who are too old; who will look after them when we die?” (FGD, Men (urban), Mukono District)

Factors reported to be motivating people to take precautions against HIV/AIDS broadly included an individual’s perception of the severity of contracting HIV/AIDS (e.g. death, long illness), perceived benefits of avoiding HIV infection (e.g. living a long and prosperous life); and events that prompt one to take precautions against contracting HIV (e.g. reminders/continuous warnings against HIV or death of friend). Fear of death, long and agonising illness and the desire to live a long and productive life were indeed among the key considerations reported to influence people to avoid risky behaviour (Figure 2).
4.3 Perceived Barriers to Behaviour Change

Figure 3 highlights the most prevalent barriers to HIV/AIDS-related behaviour change as given by the FGD participants in the six study districts. Analysis of the KII findings also yielded similar results. These results show that poverty, ignorance, and alcoholism are the three most prevalent barriers to positive HIV/AIDS-related behaviour change.

Poverty was reported to impact on all groups of people but women and adolescent girls in particular were most affected. Women and adolescent girls were said to admire a lot of things which they don’t have money to buy forcing many to engage in risky sexual behaviours for monetary gain.

“The main problem is lack of money. Because we want to live well and have good things like shoes and dresses, you find your heart pumping to do anything to get money. Our parents don’t have money. But we have to look good among our friends. No man can want a dirty girl who has no soap to wash her body and clothes. So, because of us being poor, we play sex to get some little money - even 1,000/=.” (FGD, Girls (rural), Nebbi District)
“There is a lot of poverty in the families. In some families, women indirectly send their daughters to go to sell themselves and ‘come with sugar’. Others send their daughters to work in hotels and get sex partners there. There are many bars in Mbarara Town where girls working there are only given food but no pay. The girls get money by providing sexual services to the customers”. (FGD, Males (urban), Mbarara District)

It was also reported that there are many single mothers who lack financial support to cater for their own needs as well as those of their children. Such women are easily lured into sex in exchange for money or other trinkets. Young girls, particularly those out of school, are also often forced into early marriages by their parents fearing that if they keep the girls home for long they would get pregnant. Some parents also fear that they (parents) would die before eating the bride price or seeing their grand children. Sometimes, the girls marry themselves off at a tender age in order to escape the biting poverty in their homes. Such girls are in many instances orphans, desperate to get married so that they can get a helping hand in looking after their young siblings.

![Figure 3: Major Barriers to HIV/AIDS-related Behaviour Change]

Source: Focus Group Discussions with communities, 2002
Poverty also affects adolescent boys in a number of ways both directly and indirectly. It was reported that once a boy has money, all the girls looking for money are attracted to him even when he is not interested in them. They will provoke and entice him into sex in order to get some money from him. With some bit of money, a boy can also easily be tempted to indulge in risky sexual behaviours by getting as many girl friends as he wishes or by buying cheap prostitutes who are readily available especially in the urban areas. On the other hand, a boy who doesn’t have money can easily be lured into sex by rich women (sugar mummies).

“Men tend to keep at home and reduce on extra marital affairs when they don’t have money. But once they have money they cannot settle. Because of poverty, some men tend to take advantage of other people’s wives using money, offers and gifts.” (FGD, Women (urban), Mbale District)

It was also reported that because of poverty many people couldn’t afford to buy condoms let alone raise money for transport to seek VCT services. This again affects the adolescent boys (as well as the girls) most, since the majority are not yet married and at some point find themselves involved in a sexual relationship.

“Most people are poor; there is no money to buy condoms. Even if you wanted to stay safe by using condoms, lack of money to purchase one at the time of need can lead you to getting infected.” (FGD, Girls (rural), Soroti District)

“The HIV Testing Centres are far and it is expensive to travel there. It can take even six months for one to save 10,000/= which is required for transport for two people. No boyfriend or husband can abstain from sex for that long.” (FGD, Girls (rural), Soroti District)

Ignorance also came out strongly as a barrier to behaviour change in all the study districts except Mbale. There was reported lack of knowledge, especially in the rural areas, on the proper use of condoms with some participants indicating total ignorance about them. Girls fear that condoms will slip off and get stuck into their vagina. Others believe that continuous use of condoms by their boyfriends while having sex, was a sign that they neither trust them nor love them. In such situations, the boys are left with only two options; either to abandon the girl or the condoms. They usually choose the later. The remote districts such as Nebbi are said to have not yet had any serious sensitisation about HIV/AIDS and many people were not aware of HIV/AIDS and its preventive measures such as condom use.

“Condoms are sold in busy shops where you cannot ask the shop attendant to teach you how to use them, so we just try on our own. The girls sometimes refuse the boys to wear condoms fearing that if the condom gets stuck in the vagina, it would kill her.” (FGD, Girls (rural), Soroti District)

“We have heard of condoms, we have never seen them. We hear that there are condoms for women; can you show them to us? If you have a condom with you, even if it is for men, show it to us, most of us do not know.” (FGD, Women (rural), Mbarara District)

There was another problem of self-diagnosis. Many people diagnose themselves as HIV positive simply because they have had one or two of the AIDS symptoms such as persistent fever or a skin rush or simply because they once had sex with a widow. Some of these people tend to go on a ‘revenge’ mission to ‘infect’ others when actually they may not be sick at all, in the process they end up getting infected.
Others were reported to have perceptions that a health looking person cannot be carrying the virus while others are simply reckless with their lives.

“There is a mentality that death is inevitable, that even a car can knock you dead. They say ‘let me go for sex because I shall die any way’. You show a person that woman is infected, he says, ‘that is the one I want’. People use their eyes to judge whether a woman is sick or not; when they see a health-looking woman, they say ‘I must have this one, she is HIV free.” (FGD, Men (urban), Mbarara District)

In addition, there is a belief, especially among rural men, that condoms are supposed to be used by young people and not the old. Some people are also still ignorant of the dangers posed by some of the cultural practices such as widow inheritance while others are aware but continue to practice it either because of poverty or out of greed for property.

As shown in Figure 3, alcoholism featured prominently in at least half of the study districts as a major barrier to behaviour change. Alcoholism was deemed to be a barrier because it makes it difficult for one to think and act rationally and gives one confidence to do things that one wouldn’t do when sober. Save for religious functions, alcohol is usually served – often for free - on all social and cultural functions.

In such an environment of ecstasy and free alcohol, sex and most likely unprotected was more often reported to follow. With available anecdotal evidence that alcohol is widely consumed all over Uganda, one can reasonably conclude that this problem equally affects the rest of the districts and indeed the entire country.

“When you drink alcohol, especially local brew and ‘waragi’, you don’t fear to say anything to a girl and if she accepts you even go without a condom”. (FGD, Boys (rural), Mbarara District)

Peer influence and provocation into sex were other factors identified as inhibiting change in HIV-related risky behaviour. These two factors mostly affect the adolescents who come under a lot of pressure from their peers to engage into sexual activities.

“People have girl friends. If you don’t have one they say ‘you fell off a paw-paw tree’ meaning you are impotent.” (FGD, Boys (urban), Soroti District)

The other important barriers included the malicious spread of HIV, the desire for unprotected sex to realise sweetness, and religion. The issue of malicious spread of HIV was most pronounced as a major barrier in Lira District while the desire for unprotected sex was strongly echoed in Mbarara. There was a strong link of condom use with community perceptions and ways of having sex. In Mbarara for instance, sex is only enjoyable when a woman is able to secrete large volumes of vaginal fluids. Condoms were reported to significantly impair women’s ability to do this and for this reason, men are reluctant to put them on.

Parents also came under the firing line for not giving guidance to their children on sexual issues. In some FGDs for adolescents in Nebbi, parents were accused of hounding adolescents, especially the girls, out of their homes saying that they are ‘over-grown’; they should start their own homes. This was reported to force the girls to get married to the first man they come across and some boys also decide to go and stay with ‘sugar mummies’ in towns and trading centres.
The gender inequalities that subordinate women to men make it practically difficult for most women to avoid infection even if they themselves are taking precautions. Women, especially the rural and unemployed folk reported that they are totally dependent on men and have no decisions to make in matters of sex. In all FGDs, women reported that they cannot refuse men sex.

“Some parents refuse to send their children to school especially the girls. Instead, they give them a hard time saying they should not move around. This makes the girls have great lust for sex and they use any small chance they get to play sex even in their own homes. Other parents abuse their children with bad words especially the big girls who are not yet married. This makes them run away from home.” (FGD, Boys (rural), Nebbi District)

“Men go away and commit adultery with infected widows. When they come back, we have sex with them. Even when you are annoyed, you cannot deny him sex for a week, or even two days. He will chase you away from his home.” (FGD, Women (rural), Mbarara District)

Others are religious institutions that have consistently opposed condom use, uncontrollable desire for sex, indecent dressing by women, pornography, insurgency, particularly in Northern Uganda, marital problems, weaknesses in enforcement of laws (such as on defilement), migration, defilement, and smoking of marijuana.

The findings indicate that poverty, ignorance and gender inequalities are critical impediments to behaviour change. Poverty makes access to services almost impossible, as people are unable either to travel to the service delivery points or pay for the services. Quality of care for those infected is compromised as household capacity to cope with increased demands for nutrition and medical care wanes. Vulnerability of women and young girls was particularly noted to increase with the increased degree of poverty. Under economic pressure, the likelihood of making irrational sexual decisions was seen to be higher for women.

On the other hand, ignorance was noted to be especially linked to access to information and literacy. In rural areas where access to media and other forms of HIV/AIDS campaigns is comparatively low, there were high levels of ignorance on basic facts on the epidemic. In extreme cases, some of the people in rural communities have never seen a condom. There was also strong attachment to the cultural values, some of which are inimical to risk reduction behaviour.

Women, especially those in rural areas were particularly noted to be in a compromised situation with regard to HIV/AIDS. They are the least informed and even when they possess the knowledge, their efforts to protect themselves against HIV/AIDS are weighed down by socio-economic and cultural norms that subjugate their independence.

4.4 Perceived HIV Prevalence

Informants at the district and sub-county levels, community health workers, head of HIV/AIDS-related NGOs and CBOs were asked whether they think there has been a reduction in HIV prevalence in their communities. They were further asked to indicate factors responsible for the reduction if any, and to mention the constraints to any significant reduction on prevalence. These and other study informants were also asked what categories of people have been most affected by HIV/AIDS, and give the reasons why certain categories of people were considered most affected.
The majority of informants (4-6 out of 8 per district) thought there was a reduction in HIV prevalence in their communities (Table 4.2). The reasons given for the perceived reduction in HIV prevalence were sensitisation and increased awareness of people through media and health education. Others, though, with considerable variations across districts included regular supply of condoms, increased use of condoms and establishment of VCT centres by NGOs such as TASO and AIDS Information Centre (AIC) in some of the districts.

“Yes, to some extent it has reduced because sensitisation exercises have been taking place. Counselling is being done and people are moving around in the villages educating people on condoms. People who used not to accept them have started using them. At the sub-county, there is a youth office and condoms are available so they come and pick”. (Health Assistant, Lira District)

“Overnight traditional dances, some of which could last three days have died out. People used to make love in the bush on such occasions leading to spread of HIV/AIDS but due to mass education, people are aware and the youth have changed.

Rampant drinking has reduced; over staying at funeral rights is no longer there as people now go for few hours and go back home. This has helped the communities within the district to avoid sex that would have led them to HIV infection.” (District Official, Lira District)

On the other hand, in the districts of Mukono, Soroti and Lira, some informants thought there was no reduction in HIV prevalence, with the major reason being absence of behavioural change among the people. They argued that people do not use condoms, they drink too much alcohol and many do not stick to one partner. It was reported that, although some community groups such as mothers unions have started providing guidance and counselling, they hardly talk to the youth as parents. Furthermore, sensitisation on HIV/AIDS is not enough and people are unable to read the information. In some districts, some informants admitted that it was not possible to know whether there is reduction in HIV prevalence as there are no studies that have been carried out to that effect.

“There is no HIV reduction because even the church of the Pentecostals that tries to teach sexual morals is not followed by most Christians. The born-again Christians have night prayers and also pray sex during the dark. They claim its God’s idea and yet it is Satan. So there is nothing leading to the decrease. There is also alcohol drinking by the people in the community, so there is no decrease of AIDS”. (Traditional Birth Attendant, Soroti District)

In addition, they said that much has not been done on Voluntary Counselling and Testing (VCT). Furthermore some informants argued that where VCT services exist, data from some sites portrays a gloomy picture.

In Soroti, for instance, it was reported that available data at one site in Kasiro County indicated that HIV prevalence averaged 20.8 %, which is within the same range of prevalence rates in some AIC outreaches. They reported that it is hard to say that prevalence is going down when the number of people falling sick is on the increase.

“Its hard to say whether there is reduction or not because for example there is a high demand for condoms but I don’t know whether people use the condoms or not. Also people have not gone for blood testing. So it’s hard to know who and how many are infected in this year and say compare with previous year.” (District Official, Soroti District)
“I cannot tell because it is not like food stock in a house where you can see whether it is reducing or increasing. There are cases of sick people and to date the number of sick people is high (District official, Lira District)

Table 4.2: Perceptions on HIV/AIDS Prevalence in the Study Districts

<table>
<thead>
<tr>
<th>Perception of HIV prevalence</th>
<th>District</th>
<th>Frequencies</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mukono</td>
<td>Lira</td>
</tr>
<tr>
<td>Yes, HIV/AIDS has reduced</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reasons for reduction</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>National, Local Leaders and stakeholders campaigns against HIV/AIDS</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Increased awareness through media and health education</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Regular supply of condoms</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>People are beginning to be faithful to their partners</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Establishment of VCT centres has helped</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>People now use condoms</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Care for patients by managing HIV/Related infection</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>No Reduction in HIV/AIDS</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Reasons for no reduction</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No behavioural change (none condom use, alcoholism, a lot of immorality, many people are sick etc)</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>We have not done much VCT</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>No studies have yet been carried out</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

Note: Each score represents a particular response given in 8 of the KIIs where the question was asked in each district.

Source: Key Informant Interviews, 2002

4.4.1 Perceived categories of people most affected

All the informants in the six study districts categorised people most affected by HIV/AIDS by socio-demographic characteristics of age, sex, residence, employment and education among others. The people perceived to be most affected were the youth below 30 years, women, less/non-educated, orphans, rural and urban dwellers. Businessmen were considered most affected in the districts of Soroti and Lira. Others were people living on the lakeshores and soldiers. The adults above 40 years of age, the educated and the poor were the categories of people least considered affected by HIV/AIDS in the six districts.

“The people most affected are the youth between 15-30 years because first of all they don’t have proper partners and in the process of meeting their sexual needs they are always in search for better partners. The resources they have cannot match with their demands so both men and women look for who can provide for them.” (Sub-county Official, Lira District)

“Women are more affected because according to Teso culture the man is free to marry many of them, and this is common at the landing sites and so when a husband is infected, then many women are likely to be infected”. (Head of an HIV/AIDS service CBO, Soroti District)

“According to the district data, 10% of youth aged between 15-29, 13% of 20 –24 years, 40% of 30-39 years, and 30% of 40 years and above are affected. So it is the age between 30-39 years that are most affected. The overall infection of the district is 20.8%. (District Official, Soroti District)
A number of reasons were advanced for each category of people considered to be the most affected by HIV/AIDS. Looking at the commonly mentioned categories, the reasons for each affected varied by category with few similarities as shown in Table 4.3.

Table 4.3: Categories of people considered most affected by HIV/AIDS

<table>
<thead>
<tr>
<th>Category of People Affected</th>
<th>Reasons why the category is considered most affected</th>
</tr>
</thead>
<tbody>
<tr>
<td>Youth below 30 years</td>
<td>They are sexually active with impaired reasoning and in child-bearing age so they are looking for children. They are also highly mobile looking for money and are unemployed. The girls in particular want nice things yet their parents are poor. The young girls fear using condoms that they will get stuck in their private parts.</td>
</tr>
<tr>
<td>Women</td>
<td>Men are always overall heads even when women are economically well placed. They lack money and end up being used by men. Women have a dependency syndrome and have no choice in matters of sex. Cross-generational sex such as school girls being run by rich men and not fellow students. Most of them are still illiterate and lack awareness on HIV/AIDS. They are easily exposed to infection due to social reasons such as taking care of the sick and their anatomy. They believe that its men to move with and use condoms and are either seduced or raped.</td>
</tr>
<tr>
<td>Rural dwellers</td>
<td>They are not well informed, therefore have not conceptualised how HIV is spread and others doubt its existence. The dead are buried by rural dwellers, care for the sick including those from urban areas. They are not consistent with condom use and don’t believe in condom use since it does not give good feelings of sex. They are always idle.</td>
</tr>
<tr>
<td>Urban dwellers</td>
<td>Entertainment places are concentrated there, unemployment is highest and prostitution most common.</td>
</tr>
<tr>
<td>Less/non-educated</td>
<td>They rarely use condoms because they do not believe in them and lack knowledge on HIV/AIDS. They engage in forced marriages. They also have a lot of leisure time to engage in sex most of the time.</td>
</tr>
<tr>
<td>Educated</td>
<td>They claim to be more informed about HIV/AIDS and being aware about living positively when infected. They do not care about their families and move from woman to woman.</td>
</tr>
<tr>
<td>Businessmen</td>
<td>They move place to place thinking that with money they can win any woman. Women are also attracted to rich men.</td>
</tr>
<tr>
<td>Orphans</td>
<td>They lack parental guidance, basic necessities and are exploited by the well to do who take advantage of their vulnerability being orphans.</td>
</tr>
<tr>
<td>The Poor</td>
<td>They depend on local herbs for most of the drugs and some cannot afford food. Some do not have land and shelter. They lack employment and source of income such that sex and alcohol drinking becomes their occupation. Because they do not have an income, particularly women, they depend on favours.</td>
</tr>
<tr>
<td>Truck drivers</td>
<td>They leave their wives like 200 to 300 miles away so they look for women in order to satisfy their sexual desires.</td>
</tr>
<tr>
<td>Unemployed</td>
<td>Because they are idle, many of them drink most of the time</td>
</tr>
</tbody>
</table>

Source: Key Informant Interviews, 2002

4.5 HIV/AIDS-related problems in the community

Focus Group Discussion participants and Key informants were asked what HIV/AIDS problems exist in their communities. Participants and informants gave a multi-dimensional assessment of the impact of HIV/AIDS at the individual, family and community. Findings on HIV/AIDS-related problems have been grouped into 3 major categories of: Socio-economic, Illness, and Crime and Violence (Table 4.4)
Socio-economic problems

In this category, the problem of increased orphans ranked highest reported in over 80% of the FGDs and by all key informants in each district. HIV/AIDS and its attendant problems such as the growing number of orphans needing care as well as modernisation that promotes a nucleus family were found to be threatening to tear apart the extended family institution, that acts as a safety net for the bereaved family. Some of the orphans do not have adequate care and may eventually become street children.

“HIV/AIDS has increased the dependency burden; we have many families looking after orphans. Some orphans are completely helpless without anybody to take care of them by providing food, clothing and other basic requirements. We have two cases of orphans who have died due to lack of care.” (Health Assistant, Mukono District)

“Most people now don’t want to help orphans. Most orphans remain with grandparents. After the burial, the paternal uncles and aunties go away very fast so that the orphans are distributed in their absence.” (FGD, Women (urban), Mukono District)

The second major problem reported was increased poverty. It was reported that when people fall sick they spend the available resources to seek treatment from either traditional healers or modern doctors. When they eventually die, the widows or widowers do not have any resources left to support them particularly when they also fall sick and become weak.

“When people fall sick, they tend to use the available resources on medical care and by the time they die there is nothing left …nothing is also left for the children who also end up suffering.” (Traditional Healer, Lira District)

In addition, the labour of the other family members is diverted from much of the productive work as they care for the sick leading to low productivity of families. This ultimately affects food production and household income. In most cases, the care for persons living with HIV/AIDS (PLWHA) was said to be inadequate since they need to be provided with treatment of opportunistic infections such as TB, malaria, fungal infections and others. Some of these infections require treatment whose drugs are expensive and not affordable by most families.

Participants further lamented that most people dying are those of the most productive age. This slows down the economic growth and society is unable to regenerate affecting people’s quality of life and development. As a result the vicious circle of household poverty continues.

“Even in hospitals, one needs to have money to be attended to; all they do is to put an AIDS patient on drip and things end there, it is only the relatives of doctors and the rich with money who get treatment.” (FGD, Women (urban), Soroti District)

“It has caused underdevelopment, killing productive people who would have developed the country. Days are lost at funerals and when burials take place, people do not dig, agriculture in the villages is affected.” (FGD, Men (rural), Mbarara district)

“We lost a member of the Board of Governors due to HIV/AIDS. He was a fundamental person on the Board, always contributing good ideas, so articulate and his death left a big gap in the management of the school.” (School Teacher, Nebbi district)
Crime and Violence

The second category of perceived HIV/AIDS-related problems was that of crime and violence that includes malicious spread of HIV/AIDS by some infected people, orphans that have no guidance engaging in criminal behaviour, suicide by some infected persons and deliberate discrimination of people infected and families affected by HIV/AIDS. It was reported that some people who know or suspect that they are sick usually want to revenge by maliciously spreading HIV/AIDS. This was reportedly done by well to do persons, who entice others with money particularly young girls. Malicious spread of HIV/AIDS was carried out through rape, defilement and cross generation sexual relations. This practice was mostly reported in Lira, Mukono, and Mbarara.

“In my personal experience, many people especially the youth, after getting infected, they don’t keep it with themselves as they say they cannot die alone.” (School Teacher, Lira District)

Discrimination of the sick was also reported to be taking place in some families, places of work, health service delivery points, service and financial sectors among others. In some districts, it was reported that the moment an individual begins showing signs of HIV/AIDS, people especially those ones she/he has been close to isolate him/her and join others to malign him/her. Some Focus Group Discussions reported cases where the infected are never given jobs since employers doubt their productivity and reliability on the job.

“There is discrimination of people with HIV/AIDS, people point figures at those who are infected. They reject them and sit with those who appear to be still negative. When people learn that you have AIDS, all friends disappear from you”. (FGD, Men (urban), Soroti District)

“At times they point a finger at people saying so and so is sick and at the work place, when you keep falling sick your services can be terminated”. (PLWHA, Lira District)

Mistreatment of widows and orphans by grabbing property was also reported to be common in families. The widows are accused of killing their husbands by the relatives of the deceased. In other cases, families break down even when both spouses are still alive, with either partner running or chasing away the other after knowing that they are infected. HIV/AIDS-related family wrangles were mostly reported in Mukono.

“Separation of couples these days is on the increase. If a woman realises that the husband has other extra-marital affairs, she may decide that the couple separate beds but the man cannot accept and ends up chasing the woman away.” (FGD, Women (rural), Mukono District)

“When my husband died, his relatives neglected and harassed me. I was chased from the home and all I carried away were my children. ” (PLWHA, Mbarara District)

“There is also a problem of fighting or struggle for the land of the deceased, people will encroach on the land; they can even grab away the land from the rightful children.” (FGD, Men (rural), Lira District)
Illness and Disease

The third category was illness due to HIV/AIDS. HIV/AIDS was said to facilitate quite a number of opportunistic infections like diarrhoea, cough, malaria which in turn result in a number of symptoms such as general body weakness, retarded growth for children, poor appetite, vomiting, skin rash, persistent headache, change of colour of eyes, change of hair, sores in the mouth and extensive loss of weight. Once this happens, stigma at both the individual and community level sets in. The affected person withdraws and isolates him/herself and if not assisted may become psychologically unstable and eventually run mad.

Mistreatment of infected persons often leads to rapid physical and psychological degeneration. In areas where psychosocial support services are non-existent, some people were reported to lose hope and resort to alcoholism and ultimately committing suicide as the feeling of hopelessness intensifies.

Table 4.4: Categorisation of HIV/AIDS related problems by district

<table>
<thead>
<tr>
<th>District</th>
<th>Mukono</th>
<th>Lira</th>
<th>Mbarara</th>
<th>Soroti</th>
<th>Mbale</th>
<th>Nebbi</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Socio-economic</strong> Frequencies</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Increase of orphans</td>
<td>29</td>
<td>32</td>
<td>29</td>
<td>26</td>
<td>26</td>
<td>29</td>
</tr>
<tr>
<td>Increased poverty</td>
<td>18</td>
<td>27</td>
<td>22</td>
<td>19</td>
<td>22</td>
<td>19</td>
</tr>
<tr>
<td>Widowhood</td>
<td>10</td>
<td>9</td>
<td>12</td>
<td>14</td>
<td>19</td>
<td>4</td>
</tr>
<tr>
<td>Low productivity</td>
<td>18</td>
<td>22</td>
<td>19</td>
<td>15</td>
<td>12</td>
<td>9</td>
</tr>
<tr>
<td>Death</td>
<td>17</td>
<td>21</td>
<td>17</td>
<td>19</td>
<td>23</td>
<td>8</td>
</tr>
<tr>
<td>Fear and worry among people</td>
<td>5</td>
<td>3</td>
<td>4</td>
<td>8</td>
<td>7</td>
<td>15</td>
</tr>
<tr>
<td><strong>Crime and Violence</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Malicious spread of HIV/AIDS by well to do persons</td>
<td>14</td>
<td>14</td>
<td>17</td>
<td>4</td>
<td>11</td>
<td>7</td>
</tr>
<tr>
<td>Orphans exploitation and rape</td>
<td>3</td>
<td>2</td>
<td>6</td>
<td>6</td>
<td>9</td>
<td>4</td>
</tr>
<tr>
<td>Discrimination of sick people</td>
<td>8</td>
<td>3</td>
<td>9</td>
<td>9</td>
<td>14</td>
<td>20</td>
</tr>
<tr>
<td>Ignorance about HIV/AIDS (prevention and treatment)</td>
<td>9</td>
<td>-</td>
<td>2</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Causes of misunderstanding in families</td>
<td>14</td>
<td>9</td>
<td>8</td>
<td>3</td>
<td>10</td>
<td>9</td>
</tr>
<tr>
<td>Committing suicide</td>
<td>7</td>
<td>3</td>
<td>2</td>
<td>3</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td><strong>Illness and Disease</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Many people are sick</td>
<td>4</td>
<td>9</td>
<td>-</td>
<td>-</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Mental illness has increased</td>
<td>3</td>
<td>4</td>
<td>-</td>
<td>3</td>
<td>3</td>
<td>-</td>
</tr>
</tbody>
</table>

Note: Each score represents an FGD where a particular response was given in each of the 32 FGDs per district.

Source: Focus Group Discussions with communities, 2002

In summary, the orphan crisis was reported to be the major AIDS induced problem facing communities in both urban and rural areas. Although an orphan is initially in a family, the moment orphanage sets in, the community is also likely to feel the impact through either absorbing the orphan or dealing with maladaptive behaviour such as prostitution, drug and alcohol abuse and theft, that are consequences of inadequate or no parental care.
Poverty in household and the ever-increasing orphan numbers are substantial deterrents to the natural willingness of extended families to take care of orphans. In addition to poverty, it was noted that some of the family members that are supposed to take care of the orphans are either HIV infected or are very old, which undermines their capacity to assume these roles.

Findings from Focus Group Discussions indicate that there was a near universal understanding of HIV/AIDS, expressed in terms of transmission and prevention. The increased knowledge was reported to be a result of a wide range of sources of HIV/AIDS information accessible to communities.

Information available to communities was noted to have had significant influence on HIV/AIDS knowledge, which in turn has improved HIV/AIDS risk perception. Information has also helped to improve attitudes of the community towards HIV/AIDS and the people affected. For example, communities held the attitude that HIV prevalence had reduced as a result of increased awareness of people through media and health education, use of condoms and provision of services such as VCT and care by NGOs. In addition, the information has also helped the community to know where to seek the appropriate services such as VCT, care and support and condoms.

Despite the high level of knowledge and the important role information has played, critical gaps and limitations still remain. Various misconceptions were still held about HIV/AIDS transmission and prevention, especially in rural areas. Some informants believed there was no reduction in HIV prevalence mainly basing on reasons such as absence of overt changes in sexual behaviour among the people, inadequate counselling services and the inability of many people to read and interpret IEC messages. The cost of radios, newspapers and the inability of people to read and interpret messages remain major challenges to dissemination and accessibility of HIV/AIDS information especially in rural areas.

The Integrated Behaviour Change Framework establishes a strong relationship between information, knowledge, attitudes, perceptions and behaviour change. Information that stems from the environment (family members, peers, mass media, organizations) is considered the basis for awareness and eventual knowledge, attitudes and perceptions. Empirical evidence from this study indicates that information plays a big role in raising people’s awareness and knowledge, which subsequently influence community attitudes and perceptions on HIV/AIDS. The combination of these factors was found to strongly influence people’s desire to take action against HIV/AIDS, notwithstanding the notable limitations such as poverty, ignorance and gender inequalities.
5.0 CULTURAL NORMS, SOCIAL PRACTICES AND HIV/AIDS

Desired change in behaviour cannot easily be achieved without a corresponding change in the community cultural norms and social patterns. For instance, with HIV/AIDS declining faster among the youth than in any other age group, it is believed that social and cultural factors that influence HIV transmission have changed more among youth than adults.

The Integrated Behaviour Change Framework considers cultural norms and social practices as part of the wider environment. Other aspects of this environment include local and national policies, laws and economics. The Framework also recognises cultural norms and social practices as significant factors in behaviour formation and change. These factors were noted to strongly influence individual beliefs and attitudes and consequently perception, which is the antecedent to the adaptive response.

This chapter presents empirical data on community cultural norms and social patterns and practices and how these impact on HIV/AIDS related behaviour change. Data is presented in a bi-dimensional manner, with factors inherent in the community cultural and social context that facilitate HIV transmission and those that enhance reduction in HIV incidence. Section 5.1 presents and discusses social factors while Section 5.2 focuses on cultural norms and practices reported to be impacting on HIV/AIDS in communities (Table 5.1).

5.1 Community Social Practices and their Impact on HIV/AIDS

The main social factors impacting on HIV/AIDS were reported to include discos, traditional dances, films, wedding parties, religious gatherings, games and sports and alcoholism.

5.1.1 Alcohol and drug abuse

Alcohol is strongly embedded in the cultural and social set-up of many communities in Uganda and is used to promote unity and togetherness. With responses recorded in close to 70% of the Focus Group Discussions in all the districts, alcohol drinking and alcoholism were reported to be the major social factors influencing the spread of HIV/AIDS. A number of actions and corresponding behaviour in which people particularly engage under the influence of alcohol were identified and discussed by participants. It was reported that when people get drunk, their judgment gets impaired and are likely to engage in unintended and unprotected sex. In particular, some men even get wild and lose rationality and sometimes rape other peoples’ wives or bar maids. The men may also buy a lot of alcohol for women ostensibly to entertain them but eventually rape them when they get drunk and lose control over themselves. On the other hand, some women may also abuse alcohol and end up getting taken advantage of by men who perceive them as easy and free ‘goods’. In addition, clubs/bars also act as a meeting place for potential sex partners to make appointments to have sex.

Associated with alcoholism was drug abuse particularly in urban centres, where it was said to be common. Those who take drugs normally lose their senses after and develop a high sexual desire ending up raping or defiling girls. At times such people rape even mad women whose HIV status they may not know and do not take any protective measures.
“In other cases when people are drunk, they tend to believe that ‘AIDS only exists during the day but at night, it is asleep’. (FGD, Women (rural), Lira District)

“After drinking, one loses control and one cannot for instance put on condom while drunk. Those girls (bar maids) also find it easy to entice the clients with their shaky bums and mini-skirts. (FGD, Men (urban) Mukono District)

“In the old days, people would go to drink and dance from a person’s home. These days drinking is done in bars. A man and a woman may drink from different bars, one in Byanamira, the other in Bugamba, they do what they want including sex which leads to HIV/AIDS.” (FGD, Men (rural), Mbarara District)

On the other hand, participants in some Focus Group Discussions in Mukono district reported that alcohol drinking has, to some extent, helped in reducing transmission of HIV/AIDS. They argued that drinking makes an individual forget all about sexual matters. In addition, the socialization that goes on in the drinking places also helps people to develop peer relationships, which have an inherent aspect of mutual protection.

“Alcoholism can also save someone. If one drinks and get knocked down, one will not have the guts to see this ugly woman as beautiful. So, he will just go home and fall in bed. Besides, the “mutaka” (penis) cannot erect.” (FGD, Men (rural), Mukono District)

“Drinking can also help. In bars people usually talk about those who are infected and also counsel each other on risky behaviour. So while drinking you also get to know more about HIV/AIDS from colleagues which helps you to abandon any plans you may have intended to hatch.” (FGD, Boys (rural), Mukono District)

5.1.2 Discos and Traditional Dances

Disco dance was another social activity that was widely reported as impacting on the spread of HIV/AIDS. While dancing is a social event used to depict happiness and togetherness, some people especially the youth take it as a precursor to sex. In most discos and dances, sexually provocative dancing styles, dress codes and indecent exposure are indeed dominant often leading to unplanned sexual activities. In addition, discotheques are also used as popular drinking joints.

“In discos, people don’t dance with their legs only but with their mouth too and when drunk, one may not know what will happen next. (FGD, Boys (rural), Lira District)

Like discos, traditional dances were reported to promote the spread of HIV/AIDS. In Lira, there is a local dance called ‘okeme’ which takes place once a week. In this trans-night dance, men and women, boys and girls mix up. This dance is always accompanied with drinking and as people get drunk, sexual intercourse is usually the end result. In Nebbi District, the cultural dance called ‘Agwara’; was reported to bring together all sorts of people who drink, dance and begin loving each other and having sex. The songs they sing are very obscene and intended to arouse sexual desire.

The risk to HIV infection during discos and traditional dances arises out of the fact that in most cases, those who have sex in such ceremony don’t use condoms because it is not planned. The dance also takes place during the night with a lot of alcohol, which puts people into sex moods that provoke them to engage in sex. The post-disco sexual encounters are more likely to be unprotected because access to condoms is usually limited during late hours of the night more especially in rural areas.
“The dances at night have made people get ‘slim’ (HIV/AIDS). The ‘Ndara’ dance, for example, is sexually provocative and the songs are very obscene. This puts one in mood for sex and with booze, the sex urge increases. Many times when we have these dances, you find many people having sex in the nearby bushes or behind huts. They don’t use condoms because it is not planned for”. (FGD, Boys, (rural), Nebbi District)

5.1.3 Video shows, Films and Drama

In all study districts, there were reports of marauding video shows in urban areas conducted in make shift premises. In the Video show places where adolescents and youths are the premier customers, there is neither control over the type of videos shown nor the target audience. It was reported that in most cases, the scenes screened are tempting to adolescents first because they teach them sex and those that watch them with partners sometimes go into real action. Secondly they arouse the curiosity of children and increase their propensity for sexual exploration that often leads to wrong and irrational decisions among adolescents and youths.

“The other factor is drama, where some of the presentations also depict sexual activity. The actors/actresses also dress indecently and in most cases entice people sexually. Besides, some girls come to the show without entrance fee and so when boys pay for the girls, they expect them to pay back in kind.

Drama and films have, on the other hand, had laudable positive impact on people’s sexual behaviour. Used purposively, drama and films were said to help relay the realities of HIV/AIDS to target beneficiaries; how some one gets infected, how one suffers with the disease and the after effects of one’s death. In the districts of Mukono, Mbarara and Mbale some educative films particularly on HIVAIDS were said to be very helpful in sensitising people. In addition, drama and films were also said to serve as an alternative way of social interaction other than sex.

5.1.4 Games and Sports

Sports and games are another important recreational activities, especially for youth and adolescents. In villages, where there are not many alternative recreational activities, people walk long distances to the games fields on foot. Most games, particularly football and netball, are played in the late evening and end towards dusk. As people return home during the evening, there are opportunities for camaraderie, which results in casual, or forced and often unprotected sex. However, games and sports were said to be useful in keeping youth busy and return home tired so they do not think of sex. They are also good avenues for interaction and making friends.
“People go to watch say football especially the adolescents who normally end up getting partners from there and at times they could even fall in love with the best sportsman in the field. This may lead to undesirable sex.” (FGD, Men (urban), Lira District)

5.1.5 Peer Influence

The youth were reported to be keen to model the behaviour of others. Peer influence was reported to be very significant in the villages where children perform domestic chores like collecting firewood and water in a communal manner. In urban areas, youths also participate in various social activities such as attending discos, watching films and games, reading and watching plays and drama. In the process they learn from each other many things including sex, drinking, smoking and sometimes drug abuse.

“Peer groups make it hard for some adolescents to change behaviour. When you abstain from sex, other adolescents start saying, “ogwo nendaaho”- that one is castrated.” (FGD, Boys (urban), Mbarara District)

On the other hand, peer relations are critical ingredients of human behaviour formation. Although they are often portrayed as sources of dysfunctional behaviour, they were reported in some instances, to be sources of mutual support and protection.

“We have decided to inform other boys about girls we suspect to be HIV positive. We also move around teaching fellow boys about protection. We make sure each one in our group has only one girl. If he gets more than one, we isolate him.” (FGD, Boys (urban), Mbarara District)

“For me, I normally advise my friends not to have many boy friends. I also discourage them from getting married early (below 18 years) to older people because one can easily get infected with HIV from older men who have been exposed to sex for long.” (FGD, Girls (rural), Soroti District)

5.1.6 Market days

Market days were mentioned as avenues of casual sexual relations in Focus Group Discussions in the districts of Soroti, Mbarara and Lira. In these districts, markets were generally reported to be not just places for selling and buying goods but also meeting points for both new and former lovers. Women and young girls were reported to be the most commonly vulnerable group of people in these markets. Men tend to entice them with petty gifts such as lunch, clothes and shoes, and are later asked for sex in return.

“On market days, people go to meet other people from different villages. Now a man might have asked me for sex and I promised him. When I get chance to go to the market and happen to meet him, I can go near him, and if he asks about the other promise, I will wait until evening comes and give him.” (FGD, Women (rural), Mbarara District)

“After men have sold their commodities, they go to bars for alcohol. When they get drunk, they behave irresponsibly and trick young girls with small things like panties, clothes and have sex with them.” (FGD, Boys (rural), Soroti District)

5.1.7 Worshipping

There was a wide perception from participants in most Focus Group Discussions, that night prayers conducted mainly by Pentecostal Churches create opportunities for loose sexual behaviour among the Born Again community. It was reported that, at night, when
Born Again Christians gather for prayers, some engage in sexual activities thereby increasing the risk of HIV transmission.

Some FGD participants also held the opinion that some HIV infected people join the Born Again Christian Churches to use it as a hunting ground to lure other converts into sexual escapades intended to infect unsuspecting victims. Similarly many anecdotal stories abound where religious leaders have themselves been involved in sexually exploiting their followers. There are increasing cases of misleading testimonies especially by women who claim to be holy and based on this their fellow born again men pick them for wives thinking they are safe when they are actually infected.

It was also reported that churches, especially the Catholic Church and the Pentecostal Churches, strongly discourage their followers from using condoms. This increases the risk to HIV transmission among those believers who fail to uphold the virtues of abstinence from pre-marital sex and faithfulness among the married.

“These churches have night players and these are meeting places for men and women, girls and boys of all intentions. Some use it as an opportunity to meet the opposite sex and indulge in sex.” (FGD, Women (urban), Mbarara District)

“Many people with different intentions gather during these church crusades and fellowships. Some do engage in sex to the extent that some girls have even conceived.” (FGD, Men (rural), Soroti District)

The above negative aspects notwithstanding, religious activities were reported to play very important roles in HIV/AIDS prevention and care. Religious institutions were said to be at the forefront of HIV prevention, encouraging followers to abstain from sex and to remain faithful to their partners. Spiritual counselling has also evolved as an important ingredient into the care and support of people affected by HIV/AIDS.

In addition, many people, both the infected and non-infected, were reported to have become saved (Born Again Christians) and abandoned their old bad habits which very often included alcoholism, multiple sexual relationships and adultery; factors frequently mentioned as key among those responsible for the spread of HIV. Sex outside marriage, polygamous relationships, and alcoholism are anathema to Born Again Christian virtues (Islam is also against alcohol) implying that upholding those values promotes abstinence among the unmarried and faithfulness among married couples.

“Saved girls are very difficult to ‘con’. They do not accept however much you sweet-talk them. So the rate of playing sex is low”. (FGD, Boys (rural), Mbarara District)

“The church preaches against adultery and fornication especially that they bring HIV/AIDS. So those who believe stop playing sex because it is sinful.” (FGD, Boys (rural), Mbarara District)

5.2 Cultural Norms and Practices and HIV/AIDS

This section explores both the negative and positive influences of the existing community cultural norms and practices on HIV-related behaviour. In general, FGD participants in all the study districts viewed cultural ceremonies, and traditional rites as contributory factors in the spread of HIV. They include circumcision, twin ceremonies, appeasement of spirits, cleansing ceremonies, as well as funeral rites and other traditional rituals. However, some
of these practices, were also reported to have significant positive influence on behaviour change. Those mentioned include marriage, widow inheritance and funeral rites.

5.2.1 Traditional Ceremonies

5.2.1.1 Circumcision

Male circumcision was reported to be a dominant cultural practice in Mbale district. In other study districts where circumcision was reported practiced, it was specifically linked to Bagisu from Mbale. Circumcision was reported to be a risky practice because of the way it is carried out. Aspects like sharing knives and merry making before and during the festival, all increase the risk of sexually transmitted infections.

Participants reported that circumcision festivities involving dancing, drinking, poor hygiene during first aid (smearing with eggs) and taking people far away from home remain. These festivities present an environment of intense celebration that create opportunities for adolescents and adults to engage in risky sexual practices. In addition, after circumcision (initiation into manhood), pressure is exerted upon the newly circumcised adolescents to prove their manhood. The post-circumcision dance of ‘Inemba’ (cleansing of the newly circumcised) openly encourages boys to have sex with any woman. This is inimical to the notion of abstinence. Sharing of knives, though reducing, was reported to be in practice, especially in remote villages.

“Circumcision involves a lot of ‘Kadodi’ dancing, drinking and moving around even to far places visiting friends and relatives. All those that participate go with other intentions including having sex with whomever they are attracted to. And during the ‘Inemba’ dance (cleansing ceremony for the newly circumcised), the newly circumcised men are encouraged to have sex with any woman and, in the process, they actually force girls and women into unprotected sex under the guise of cleansing themselves.” (FGD, Men (rural), Mbale District)

However, in some Focus Group Discussions, especially in Mbale district where the practice is dominant participants reported that with continuous and consistent education there has been a radical change in the way some of these practices are done. For instance sharing of knives is discouraged. It is also encouraged that festivities take place during the day and for a shorter time. In addition, boys are circumcised at an early age when they are not yet sexually active and many parents prevent their children from joining the cerebrations.

5.2.1.2 Marriage Ceremonies

Marriage ceremonies in most communities visited involve the ‘give away’ and the wedding parties. In each of the parties, people drink a lot, eat and dance. To many adolescents and youth, wedding parties are perceived as opportunities for meeting friends and having sex.

“In Alur culture, boys who go for marriage ceremonies are supposed to come back with girls; so all boys try to get girls and girls are also aware of that.” (FGD, Men (rural), Nebbi District)

In most rural areas, it was reported that most people just get married without first testing for HIV. This was seen to be putting most couples at risk of marrying someone who may be HIV positive. There were various anecdotal stories told of newly married couples falling sick and dying either with one child or even before producing a child.
“In most cases, marriage here is always influenced by we mothers dragging our daughters into marriage without a blood test. At the end of the day when they start falling sick, then we start regretting when it can no longer help.” (FGD, Women (rural), Lira District)

On the other hand, marriage was reported to play a significant role in influencing and sustaining sexual behaviour change. Marriage ceremonies were seen to be impacting on people’s sexual lives in a number of ways. In all districts, marriage ceremonies were reported as moments where people are advised, counselled, admire and respect the couples, which helps them to be faithful and avoid risky behaviour. During wedding functions, whether done in church or traditionally, faithfulness to the newly wedded couple is greatly emphasized. Religious weddings are highly cherished and for this reason they serve as a motivation to boys and girls to take precautions against HIV/AIDS in order to achieve the same.

Apart from spiritual counselling, some churches insist that couples receive VCT before they are united in marriage. However, it was reported that even when one or both couples are HIV positive, the church can unite them as long as both are aware of each other’s status.

In Nebbi District, the cultural practice of where elders and relatives vetting the couples before marriage was still strong. In most of the FGDs, it was reported that culturally arranged marriages have assisted in curbing pre-marital sex of the couples and play a big role in investigating the character of girls and boys before they get married. The arranged marriages have also helped so much in reduction in HIV transmission by keeping couples together and prevention of illness. In testimony, the communities said that most of the old generation had their parents chose partners for them. The arranged marriages ensure that the person you are going to be given is someone whose background is known by the parents and the aunties. In Mbarara district where the practice of pre-arranged marriages was reported to have been eroded by modernisation, youths reported significant difficulties in finding reliable partners.

“In men would not disturb, knowing that this one is someone’s future wife. The girl would be looked after until she is ready for marriage and the Auntie would deliver her to the husband’s home after the bride price ceremony is complete” (FGD, Girls (urban), Nebbi District)

“The issue of finding ourselves marriage partners also puts us at risk because you don’t get to know the behaviour of the girl you intend to marry. Parents of long ago would get you a girl they knew well from childhood. Now you go and get a girl from far away, who may be infected. Because there are no testing facilities here, she infects you.” (FGD, Boys (rural), Mbarara District)

In addition, there is the ‘Senga’ (paternal aunt) cultural institution in some parts of Uganda, especially Central, used to prepare adolescent girls and brides-to-be for the marriage institution. Sengas advise would-be brides about, among other things, ‘how to please their husbands’ and also emphasize faithfulness to their husbands to ‘avoid bringing shame’ to the bride’s parents. Sengas put a lot of emphasis on ‘bedroom matters’ so that their future sons in-law don’t indulge in extra-marital sex due to sexual dissatisfaction at home. Sengas also counsel young girls to jealously guard their virginity until marriage because culturally, girls are expected to remain virgins until marriage. In general, engagement in pre-marital sex was strongly discouraged, especially among girls. Girls who engage in pre-marital sex were usually looked at as prostitutes who were no good marriage partners. However, the tradition of girls remaining virgins until marriage is
increasingly being swept away by modernisation and adoption of western cultures. According to FGD participants in Mukono, these days the Sengas also emphasize going for HIV testing before marriage and in so doing they promote seeking of VCT services by adolescents.

5.2.1.3 Other Traditional Ceremonies

The other common ceremonies reported were the twin and child naming. The twin ceremony was said to be a cultural ritual of formally integrating the twins in the family and cleansing the mother and father of the rather considered bad omen of producing twins. According to the FGD participants in Mukono, the songs that are sung in such ceremonies are very obscene intended to make people get sexually excited. Like other ceremonies, the twin and child naming ceremonies, bring many people together, they drink and dance. The festive atmosphere creates opportunities for casual sex.

"Most of the words used in the twin naming ceremonies are very obscene. The excitement they cause leads people into thinking of sex. They say if you do not speak vulgar words, the twins can ‘burn you’. It is like an obscene word competition.” (FGD, Women (rural), Mukono District)

5.2.2 Traditional Rituals

5.2.2.1 Funeral Rites

Funeral rites were reported to be particularly risk-enhancing ceremonies in that they also bring many people together in a ceremonial atmosphere. During the funeral rites, a lot of eating and drinking takes place and because they stay longer, people have opportunities to meet and sexually interact with new partners. It is also common that women who were born in that particular village and got married elsewhere return to attend the functions. Some of the women could have had boy friends in the village before they got married. Since men do not easily migrate, this gives an opportunity for reunion. This was reported to pose a risk of infection since these people have not been in contact and cannot therefore easily know the HIV status of each other.

"In Alur culture, when a girl comes back home during burials/funerals, she becomes a girl and when they are playing ‘Adungu’ a local musical instrument, she goes to dance and can easily be picked by her old boy friends.” (FGD, Men (rural), Nebbi District)

On the other hand, it was reported that people talk about HIV/AIDS during burials, advising mourners to avoid risky behaviour that could lead to HIV infection. In addition, the urology given by caretakers at burial ceremonies detail the suffering the deceased went through and how they finally died. These have a lot to teach to those present at the funeral. For example the size of the dead body that is usually small scares mourners and help them to decide to stop engaging in irresponsible sexual practices.

"People are no longer hiding the cause of death. At funerals, they talk about it saying, “it is AIDS that killed the deceased.”(FGD, Male (urban), Soroti District)

“When memories of a person you saw ailing with the disease come, you are motivated to pull back so you survive in that way.” (FGD, Women (urban), Mukono District)
“At funerals, people gather and before burial religious leaders are invited to preach and during this period mourners are counselled against risky behaviour and those who listen to such messages attentively change their behaviour and help share with others.” (FGD Men (rural), Mbale District)

5.2.2 Other Traditional Rituals

In Lira, it was reported that there is a traditional ritual, known as ‘lokonga kidi’, where a married woman who has been producing only a single sex or not producing at all is made to have sex with her brother in-law for a change without her husband’s knowledge. The arrangement is essentially between the woman, her brother in-law and her mother in-law. If one of them happens to be infected, the other two are also likely to get infected.

In Nebbi, cutting the face for decoration (tattooing) and removal of the four middle teeth was being done as an initiation into adulthood. The decoration on the face, piercing of the ears and shaving of private parts was said to be usually done in groups using one knife/needle (‘ogol’) which increases the risk of HIV infection through the sharing of instruments.

In Mbale district there is a sexual ritual known as ‘Khukhala Kumulindi’. This is a sexual ritual carried out by a widow or widower upon the loss of a partner or after circumcision. This ritual is meant to shade off bad luck associated with the late partners death or before circumcision. As part of the cleansing process, the widow(er) is encouraged to have unprotected sex with a stranger making the practice quite risky.

In Mbarara District, it was reported that rituals such as burying childless persons with banana stems puts a lot of pressure on young people to produce children lest they die and be buried dishonourably. Thus, even people who already know their sero-positivity do everything possible to produce children and in the process end up infecting other people.

Wife sharing and the bride wealth institution were also blamed for the wayward sexual behaviours in some of the study districts. In Mbarara, for example, it is culturally acceptable for brothers in-law to have sex with their sisters in-law. Similarly, fathers in-law used to first ‘test’ (play sex) their new daughters in-law in order ‘to see what the cows bought’. Such traditions, although dying out mainly because of the HIV/AIDS scare, promote multiple sexual relationships where they still exist, thereby putting the lives of entire families and clans at risk.

“Wife sharing is done by the elders to strengthen their relationships with friends. When a friend visits his fellow elder, he could be given a sex offer by his wife who normally sleeps with this visitor.”(FGD, Boys (urban), Nebbi District)

5.2.3 Traditional Healing

Traditional healers especially those less educated or illiterate were reported to be continuing with practices that increase the risk of HIV transmission. For instance, while performing certain traditional rituals, some traditional healers prescribe medicine that can only be administered through sexual intercourse. The barren women, in desperate search of children, were reported to be particularly vulnerable to this kind of exploitation.
Furthermore, it was reported that some male traditional healers play sex with their female clients especially those that are poor. This is because, the women tend to think that by accepting to play sex with the healer, they could be either exempted from the burden of paying the treatment bill or asked to pay less. Other traditional healers deliberately hike their charges so that the clients are forced to pay in kind. In addition, most traditional healers were said to use the same sharp and un-sterilised instruments such as horns and knives on their patients in the process of treating them. When used on a person infected with HIV/AIDS, it is most likely that it will be transmitted to the one who does not have it.

“Yes, those witchdoctors are wrong people. There is a way one changes his voice and speaks in a fierce way to scare their patients. When a woman is given orders to lie on the bed, she cannot resist. And as you know they don’t use condoms.” (FGD, Boys (urban), Mukono District)

“Sometimes traditional healers, especially those with shrines have put very strict rules on their clients. For instance some insist that in order to enter their shrine, one must be naked. In all cases, they would be tricking their clients to have sex with them.” (FGD, Women (urban), Mukono District)

Despite these weaknesses, there were also strong views held by the communities in the study districts that some traditional healers are playing critical roles in HIV/AIDS prevention and care. Some were reported to be actively involved in educating their clients on HIV/AIDS while others dispense herbal medicine that has been found to be effective in treating some opportunistic infections.

“People these days use ‘budomola’ (traditional herbs) to sooth AIDS-related infections. People have trust in the traditional medicine.” (FGD, Women (urban), Mukono District)

### 5.2.4 Widow inheritance

The traditional practices of widow cleansing and inheritance are intended to integrate the widow(s) into the community. In the former, a sexual partner is selected to perform the ritual and for the latter a member of the family is selected by the clan/family to take over the responsibilities of the deceased’s family including marrying the widow. One of the brothers of the late husband is supposed to inherit the widow but in his absence other close relatives or community members take advantage. Although, a lot of education has been done targeting this practice, it was reported in Focus Group Discussions in all study districts other than Mukono, that widow inheritance was still a common practice. In most cases this is done without going for VCT even in situations where it was already known that the husband died of AIDS.

In Lira District, the practice of inheriting widows was reported to be so rampant to the extent that, at times, a widow may not be allowed to mourn for her husband for a month before one of her late husband’s brothers or relatives takes her over. In Soroti District, it was pointed out that widow inheritance was seen as a source of free sex since there is no one to claim the widow other than the brothers or other relatives of the late husband.

“People are not bothered about HIV/AIDS. And it is the men spreading this HIV. If you tell them you are widowed by AIDS, they say, if you do not want me to inherit you, bring back our bride price.” (FGD, Women (rural), Lira District)

“In Alur society, when a man dies, the widow belongs to the clan and has to be inherited by the brother of the late husband or a relative and yet the man might have died of HIV/AIDS.” (FGD, Men (urban), Nebbi District)
A number of reasons were advanced for the continued practice of widow inheritance. In Lira and Nebbi Districts, for instance, some people still associate HIV/AIDS with witchcraft, and therefore perceive no risk in inheriting the widow. Quite often, widows are inherited for purposes of gaining access to the property left behind by the deceased.

There is also another dimension to the problem. In some study districts, when a woman dies and leaves a husband with children, a sister to the late wife is brought in to take care of her late sister’s children as well as the husband. This is also often done without testing blood for HIV and where the wife has died of AIDS, the sister inheriting the widower may be infected.

Despite the many negative connotations that go with widow inheritance, in absence of a government social welfare system, the practice was portrayed as an innovative way of providing both social and financial security to the bereaved family. The practice ensured that a household that had lost its head did not disintegrate by providing the widow with a new husband and the children with a new father to give them parental love, care, and guidance.

This was said to help the children grow up responsibly and not get themselves into mischief such as theft, early sex, early marriage, or prostitution. It was reported that the practice also ensured that the widow does not move around looking for other men to meet her sexual as well as financial needs.

However, due to increased HIV/AIDS awareness, widow inheritance was reported to be increasingly done with the primary objective of taking care of the orphans and the widow, but not necessarily having sex with the widow.

In other cultures, like in Central Uganda, where widow inheritance is not commonly practiced, widows, especially those with children, are not expected to engage in sexual relationships let alone remarry. If the tradition is adhered to, it helps prevent the spread of HIV in case the widow is infected. The orphaned children become the responsibility of their late father’s close relatives (the uncles, aunties, and grandparents) who provide the moral and material support as well as guidance to them.

5.2.5 Other Cultural Norms and Practices

Polygamy was also reported to be another cultural practice that increases the risk of HIV infection. There was general consensus in all women Focus Group Discussions that in polygamous marriages, not all women get sexual satisfaction, such that some opt to seek sex outside marriage. On the other hand, in polygamous marriages, in case one of the wives is unfaithful to the husband, the risk of infection spreads across the entire family.

“In Alur culture, if you are wealthy, you could marry many women as an expression of wealth and it is still going on though it has reduced. Marrying more than one woman, you find that you have married one who is HIV positive and this is transmitted to the others and at the end it is spread.” (FGD, Men (rural), Nebbi District)

Among the communities, which still observe the taboos, it was reported that the prohibition of extra marital sex before a child grows teeth helps reduce HIV transmission.
However the problem is that the majority of people have deviated from most cultural practices saying that most taboos are archaic.

The other taboos mentioned by FGD participants in Mbarara District include not having sex outside marriage during the millet-growing season until the millet is harvested and eaten by the husband and father-in-law. It is believed that if a woman had extra marital sex during that season, the husband and father-in-law would both die if they ate the millet. This was reported as having helped in reducing HIV transmission since most women tend to be faithful to their husbands. Another taboo, reported in Mbarara, was the one restricting the husband not to play sex outside marriage before one’s wife after she has given birth. This practice, known as ‘Okucwa Ekizire’ (breaking the delivery) is supposed to be performed after one month of delivery. A similar practice was reported to be prominent in Buganda where it is believed that extra-marital sex during pregnancy and within three weeks of delivery will cause illness to the baby. However, this was said to be only a temporary measure as the man can resume sex with multi-sexual partners after performing this ritual.

"‘Okusobya Abaana’ (messing up children) belief in the Baganda aims at reducing adultery because it is believed that if your wife is pregnant and you have sex outside she can take long to deliver or if your wife gives birth and you have sex outside but come back and have sex with her at home the child will develop chronic physical and mental disorders so you get scared and wait to have sex with your wife when she is ready.” (FGD, Women (urban), Mukono District)

Additionally, in Mbarara, it was reported there is belief that casual sex during social gatherings can be prevented by prior administration of herbal medicine (Okusirika Embaga). When this is done, it is believed that no sex will take place in the entire duration of the gathering. Participants in FGDs in Mbarara District were longing to see this practice restored in many communities.

“If it is done, especially by our man called Kasiisi, you cannot con a girl and she accepts and this prevents infection.” (FGD, Men (rural), Mbarara District)
Table 5.1: Social Cultural factors positively impacting on HIV/AIDS

<table>
<thead>
<tr>
<th>Factors helping to reduce HIV transmission</th>
<th>District</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mukono</td>
</tr>
<tr>
<td><strong>Social factors</strong></td>
<td></td>
</tr>
<tr>
<td>Social festivities (discos, traditional dances, films) have increased the use of condoms</td>
<td>1</td>
</tr>
<tr>
<td>Some educative films on HIV/AIDS are helpful in sensitising people</td>
<td>4</td>
</tr>
<tr>
<td>Marriage ceremonies help people to admire couples, are advised by elders on being faithful</td>
<td>17</td>
</tr>
<tr>
<td>Go-betweens play a big role in investigating the character of girls and boys before marriage</td>
<td>-</td>
</tr>
<tr>
<td>Games and sports occupy most adolescents and divert their attention to sex</td>
<td>9</td>
</tr>
<tr>
<td>In church people are advised and counselled to be morally upright and get saved</td>
<td>21</td>
</tr>
<tr>
<td>Parental guidance (aunt) helps girls to be faithful and manage their marriage relationships</td>
<td>1</td>
</tr>
<tr>
<td>Parents educate children about cultural roles and norms at home</td>
<td>-</td>
</tr>
<tr>
<td>Peer grouping helps sharing of information</td>
<td>-</td>
</tr>
<tr>
<td>Polygamy causes faithfulness</td>
<td>-</td>
</tr>
<tr>
<td><strong>Cultural norms and practices</strong></td>
<td></td>
</tr>
<tr>
<td>Burial of people that have died of AIDS serves as a warning to mourners</td>
<td>13</td>
</tr>
<tr>
<td>Non-payment of bride wealth reduces sexual pressure on daughter in laws</td>
<td>-</td>
</tr>
<tr>
<td>Taboos help keep father in laws away from daughter in laws</td>
<td>1</td>
</tr>
<tr>
<td>Circumcision initiates one into manhood and makes him able to marry and become a faithful partner</td>
<td>-</td>
</tr>
<tr>
<td>Child development ceremonies act as forums for open discussions on sex and HIV/AIDS</td>
<td>3</td>
</tr>
<tr>
<td>Arranged marriages help curb pre-marital sex</td>
<td>-</td>
</tr>
<tr>
<td>None of the social factors, cultural norms and practices has helped reduce HIV transmission</td>
<td>2</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>Seminars help people to share experiences and know much about HIV/AIDS</td>
<td>9</td>
</tr>
</tbody>
</table>

Note: Each score represents an FGD where a particular response was given in each of the 32 FGDs per district

Source: Focus Group Discussions with communities, 2002

A number of social patterns and cultural practices significantly impact on the spread and prevention of HIV/AIDS. Most of the social cultural factors are generally seen to be enhancing the spread of HIV/AIDS. Alcohol drinking and drunkenness were particularly seen as key factors that enhance the spread of HIV.

Many acts, such as casual unprotected sex, rape and defilement, which significantly increase the risk of HIV transmission, were associated with alcohol and drug abuse.
Similarly, cultural practices such as widow inheritance and circumcision were reported to be critical in enhancing HIV transmission. Widow inheritance was reported to be impacting negatively on abstinence and avoidance of multiple sexual relationships. Circumcision on the other hand, was seen as a cultural practice that increases the risk of HIV transmission through sharing of un-sterilized equipment performance of associated rituals and prolonged festivities involving drinking and dancing that create an environment conducive to casual and unprotected sex, particularly in rural areas.

Religious crusades particularly night prayers were also reported to gather a lot of people some with intentions of having sex. In a religious environment, access and open demand for condoms is limited hence a high risk of unprotected sex. Given that salvation was widely reported as a coping strategy for many people infected with HIV/AIDS, casual and unprotected sex within such religious gatherings entails very high risk of HIV infection.

It is important to note that some of the social and cultural factors reported to be enhancing HIV transmission were at the same time said to reduce the risk of transmission. For example, marriage ceremonies, religious gatherings and funerals were reported to be major avenues for intensive HIV/AIDS education. Marriage ceremonies and religion help to promote faithfulness in marriage and abstinence. Cultural norms such as preservation of virginity until marriage, culturally arranged marriages and the paternal aunt institution were reported to enhance abstinence and mutual faithfulness. However, these norms and institutions were also reported to be threatened by modernization and globalisation which undermine people’s efforts, particularly the youth to remain abstinent.

In the Integrated Behaviour Change Framework, social and cultural aspects of the environment in which people live were highlighted to be playing critical roles in behaviour formation. Findings from this study confirm that social patterns and cultural practices play a significant role in HIV/AIDS related behaviour, on one hand influencing transmission and on the other, enhancing prevention.
6.0 COMMUNITY STRATEGIES IN RESPONDING TO HIV/AIDS

The response to HIV/AIDS in Uganda has been characteristic of a social revolution that has involved people at all levels. The community involvement has been demonstrated through continuous initiation and implementation of home grown approaches to HIV/AIDS. This has been one of the most significant factors behind the laudable success in responding to HIV/AIDS in Uganda. The community efforts have greatly been complemented by those of other partners to increase HIV/AIDS services such as raising awareness, education, care, support, mitigation, IEC materials, condoms and VCT.

In the Integrated Behaviour Change Framework the entire spectrum of community involvement, support from other partners and services is referred to as infrastructure. The infrastructure is composed of service delivery points, social networks and support organizations and donor agencies. These aspects of the infrastructure are viewed as critical in facilitating individual behavioural intentions and sustaining the new behaviour.

This chapter presents findings on community initiatives; HIV/AIDS services and the role these have played in influencing change in HIV/AIDS related behaviour.

6.1 Districts Response

The district response has ranged from provision of facility-based services such as treatment of opportunistic infections, support to voluntary counselling and testing, provision and support to HIV/AIDS education to mobilisation of resources for HIV/AIDS. All HIV/AIDS activities have, until recently, been coordinated by the District Director of Health Services (DDHS), whose office has been instrumental in organizing Information, Education and Communication interventions focussing mainly on AIDS education workshops, film shows and distribution of visual materials such as posters and pamphlets that are displayed in public places to inform people about HIV/AIDS. Similarly the DDHS office has been the major outlet for condoms.

Through the network of health units (Hospitals, Health Centres IV and III), districts have also implemented programmes such as Voluntary Counselling and Testing (VCT) though they are few and mostly urban based. They have also built capacity of health facilities to provide care through regular supply of drugs for treatment of opportunistic infections and condoms. It was also reported in some districts, such as Mbale, Lira and Mbarara, that Prevention of Mother to Child Transmission (PMTCT) services are available in the regional hospitals.

The districts have also employed the multi-sectoral approach to improve coordination of HIV/AIDS activities and enhance partnership with other stakeholders such as NGOs, CBOs and the private for profit sector. Institutional structures such as the District AIDS Task force (DAT) and the District HIV/AIDS Committee (DHAC) have been formed to support the coordination of the multi-sectoral approach.

There is strong partnership with existing NGOs/CBOs in the districts to enhance skill and resource complementarities. In Lira and Soroti, for instance, the districts reported close collaboration with the AIDS Integrated Model Program (AIM), which is assisting in building community and district capacity to plan and implement HIV/AIDS activities. Similar partnerships were reported between TASO, AIC and Mbarara district.
In Nebbi, it was reported that the district was collaborating with the UNICEF supported District Response Initiative to build capacity in planning and mainstreaming HIV/AIDS interventions in the district plans.

Since 1988 UNDP has been working in partnership with Government of Uganda and local organisations by supporting both governmental and non-governmental efforts to prevent the spread of HIV and mitigate the impact of the epidemic at the individual, family, community and sectoral levels. The activities in the districts were reported to building upon efforts of various UNDP programmes particularly the Micro-projects to combat HIV/AIDS (1992 -1995) and follow on HIV/AIDS Prevention and Poverty Reduction programme (1995 –1997). Other similar programmes included the STI Project and the current World Bank funded Multi-Sectoral AIDS Program (MAP).

“AIC and TASO are here in Mbarara. It is the district purchasing the reagents for testing and drugs for opportunistic infections. They are accessed using funds directly from the field. Each health centre presents the needed requirements and they are given to them including drugs.” (District Official, Mbarara District)

“Through the politicians people have been sensitised about HIV/AIDS and have supported projects that have been brought to the district. In addition plans are made by the districts and sent to donors and ministries to solicit for funding of HIV/AIDS activities.” (District Official, Soroti District)

At sub-county level, there appeared to be no HIV/AIDS programs initiated at that level. The only HIV/AIDS activities reported were supported by NGOs using external donor funds.

“There is no program at all initiated by the sub-county. The STI program and the condoms we give people are directly coming from the Ministry of Health. The Sub-County has no stake in it. For the sub-county, I see nothing.” (Sub-County Official, Mbarara District)

In some instances, it was reported that some sub-counties make links to NGOs such as TASO, to educate people on HIV/AIDS and also provide care and support to the affected and infected members of the community. By so doing they help fill gaps in HIV/AIDS service delivery in their localities.

“The sub-county authority (LC3) sat down and decided to write to TASO to come and do sensitization. Indeed TASO came and trained people to work as community health workers and formed an anti AIDS club of Mwizi. This club helps in mobilizing all people to come and attend in case of a meeting or drama presentation.” (Community Health Worker, Mbarara District)

Resource constraints were, however, reported as a major limitation to the district and sub-county response in all the six districts. There were no specific budget votes for HIV/AIDS from Central Government and district-generated revenues remain paltry due to narrow tax bases and low levels of tax compliance among the poor local people. Income sources have dwindled due to low prices offered for agricultural commodities and the decimation of coffee and cattle by the coffee wilt and the Karamojong rustlers, in Mbarara and Soroti Districts respectively.

“As I have told you the spirit is willing but the body is weak. There is very little financial support from the district and most programs on HIV/AIDS are supported by NGOs and Ministry of Health. The district has never come to support proposals even if I tell them”. (District Official, Mbale District)
“The sub-county response to HIV/AIDS has not been encouraging. The sub-county has not done much because the officials in-charge give the obvious reason of lack of funds, and as such end up not facilitating extension staff. For example, no effort has been made to lobby care and support organisations to bring down HIV/AIDS services to the local communities. What is surprising is that we continue to budget for health programs but hardly implement any with regard to HIV/AIDS control”. (Sub-County Official, Mbale District).

6.2 Community Response

FGD participants and key informants were asked about the contribution of local communities in the fight against HIV/AIDS. In all the districts, it was reported that the local leaders have established and enforced by-laws on circumcision, aimless loitering by youths and closing entertainment places early mostly in rural areas. Local leaders were also reported to be vigilant in the enforcement of laws on rape and defilement. The participants reported that LC meetings involve sensitising people about preventing HIV infection.

The community, including the relatives and extended family, has been involved in the care and support for the sick, widows and orphans. In addition, communities have formed themselves into self-help groups such as the burial that provide food and money for burial necessities and offer psychosocial support to the bereaved family including the orphans and widows/widowers.

In the face of increased challenges posed by HIV/AIDS, some community groups such as widow associations have evolved to help members psychologically and also meet other common needs.

“Here there are strict rules on defilement and rape. When they get you defiling or raping someone, you are arrested and handed over to police immediately.” (FGD, Women (rural) Nebbi District)

“Adults at the bars also chase us away from bars and trading centres when we go there. They say it is not the right place to be; we should be at home so they have also helped us.” (FGD Girls (rural), Soroti District)

“Generally people have been mobilized to work and not be idle. So now you find people in their gardens the whole day with no time to waste. This includes the youth also although in the evening they may have some free time.” (FGD, Men (rural), Mukono District)

In Mukono and Mbale, it was reported that the communities have tried to mobilize resources for adolescents to initiate IGAs in order to be occupied and avoid redundancy that would lead them into risky behaviours. In most FGDs, participants reported occasional counselling and guidance provided by church leaders to the communities encouraging people to be morally upright, abstain and be faithful to partners. Furthermore, communities have helped to create HIV/AIDS awareness through circulation of information amongst themselves in LC meetings and discouraging widow inheritance.

“The community at times gives some small assistance to orphans like food but communities themselves are also poor and they cannot do much” (FGD, Women (urban), Lira District)

“The community is so strict on the idea of widow inheritance and people are leaving it.” (FGD, Men (urban), Lira District)
In all districts, it was reported that sex education has been introduced in schools and students are being sensitised about HIV/AIDS and how to take preventive measures. Although there was still a problem of children getting attracted to new cultures such as dressing in miniskirts and tight jeans, films shows and pornographic publications, most schools have instituted tight regulations on sexual relations and dress codes.

“Many adolescents who go to school have learnt how to protect themselves against AIDS.” (FGD Boys (urban), Mbarara District)

However there were people in some Focus Groups, especially youths who felt that the community has done nothing or has not done much to respond to HIV/AIDS. Some adolescents felt that the community has not done much to safe guard them against HIV/AIDS.

“It is only parents trying to help their children in their homes by advising them and restricting their movement. We don’t see anything the community has done to help adolescents in this area.” (FGD, Girls (rural), Soroti District)

6.3 Individual Response

This sub-section presents findings from Focus Group Discussions with regard to the strategies that individuals have adopted in response to the HIV/AIDS epidemic. These were found to vary across age groups and for this reason, strategies adopted by adults and those of the youth are presented separately.

6.3.1 Strategies Adopted by Adults

Focus Group Discussions with adults in the six study districts indicate that both men and women have responded to HIV/AIDS by mainly changing their behaviour. Faithfulness to one another among married couples was widely reported. Women, especially, reported that being faithful to their husbands was the only sure way of halting the spread of HIV. However, sometimes women get frustrated by husbands who are not reciprocating by being equally faithful. They also reported that many women are now engaged in income generating activities to fight poverty which is a major factor leading many women and young girls to engage in risky sexual behaviours.

“Our men are worse, even when we tell them to stop messing up, they tell us they are our bosses and that we should keep quiet.” (FGD, Women (rural), Lira District)

“For us women, we have tried to be faithful but we don’t know about our husbands.” (FGD, Women (rural), Mbale District)

“We have formed clubs to enable us earn some income to fight poverty and avoid looking at men as bread winners. We can now afford to buy soap and clothing for ourselves instead of looking for men to do it for us.” (FGD, Women (rural), Mbale District)

Most adults, participants reported that they have spent more time on strategies to safeguard the youth against HIV infection more than on themselves. In particular, they reported that they spend time talking to children about HIV/AIDS and sex and how to avoid risky behaviour. Adult participants reported that their discussions with children on HIV/AIDS range from casual talking and counselling to real sex education. Some of the parents reported that after these discussions, they were able to discern reality surrounding the lives of their children. Consequently, some are facilitating their children to have constant access
to condoms. Parents also reported that they are increasingly making efforts to meet the social and economic needs of their children, such as clothes and pocket money, especially for those in schools and institutions in order to lessen the risk of them being tempted by people with money.

However, some of the youths were said to be difficult to control and could not adhere to the advice given by parents. In such cases, attempts were made to place school going youths in single sex boarding schools and those out of school are encouraged to marry. Participants in all the groups across the study districts also lamented about the impact of the children’s rights on the conduct of the children. They said that rights have given false impressions to the children that they are free to behave the way they want.

“Me, I have encouraged my son to use condoms if he must have sex. I also tell other boys in the area like his friends and I even buy for them these condoms at times when I have the money.”
(FGD, Women (rural), Soroti District)

“For boys who are mature enough, we are marrying for them women to stop them going to have risky sexual intercourse and the same applies to girls. But others even if you give them wives, they don’t listen and still go out and bring other women ending up with more than one wife.” (FGD Women (rural) Soroti District.

“The children of today, you cannot tell them anything. They may sue you because you are encroaching on their rights. So, as a parent, you give up in fear of being imprisoned”(FGD, Men (rural), Mukono District).

Getting saved also featured prominently as an individual strategy of responding to HIV/AIDS in all Focus Group Discussions in the six study districts. Salvation was reported to assist people to remain loyal to the cardinals of religion, which emphasize, among others, abstinence and mutual fidelity. This assisted people to remain faithfully attached to their partners and reduces the risk of acquiring HIV. Salvation was also widely reported as a coping strategy by those already infected. Not only did it help them to remain abstinent or faithful, it also helped them to reconcile with God, regain hope for life and live the rest of their lives upright.

“I am saved and living positively. I know I will see my son through up to University and even see him wed.”(PLWHA, Lira District)

Another important strategy adopted by the community to respond to HIV/AIDS was reported to be the provision of space and an enabling environment for people living with HIV/AIDS and those playing unique roles in the community such as traditional healers and birth attendants to participate in HIV/AIDS prevention and care. The three categories of people mentioned were among those interviewed in the six study districts to find out the roles they play in the HIV/AIDS response and the community perception of their roles. Traditional Healers and Birth Attendants self-reported that they were actively involved in educating their clients on HIV/AIDS and encouraging them to go for VCT services. They all reported having received training from Ministry of Health and other NGOs, which has helped them to reduce risks of infection to their clients and themselves. Traditional Healers also reported that they administer herbal medicine for some opportunistic infections.

People living with HIV/AIDS also reported their active involvement in community education through drama and personal testimonies. They held strong views that their
services, albeit poorly facilitated, were playing critical roles in changing people’s behaviour.

They also reported improved community attitudes towards them, saying that HIV/AIDS has affected each and every household and therefore it makes no sense for any one to ostracise any person affected by HIV/AIDS. Efforts have been made to form community-based associations of persons living with HIV/AIDS for purposes of providing mutual counselling and support and also educating people on HIV/AIDS. These efforts were, however, reported to be increasingly thwarted by resource and capacity constraints.

“I am a role model. Like on World AIDS Day, I went and gave them (the audience) my experiences. People wondered and came to learn that they do not die as soon as they get infected. People even look for me to take them for VCT and they are really changing behaviour because of my declaration.” (PLWHA, Soroti District)

In spite of their efforts to educate communities, PLWHA reported frustration that some community members were not heeding their advice. Many have refused to change their behaviour and others even do not believe the authenticity of what PLWHA tell them about their sero status and life history.

“One boy came and raped me. I even told him and pleaded that I was sick but he refused to listen, continued and raped me. I conceived out of this rape and I now carry a boy of 2 years from this rape.” (PLWHA, Soroti District)

Despite the efforts expended by adults to safeguard the youth, they reported to be facing major challenges in guiding youth and adolescents against HIV/AIDS. Some problems were parent/guardian related while others were on the side of adolescents themselves. Nearly all groups mentioned that adolescents are unruly, stubborn and do not listen to parental advice because they think they know more.

On the other hand it was reported that some parents feel shy to talk about sex with their children let alone giving condoms to their children. It was also reported that talking about sex with their children was teaching them “bad manners” including playing sex. Some parents strongly oppose use of condoms by their adolescent children.

There was concern that condoms simply promote sexual immorality and make their children promiscuous. This concern was echoed most in rural areas. The parents also have a genuine fear that the children do not know how to use condoms and even if they did, they would not use them consistently.

“As we told you some of these kids are stubborn. They do not want to listen. If for example you put a home curfew, they will wait for you to sleep and then sneak out to the discos.” (FGD, Men (rural), Mukono District)

“My, I cannot tell my child to use a condom because I feel that I am teaching him/her bad manners. Moreover, not many parents know much about condoms. You do not know how to put it on, so what do you tell the child?” (FGD, Men (rural), Mbarara District)

“We are shy to tell our children straight off in the eye what we exactly mean but go on beating about the bush so we lack tricks of counselling them.” (FGD, Women (urban), Mukono District)

Further more some groups indicated that parents were poor and could not afford to provide everything to their children, who are then lured into sex by those who can provide them. In
all districts it was reported that defilement of children by rich people who give them favours was a serious problem. Others were strong peer influence, minimal control over their students in hostels and day schools and parents not able to spend time with their children and provide guidance.

“We have been greatly affected by poverty. We cannot fully satisfy the needs of our children especially the girls.” (FGD, Women (rural), Mukono District)

“Government should reduce fees for private students in higher institutions because parents spend a lot of money on school fees and fail to give children enough pocket money. When the child goes to school, she survives on sex.”(FGD, Men (rural), Mbarara District)

6.3.2 Strategies by Youths

In the study, particular attention was given to the youth, with the aim of establishing their understanding of the dynamics of HIV/AIDS, and response to the epidemic. In particular, attention was devoted to discerning their knowledge and possession of Life Skills that are crucial to their growth and development in an HIV/AIDS era. Life Skills include those skills traditionally passed on to children and adolescents by parents, elders, other members of the community and sometimes peers to enable them survive as well as fit in the society (GoU/UNICEF, 1996).

There is no definite list of adolescent Life Skills, but from the Focus Group Discussions, those that featured prominently included: ability to behave in a manner consistent with one’s gender; knowledge of what adolescents can or cannot do as individuals; interpersonal skills; creative and critical thinking; decision-making on the appropriate course of action; mutual support and guidance; awareness of purpose for living and; desire to win respect, possession of long-term goals and conscious feeling of independence.

In an effort to establish whether the youth and adolescents were in possession of and actually utilising these skills, they were asked what they are doing to avoid infection.

Many of the youth participants especially in urban areas reported that they were abstaining from sex or using condoms. Impressively, girls confidently reported that they couldn’t be drawn into sexual activities unless they so wish. They also reported that they have the power to say NO and mean it. Pressed further as to what they would do if a demanding partner insists, responses ranged from repeating the NO, walking away and abusing the one insisting to reporting to parents or government official.

Other adolescents reported that they had steady boy and girl friends and were using condoms. They also reported that they are able to insist on condoms, and in some cases, girls also move with them.

“For me I tell my boyfriend that we have to use a condom. I insist and say no condom, no sex.”(FGD, Girls (urban), Mbarara District)

“We are serious about condoms. If a boy doesn’t have it, you can’t accept to sleep with him. Some of us are also trying to abstain from sex until marriage.” (FGD, Girls (urban), Mbale District)

Most youth and adolescents in the discussions reported that they are committed to avoiding HIV infection in order to live and fulfil their life long dreams. Desire to live an upright life
– “avoiding to embarrass oneself, parents, relatives and communities who have hope in us” also featured prominently especially among youth in rural areas.

“I also want to be a popular person in future. After my studies I want to join in the footsteps of those that were important in developing the community.” (FGD, Girls (rural), Mbarara District)

Another important skill mentioned in most FGDs in the six districts was taking care to avoid groups and situations that increase risk. These were reported to include walking at night, groups (both male and female) that have bad traits, being in company of people one does not trust and over drinking.

Financial independence was also mentioned as another skill utilised by youths to avoid HIV infection. It was reported that youth are increasingly becoming active in activities such as brick-making, trading, knitting, tailoring and gardening that enable them raise money to meet their personal needs. In this way, they argued that it would be difficult for anyone to lure them into sex because of money. These activities also keep them busy such that they do not get time to ‘chase’ after girls.

“My parents (mother) now buy me things that I ask for so that I don’t go for men to buy me those things.”(FGD, Girls (urban), Mbarara District).

“In some homes adolescents are also given a garden of cassava so that when they want money they can sell that cassava so that they don’t get tricked by rich men.” (FGD, Girls (rural), Soroti District)

Interpersonal relations were also reported as a skill playing positive roles in preventing youth from HIV/AIDS. Youths reported that they are very choosy in selecting their peers, and that these peers include both sexes. They have common goals and rules, which they mutually enforce.

Cross-sex interpersonal relations were reported to be positive and in fact many reported that they relate as brothers and sisters which makes it hard to develop feelings for each other. They know each other’s friends and there was a lot of mutual dependence in terms of information, advice and even material support.

“If you do not have money, you get it on credit and if you cannot you run to a friend. We help one another. You talk to your friend and say give me a ‘bullet’ (condom), another time when he does not have I give him.” (FGD, Boys (rural), Mukono District)

Suffice to note that there were variations in knowledge and practice of the critical life skills between rural and urban areas, largely due to limitations in access to services that support sustained behaviour change. Foremost, access to VCT services was severely limited in rural areas. In all FGDs of adults and adolescents, participants decried the limited coverage of VCT services. Travel cost and fees for the services were cited as the major limitations. Many youth participants who would have wanted to know their sero status to make critical decisions such as marriage were being held back and end up choosing partners without any knowledge of each other’s status.

“Transport to Mbarara is expensive. If you put it on top of buying new clothes for the girl (prospective bride), you end up marrying your girl without testing. If she is sick (infected), you also get sick and wait for death.” (FGD, Boys (rural), Mbarara District)
Ability to sustain condom use was also found to vary between youth in urban and those in rural areas. Much as youth in urban areas were more affirmative on sustained use, those in rural areas sometimes sounded non-committal, citing reasons like erratic availability of supplies, lack of money and false beliefs. A commonly reported belief was that sustained use of condoms demonstrates mistrust to the partner.

“We don’t use condoms always because the girl starts asking: Why do you continue with a condom? Do you mean you don’t trust or love me?” (FGD, Boys (rural), Mbarara District)

6.4 HIV/AIDS Services available to communities

HIV/AIDS services available to communities reported by informants and participants included those related to prevention such as IEC materials, condoms, VCT, treatment of opportunistic infections and provision of ARVs (Table 6.1). Care and Support services included home based care, counselling and care for PLWHAs. Others are mitigation services that include combating the effects of HIV/AIDS such as orphan care and support to widows through income generating activities (IGAs).

Condoms were said to be available in shops and health centers. They were also reported to be distributed by NGOs/CBOs and Community Based Distribution Agents (CBDAs) free of charge though not on a regular basis.

“Condoms are sold in the shops at 250 Ug.Shs a packet of three and Engabu is given out free at the clinics.” (FGD, Men (urban), Soroti District)

“There are free condoms distributed by TASO through Nkoma youth development project.” (FGD, Boys (urban), Mbale District)

The other services are Voluntary Counselling and Testing (VCT), reported available in some district hospitals and the AIDS Information Centre (AIC) all of which are urban based. AIC and TASO also have outreach services in the districts they operate in. The prevention of mother to child transmission (PMTCT) services were said to be available in some hospitals like Mbarara, Mbale and Lira. These are services available only to pregnant mothers who are HIV positive and accept to register for them. Mothers are referred to hospitals where these services exist.

“People can now test blood at Angal hospital. This testing started four months ago (August, 2002). It is 9 miles from here. Testing is free. They also give free condoms.” (FGD, Girls (rural), Nebbi District)

The care and support services to HIV/AIDS patients and orphans were offered mostly by NGOs and CBOs. Counselling was also provided by NGOs such as AIC and TASO, and by health workers. In Soroti district, it was reported that there were some implementers of HIV/AIDS activities like Health Need Uganda and TESO AIDS Project (TAP), doing mostly counselling. In addition, home-based care was being encouraged by health workers.

In health facilities, there are services for the treatment of opportunistic infections with some providing drugs including ARVs. Some urban areas had youth centres that were offering a range of services to the adolescents and youths.
“We have a youth centre at Lugazi it teaches us about AIDS, consoles people, and stages drama. They offer counselling, test for HIV and give out condoms, newspapers and pamphlets.” (FGD, Boys (urban), Mbarara District)

“The youth centre occupies most of our time as we do drama much of the time. We also get enlightened on HIV/AIDS from the films that are screened.” (FGD, Girls (urban), Soroti District)

There are other groups that support people living with AIDS to start income generating activities by training some of the clients in business skills. In addition there is support from the community, individuals and groups like the local burial groups that help the sick by providing food and other necessities.

“For us when a person is sick you go there and dig for her. Then there is a centre for this county, Rwampara at Buteraniro. TASO brings food which they give to people living with HIV/AIDS.” (FGD, Women (rural), Mbarara District)

Table 6.1 Available HIV/AIDS Services to the Communities

<table>
<thead>
<tr>
<th>District</th>
<th>Condoms in Shops</th>
<th>Free condom distribution</th>
<th>Condoms from Health centers</th>
<th>Care and Support</th>
<th>VCT Services</th>
<th>Counselling by NGOs</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequencies</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mbarara</td>
<td>13</td>
<td>8</td>
<td>5</td>
<td>6</td>
<td>10</td>
<td>15</td>
</tr>
<tr>
<td>Mukono</td>
<td>16</td>
<td>13</td>
<td>2</td>
<td>10</td>
<td>20</td>
<td>6</td>
</tr>
<tr>
<td>Mbale</td>
<td>17</td>
<td>12</td>
<td>7</td>
<td>14</td>
<td>11</td>
<td>4</td>
</tr>
<tr>
<td>Nebbi</td>
<td>15</td>
<td>11</td>
<td>4</td>
<td>4</td>
<td>10</td>
<td>9</td>
</tr>
<tr>
<td>Lira</td>
<td>18</td>
<td>15</td>
<td>2</td>
<td>17</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>Soroti</td>
<td>25</td>
<td>16</td>
<td>10</td>
<td>15</td>
<td>23</td>
<td>8</td>
</tr>
</tbody>
</table>

Note: Each score represents an FGD where a particular response was given in each of the 32 FGDs per district

Source: Focus Group Discussions with communities, 2002

6.4.1 Adequacy of available HIV/AIDS services

Participants and informants were further asked if the available HIV/AIDS services were adequate. The adequacy of services was reported in terms of cost and geographic accessibility. In all districts, condoms were reported to be available in shops, clinics and health centres though at a fee. In all districts, there were outlets for free or subsidized condoms, which increase the availability and use of condoms. Condoms were more readily available in urban areas than rural areas. Condom access varied greatly from steady in big urban areas to intermittent in trading centres and near total inaccessibility deep in the rural areas.

The few groups in the districts of Soroti, Mbale, and Nebbi that reported the availability of free distribution of condoms, also said that at times condoms are not available and the supply was irregular. In some cases, agents who distribute the free condoms are old people who cannot easily be approached by adolescents. There were also complaints that some free condom distribution outlets divert the condoms and sell them thereby causing shortages of free condoms. In addition, shops, which sell condoms, were reported to close early between 6 and 7 p.m., yet one may need condoms in the middle of the night. There were also doubts about the quality of condoms, especially in the rural areas. Adolescents pointed out that the condoms available in shops are often expired and poorly stored (exposed to the sun).
“We have free condoms distributed by community health workers. Condoms are also readily available in the shops. They are sold at 300/= a pack though when you read on the pack, the price is 100/=”. (FGD, Boys (Urban), Mukono District)

“Condoms are not easily accessible. Those who are supposed to supply them freely tend to sell them. Sometimes at the shop, they are not there. Even now, they are not there until the shop owner brings them. Five hundred Shillings a packet is very expensive”. (FGD, Boys (rural), Soroti District)

“Condoms are inadequate, not readily accessible and are of poor quality. The youths don’t trust them because they stay in shops for long”. (FGD, Boys (rural), Mbarara District)

“There are condoms in shops but they don’t put them in shelves. They hide them and only give them to you if you are a regular customer. You must be knowing that in that shop they sell condoms”. (FGD, Women (rural), Mbarara District)

VCT services were said to be confined to urban areas and were not free. In the districts of Soroti, Mbarara, and Nebbi most participants in the rural areas reported that the centers were far and results were not given on the same day. In Mukono District, VCT services were offered on specific days and were only free for adolescents.

The participants considered the availability of free services, especially for adolescents, to be important in that they could take advantage and utilize them. In addition, counseling services by NGOs such as TASO were not easily accessible to the majority of people who needed the services. More so, it was said that TASO services were limited to urban areas with few outreaches.

“We don’t have services. As for VCT, it is in Mbarara Town where we don’t go because we don’t have transport. We wait for AIC to come here and they come only once in a while”. (FGD, Women (rural), Mbarara District)

“The distance to the VCT Centre (Soroti Town) is very far and transport costs are very high. Moreover, the results are not available right away or within a day. You may have to return 3 times before you finally get them.” (FGD, Girls (rural), Soroti District)

Other services were treatment of opportunistic infections, although stock outs of drugs and other supplies were reported to occur often in some health facilities. Community HIV/AIDS sensitisation was also reported to exist in communities but health educators are very few compared to the population served.

“These services would be of quality and reliable because they cure opportunistic infections but they are of high cost. They are expensive so they are not affordable.” (FGD, Women (urban), Mbarara District)

“They are inadequate. These people who come to sensitise people take 8 months without coming back. And if a person misses on that day, he will not get sensitisation.” (FGD, men (urban), Mbarara District)

6.4.2 Impact of available Services on HIV/AIDS related Behaviour

The study wanted to find out the role these services have played in influencing HIV/AIDS related behaviour in the communities visited. All groups mentioned that availability of condoms in shops and health centres and some that are distributed free of charge by NGOs/CBOs has helped people especially adolescents in using condoms.
“The condoms have helped the youth mostly. They are very interested and come for them from the counselors without fearing.” (FGD, Women (rural), Mukono District)

Some FGDs reported that HIV/AIDS sensitisation, VCT and care and support to PLWHA has helped to promote positive living and stigma has reduced among the infected persons in some communities (Table 6.2). The sensitisation on HIV/AIDS especially by NGOs and CBOs was said to have increased their knowledge on HIV/AIDS. It was reported that people were now cautious about HIV/AIDS and married people tend to be faithful to their partners and adolescents/people abstain from sex. VCT services, although still limited in coverage, they were being utilized by many adolescents and other community members. In some villages, organized groups and initiatives have come up with action plans to look after the sick, care for orphans and have them forwarded the districts for support. More people were reported to be relying more on trained health workers for treatment than peers and witchdoctors. Care and Support for AIDS patients and orphans by NGOs/CBOs has also been instrumental.

“Testing and counselling has helped all those who have gone for it because those who are negative protect themselves against acquiring HIV/AIDS while those who test positive also change and try to prolong their lives. This is as a result of counselling.” (FGD, Women (rural), Nebbi District)

“The most important role is that PLWHA have gained hope and have come out to give testimony after testing, some have remained productive unlike before“. (Community Health Worker, Mbarara District)

“They have made people live longer say if one is in TASO he gets drugs. If he knows that he is sick and avoids drinking and playing sex, he can live long.” (FGD, Women (urban), Mbarara District)

“Knowing that the services are there, people are eager to know their status, which is very good to us. Knowing that one is positive they join their organization and if negative, they know what to do.” (District Official, Mukono District)

Table 6.2 Impact of Services on HIV/AIDS Related Behaviour

<table>
<thead>
<tr>
<th>District</th>
<th>People especially Adolescents know how to use condoms</th>
<th>Some adolescents are taking HIV tests</th>
<th>Increased knowledge on HIV/AIDS due to sensitization</th>
<th>People are now cautious about HIV/AIDS</th>
<th>Some Adolescents/people abstaining</th>
<th>Positive living among the sick who received counseling</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mbarara</td>
<td>8</td>
<td>7</td>
<td>2</td>
<td>2</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Mukono</td>
<td>18</td>
<td>10</td>
<td>5</td>
<td>5</td>
<td>10</td>
<td>7</td>
</tr>
<tr>
<td>Mbale</td>
<td>17</td>
<td>7</td>
<td>8</td>
<td>5</td>
<td>5</td>
<td>-</td>
</tr>
<tr>
<td>Nebbi</td>
<td>27</td>
<td>6</td>
<td>14</td>
<td>13</td>
<td>9</td>
<td>-</td>
</tr>
<tr>
<td>Lira</td>
<td>15</td>
<td>4</td>
<td>8</td>
<td>8</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Soroti</td>
<td>27</td>
<td>18</td>
<td>-</td>
<td>1</td>
<td>4</td>
<td>2</td>
</tr>
</tbody>
</table>

Frequencies

<table>
<thead>
<tr>
<th>District</th>
<th>People especially Adolescents know how to use condoms</th>
<th>Some adolescents are taking HIV tests</th>
<th>Increased knowledge on HIV/AIDS due to sensitization</th>
<th>People are now cautious about HIV/AIDS</th>
<th>Some Adolescents/people abstaining</th>
<th>Positive living among the sick who received counseling</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mbarara</td>
<td>8</td>
<td>7</td>
<td>2</td>
<td>2</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Mukono</td>
<td>18</td>
<td>10</td>
<td>5</td>
<td>5</td>
<td>10</td>
<td>7</td>
</tr>
<tr>
<td>Mbale</td>
<td>17</td>
<td>7</td>
<td>8</td>
<td>5</td>
<td>5</td>
<td>-</td>
</tr>
<tr>
<td>Nebbi</td>
<td>27</td>
<td>6</td>
<td>14</td>
<td>13</td>
<td>9</td>
<td>-</td>
</tr>
<tr>
<td>Lira</td>
<td>15</td>
<td>4</td>
<td>8</td>
<td>8</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Soroti</td>
<td>27</td>
<td>18</td>
<td>-</td>
<td>1</td>
<td>4</td>
<td>2</td>
</tr>
</tbody>
</table>

Note: Each score represents an FGD where a particular response was given in each of the 32 FGDs per district.

Source: Focus Group Discussions with communities, 2002

The study findings indicate that the district remains the nucleus for HIV/AIDS activities and services. The private sector, mainly NGOs and CBOs and their donor partners continue to be the major providers of HIV/AIDS activities at district and sub-county level. District and sub-county involvement is limited to facility-based services and a few IEC activities that are provided when donor support is obtained. Although efforts are being made to enhance coordination of stakeholders and realign their activities with the overarching district
development plan, capacity in terms of personnel and other resources remains a big challenge to the districts.

The strategies adopted by the community to fight HIV/AIDS seem to be correctly directed at the most vulnerable age cohorts earlier identified as the most affected. Equally important, the life skills mentioned by adolescents and youth are significant in helping them to minimise their vulnerability. However, some of the revelations by both adults and adolescents indicated that the knowledge about HIV/AIDS has not been fully translated into practice. Youth especially in rural areas face serious challenges with regard to sustaining behaviour change due to a dearth of supportive services. VCT services, access to print and electronic media, steady supply of condoms and their sustained use remain major challenges. On the other hand, poverty, life styles and some of the government policies, such as the Children’s’ Statute, tend to undermine the efforts of the communities and parents in guiding the youth to the desired life skills.

The efforts of local leaders in establishing by-laws against risky behaviour such as loitering at night, regulating hours for night events and enforcement of laws against criminal acts like rape and defilement were all commendable. However, weaknesses remain with regard to dispensation of justice during settlement of HIV/AIDS related cases such as rape and defilement. It was reported in various discussions that local leaders commonly advise parents whose children are raped or defiled to settle the cases out of court.

The study has also shown that a number of service delivery points by Government and Civil Society Organisation (CSOs) provide a wide range of services related to HIV/AIDS which include prevention, care and support, and mitigation. The availability of these services and information has enabled people to utilize them and be more knowledgeable about HIV/AIDS.

However, there were critical gaps in the availability and reliability of most of the services to the communities. VCT services were particularly noted to be inadequate. In districts where they exist, testing centres are located in urban areas with limited outreaches. While the demand and need for VCT in rural areas was found to be overwhelming, there were severe limitations to access including travel costs and the actual fees required for the services. In addition, health units were noted to be prone to stock outs of essential drugs and other supplies required to effectively manage opportunistic infections. There were also gaps in human resources in terms of skills and numbers. With regard to condom access, it was noted that cost, minimal as it may sound, was the major limitation especially in rural areas. There were also other notable handicaps such as limited condom outlets, some of which close early in the evening when it is the appropriate time for youth to buy them and also condom outlets being manned by adults, which creates an access barrier.

Given the generally inadequate HIV/AIDS services, especially in the rural areas, the community response to fill in the gaps has been admirable. Significant efforts have been made to seek and share information on HIV/AIDS through village meetings, burials and other functions. As the challenges of HIV/AIDS increase and household resilience weaken, the community responded by making care and support of those affected by HIV/AIDS a shared responsibility. Community organised support groups have evolved that offer mutual support in times of illness and death. Community level efforts have also been made to safeguard youth from HIV/AIDS through counselling and education.
In the Integrated Behaviour Change framework, community initiatives and supportive services, both key variables of infrastructure, are seen to be critical to the behaviour change process. Community initiatives have been found to be key in addressing common needs of people at community level and provide an effective mechanism for initiating and sustaining behaviour change. Similarly, services are deemed essential in the provision of psychosocial support to those in distress. The community initiatives and services have been found to have greatly assisted people with HIV/AIDS and enhanced their participation as frontrunners in advocating for adoption of desired behaviour.
7.0 CHANGES IN HIV/AIDS RELATED BEHAVIOUR

With no known cure for HIV/AIDS, the only effective response to the epidemic is prevention, primarily through behaviour change. In Uganda, HIV/AIDS transmission is primarily through sexual contact. However, this happens within a broader social and cultural context. Therefore, comprehensive changes in cultural beliefs and practices, sexual patterns and practices; attitudes and perceptions to health care seeking and delivery are required to effectively halt the epidemic. Uganda’s response has been pursued in the realm of comprehensive strategies. It is believed that change in sexual behaviour, mainly through changes in age of sexual debut, casual and commercial sex trends, sexual partner reduction, and condom use, explain the dramatic decline in HIV prevalence. Uganda’s response has been systemic, and addressed HIV/AIDS from all these perspectives.

The Integrated Behaviour Change Framework considers behaviour change to be a process, arising out of a complex relationship between an individual and his/her immediate environment. The interaction between individual perceptions and the immediate environment acts as an engine to decision making/action towards a desired behaviour.

The process of change begins with perception, which is seen as a precursor to behavioural change. The interaction between individual perceptions and the immediate environment results into formation of intentions towards a desired behaviour. The intentions are transformed into action through the influence of the environment and reinforcement from a supportive infrastructure. Consequently, behaviour change is viewed as a product of a complex process that begins with an individual forming a perception about a phenomenon, which is greatly influenced by the environment before deciding on the action. For the action to transform into behaviour, there may be a need of an adequate infrastructure to reinforce and sustain the action taken.

This chapter examines the type of behaviour changes that have taken place in the communities visited and the significance of those changes to the reduction in the spread of HIV.

7.1 Changes that have occurred in HIV-related Behaviour

Results from Focus Group Discussions and Key Informant Interviews show that a number of behaviour changes have taken place in all the communities. According to participants, the major behaviour changes that have taken place include: condom use; faithfulness to sexual partner; abstinence; going for HIV testing; and people becoming saved (Table 7.1). In most of the FGDs and Informant interviews conducted, condom use was mentioned as the most significant change that has occurred in HIV-related behaviour. This was followed by faithfulness to sexual partner and abstinence from sex. In over a third of all the FGDs, getting saved was cited as a major change in HIV-related behaviour. However, a few of the groups, especially in the rural areas, intimated that those who report that they have abstained do it for a short duration and those who use condoms don’t use them consistently.

“Information and education have helped very few to abstain but only for a short period say 3 months.” (FGD, Women (rural), Soroti District)
In general, there was consensus about the type of behaviour changes that have been most significant in HIV/AIDS risk reduction. As Figure 4 shows, the majority of FGDs expressed the view that use of condoms was the most important behaviour change that has contributed to the reduction in the risk of HIV transmission. Others were abstinence and faithfulness to sexual partner, which were mentioned in at least a third of all the FGDs conducted in all the six study districts.

“The use of condoms has been the most important because without them, most of us would be dead. Sticking to one partner and avoiding sharing of sharp instruments have also played a big role.” (FGD, Boys (rural), Mukono District)

“Use of ‘boots’ (condoms) has been the most significant. In the past, one could not even mention a condom in public but today everyone carries them, including school children. It is part of their pack when going to school. Abstinence has also helped although few people are practicing it.” (FGD, Men (urban), Mukono District)

Most adolescents were reported to be using condoms especially in the urban areas. On the other hand, condom use in most rural areas was reported to be still low, especially in the districts of Mbarara, Nebbi, and Soroti. There are a number of reasons for low condom use not least among others: people not being able to afford them; desire for unprotected sex to fully enjoy sex and misconceptions about the effectiveness of condoms. Others are allegations that they can cause diseases such as cancer; people not knowing how to use them; condom use being associated with lack of trust and love between sexual partners; and inadequate condom supplies.

“In the past, we now speak to our children openly. You tell your children that please, use this ‘Engabo’ (condom). We, at the same time, tell them to abstain until marriage but if they can’t they should use Engabo”. (FGD, Men (urban), Mukono District)

“In the past, we now speak to our children openly. You tell your children that please, use this ‘Engabo’ (condom). We, at the same time, tell them to abstain until marriage but if they can’t they should use Engabo”. (FGD, Men (urban), Mukono District)
**Table 7.1: Changes in HIV/AIDS-related Behaviour**

<table>
<thead>
<tr>
<th>Type of Change</th>
<th>District</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Nebbi</td>
</tr>
<tr>
<td>Condom Use</td>
<td>30</td>
</tr>
<tr>
<td>Faithfulness to sexual partner</td>
<td>19</td>
</tr>
<tr>
<td>Abstinence especially among young adolescents</td>
<td>15</td>
</tr>
<tr>
<td>HIV Testing</td>
<td>11</td>
</tr>
<tr>
<td>People have become saved and have abandoned risky behaviour</td>
<td>11</td>
</tr>
<tr>
<td>Seeking care and support/treatment</td>
<td>2</td>
</tr>
<tr>
<td>Moving away from widow inheritance/wife sharing</td>
<td>13</td>
</tr>
<tr>
<td>Non-sharing of body piercing/cutting instruments</td>
<td>10</td>
</tr>
<tr>
<td>No behaviour change</td>
<td>1</td>
</tr>
<tr>
<td>People who believe they are sick have become reckless</td>
<td>-</td>
</tr>
</tbody>
</table>

**Note:** Each score represents an FGD where a particular response was given in each of the 32 FGDs per district.

**Source:** Focus Group Discussions with communities, 2002

There are also certain behaviour changes that were significant in a few districts but not common to all. These changes were mostly related to cultural practices that increase the risk of HIV transmission. For example, one in three of the FGDs in Nebbi, Lira, and Mbale districts, reported that widow inheritance, which was once widely practiced, has substantially reduced because people fear to get infected. Key-informants in Soroti and other districts as well reported that widow inheritance has reduced.

“Inheritance of a widow (‘Lago dhako’) used to be a must. When a woman’s husband dies, her brother-in-law must take care of her and the children. Even if he is married, he has to keep his brother’s name alive by producing more children and also ensure that the bride price is not wasted. Nowadays, there is no more ‘lago’ if people know your husband died of ‘slim’ (AIDS) or diseases associated to ‘slim’ (AIDS) such as TB of the bones, diarrhoea or vomiting.” (FGD, Girls (rural), Nebbi District)

“Widow inheritance has almost died out. If there are any relationships with the widow, it is a personal arrangement and not a clan issue as it used to be.” (Community Based Health Worker, Soroti District)

Wife replacement, a practice that was widely practiced in Nebbi was also reported to have significantly reduced because of the AIDS scare. Furthermore, in Mbale and Nebbi, at least one in three of all the FGDs reported that sharing of body piercing/cutting instruments during circumcision or when the traditional healers are administering their herbs through incisions has respectively decreased.

In Mbale, the ‘Inemba’ dance where newly circumcised men are encouraged to have unprotected sex with any woman of their choice was reported to be no longer widely practiced in most communities. Similarly, the practice of wife sharing and that of father in-
laws sleeping with their daughter-in-laws reported to have been common in Mbarara has virtually died out.

It was also reported in a few FGDs in a number of study districts that there was a tendency for men to avoid socialising with women especially in drinking places. In some districts such as Nebbi, couples have also become overly protective of each other. Most parents also try to stop their children from attending night ceremonies and functions. In addition, the level of stigmatisation and rejection of HIV/AIDS patients was also reported to be decreasing in all districts.

“Our parents stop us from going to traditional marriage ceremonies (‘Keny’). These celebrations have become dangerous and parents allow only the bigger boys who are over 20 years. Some of us who have wives go with them so that they don’t feel hunger for sex. We fear to leave them for other men.” (FGD, Boys (rural), Nebbi District)

“It was hard those days even to touch anything belonging to an infected person. I could not even carry anybody’s baby because of discrimination. Attitudes have now changed. People share everything with me and other infected persons too. They help patients freely like cleaning their houses, cooking food, bathing them and any other assistance. They also advise us not to force ourselves to work hard”. (PLWHA, Soroti District).

“People are no longer pointing fingers at AIDS patients. Harassment is no longer there. Actually, it is us who harass them by telling them to get away from living in the dark. AIDS patients get good care from relatives, friends and TASO. Even if I called my brother now that I am in pain, he would come immediately and give all the care that is necessary.”. (PLWHA, Mbarara District).

Seeking treatment, care and support from organizations such as TASO was also mentioned as another important change in behaviour in at least one in every four FGDs in Mbarara, Mbale, and Soroti Districts. The drastic reduction in stigmatisation of those infected and affected, has resulted into an atmosphere conducive to HIV/AIDS service seeking behaviour. However, changes in treatment seeking behaviour was mostly mentioned by FGD participants in urban areas where VCT and other related HIV/AIDS services are more readily available. VCT services were also recognised, especially by adolescents, as playing a very important role in saving people’s lives particularly among those seeking marriage.

![Figure 4: Behaviour changes most significant in HIV/AIDS risk reduction](image_url)
Despite the above reported changes, in the districts of Mbarara and Lira, participants were of
the view that there has been no behaviour change whatsoever. This view was mostly held by
women and men in rural Mbarara as well as women in rural Lira Districts.

There were also some negative behavioural changes that were reported especially in Mbarara. In
all the FGDs that were held with adolescent boys in the rural communities of Mbarara, it was
reported that people who believe were HIV infected tend to go on rampage by selling all their
properties, refusing to engage in any productive work, and having sex with anybody. Some of
the widows suspected of having HIV/AIDS were also frequently accused of maliciously
spreading HIV.

“There is a lot of hopelessness. When adolescents play sex without a condom, they get worried
that they are already sick. Some girls even fail to get married because they think they have AIDS.
When a person knows that he has AIDS, he becomes reckless and starts defiling young girls.
When the youth play sex with widows, they think they are dead so they increase their sexual
activities.” (FGD, Boys (rural), Mbarara District)

At the community level, there have also been a number of positive changes in HIV/AIDS-
related behaviour. These changes were mostly related to the abandonment or modification of
cultures and ceremonies that increase the risk of HIV transmission. There was also increased
information sharing on HIV/AIDS among community members and between parents and
children.

Parents also try as much as possible to assist their adolescent children in order to prevent them
from getting into compromising situations. In addition, most communities were quite vigilant
in the enforcement of national laws especially on defilement and rape in order to curb the
malicious spread of HIV/AIDS and other related problems.

From the foregoing, it was clear that there have been a number of significant HIV/AIDS-related
changes at both the individual and community level in all the six study districts. The findings
show that condom use was much more prevalent among adolescents in urban areas was because
adolescents, or more generally young people, were more sexually active and most get involved
in several transient sexual relationships as they seek for better sexual/marriage partners.

However, in the rural areas, condom use is still low even among adolescents for a wide range of
reasons including cost, availability and mechanisms through which they are accessed. Thus,
abstinence especially among adolescents, faithfulness to sexual partner, and reduction in sexual
partners appear to be the most prevalent behaviour changes.

Use or non-use of a condom has also remained more or less a male domain. It is the boys and
men who buy the condoms and ultimately decide whether to use it or not though in a few cases
girls and women may resist its use either on safety grounds (it may get stuck in her private
parts) or because they think condom use shows lack of mutual trust.
8.0 CONCLUSIONS

8.1 The Integrated Behaviour Change Framework

In the process of verifying the relevance of the Cautious Shift Model it was revealed that this model does not actually exist. This was only found to be a proposed Theoretical Framework to explain behaviour change in the context of HIV/AIDS in Uganda. In-depth review of commonly used models/theories revealed that no model singularly explains the behaviour change that has occurred in Uganda with respect to HIV/AIDS. Their focus was limited to the individual and most did not consider the important role played by the contextual factors such as environment and infrastructure on the behaviour formation process.

The development of the Integrated Behaviour Change Framework was therefore a necessary step intended to explain behaviour change with respect to HIV/AIDS. The framework depicts an interaction between individual perceptions and the immediate environment that acts as an engine to decision making/action towards a desired behaviour. Consequently, behaviour change is viewed as a product of a complex process that begins with an individual forming a perception about a phenomenon, which is greatly influenced by the environment before deciding on the course of action. The framework clearly explains Uganda’s multi-sectoral HIV/AIDS response by its emphasis on contextual factors that support or inhibit behaviour formation and a need of an adequate infrastructure to reinforce and sustain the action taken.

8.2 Community knowledge, attitudes and perception of HIV/AIDS

There was universal awareness and near universal knowledge of HIV/AIDS in communities. Radio and print media were mentioned as the most prominent avenues through which HIV/AIDS information was disseminated to communities to raise awareness and increase knowledge of HIV/AIDS. However, access to both radio and print media was still limited, especially in rural areas, due to low incomes (inability to buy radios or even batteries), inability to read and interpret messages correctly and the long distances to service delivery points. There are also critical problems with regard to targeting of information to ensure that the right messages reach the right audience.

Despite this increased knowledge and awareness, there were still strong misconceptions especially in rural communities about the cause and some of the scientific ways to prevent oneself from HIV/AIDS. Some people still associate HIV/AIDS with witchcraft, while others speculate that it is maliciously spread through immunization and drugs given in health units. There are also those who doubt the effectiveness and safety of a condom as a preventive measure and others who believe that HIV/AIDS is exclusively an urban disease. Such misconceptions about HIV/AIDS are a clear indication of existing knowledge and intervention gaps in combating the disease.

Key informants’ views about Uganda’s celebrated success in stemming the HIV/AIDS epidemic varied, with the majority of the people saying that there was a reduction in prevalence while others argued there wasn’t any change. Both opinions were based on proxy indicators such as intensified campaigns against HIV/AIDS, use of condoms and people being faithful. The varied opinions appeared to be driven by the fact that there was no adequate data and means of verification of available information on HIV prevalence.
The data used to monitor the HIV prevalence in the country based on a small cohort of women in reproductive ages, and seeking institutionalised antenatal services, may not be representative. Furthermore, anecdotal evidence indicates that prevalence rates seen in some VCT centres across the country are more than double the official rate of 6.5%

AIDS has had multidimensional impact on communities, families and individuals. It has exacerbated the poverty situation at household level and minimised the capacity of families to meet basic needs. The most pressing problem reported was the increasing number of orphans in the communities. Traditionally, it was the responsibility of families to absorb the orphans. However, this institutional mechanism can no longer cope mainly due to poverty, high mortality due to AIDS and high fertility (many children per household). The high fertility implies that many orphans are left behind when parents pass away. In addition, in a situation of high HIV prevalence, it is likely that the would-be caretakers are also grappling with the effects of HIV/AIDS in their own households. The rise in the number of homeless children roaming the streets could be a clear indication of the dwindling community capacity to care for orphans and a signal of a looming disaster of multiple dimensions.

The study revealed that socio-economic and demographic characteristics of an individual, perceptions, environment, infrastructure and cues to action, which are the major components of the framework, play critical roles in behaviour change. For instance, one’s age and level of education greatly influence one’s attitudes and behaviour while area of residence has a great influence on one’s vulnerability and access to basic HIV/AIDS services. Perception of the threat posed by HIV/AIDS and the benefits of surviving the infection were reported as major factors motivating people to change behaviour in response to HIV/AIDS. The role of personal experience such as caring for a relative who had HIV/AIDS and loss of a close relative or friend to AIDS are also major factors driving people to avoid HIV/AIDS.

8.3 Cultural norms, Social practices and HIV/AIDS

The study identified a number of social factors and cultural norms and practices that impact on HIV/AIDS. The first category constitutes of factors that were said to promote the spread of HIV/AIDS such as alcohol drinking and drunkenness. To that effect, all social and cultural functions that involve large gatherings, alcohol drinking and dancing were seen to be greatly contributing to the spread of HIV/AIDS.

The second category is of those that influence the reduction in the risk of HIV transmission such as promotion of virginity, seeking God and arranged marriages. Interestingly, some of the main social factors, cultural norms and practices that increase the risk of HIV transmission were seen to also play significant roles in risk reduction. For instance, church gatherings, weddings, and burials were singled out as major avenues for promoting positive sexual behaviours yet some people use them to engage in risky behaviours.

HIV/AIDS and the Social and Cultural set-up of communities have impacted on each other. In the context of HIV/AIDS, social and cultural practices play dual roles, on one side enhancing HIV transmission while on the other facilitating reduction in incidence. However, social factors, cultural norms and practices were seen to be more of facilitators than inhibitors of HIV transmission. Consequently, there have been drastic changes in the social and cultural practices in most communities.
Many of the practices that are deemed to directly increase risk of HIV transmission such as circumcision, and tattooing continue to be made safe while others such as widow inheritance, wife sharing, and wife replacement are being abandoned.

8.4 Community Strategies in Responding to HIV/AIDS

Strategies adopted by the community in response to HIV/AIDS varied between the district, community and individuals. District response was found to be largely institutional, focusing on supporting delivery of HIV/AIDS services through health units and coordination of all HIV/AIDS activities. However, limitations in terms of personnel and other resources remain a big challenge to districts efforts to combat HIV/AIDS.

On the other hand, communities have come up with a number of strategies to deal with the epidemic, through informal structures. Community groups as well as individuals have evolved strategies that enhance sharing of HIV/AIDS information and provision of mutual support in times of acute sickness and death. Some have also enacted bylaws to regulate social and cultural functions, which are deemed to increase the risk of HIV transmission. Other important strategies are increasing the role of PLWHA in HIV/AIDS education, parents’ protection of their children from risks and equipping the youth with livelihood skills to support them avoid risky behaviour.

However, poverty and lack of supportive services such as VCT and condoms remain major limitations especially for the youth to sustain behaviour change. Accessibility to these services is also limited to the majority of the poor especially in rural areas. Moreover, services such as VCT, care and support and condoms are not adequate in terms of availability and reliability.

8.5 Changes in HIV/AIDS Related Behaviour

The major behaviour changes noted were increased condom use and abstinence prominently among the youths, reduction in multiple sexual partners and mutual faithfulness among married couples. Significantly, parents have come out to discuss issues of sex, sexuality and HIV/AIDS with their children albeit with some constraints. The proliferation of Pentecostal Churches has further enhanced reduction of risk through continuous involvement of the youth and other community members in religious activities.

People’s attitudes towards HIV/AIDS have changed positively as reflected by the growing demand for VCT and the integration of PLWHA in the community. This has resulted in improved health seeking behaviour among people infected and subsequent involvement in HIV/AIDS prevention.

Despite these positive developments and increased knowledge about what communities can do to avoid HIV infection, there are still critical contextual factors such as poverty, illiteracy, inequitable distribution of services and gender inequalities that encumber them to continuously practice protective behaviour. For instance, women who are faithful to their husbands may still get infected because they are not in position to negotiate for safe sex even when they know their husbands are engaging in risky sexual practices. Similarly, adolescents and youths who would have wished to get married after an HIV test are unable to do so because VCT services are not accessible.
9.0 **RECOMMENDATIONS**

- The integrated Behaviour Change framework mirrors Uganda’s HIV/AIDS response and the subsequent behaviour change in Uganda. The study findings revealed that socio-demographic characteristics such as age, sex and residence; strategies and information; services and support and; personal experience among others combine to influence and sustain behaviour. It is, therefore, recommended that the framework be subjected to further empirical verification in the HIV/AIDS context in Uganda with the purpose of adopting it as a model for planning of future interventions and replication elsewhere.

- The problem of orphans featured as the main HIV/AIDS challenge facing families and communities indicating the magnitude of the orphan crisis. The widespread household poverty has severely eroded the capacity of the extended family system to effectively absorb orphans as manifested by the growing number of homeless children. Interventions that enhance the capacity of foster families to earn income, keep orphans in school, give them tradable skills and guarantee their protection and that of their property by enacting relevant laws to curb vulnerability of orphans and widows are highly recommended.

- The findings showed universal awareness and high levels of HIV/AIDS knowledge in communities. However, there are still misconceptions about HIV/AIDS, significant enough to deter people’s efforts to change behaviour. There is need for specific and targeted interventions to tackle the misconceptions held by the community on HIV/AIDS. The interventions should mainly target rural areas, and illiterate women and men in particular and improve sensitisation on HIV/AIDS in general.

- Basing on proxy indicators of behaviour change such as condom use, abstinence and reduction in the number of partners, there was general consensus in communities that HIV prevalence has gone down. However, people asserted that the exact prevalence rate is not known due to lack of comprehensive and reliable data. It is imperative, therefore, that a national population based sero status survey similar to one conducted in 1988 be undertaken on a 10-year interval to regularly establish the HIV prevalence rate. Whether the rate turns out to be higher or lower, it would be the locus of Uganda’s renewed commitment to fighting the epidemic.

- Social and cultural patterns of life in communities are institutional and have been passed on generations. These patterns of life are strongly cherished and allegiance to them is regularly renewed through performance of rituals and rites. Though most of them seem to promote HIV transmission, it is rather the activities associated with them such as alcohol and dancing that makes them risky. In this context it is recommended that targeted interventions that seek to make these practices safe be designed and also include activities aimed at eliminating those found to directly promote HIV/AIDS. Similarly, interventions are necessary to consolidate the social factors, cultural norms and practices that are found to be useful in promoting desired behaviour.

- Communities reported commendable efforts already being made in adapting their cultural norms and social practices to the HIV/AIDS context. It is therefore recommended that an empirical study be undertaken to establish the extent to which the changes in cultural norms and practices reduce the risk of HIV/AIDS transmission in order to strengthen the efforts and develop relevant interventions.
- Radio featured prominently as the major source of HIV/AIDS information to communities. Access to radio was noted to have improved greatly with the growth in the number of privately owned FM stations that air programmes in local languages. It is recommended that radio as a cost-effective medium of delivering HIV/AIDS information to the communities be harnessed and supported. Programmes that target specific behaviours or even localities should be designed and aired consistently and innovatively to the target population.

- The major limitations to utilisation of services such as VCT services was noted to be costs of transport to the apparent far away service points and waiting time including the need to return to pick results weeks after testing. This was found to entail a lot of costs notably transport. It is therefore recommended that where VCT services exist, protocols that allow for same-day results should be introduced and adopted as a national approach to VCT. In addition, organisations providing HIV/AIDS services should initiate community outreach programmes to be able to deliver services where they are greatly needed. This would go a long way in minimising costs of services, building customer confidence and consequently encouraging more clients to seek the services.

- It was found out that direct involvement of the districts and sub-counties in HIV/AIDS activities was limited and most of the interventions are championed by NGOs, CBOs and other civil society organisations. Even then, the activities of these partners remain largely uncoordinated, with high potential for duplication and ignoring of deserving areas especially the remote and resource-constrained rural areas. On the other hand, the communities have come up with various strategies to respond to HIV/AIDS. However, there is dearth of behaviour change supportive services such as condoms, VCT, care and support at community level. More concerted efforts need to be made to extend free HIV/AIDS services especially VCT and condom distribution to the rural areas where the majority of the people live.

In addition, programmes that encourage training of community based youth counsellors and volunteers should be encouraged to help create resource persons that offer on-going support to the youth and other people in the community.

- Although there has been significant behaviour change, the study revealed that communities are not yet complacent as reflected by their belief that HIV/AIDS is still a major problem affecting their lives. Therefore, there is need to consolidate the existing behaviour changes through programs that target rural communities. There is also need to initiate new programs that seek to transform knowledge acquired by communities into behaviour change.

- Findings indicated that people’s efforts to change behaviour were often thwarted by extrinsic factors such as poverty, gender inequalities and inadequate supportive services. It is recommended that future interventions should further seek to address contextual limitations such as household poverty, emancipation of women, and literacy to be able to achieve and sustain the desired impact.
REFERENCES


