A Study on
Knowledge, Attitudes and Practices
related to
HIV/AIDS Stigma and Discrimination
among People Living With HIV, Caretakers of
HIV+ Children and Religious Leaders

By Agatha Kafuko

Kampala, March 2009
This study was conducted by the Johns Hopkins Center for Communication Programs in conjunction with Uganda AIDS Commission. The study was made possible through financial support provided by the United States Agency for International Development (USAID) under the terms of JHU/CCP Health Communication Partnership (HCP) Award.

The opinions expressed herein are those of the author(s) and do not necessarily reflect the views of USAID or HCP.
Acknowledgements
This study was conducted by Dr. Geoffrey Mujisha and Ms. Agatha Kafuko. Dr. Mujisha mobilised, conducted and prepared the transcripts for the focus group discussions. Ms. Agatha Kafuko conducted the key informant interviews, reviewed documents, analysed the data and prepared the report for the study. The consultants would like to thank: Health Communication Partnership for the opportunity to participate in this assessment. In particular, Mr. Venansio Ahabwe, Dr. Robert Kalyebara and Mr. Emma Kayongo, who provided constructive and helpful advice and guidance; the entire research team who collected data and prepared transcripts for the assessment. Thanks go to the Uganda AIDS Commission, particularly to Mrs. Namulondo Joyce Kadowe and Mr. James Kigozi for the support given to the entire process. The consultants extend their gratitude to the men and women who took part and who gave generously of their time to discuss their experiences frankly and openly.
# Table of Contents

Acronyms iv  
Executive Summary ........................................................................................................ v  
Chapter 1: Introduction .................................................................................................... 1  
1.0 Introduction .............................................................................................................. 1  
1.2 Background to HIV/AIDS Stigma and Discrimination .............................................. 1  
1.3 Rationale/justification for the study ........................................................................... 3  
1.4 Objectives of the study ............................................................................................... 4  
1.5 Structure of the report ............................................................................................... 4  
Chapter 2 Methodology .................................................................................................. 5  
2.0 Scope of the study ....................................................................................................... 5  
2.2 Description of data collected for study ....................................................................... 5  
2.3 Data analysis ............................................................................................................. 7  
2.4 Ethical Considerations ............................................................................................... 7  
Presentation and discussion of findings ........................................................................... 8  
3.0 Responses generated from the PLHIV ...................................................................... 8  
3.1 Knowledge and Attitudes of PLHIV towards Stigma ................................................. 8  
3.3 Practices that promote stigma and discrimination towards PLHIV .......................... 12  
3.6 Impact of stigma and discrimination on PLHIV ...................................................... 19  
3.7 Barriers to overcoming stigma and discrimination .................................................. 21  
3.8 Proposals to reduce stigma and discrimination by PLHIV ...................................... 22  
4.0 Findings from the caretaker audience ....................................................................... 24  
4.3 Practices that promote stigma and discrimination .................................................... 26  
4.5 Impact of stigma and discrimination on PLHIV ...................................................... 30  
4.6 Barriers to overcoming stigma and discrimination .................................................. 31  
5.0 Presentation of findings from the religious leaders .................................................... 35  
5.2 Results on knowledge and attitudes of religious leaders towards stigma 39  
5.3.4 Practices that promote stigma and discrimination in FBOs ................................. 44  
5.5 Proposals by religious leaders to reduce stigma and discrimination ....................... 48  
Conclusions and recommendations ............................................................................... 54  
Chapter 6: Conclusions and recommendations ............................................................... 54  
6.0 Introduction .............................................................................................................. 54  
6.1 Summary of findings ............................................................................................... 54
### Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AIDS</td>
<td>Acquired Immunodeficiency Syndrome</td>
</tr>
<tr>
<td>ART</td>
<td>Anti-Retroviral Therapy</td>
</tr>
<tr>
<td>ARV</td>
<td>Anti-Retroviral</td>
</tr>
<tr>
<td>BCC</td>
<td>Behaviour Change Communication</td>
</tr>
<tr>
<td>COU</td>
<td>Church of Uganda</td>
</tr>
<tr>
<td>FBO</td>
<td>Faith-Based Organisations</td>
</tr>
<tr>
<td>FGD</td>
<td>Focus Group Discussion</td>
</tr>
<tr>
<td>HCP</td>
<td>Health Communication Partnership</td>
</tr>
<tr>
<td>HCT</td>
<td>HIV/AIDS Counselling and Testing</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
</tr>
<tr>
<td>MOH</td>
<td>Ministry of Health</td>
</tr>
<tr>
<td>NAFOPHANU</td>
<td>National Forum of PLHIV Network in Uganda</td>
</tr>
<tr>
<td>PLHIV</td>
<td>Persons Living with HIV/AIDS</td>
</tr>
<tr>
<td>PMTCT</td>
<td>Prevention of Mother to Child Transmission</td>
</tr>
<tr>
<td>SDA</td>
<td>Seventh Day Adventist</td>
</tr>
<tr>
<td>UAC</td>
<td>Uganda AIDS Commission</td>
</tr>
<tr>
<td>UMSC</td>
<td>Uganda Muslim Supreme Council</td>
</tr>
<tr>
<td>UNAIDS</td>
<td>Joint United Nations Programme on HIV/AIDS</td>
</tr>
<tr>
<td>UNATU</td>
<td>Uganda National Teachers Union</td>
</tr>
<tr>
<td>USAID</td>
<td>United Stated Agency for International Development</td>
</tr>
<tr>
<td>UWESO</td>
<td>Uganda Women’s Effort to Save Orphans</td>
</tr>
<tr>
<td>VCT</td>
<td>Voluntary Counselling and Testing</td>
</tr>
</tbody>
</table>
Executive Summary

This study sought to examine knowledge of HIV/AIDS stigma and discrimination, attitudes towards people infected and affected by HIV/AIDS, and attitudes and practices among three groups: religious leaders, caretakers of children infected with HIV/AIDS, and people living with HIV (PLHIV). This was based on the recognition that these population groups are key allies in addressing stigma and discrimination. The need to obtain the existing knowledge and attitudes of these groups was considered a critical prerequisite to the development of national communication initiative to address HIV and AIDS stigma and discrimination.

The specific objectives of the study were as follows:
(a) To identify and document knowledge of HIV/AIDS stigma and discrimination among caretakers, religious leaders and PLHIV in Uganda;
(b) To identify the attitudes of caretakers, religious leaders and PLHIV towards stigma and discrimination;
(c) To identify practices related to stigma and discrimination among caretakers, religious leaders and PLHIV; and,
(d) To identify and document proposals on how to reduce stigma and discrimination.

The study utilized a number of techniques. They included qualitative data collection and analysis; review of existing literature on stigma and discrimination related to religious denominations; Focus Group Discussions (FDGs) and key informant interviews of clergy from select religious groups.

Summary of findings

The study reveals that all three groups demonstrate an understanding of what constitutes stigma and discrimination. They can distinguish between self, enacted and felt stigma. However they cannot link discrimination to human rights.

In addition the study shows that PLHIV experience stigma and discrimination from their families and friends. For the caretaker audience, children who have HIV/AIDS are seen as a source of stigma and shame by their parents. These children face discrimination and are denied their rights to association and play.

Religious groups advocate for acceptance and love towards those infected with HIV and AIDS. Most religious groups believe in non-judgmental responses to PLHIV. Religious leaders are aware of the link between HIV/AIDS, sexual immorality and sin. The position of the Islamic religious group differs from other religious groups in that they believe that PLHIV are afflicted by God, and may be responsible for their status. Religious groups are convinced that behaviour change is the key to addressing HIV and AIDS prevention. All religious leaders stated that their faith was against the use of condoms.
All three groups identified stigma and discrimination as a problem that impedes access to and utilization of HIV prevention/mitigation services; and that it creates a culture of silence hence fuelling the HIV epidemic. HIV/AIDS stigma and discrimination affects men and women differently. Women are often abandoned by their spouses in addition to bearing the burden of caring for children affected by HIV/AIDS.

The study identified different practices that fuel HIV/AIDS stigma and discrimination. One such practice is the use of derogatory names and terms when referring to PLHIV. Other negative care practices include, refusal to provide food and appropriate care for the PLHIV. Positive care practices may become stigmatizing in cases when PLHIV are over pampered and denied the opportunity to be self-reliant. Stigma and discrimination is experienced in different forms in homes, workplaces, schools, and health facilities. In the homes, PLHIV are often treated as worthless beings and may not be cared for properly and/or are sometimes denied access to their property. At the family level, PLHIV are often excluded from discussions and decision-making.

Regarding children living with HIV/AIDS, the study shows that this group is denied love and affection from their guardians. They are also denied access to basic needs such as food, health and education. At the workplace, PLHIV sometimes experience loss of employment, diminished opportunities for promotion, and demotion to lower positions. In the health units, many health workers have a bad attitude towards PLHIV, which has the potential of resulting in poor quality of care. Health workers often discourage caretakers from spending a lot of effort and resources on the treatment of children.

Within the school setting, HIV+ children are sometimes forced to drop out of school due to stigma and discrimination. At times, other children do not want to share desks with children infected with AIDS. They may be denied an opportunity to participate in activities that are considered to be physically straining. Within the church, there are some practices that tend to isolate PLHIV. For example, within the SDA church, people who are known to have HIV are the last to be dipped at baptism ceremonies, which is evidence of low knowledge about HIV transmission.

Among all groups, there was recognition that ignorance continues to drive and fuel stigma and discrimination in Uganda. While the study shows an understanding of stigma and discrimination among these groups, they acknowledge inadequate awareness on HIV/AIDS transmission and existing services within the population. This study shows that the experiences of these groups relating to HIV/AIDS stigma and discrimination provides an opportunity to create greater awareness about the nature and magnitude of HIV/AIDS stigma and discrimination and how it can be overcome amongst their congregations.
Chapter 1: Introduction

1.0 Introduction
This is a report on the knowledge, attitudes and practices related to stigma and discrimination among health care workers, religious leaders, PLHIV, and caretakers of children infected with HIV. These are audiences which have been identified for targeted anti-HIV/AIDS stigma messaging. The study was commissioned by Health Communication Partnership (HCP) and Uganda AIDS Commission (UAC), with funding from USAID. These agencies are working with other partners in Uganda to develop a national communication initiative to address the problem of HIV/AIDS stigma and discrimination in Uganda. The strategy is to implement social and behaviour change communication programmes through which HIV/AIDS related stigma and discrimination can be reduced. This formative research was commissioned as a result of gaps identified in the information concerning the knowledge, attitudes and practices among these targeted audiences.

1.2 Background to HIV/AIDS Stigma and Discrimination
Uganda has braved a severe generalized HIV epidemic for almost a quarter of a century. HIV/AIDS continues to pose serious public health challenges that greatly contribute to morbidity and mortality rates in Uganda. It is estimated that almost one million people, 6.4% of all adults aged 15-49 years, are infected with HIV (UAC 2007). A number of factors, both behavioural and economic, are drivers of the HIV epidemic in Uganda. The National HIV/AIDS Strategic Plan 2007/8-2011/12 identified stigma and discrimination as one of the socio-cultural factors that drives the epidemic. It is acknowledged that discrimination on the basis of sero-status sets in motion a string of human rights violations, which require legal protection. Persons affected by HIV, especially orphans and widows, are largely powerless and vulnerable to many kinds of rights abuses (UAC 2007).

Stigma is defined as the ‘holding of derogatory social attitudes or cognitive beliefs, the expression of negative affect, or display of hostile or discriminatory behaviour towards members of a group on account of their membership of that group’ (Brown, 1995, in Mukasa 2008). The literature review commissioned by HCP in 2007 defines HIV/AIDS-related stigma as a “process of devaluation” of people either living with or associated with HIV/AIDS (UNAIDS, 2002). HIV/AIDS stigma results from a negative association and underlying stigmatization of sex and intravenous drug use, which are two primary routes of HIV infection. Stigma affects those who are infected and those affected by association, such as orphans or children and families of people living with HIV (Mukasa, 2008). Stigma derives from negative thoughts based on a prejudiced position (out-casting) and affects the thinking and behaviour of people whereby a person is looked at in a negative and judgmental way. Stigma has deep roots in culture, personal and social fears, denial, misconceptions, myths and even religious beliefs. It is mainly due to limited knowledge about HIV transmission or
fear of risk of HIV infection. Persons most affected by stigma include, PLWHA, OVC, adolescents, especially if pregnant, and single mothers (UAC, 2007b)

Mukasa (2008) identified three basic types of stigma; enacted stigma, felt stigma and self-stigma. Enacted stigma refers to the discrimination and violation of human rights that PLHIV or people assumed to be infected with HIV/AIDS may experience. Felt stigma refers to the feelings an individual has about his/her condition and the fear of how others will react to this condition. Felt stigma is the fear of, or anticipation of enacted stigma. Felt stigma impairs the individual's perception of available support. Self-stigma arises out of both enacted and felt stigma and is expressed when an individual internalizes enacted- or felt-stigma in such a way that results into devaluation of one's identity both socially and at a personal level.

Discrimination is a result of stigma. It consists of actions or omissions that derive from stigma and is directed towards those individuals who experience stigma. Discrimination is any form of arbitrary distinction, exclusion, or restriction affecting a person, usually but not only by virtue of an inherent personal characteristic or perceived to be belonging to a particular group (Mukasa, 2008). It includes actions that negatively impact the rights and entitlements of others based on prejudiced viewpoints or positions and ensue when a distinction is made against a person, the result is unfair or unjust treatment based on their HIV sero-status or risk status (UAC 2007b). Discrimination is a violation of human rights. Stigmatizing and discriminatory actions violate the fundamental human right to freedom from discrimination. Discrimination directed at people living with HIV or those believed to be HIV-infected, leads to the violation of other human rights, such as right to health, dignity, privacy, equality before the law, and freedom from inhuman, degrading treatment or punishment (Mukasa, 2008).

It has been reported that in some African nations such as Ethiopia and Zambia, the link between sex, religion, and stigma is particularly strong; it is believed that HIV is a punishment from God for sexual sins committed by individuals and communities (Nyblade et al 2003 in Mukasa 2008). Religious institutions are reported to play a contradictory role towards PLHIV. Mukasa (2008) reports that a number of studies show religious leaders as active proponents of stigma towards PLHIV in that religious leaders reportedly associate HIV with sexual immorality.

HIV/AIDS stigma and discrimination undermines public health efforts to combat the epidemic. It negatively affects preventive behaviours such as condom use, HIV test-seeking behaviour, care-seeking behaviour, quality of care given to HIV-positive patients, and perception and treatment of PLHIV by communities, families, and partners (Mukasa, 2008). Stigma, fear and discrimination are mentioned by various stakeholders to be key factors that hinder people living with HIV/AIDS (PLHIV) from accessing ART (MOH and ORC Macro 2006). In some cases, PLHIV are denied treatment and are prematurely discharged once it is realized they are HIV positive.
In addition, health workers may refer a PLHIV to other AIDS service providers who lack fully-fledged medical units to provide all the medication required. Health workers pay little attention to PLHIV due to the belief that they were going to die, while others charge AIDS patients much higher fees for medical services (Mukasa 2001 quoted in Mukasa 2008). Reports from Kenya show that in some cases due to fear of stigma, PLHIV (who are slightly better off financially) make illegal purchases of ARVs from other PLHIV (considered poor). This puts them at risk of taking the wrong dosage, since ARVs should be taken under direct supervision of approved medical workers (Mukasa, 2008).

Stigma and discrimination undermine prevention, care, and treatment efforts and increase the impact of the epidemic on individuals, families, communities and nations’. Therefore, addressing HIV/AIDS stigma and discrimination is critical to improving access to public health services, preventive care and support services.

1.3 Rationale/justification for the study
In May 2008, the Uganda Aids Commission, with technical support from Center for Communication Programs/Health Communication Partnership, held a training workshop for partners on the National Campaign Strategy to Reduce HIV/AIDS Stigma and Discrimination in Uganda. The workshop aimed at; updating partners’ knowledge and skills on HIV and AIDS stigma and discrimination, seeking partner input in developing a campaign strategy for the reduction of HIV/AIDS, and devising ways for future implementation of the strategy. During the training workshop, participants identified priority communication issues and primary target audiences for the national campaign to reduce HIV stigma and discrimination. The primary audience included health workers, political leaders, caretakers of HIV+ children, people living with HIV/AIDS and religious leaders.

The audience analysis for the target audiences revealed lack of information on knowledge and attitudes of stigma and discrimination among specific target audiences, namely religious leaders, caretakers of HIV+ children and people living with HIV, making it necessary to conduct this assessment. Workshop participants recommended further interaction, through FGDs, with the remaining audiences in order to understand the dynamics of their activities and how they contribute to stigma against people affected by and/or infected with HIV/AIDS. This would involve the analysis of the audiences’ Knowledge, Attitudes, Behaviour and Practices (KABP) regarding HIV and AIDS-related stigma and discrimination. This study sets out to identify and document the HIV and AIDS related knowledge, attitudes and practices of the dominant religious groups in Uganda.
1.4 Objectives of the study
The aim of this assessment was to generate information of specific primary target audiences for the national HIV/AIDS stigma and discrimination communication strategy.

Specifically, the assessment objectives included:
1) To identify and document the knowledge of HIV/AIDS stigma and discrimination among caretakers of HIV+ children, religious leaders and PLHIV in Uganda;
2) To identify the attitudes of caretakers of HIV+ children, religious leaders and PLHIV towards stigma and discrimination;
3) To identify practices that related to stigma and discrimination from the perspectives of caretakers, religious leaders and PLHIV; and
4) To identify and document the proposals from the target audience on how to reduce stigma and discrimination

1.5 Structure of the report
The report is divided into four chapters. Chapter One includes the introduction, which gives a brief background to HIV/AIDS stigma, justification for the study, and the study objectives. Chapter Two highlights the methodology, providing information on where and how the study was executed. Chapter Three presents the findings of the study and Chapter Four presents the conclusions and summary of the study, giving possible interventions to address stigma and discrimination, as well as recommendations and gaps for future research.
Chapter 2 Methodology

2.0 Scope of the study
This study was designed as a qualitative study meant to generate information on the knowledge, attitudes and practices regarding stigma and discrimination among three key population groups. The study location comprised of rural and urban areas in order to capture different perspectives from these different population groups. The urban area selected was Kampala City, while the rural areas were represented by respondents from Mukono and Wakiso Districts. The study population comprised of religious leaders, people living with HIV/AIDS and caregivers of children affected by AIDS.

Selection of caretakers (teachers) was undertaken with the support of the Uganda National Teachers Union (UNATU). Deliberate efforts were made during selection to ensure teachers with the experience to deal with HIV+ children in schools were contacted from both primary and lower secondary schools. Gender balance was also considered in the selection of teachers. Selection of parents and institutional caretakers was done with the help of National Forum of PLHIV Networks in Uganda (NAFOPHANU) and Uganda Women's Effort to Save Orphans (UWESO). Field officers from these organizations were given the selection guide and asked to nominate names of individuals (for the case of NAFOPHANU registered PLHIV clubs) and caretakers (for UWESO) for vetting by the research assistants. The selection of PLHIV was undertaken with support from NAFOPHANU, which is a national network and thus ensured the sample selection had a national dimension. PLHIV were selected from men’s, women’s, and youth clubs registered with NAFOPHANU within the districts of Kampala, Mukono and Wakiso.

The selection of religious leaders was through national religious institutions, which enabled the study to obtain a national outlook from the participating denominations. The religious groups that participated in the study included, the Anglican Church (Church of Uganda), the Catholic Church, the Moslem Community, the Orthodox, the Pentecostal Churches (through the National Fellowship of Born Again Churches in Uganda) and the Seventh Day Adventist Union in Uganda. These are the most dominant religious organizations in Uganda. They were selected from Kampala where most of these institutions have their headquarters. It was thought that the doctrinal positions and practices elicited would be representative of the country.

2.2 Description of data collected for study
The study was qualitative and conducted through focus group discussions with the target audiences. The FGDs were held in August 2008 while key informant interviews with religious leaders representing the six selected denominations in Kampala were held in December, 2008 and January, 2009. These interviews
supplemented the data from the FGDs with the religious leaders. In all, six FGDs were held, comprising of three for caretakers of HIV+ children (males, females and teachers), two for PLHIV (male and female) and one for religious leaders. The table below summarizes the composition of FGDs held.

<table>
<thead>
<tr>
<th>Category</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caretakers</td>
<td>18</td>
<td>19</td>
<td>37</td>
</tr>
<tr>
<td>PLHIV</td>
<td>11</td>
<td>18</td>
<td>29</td>
</tr>
<tr>
<td>Religious Leaders</td>
<td>3</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>32</strong></td>
<td><strong>41</strong></td>
<td><strong>73</strong></td>
</tr>
</tbody>
</table>

2.2.1 **Focus group discussions with PLHIV**

2 focus groups, one for male and one for female respondents were held in Kampala. The main topics for discussion included understanding the concepts of stigma and discrimination, community attitudes towards PLHIV in regard to stigma and discrimination, experiences of PLHIV regarding stigma and discrimination, impact of stigma and discrimination, and suggestions for addressing stigma and discrimination.

2.2.2 **Focus group discussions with caretakers of children affected by HIV/AIDS**

3 focus group discussions were held with caretakers of children affected by HIV/AIDS. Two categories of caretakers, namely parents/guardians and teachers, were targeted by the study. Two FGDs with parents/guardians and one FGD with teachers were conducted. The topics for discussion focused on caretakers’ knowledge of stigma and discrimination, community response towards children living with HIV/AIDS, stigma and discrimination by caretakers, impact of stigma and discrimination on children, obstacles to overcoming stigma and discrimination, and proposals for responding to stigma and discrimination.

2.2.3 **Focus group discussion with religious leaders.**

1 focus group discussion was held with religious leaders. This FGD focused on the personal understanding of stigma and discrimination, manifestations of stigma and discrimination within their religious communities, and relations between religious leaders and PLHIV.

2.2.4 **Key informant interviews**

Key informant interviews were held with clergy who provided complementary information to the FGDs with religious leaders. Religious leaders were selected based on their position within the church. Those who were deemed to be in a position that empowers them to articulate the official positions of their religions
concerning HIV and AIDS stigma and discrimination were asked to participate. The six key informants represented the Catholic Church, the Church of Uganda, Uganda Muslim Supreme Council, the Orthodox Church, Seventh Day Adventists Church and the Fellowship of Born Again Churches in Uganda.

2.3 Data analysis

The analysis of data included transcribing of tape-recorded data into text. The transcripts were reviewed to delineate issues relevant to the research questions and objectives. Analysis of data was done thematically. Sub themes were developed from the study objectives and the data collected. The issues were reviewed to extract key insights, explanations, interpretations and quotations. In the report, quotations made in the FGD and key informant interviews are utilized to illuminate the knowledge and attitudes of respondents.

2.4 Ethical Considerations

All respondents who participated in the FGDs and key information interviews were given information concerning the study objectives. Respondents were not promised any immediate benefit from their participation, but were informed that the findings of the study would be used as an input for the development of the national communication strategy on HIV stigma and discrimination. Participation of the respondents was voluntary. Respondents were assured of confidentiality. The names of the respondents are not disclosed against the quotations that are extracted from the transcripts of FGDs and interviews.
Presentation and discussion of findings

The next chapters present the findings of a study on the knowledge, attitudes and practices related to HIV/AIDS stigma and discrimination among three key target audiences; PLHIV, religious leaders, and caretakers. The findings of the study are presented separately for each of the target audiences starting with people living with HIV/AIDS in Chapter 3, followed by caretaker audiences in Chapter 4; and religious leaders in Chapter 5.
3.0 Responses generated from the PLHIV

3.1 Knowledge and Attitudes of PLHIV towards Stigma

In this section, findings on the knowledge and attitudes of PLHIV towards stigma and discrimination are presented in five themes; 1) definition of stigma, 2) definition of discrimination, 3) attitudes and perceptions of stigma, 4) identification of stigma and discrimination, and 5) the extent to which stigma and discrimination are perceived as issues.

3.1.1 Definition of Stigma by PLHIV

PLHIV are knowledgeable about stigma. They were able to offer varied definitions of stigma, which demonstrated that PLHIV possess a clear understanding of stigma. This knowledge did not change between men and women. PLHIV are aware that stigma is a negative attitude ascribed to individuals because of their HIV status. PLHIV definitions of stigma related to loss of social status of an individual on the basis of their HIV status. The quotations below are extracted from FGD transcripts to show the understanding the PLHIV audience has in regards to stigma and discrimination.

“It is having negative thoughts or feelings about a person, or the attitude towards PLHIV.” (Male FGD)

“It is a state that causes someone dishonour, shame, disrespect..., causing those feelings to someone who is either HIV positive or suspected to be living with HIV AIDS.” (Female PLHIV)

“To me, I think it is an attitude, towards someone because of their HIV status. People begin to talk, backbite and mistreat him or her.” (Female PLHIV)

Individuals within this audience were aware that an individual who is stigmatized is at risk of losing respect from society and undermining their social status. Stigma was associated with loss of personal dignity, self-respect and worth of an individual. While most of the discussion focused on HIV/AIDS instigated stigma, PLHIV are aware that stigma is a broader phenomenon that can apply to situations where individuals or groups carry labels that are considered socially inappropriate and demeaning.

“Stigma is not only related to HIV/AIDS, if you are too fat, you may stigmatize your self or the community will stigmatize you. If you are disabled, likewise, so stigma in this case would be a state of negative attitude in relation to an individual in relation
The PLHIV target group is able to distinguish between different types of stigma, specifically enacted stigma and self-stigma. In both the male and female group discussions, there was a clear understanding that stigma emanates from both the wider community, and the affected individuals. PLHIV are aware of the existence of enacted stigma, which is experienced when others behave in a way that labels and discriminates an individual or group because of their HIV status. They are also aware of self-stigma, which originates from personal insecurities and inadequacies, resulting from feelings of the individual about their HIV status and the fear of repercussions of others towards an individual who is affected by HIV/AIDS. PLHIV groups reported that in some cases, HIV/AIDS stigma was self-inflicted, and that people with HIV are self-conscious and tend to experience stigma even when others in the community were not behaving in a way that communicates stigma and discrimination.

“In my own opinion, stigma is two-way traffic; I can stigmatize myself and the surrounding community or society also stigmatizes me. So, in brief, I think, stigma is where by you get to know your sero-status and after understanding that you are HIV positive, you start (you yourself within your mind), thinking, “that person looking at me knows that I have HIV.” (Male PLHIV)

“It is an attitude you get, if you are HIV positive, either from an individual, society or even at a personal level. Because it varies, someone might not have disclosed to anyone, but feels fear, that they saw me going to a counselling room at some clinic and I met so and so. Maybe, he or she knows that I am HIV positive. So at the end of the day, the PLHIV stigmatize themselves, they become uncomfortable.” (Female PLHIV)

“Like self-stigma, if you are told that you are HIV positive, you think about the way forward. Look at me...Now how will I be? That is self stigma; you can even drop out of the job.”(Female PLHIV)

The above quotations demonstrate that PLHIV are knowledgeable of stigma. They are also aware that stigma is external, propagated by others, as well as internal, resulting from the fears and insecurities of the affected individuals.

PLHIV are aware that stigmatizing people affected by HIV and AIDS results from lack of knowledge among the population.

“I think that all this is brought about by ignorance. If somebody suspects to be infected, they then believe they are to die and that it was God’s plan. Whether you have AIDS, fever, or whatever disease, you have to know that you have to die. So if people know that AIDS is like other diseases, they
would not be discriminating people with HIV. They should be sensitized to know that this is a normal disease whereby anybody can get infected.”
(Female PLHIV)

3.1.2 **Definition of discrimination by PLHIV**

The focus group discussions with PLHIV did not explicitly focus on the target groups’ understanding and definition of discrimination. Nonetheless, group participants alluded to discrimination and demonstrated awareness of the concept. The discussions showed that PLHIV are aware that discrimination constitutes acts associated with isolation and unjust treatment of an individual on the basis of their HIV status. Discrimination was linked to isolation against PLHIV. This isolation can be initiated by the PLHIV themselves, or by the rest of the population.

“To isolate yourself from others because you feel you do not fit in there. You go by the side and isolate yourself or they isolate you. They may give you two or three reasons as to why you should not be with them. That is discriminating.” (Male PLHIV)

PLHIV further noted that they were generally regarded as an inferior population group, which resulted in discriminatory tendencies and practices.

“People with HIV suffer discrimination because they are regarded as second class citizens. They are hence denied most of their privileges because of their status.” (Male PLHIV).

However, the ensuing discussion showed PLHIV had a limited understanding of discrimination. They mostly associated discrimination to exclusion and denial of employment opportunities and access to social services such as health care and education. They did not conceive discrimination as a human rights violation. Although HIV/AIDS discrimination is a violation of human rights, then PLHIV FGDs did not associate discrimination to human rights violations.

3.2 **Attitudes and perceptions of stigma towards PLHIV**

The focus group discussions reveal that PLHIV are generally apprehensive about HIV/AIDS stigma and discrimination. A person living with HIV takes on a new identity that arises from stigmatizing attitudes. This attitude represents felt-stigma where PLHIV are fearful of others’ reactions towards them, as well as self-stigma where PLHIV act as though they are stigmatized, even if when this is not the case. Discussions with female PLHIV showed that there is a belief that once people suspect or find out that a person has HIV/AIDS they automatically perceive them differently and begin to treat them in a stigmatizing way.
“Once people suspect or confirm that you have HIV, they begin to talk about you. Once they know your status, they develop a negative attitude towards you.” (Female PLHIV).

In the discussions, male PLHIV also confirm that once an individual is known to be living with HIV and AIDS, then this leads to loss in their personal dignity. PLHIV report that they feel inferior to others in society. Subsequently, as a coping mechanism, some PLHIV prefer to keep their HIV status a secret. People living with HIV/AIDS experience attitudes of fear and uncertainty about the future. They also worry about coping with HIV and AIDS. These feelings translate into self stigmatization. FGDs show there is a lot of fear associated with discovering other people suspect or know a person has HIV or AIDS. There is fear that once people know a person is HIV positive, they will begin talking evil of them and stigmatizing them.

“...due to fear of stigma, you do not disclose your HIV status because of the fear to lose your dignity. You are convinced that they will talk about you which will result in your loss of dignity. So you decide to keep silent, never disclose what you are.” (Male PLHIV).

PLHIV also perceived HIV/AIDS stigma and discrimination to be a result of the association of HIV/AIDS to sexuality and sin. HIV/AIDS is not perceived as any other disease, rather it is closely linked to sex and morality. PLHIV are conscious that disclosure about one’s HIV status exposes him/her to being discriminated against on the basis of suspicion of immoral sexual behaviour.

“...most people assume that someone with AIDS is immoral. They do not realize that there are other ways of transmission. They simply believe that if someone has AIDS, they must have acquired it through immoral behaviour. They associate you with criminals and hence discriminate against you.” (Male PLHIV)

PLHIV also experience apathy and feel they are perceived as failures by the rest of society. PLHIV feel that they are considered to be worthless individuals, who lack the ability to meaningfully contribute to society.

“When people look at us, they think we are just complete failures in life and that there is nothing much we can achieve even when we are to be given a job. Yet we are people who have potential to do any work available.” (Male PLHIV)

HIV/AIDS stigma and discrimination varies in relation to the physical condition of a PLHIV. PLHIV are most likely to feel stigmatized when they are critically ill. As long as someone is healthy and does not have AIDS opportunistic infections, they may not experience stigma. It is during times of sickness when one needs acceptance that they are more likely to encounter stigma and discrimination.

“Stigma depends on what stage you are. If you are still looking healthy, people will pretend to be very supportive and everybody seems to be there for you. They even
consult you for your ideas because you are productive and can support them in some ways. However when your health deteriorates, and you are possibly on your death bed then things turn around. Even this person you expected to support you will start fearing even to touch you. They may come around to see you, but they fear touching you thinking they will get infected in the process.” (Female PLHIV FGD)

3.3 Practices that promote stigma and discrimination towards PLHIV

HIV/AIDS stigma and discrimination is experienced by PLHIV in various settings such as the home, workplace, schools, health units and community. PLHIV discussions revealed PLHIV suffer from self-stigma, enacted stigma and discrimination in these various settings. According to PLHIV, stigma and discrimination can be identified through care practices, and how others respond to the PLHIV. The findings below show practices in different settings demonstrating stigma and discrimination against PLHIV.

3.3.1 Stigma and discrimination towards PLHIV at the workplace

At the workplace, PLHIV experience enacted stigma and discrimination. Enacted stigma occurs when work colleagues display negative attitudes towards PLHIV, while discrimination is experienced when PLHIV are sent away from work, or denied opportunities for career growth at the workplace.

3.3.2 Enacted Stigma at the Workplace

Enacted stigma at the workplace is also experienced when workmates talk negatively of PLHIV, tending to demonize him/her by considering them to be immoral. Workmates sometimes openly refuse to associate with PLHIV. In some instances, the affected PLHIV are not able to withstand the situation, and opt to voluntarily leave their jobs.

“I tested for HIV when I had just finished college. At that time I was a school teacher in a Catholic-based secondary school. However, my positive sero-status forced me to leave the teaching profession hoping to find solace elsewhere. Whenever we were seated in the office, my colleagues would bring out stories of people infected with HIV, relating those people immorality, prostitution or as people with multiple partners. I could not imagine myself sharing into such discussions. I was always uncomfortable, so I had to leave the teaching profession to find work with other groups who could accommodate me.” (Female PLHIV)
3.3.3 **Discriminatory practices towards PLHIV at Workplace**

In the discussions, PLHIV reported that they were faced with threats of imminent loss of employment, due to a positive HIV status. Employers were skeptical about the ability of PLHIV to continue work. Employers also wanted to avoid the costs associated with employing a PLHIV, such as medical costs and costs associated with absenteeism. Workplaces fail to support and provide care for their employees when they become ill with HIV/AIDS. Supervisors block the promotion of staff who are HIV positive. In some cases, PLHIV are reassigned to lower positions within the organisations. Some PLHIV reported they had lost their jobs due their HIV status.

“When I disclosed my HIV status to my head of department they terminated me.”
(Male PLHIV)

“Employers do not want to give care to PLHIV when they become sick. Instead of giving care to this person and support him so that he can continue with his work, he looks for a replacement. This is stigmatizing.” (Male PLHIV)

3.3.4 **Stigma and discrimination experienced in the home by PLHIV**

Although the home is supposed to provide a loving and caring environment, PLHIV experience stigma and discrimination in their homes. Results show a belief among some PLHIV that HIV/AIDS stigma and discrimination at the household level is gender-based. Female PLHIV are more stigmatized than men. PLHIV reported that when men test positive, they expect to receive a lot of support and care from their spouses. On the other hand, when the women test positive, the men are not willing to support them.

“In some communities when a married woman has tested positive, they are not given support. However when the husband tests positive, they expect maximum support from their wives.” (Female PLHIV)

Lack of spousal support was cited as a major form of HIV stigma and discrimination by female PLHIV. Discussions show that some men failed to support their spouses and instead abandoned them. This increases stigma and leads to discrimination among the affected persons.

“...often when a married woman is known to be HIV+, the husband will leave her ‘to suffer on her own’, it is assumed she knows best how she acquired the disease. She is left to fend for the children and to seek her own means of survival. The husband even goes ahead to remarry and start another life elsewhere.” (Female PLHIV)

These findings reflect the literature, which contends that HIV-related stigma and discrimination is tied closely to the gender-based roles, capacities, and potentials in each society (Mukasa 2008). Regardless of who first contracts the virus for couples,
the blame is often directed to the women. This is attributed to the belief that women are expected to uphold the moral traditions of their societies, and the presence of HIV is regarded as evidence of their failure to fulfil this important social function (Bond, Chilikwela et al. 2003 quoted in Mukasa 2008).

### 3.3.5 Enacted stigma against PLHIV in the home setting

One of the ways through which PLHIV experience stigma is when family members and friends begin to treat them as if they were already dead. This practice is manifested when family members scramble for and distribute the property of bedridden PLHIV, even before the latter pass away. PLHIV also reported that some family members were scared about the burden of care associated with long illnesses and preferred that the PLHIV died quickly, as a way of saving resources that would otherwise be spent on caring for the sick.

“In some families, once they get to know that your HIV positive their prayer is that you ‘die quickly’. They try their level best to stress you so that you can pass away in a very short period of time to take your possessions. This happened to my colleague. All of his property was taken because he was bedridden. However when he unexpectedly recovered, very serious family wrangles took place.” (Male PLHIV)

“There are some families which are so bad. When they hear that you are HIV positive they tend to really look at you as if you are not living.” (Female PLHIV)

The lack of caring professionals in Uganda means family members have to take-up the care-giving roles when a close relative becomes bed-ridden due to AIDS. Many family members lack the knowledge and skills to provide quality care and nursing services for PLHIV. Caretakers are stressed and overwhelmed by the caring responsibility.

Caretakers stigmatize PLHIV when providing care. For example, there are cases where PLHIV are denied food and/or are not cleaned when they defecate. Soiled clothes are not washed; they are kept until the PLHIV gets better and gains enough strength to wash their own clothes. This kind of treatment does not happen when people are sick with other ailments such as malaria.

“My mother-in-law has lost so many children to HIV. Recently she had another daughter who was suffering from diarrhoea and vomiting. She did not want to touch her and she would push everything she uses under the bed saying that ‘when she gets better, she will wash herself.’ One day she openly stated that ‘We should stop giving her food, because when we give her food, she vomits.’” (Female PLHIV)

Because of the stigma and discrimination that accompanies HIV and AIDS, families need to handle the information that a member is HIV positive with care. In some cases however, the news that a family member has HIV is not handled sensitively
and in confidence. All members within a family are told about the positive status of an individual, and yet they may not have skills or ability to treat such information confidentially. In some cases, family members, including children will tell other people about the HIV status of the affected individual. This is stigmatizing to PLHIV.

“There is a girl whose mother was HIV positive. When the mother died, the girl went to live with her father. Her step mom openly warned the other children to be careful with her since she is HIV positive. ‘You do not have to share the basin and utensils.’ The children revealed this information to the neighbourhood. They were also telling everybody to be careful.’ Eventually wherever the girl would go, they would tease her that she is bound to infect them.’

PLHIV also experience enacted stigma when a chronically ill AIDS patient is transported to the village (i.e. to their ancestral burial grounds) in anticipation of their death. This is usually done to avoid costs of transporting the dead body. PLHIV are not consulted when decisions are made to transfer them to the villages. Such practices communicate to the affected PLHIV, that the family has given up hope, and want to see them dead.

“One of our colleagues was bedridden and they transferred her to the village and put her in a house at their burial place. This was because they wanted to save of the high costs of transporting her for burial. However when she did not die and when she returned from the village, she was so bitter, saying ‘they wanted to bury me when I am still alive’. I do not want to go back there since I no longer recognise my mother as my own.’ She was so much stigmatized.” (Female PLHIV)

3.3.6 Self Stigma faced by PLHIV in the home setting

Families caring for people with AIDS make attempt to adopt infection control practices in order to minimize illness within their households. Infection control within the families comprises of separating utensils and other facilities used by the PLHIV from those used by the rest of the household members. This practice is viewed by the PLHIV as discriminatory and stigmatizing. PLHIV who are already experiencing felt stigma tend to translate family level infection control practices as unfair, which results into self-stigma. This illustrates the need to sensitize PLHIV and their carers that the virus cannot be transmitted through sharing utensils and implements for washing or eating.

Sometimes family members and communities stigmatize PLHIV unintentionally as they try to help them. Out of concern, some family members offer to assist PLHIV, even where the latter feel they do not need help. Offering help, where it is not needed, makes the PLHIV feel worthless. This help comes at a time when PLHIV want to prove their independence and self reliance, and as such assistance may not be welcome.
People living with HIV/AIDS at times experience stigma and discrimination when they are recipients of acts of kindness and compassion. When caretakers and others offer to help PLHIV, this makes the latter feel inadequate and stigmatized. Caretakers unintentionally stigmatize PLHIV when they pamper and treat them as individuals with exceptional needs and who require assistance with every detail of their lives. PLHIV want to prove that they are persons of worth who are capable of making valuable contribution to society. In this regard, offers of help may signal to the PLHIV that they are no longer capable of doing anything valuable.

“There are often great concerns about a person’s health. However the PLHIV at times feels stigmatized especially when dealing with large groups.” (Female PLHIV)

“...In some ways caretakers are of great help. However in other situations they indirectly stigmatize you without even knowing it. For example, they might say, ‘ohh..., it is so cold, you do not have to do this, you are not well.’ It is feeling for someone, but it is also stigmatizing.” (Female PLHIV)

3.3.7 Discrimination against PLHIV in the home setting

One of the reported common practices within families is the exclusion of a PLHIV in family discussions and decision-making processes. PLHIV are denied the opportunity to participate in family level decision-making. People living with HIV/AIDS feel discriminated against when they are not given an opportunity to participate in activities on the basis of their HIV status. They begin to feel that they are not of any use to their families.

“...Though everyone is aware that we are living, they do not consider us as adults. If we are in a family meeting and you say something, they will openly tell you that you no longer think straight.’ Nothing of value is expected from us.” (Female PLHIV)

In some cases, families are hesitant about spending money on medical and non-medical needs of PLHIV, because of fear they may not recuperate completely.

“Other families believe that spending any resources or funds on an HIV positive person is a complete waste. So they consider people who are HIV positive to be of no use.” (Male PLHIV)

Children infected with HIV/AIDS are often denied the opportunity to attain education. Education is seen as an investment and families are not willing to invest in the education of children, whose chances of surviving up to adulthood are in the balance. Information from the PLHIV indicated that although ARVs have become more available and accessible, compared to the past, there is insufficient public knowledge regarding the benefits of ARVs. The views that children with HIV/AIDS will die continue to persist.
“In some cases children are denied education because they are HIV positive. Take for example orphans who are HIV positive tend to miss out on education since relatives say this is a waste of time as they are going to die any time. There is lack of information that people can live long if they are on ARVs.” (Male PLHIV)

The above findings show that there is a lot of stigma and discrimination directed to PLHIV by family members at the household level. PLHIV tend to experience self-stigma, enacted stigma and discrimination within their homes. The family is a basic unit of society, responsible for providing love and support to its members. The family however lacks adequate information and skills to respond appropriately to the needs of PLHIV and has become a proponent for stigma and discrimination.

3.4 Stigma and discrimination faced by PLHIV at community level

At the community level, there are practices that tend to lead to enacted stigma among PLHIV. Some PLHIV have experienced situations where the communities in which they live fail to see HIV/AIDS as the problem, but instead focus on those who are HIV positive as the problem. This often results in labelling and treating those with HIV as a category. Community members fail to recognize PLHIV are individuals, with inherent dignity, feelings and rights. In the discussions, some participants shared experiences where communities treated PLHIV as a category, which dehumanized them and made them feel stigmatized.

“The community’s ideas towards HIV positive people are unfriendly and inhuman. For example, I was in Kumi for training and the community said all HIV positive people should be killed to get rid of the virus. Another one said they should have a unique spot, so they can be easily identified. These are dehumanizing statements.” (Male PLHIV)

Statements, such as the one above have profound stigmatizing effects on PLHIV, especially when stated explicitly. The community attitudes perceive PLHIV as unworthy, leading to stigma and discrimination.

PLHIV experience stigma through names they are called and labels that are used to refer to them which are often derogatory and have negative connotations. They imply usefulness and death. Most of the names given to PLHIV were in vernacular. The names and their interpretations are presented in the text below: Yayibika (he/she burst), nakawuka (someone with the virus), omulambo ogutambula (a walking corpse), abembwa beyaluma (one who has been bitten by a dog), wolira wofira (you die at the eating place), abekika (clans mate), abekikosi (people in the same camp), omusayi gwafee (of the same blood), Abensenene (having the virus).

Some of the terms used like clan’s mate, people in the same camp, of the same blood were coined by PLHIV to refer to each other, but have since been taken as stigmatizing. It is observed that such names are only positive as long as they are
used among the PLHIV. Once the general population learns about and begins to use terms coined by PLHIV, the terms takes on a stigmatizing and negative connotation.

“Abembata, Abensenene, Abekika- were started by PLHIV themselves though and were taken on by the rest of society. They are now negative names.” (Female PLHIV FGD)

The use of names to refer to PLHIV makes them feel that they are being stigmatized. It denies them the feeling of individuality.

“The names are negative and discriminating. For example, when I was passing through the market, one of the people shouted out to me, calling me out, ‘welira’. I felt bad.” (Female PLHIV)

From the above, it can be inferred that, through their own innovations with names, PLHIV inadvertently contribute to stigma, which arises out of the process of labelling and identify others within their group. In seeking to identify each other, PLHIV coin names that may later turn into stigmatizing terms.

Stigma faced by PLHIV is all encompassing and often extends to other members of the family, particularly children. The tendency to associate children of PLHIV to their parents HIV status is stigmatizing. PLHIV experience a lot of stigma when their children are suspected to be HIV positive. While PLHIV want to protect their children from the pain that comes with stigma, they are almost helpless. From the discussions, it is observed that a parents’ HIV positive status automatically arouses suspicion about their children. Children of PLHIV are usually suspected to be HIV positive which is stigmatizing to both the PLHIV and the children.

“...much as my kids are HIV negative, it is very difficult to convince people not to think so. For instance I have a daughter who small in size but they can not believe when I tell them that my kid is negative. Each time the girl falls sick they I should take her for medication for AIDS patients.” (Female PLHIV FGD)

3.4.1 Self Stigma faced by PLHIV at Community Level

Acts of kindness that stigmatize PLHIV are not limited to personal care activities but extend to the community. Some communities are sensitive to the unique needs of PLHIV and make public display of care, which the PLHIV may find stigmatizing. In some cases, PLHIV are given first priority to eat food at public functions in recognition of their nutritional needs.

“Some people stigmatize us, but when in actual sense they are trying to be helpful. For example, they may say, ‘oh, you positive ones go eat first.’ They may want to make us feel welcome and make statements such as, ‘we would like to recognize our positive clients.’ Recognizing us in public is shameful...” (Female PLHIV)
HIV/AIDS stigma affects even those PLHIV who have openly disclosed their status. While it is commonly believed that being open about one’s HIV status is a key milestone in addressing stigma, experience shows that stigma is prevalent even among those PLHIV who are open about their HIV status. PLHIV who have come out in the open about their positive status are selective about whom and where to disclose their status. Group discussions revealed that some PLHIV who have come out with their positive status, avoid being openly associated with groups that provide support to people living with HIV/AIDS.

“We have even seen people who claim to be open about their status running away when we are doing home visits simply because of a vehicle which is known to be from an HIV/AIDS support organisation is turning into their compound. Often these are visits on appointment. These clients behave as if they do not know the service provider. This is they do not fear the service but the stigma they will receive after the visit.” (Female PLHIV)

“By the way, people disclose up to a certain level and only to some individuals. For instance at a party, this individual would not like to be publicly recognized on the basis of their status. This is because much as they have disclosed, it was at a different level and not at the community level.” (female PLHIV)

### 3.5 Stigma and discrimination faced by PLHIV at health facilities

Health workers discriminate against PLHIV in health facilities. They treat PLHIV differently from other patients. Some health workers are rude towards the PLHIV and lack respect for PLHIV. This affects the quality of care that PLHIV receive.

“You will realize that in some instances health workers who are HIV negative normally discriminate or stigmatize their clients. For instance nurses tend to stigmatize the clients in the way they talk them.” (Male PLHIV)

In order to improve access to treatment, health facilities have designated HIV/AIDS clinics run for PLHIV. However, findings from the study show that having separate clinics or facilities for PLHIV was stigmatizing. Anyone attending these facilities is stigmatized and automatically labelled as an HIV+ person. This may mean that some people fail to seek services, out of fear of being labelled.

“….look at Mulago. They had known that is it 4C! When some body hears that you are in 4C they will just assume you are HIV positive.” (Male PLHIV).

### 3.6 Impact of stigma and discrimination on PLHIV

The research considered the impact of stigma and discrimination from the perspective of PLHIV. Among the PLHIV, stigma and discrimination is perceived as a problem, particularly with regard to the behaviour that results when they are
silenced and unable to disclose their status. It fuels the epidemic because PLHIV will also want to have normal relationships, to quell any suspicion that they could be hiding something. There is also knowledge that HIV/AIDS stigma is a barrier to access of HIV and AIDS services among PLHIV. This target audience identified the failure to disclose HIV status as the most dominant impact of stigma and discrimination. The fear of stigma and discrimination makes it difficult for PLHIV to disclose their status. Although they recognize the need to disclose, PLHIV are apprehensive because of the likelihood of rejection and stigma.

“Stigma is that big hindrance to disclosure faced by the majority of PLHIV. We know the consequences of disclosure. I would rather die without disclosing because I know what I am going to face. We have seen so many people facing it. We have good people who are HIV positive who can do good work but say no because of stigma.” (Male PLHIV)

### 3.6.1 Impact of stigma and discrimination on medication

FDGs revealed that when PLHIV face stigma and discrimination they would prefer to die than take up medication. There is recognition among PLHIV that HIV/AIDS related stigma has adverse consequences on prevention. PLHIV are aware the stigma enhances secrecy, discourages disclosure, and hinders prevention of the spread of HIV. PLHIV discussions identified denial as an impact of HIV stigma and discrimination. Some PLHIV are afraid of the consequences of living with HIV and fail to come to terms with the reality of their status. In some instances, some PLHIV turn to religious leaders for prayer and healing. Those who are convinced that they are healed may fail to access the necessary care and support services, which has implications for the HIV response. Some PLHIV also denied that they are HIV positive and instead attribute their failing health to acts of witchcraft.

“There is continued denial. There are so many people who are aware of their HIV sero status but they feel they are not affected. They go to pastors for healing and start believing that they are healed.” (Male PLHIV)

PLHIV isolate themselves from their communities due to the fear of stigma and discrimination. PLHIV keep away from the public eye as a coping mechanism.

“Because you feel stigmatized then you face self-stigma. You realize that when you go out, community members will start stigmatizing your. You hence stop attending meetings, you don't access services, you do not talk openly about what the problem could be, and then you could end up even dying.” (Female PLHIV)

### 3.8.2 Impact of stigma and discrimination on prevention

Some people who test HIV positive cannot disclose their status because of stigma. This has serious implications for HIV/AIDS interventions. For example, mothers who
seek PMTCT to minimize the chances of infecting their babies with HIV/AIDS are not able to follow all the advice given by health workers, particularly regarding nursing practices. Discussions with PLHIV reported that because of fear of rejection by spouses, family, and community members, PLHIV fear to disclose their HIV status and make wrong decisions in an attempt to quell suspicion. Focus group discussions with female PLHIV disclosed some women continued to breastfeed their babies, even when they knew that it was risky, because of fear of arousing the suspicion of others around them.

“There is an HIV positive woman who wanted to be a mother. She went for counselling and was trained on how to deliver without infecting her baby. However she did not disclose to her husband. She also realised if she did not breastfeed, the community would find out about her status. She hence resorted to breastfeeding her baby, even going beyond the months she was supposed to. So, at times we do these things, not because we lack information, but we fear the surrounding we are living in.” (Female PLHIV FGD)

3.7 Barriers to overcoming stigma and discrimination
PLHIV identified several barriers to overcoming stigma and discrimination, including low response to HIV counselling and testing (HCT), fear, weak policy environment and lack of accurate information.

3.7.1 Fear of loss of social status
Uncertainty about the response of significant others is also a barrier to overcoming stigma and discrimination. PLHIV have a frontline position in the fight against stigma and discrimination. The PLHIV are however faced with fear over the reactions of others, when they find out their HIV status. Fear of rejection and uncertainty of future social relations after disclosure means that some PLHIV do not disclose and are not able to lead the crusade against stigma and discrimination.

3.7.2 Inadequate legislative and policy environment
PLHIV identified the lack of laws and policies to protect PLHIV against stigma and discrimination as a major barrier. The weak legal environment means that people who stigmatize and discriminate against others are not held responsible. The lack of HIV related laws that address stigma by asserting social norms of respect and equality for PLHIV, their families, and those at risk of contracting HIV are a major barrier to addressing stigma and discrimination. The laws that guarantee the rights of PLHIV to education, employment, confidentiality, information, and treatment are either weak or not adequately enforced.

“Lack of laws and polices to protect individuals against stigma and discrimination is another barrier. Some time back there was news of a child who was sent away from school. He was HIV positive and I think up to now nothing has been done. So, lack
of laws has also contributed to stigma and discrimination yet nothing is being done to protect them.” (Male PLHIV)

3.7.3 Ignorance and lack of sufficient knowledge

PLHIV identified the lack of adequate knowledge about HIV and AIDS as one of the barriers against addressing HIV stigma and discrimination. Many people are not aware of the distinction between HIV and AIDS. As a result, individuals think people who are HIV positive are sick, and on the verge of death. This means that PLHIV continue to be treated as if they are dying soon. Stigmatizing labels like the “living dead” continue to be relevant to most people when referring to PLHIV. PLHIV also believe there is insufficient knowledge on HIV transmission. They reported that some people believe casual contact with PLHIV can lead to HIV infection.

“It is believed that most people know about HIV transmission, but others do not know. They think that when they sit, eat or do something with someone with HIV, they can get the virus. Others consider putting any resources or funds into an HIV positive a waste. They consider people with HIV to be of no use.” (Male PLHIV)

PLHIV also attributed lack of sufficient information to low response towards HCT services as a major barrier to overcoming stigma and discrimination. In addition, lack of knowledge among the population about their HIV status leads a low perception of risk. Many people do not identify with HIV at a personal level and fail to see how it can affect them. PLHIV believe that failure of people to go for HCT is the reason for the persistence of stigma and discrimination.

“I would say most of the people or good number of people do not come out to go for VCT and this really is the reason why stigma and discrimination is on the increase. People have not tested but think they are negative.” (Male PLHIV)

3.8 Proposals to reduce stigma and discrimination by PLHIV

With the exception of fear of loss of social status all the proposals to address the barriers identified by PLHIV are directed to the public and policy makers. This is an indication that the fight against stigma and discrimination is not restricted to PLHIV but should be embraced by all population groups. The PLHIV provided suggestions on how stigma and discrimination should be overcome as follows:

3.8.1 Creation of public awareness through sensitization

PLHIV identified sensitization of communities on HIV stigma and discrimination as a major intervention and proposed that attempts to address HIV stigma and discrimination should begin where the people are. They suggest the starting point in
changing attitudes people have towards PLHIV lies with addressing the stigmatizing phrases that are currently used to refer to PLHIV.

### 3.8.2 Involvement of PLHIV in campaigns

According to PLHIV, interventions to address HIV/AIDS stigma should also target PLHIV themselves in order to help them to find ways they can respond to stigmatizing situations. While it is important to target non-PLHIV, it is even more critical to target PLHIV because they are most affected and their responses to stigma are critical in HIV prevention efforts.

### 3.8.3 Targeting religious leaders and caregivers

PLHIV recommended that messages on stigma reduction should specifically target religious leaders and caregivers. Religious leaders were identified as a target audience because of their influence on community attitudes. Caregivers were also identified because their responses and attitudes to PLHIV under their care are critical in determining the welfare of the PLHIV.

“Messages should be educative on how to handle PLHIV especially targeting caregivers. You might not be killed by the AIDS, but by how you are handled. Religious leaders should also be involved because they have a very big impact on people, and they greatly influence the society.” (Female PLHIV)
4.0 Findings from the caretaker audience

This chapter focuses on responses generated from caregivers, another key target audience for the campaign on stigma and discrimination. Caretakers of children affected by HIV/AIDS were divided into two sub-categories of caregivers including: 1) parents and guardians, and 2) teachers. Teachers are key agents of socialization because they spend a lot of time with children in school. As persons who are responsible for children during their formative years, teachers interact with children who are affected with HIV/AIDS and are likely to influence attitudes towards stigma and discrimination. The findings are presented in four areas: definition of stigma, definition of discrimination, attitudes and perceptions towards stigma, and the extent to which caretakers consider stigma and discrimination to be a problem.

4.1.1 Definition of stigma

Caretakers in the study are able to identify dimensions of stigma which include isolation, labelling, loss of self-esteem, neglect, shame, and loss of social status. Caretakers are also aware of enacted and self-stigma. They demonstrated the following understanding; stigma is an attitude, which is usually negative, directed towards a person on the basis of a characteristic they possess. The following quotations show how caretakers defined stigma.

“Stigma is being isolated and being pointed at, in a situation like if someone is positive.”

“Stigma is an attitude where by you are being pointed at or you have self-stigma. There are times when people look at you and you begin to think it is because you have AIDS. Then there is stigma that is caused by the community and by the schools.”

“Stigma means being neglected and ashamed of yourself”

Knowledge of stigma among caretakers was not universal. There was a mix-up among teachers between the definition of stigma and discrimination. Some teachers equated stigma to discrimination and isolation of individuals, while other demonstrated lack of clarity on the cause and effect relationship between stigma and discrimination. Some focus group participants described stigma as an effect of discrimination.

“I think that is a psychological part of torture one experiences as a result of discrimination or isolation or torture.” (Teacher FGD)
“For me I think stigma is being isolated and being pointed at in a situation, if someone is positive. Before counselling services became popular, fingers were pointed out that so and so is HIV positive. Once you knew that, you became isolated, and neglected in society. You can not be employed, just because you are, HIV positive.” (Caretakers FGD)

It is also observed that some respondents linked stigma to the resistance or unwillingness within an individual to find out their HIV status because of fear or uncertainty of what will happen.

“Stigma is to fear about your exact health status in relation to HIV/AIDS. When people are advised to go for an HIV test, they are reluctant because of finding out that they are already positive (sick). They always ask about what will happen? That is what we call stigma.” (Caretakers)

The above point illustrates that knowledge of stigma is not universal; rather it is a potential barrier to accessing HCT services.

4.1.2 Definition of discrimination

Some caretaker respondents provided descriptions for discrimination. Some teachers correctly identified discrimination as actions that result from stigma. Discrimination was associated with isolating individuals from the rest of society. Although not comprehensive, caretakers’ definition of discrimination was broad and encompassed some dimensions of human rights violations.

“Discrimination is isolation. They will not let you sit with them.” (Caretakers)

“For me, I think stigma leads to discrimination, for example, like we are here all together, I will not be allowed onto this table because I am being discriminated against. You don’t want to associate with me and deny me the right to associate.” (Caretakers)

4.2 Attitudes and perceptions towards HIV affected children which enhance stigma and discrimination

The caretakers’ focus group discussions identified attitudes within members of their communities that were said to be responsible for aggravating stigma and discrimination among HIV+ children. For example, HIV+ children are perceived as useless and have no worth to live. They are constantly reminded that their mothers are promiscuous. HIV+ children are dreaded by other children in their communities. They are seen as children whose parents were sexually immoral. It is believed that they are useless because of the imminent threat of death arising from their positive HIV status. The children are feared and shunned due to their poor health. In extreme situation, some people come to believe they are better off dead than alive.
“Some of these children are being abused by their fellow children, ‘saying look at this child, her mother died of HIV’. They criticize and abuse these children. They ask them questions like, ‘hey you, why was you mother promiscuous?”

“People fear associating with these kids because of the perceptions that the child would die soon.”

Biological parents whose children have HIV/AIDS perceive such children as a source of stigma. The children are seen as evidence of the parents own HIV positive status. Subsequently these children face discrimination from their own parents. The parents try to hide these children from public view, in order to conceal information of their own HIV status. Caretakers shared experiences where children were a source of stigma for their parents.

“Children who are HIV positive are said to be a source of shame to their caretakers. They seem to provide evidence to the public that both parents are also positive... For example, there was a man in my village who used to hide his wife and kid in the bedroom. When the woman died the grand mother revealed that child was also sick and needed medication. The man was extremely annoyed and threatened to kill the old lady. The local authorities came to the child’s rescue but it was almost dead. Shame hence greatly contributes to stigma and discrimination for children” (Caretaker FGD)

On the other hand, caretakers may not be aware that they stigmatize children, even when they are doing so. For example one caretaker said:

“The government should take action to reduce the stigma that these children suffer in schools building them separate schools, which will accept them.” (Caretaker FGD)

4.3 Practices that promote stigma and discrimination

The study focused on practices related to stigma and discrimination at the household level, in schools, health units, and within the family from the perspectives of the caretakers. The study identifies the type of stigma and discrimination within each context.

4.3.1 Stigma and discrimination in the home

Although the home should provide a foundation of love for children living with HIV, it was identified as the place where children experienced stigma and discrimination the most. According to caretakers, children with HIV experience enacted stigma and discrimination within households. Children living with HIV/AIDS are kept away from public view particularly when they are sick. Caretakers and parents do not allow the
children to venture outside the house. Their interaction with visitors is restricted and they are not allowed to play freely with others because of fear of risk of infection.

“...an HIV positive child is often kept away from greeting visitors because his physical condition would be used as an indicator that the parents might also be infected.” (Caretaker FGD)

“They are also not allowed to socialize with other children since these parents believe that their children will also be infected. They frequently warn their children to desist from playing with the HIV positive child.” (Caretaker FGD)

Caretakers often deny children with HIV/AIDS love and affection. This is particularly true for the total orphans, usually fostered by their extended families. They may be denied food and face discrimination. Within the family, there is fear about risks children living with HIV pose to other children who are not infected. Families are afraid children with HIV may pass on the infection to others. Caretakers reported fear of contracting HIV through casual contact as one factor that results in discriminatory practices. For example, separation of utensils, sleeping arrangements and reduced contact with children living with HIV. Caregivers communicate the fear of HIV infection through casual contact to other members of the family, who in turn stigmatise the PLHIV in the household. Children infected with HIV/AIDS are also affected by fear they will infect others with HIV.

“I know of a child who lost both parents and lived with a maternal uncle. While the uncle liked the boy, his wife completely disliked him. She had the fear that the boy will infect her children since he was constantly sick. Subsequently, the boy was thrown out of the house.” (Caretaker FGD)

Investment in health care and education for children living with HIV/AIDS are viewed with futility. As such, these children may be denied access to medical services because of the belief they are about the die. Children living with HIV/AIDS are not given an opportunity to develop their potential owing to lack of willingness to invest in their education. Education for children living with HIV/AIDS is generally considered a ineffective venture.

“They rights are denied, for example, the right to education. There are many incidences where children do not attend school because people feel that this is a waste of money since they are going to die.” (Caretaker FGD)

“...their education is not valued at all. For example a father of three had lost two of his children while they were in school. The one remaining child who is also HIV positive has already been withdrawn from school since it is believed he is going to die. He strongly believes that educating a child who is HIV positive will not be of any use. So their education in our communities is not valued at all.” (Caretaker FGD)
Lack of willingness to invest in children infected with HIV/AIDS was mainly associated with low family incomes. This is because families are confronted with several demands and yet have inadequate resources. As a result, they do not consider it prudent to invest the little that is available in the children who are living with what is considered to be a terminal illness.

“These children are treated negatively in our communities simply because they need special medical care and a good diet which require a lot of money. People continue to ask themselves why they have to spend all this yet this child is going to die anytime” (Caretakers FGD)

Parents of HIV+ children sometimes refuse to disclose to household members about the status of the children. Instead, they prefer some form of preferential treatment to the infected children. Although this is done with the intention of protecting the HIV+ child, it ends up putting a wedge between the infected child and the other children who may think that they are being treated unjustly.

“My wife and I have 10 children, seven are negative, three are positive. We find ourselves giving special treatment to the infected ones. At specific times you have to call them to the bedroom to take drugs. The other children are curious to know why they are always called to the bedroom to take drugs. We have not told them the truth. I do not know how to tell the children the truth.” (Caretaker)

4.3.2 Stigma and discrimination within schools

Children living with HIV/AIDS who attend school also experience stigma and discrimination from teachers and fellow children in several ways. There are cases when teachers refer to children with HIV/AIDS as ‘patients’, regardless of whether they have an illness. Some teachers also use stigmatizing phrases such as, ‘living dead’, when referring to children who have HIV. At another level, there is preferential treatment, where the children are not given heavy physical punishment because they are considered frail. Such responses by teachers to children living with HIV/AIDS may however be detrimental, leading to high levels of stigma among the children.

“Children with HIV are even called patients or the ‘sick’. Other teachers will often tell you that do not mistreat that child as he is sick even when he has no signs and symptoms.” (Teacher FGD)

HIV+ children are given names by other children, which are considered stigmatizing. Within schools, there is a tendency among children to create names, which they use to refer to those who have HIV. In some cases, these names result from the special treatment, which HIV+ children receive on account of their status.

“Like in my school, there are many children living with HIV but children give them nicknames like “munene munene.” Children who are living with HIV are sometimes
In some schools, teachers are kind and considerate towards HIV+ children. Although this was done with the objective of protecting these children and responding to their unique needs, it is sometimes construed to be stigmatizing.

“Because of sensitization, HIV+ children are given special care in schools. Teachers show them extraordinary love and care in most cases at school; they are loved, they are not allowed to do the sweeping, they get food earlier than the rest. Sometimes at school when teachers give extraordinary care to these children, it alerts the others to them. This sometimes results into negative feelings.” (Teacher FGD)

Participation of children living with HIV in some school activities that are considered strenuous are restricted. This may not always be done with the intent to discriminate, but may sometimes be perceived to be in the best interest of the child. However, this treatment may be perceived as discrimination by the affected children.

“At times people would not like them to participate in any some activities. However because of their status, they are often left to rest. This kind of sympathy is given to them just because of their status. The children are however left wondering why they are not allowed to participate or being stopped from joining the group.” (Teacher FGD)

4.3.3 Discrimination

Children living with HIV/AIDS face discrimination from other children in the classroom, particularly if the knowledge of their status is public. Children do not want to share their classroom desks with others who are HIV positive because of fear of infection.

“...in class children are supposed to share desks. However for those who are HIV positive, the other children are not willing to be close, hence keep on giving them space. This is because they think that sitting close may result in contracting the disease.” (Teacher FGD)

4.3.4 Stigma and discrimination within health care system

Caretakers reveal that health workers tend to regard the treatment of children with HIV/AIDS as futile and that spending time and resources to treat these children is considered a waste. Health workers pay little attention to children affected by HIV because of the belief that they will die anyway.
“When we get to health facilities, you find the health workers saying that, ‘you are wasting your time on that child.’” (Caretaker)

Even with the improvement in treatment options for PLHIV through increased availability of ART, some health workers continue to consider the treatment of HIV+ children worthless. Instead of supporting families, they discourage them by casting doubt on the possibility that these children can recover and live meaningful lives.

4.4 Stigma and discrimination at the community level

Focus group discussions with caretakers show that they experience stigma when other parents in the community caution their children against playing with those infected with HIV. Caretakers reported that people in their neighbourhoods perceive them to be HIV positive because they care for infected children. In this regard, parents within the communities instruct their children not to socialize with the caretakers, nor their children. There is fear among parents in the communities that caretakers of children living with HIV may deliberately pierce their children or engage in sexual relations with them, with intent of infecting them with HIV.

“They think we might stab their children because of jealous; that we might harm their children and let them catch HIV as well so they tell their children not to come to us. I have seen people around worry? What are you doing with that child? Why are you so much close to those children?” (Caretakers)

The focus group discussions with teachers and caretakers did not reveal any experiences of how teachers experience stigma and discrimination. This could mean that teachers who care for affected children are not associated with the stigma and discrimination that is directed towards the children.

4.5 Impact of stigma and discrimination on PLHIV

Caretakers identified a range of impacts of stigma and discrimination that are experienced by children whom are infected with HIV. The effects are mostly psychological, including, loss of hope, withdrawal, loss of self-esteem, and feelings of unworthiness. Some children also become vengeful and want to hurt others in return. Stigma and discrimination leads to anguish and hopelessness among the affected, arising from the belief that their chances of surviving childhood are nonexistent and they are a burden with no purpose in life. In some cases, children look forward to death as an escape from their situations. This has implications for their willingness to take medication.

Children with HIV withdraw from society due to stigma and discrimination. They feel unloved and unwanted, preferring to keep to themselves. Group participants shared experiences of children who isolated themselves from others, due to stigma and fear of being discriminated against. Withdrawal and isolation denies children the
opportunity to develop skills of relationship building and socialisation which are essential to an individual.

“I will give you an experience. I had this HIV child in my home, in a community we had just moved into. Whenever I went back home, I discovered on inquiry whether he had played with other children around he always kept to himself inside the house. This is because since he knew that he was HIV positive, he thought that the whole community would notice this and would stigmatize him. He declined to socialize with the other kids.” (Caretaker FGD)

Caretakers reported that stigma and discrimination compromises drug adherence, especially among children who spend time in the company of others within the school and community. Reports show children do not take their drugs at the right time because the school environment does not offer privacy and children do not want to be seen by others when taking their medication.

“When they go to school, they even fear to take drugs when the others are seeing them. They try to hide and you find they have taken the drugs late.” (Caretaker FGD)

4.6 Barriers to overcoming stigma and discrimination

4.6.1 Lack of Awareness

Caretakers identified lack of awareness as a barrier for overcoming stigma and discrimination. According to caretakers, there is a lack of interactive communication on various aspects of HIV/AIDS, which may be responsible for HIV stigma and discrimination. HIV/AIDS communication is general in nature and does not allow for feedback. Caretakers also believe that many people who require information are not reached.

“Most of the sensitization information stops at a certain level, so we have a situation whereby the majority (including the teachers themselves) do not know about AIDS. So sensitization campaigns should be extended to those who are ignorant as one of the effective ways to reduce stigma.” (Caretaker FGD)

“I think there is lack awareness. I lost my husband to that disease yet previously I could not even interact with someone with AIDS. After having gone through this experience, I have more knowledge about it including how it is transmitted I think that if people could get more knowledge, stigma and discrimination would reduce.” (Teacher FGD)

4.6.2 Inadequate Family Resources

Inadequate resources to support all the needs of children who are affected by HIV/AIDS is a barrier to overcoming stigma and discrimination. Caretakers identified
low household income as a barrier to discrimination. Households are confronted with low incomes and a myriad of needs, making it difficult to fully provide for all the children. This leads to prioritization of needs. Families sometimes prioritize the needs of those children who are HIV negative, because the probability of survival is greater than that of HIV positive children.

4.6.3 Fear

Fear of HIV/AIDS within the population was a barrier to addressing stigma and discrimination. As a life-threatening disease, HIV/AIDS is associated with rejection, suffering and death, creating fear and panic among people. Individuals fear to know their HIV status or to associate closely with those who are affected. There is fear of what will happen if an individual tests positive. Closely linked to fear, is the problem of non-disclosure. Those who are aware they are HIV positive are stigmatized and have low self-esteem. They are fearful of disclosing their status.

“Fear is a major problem. People are afraid. They fear to be talked about by society, friends etc. They just fear. People have a low self-esteem and fear to come out. That is a problem.” (Caretakers)

“In the community you find people who say that going for an HIV test is useless because HIV has no cure. This remains a big obstacle.” (Caretakers)

4.6.4 Limited community involvement

Limited involvement of the wider community was also identified as a barrier in efforts to address HIV/AIDS stigma and discrimination. Caretakers observed that previous efforts to address stigma and discrimination tended to enlist the active involvement of those who are infected or affected, leaving out the rest of the community. It was also observed that individuals who are affected are in some cases, lone voices within their communities, trying to respond to stigma and discrimination. Subsequently, addressing stigma and discrimination remains a concern for the affected, leaving out the others, who in most cases are least informed about HIV and AIDS. This results in a lack of collective responsibility and response to stigma and discrimination.

“Lack of community involvement is a problem. You may come up as an individual to fight against stigma but the community may be looking at you as somebody who is useless because you have AIDS. There is no collective responsibility to fight against stigma and discrimination.” (caretaker FGD)

Related to inadequate community involvement, the teacher’s FGDs identified the limited involvement of teachers in supporting children affected by HIV in schools as a major barrier. It was observed that within schools, there are few teachers who
provide support to children affected by HIV/AIDS. Many of the teachers lack the skills and interest to support the affected children.

“One of the obstacles is that teachers do not take keen responsibility for children identified as HIV positive. Instead they leave the responsibility to a few teachers who are interested. They say, ‘hey, here is your child, you are the one who handles such issues.’” (Teachers’ FGD)

4.6.5 Low political will

The limited involvement of political leaders in addressing stigma and discrimination is a barrier. Caretaker group discussions noted that political leaders avoid getting involved in efforts addressing stigma and discrimination for fear they will be associated with HIV/AIDS. Caretakers had a view that political leaders do not get involved in fighting for the rights of PLHIV for fear their actions may be construed to mean they (the leaders) are HIV positive. In communities where there is hostility towards HIV positive people, involvement of elected leaders in stigma and discrimination interventions have implications for their re-election to political office.

“Leaders fear to fight for rights of people living with HIV because they will loose votes. Since they are seen to be helping people living with HIV, by association, they will be taken as being HIV positive”. (Caretakers)

4.6.6 Negative attitudes about HIV/AIDS

Existing attitudes which link HIV/AIDS to sexual immorality have been identified as a major barrier to addressing stigma and discrimination. Since HIV is predominantly transmitted through sexual intercourse in Uganda, it is believed those who acquired HIV were sexually immoral. Caretakers largely associated this belief to religious communities. Equating HIV to sexual immorality not only stigmatizes those who are affected; also some of the people affected or infected with HIV/AIDS tend to deny the reality of the disease and consequently keep silent about their health and emotional conditions, and this stifles efforts to respond to stigma and discrimination.

“According to me we have a barrier that is religious or you can term it as moral beliefs that exist in our community. Some people believe having HIV/ AIDS is a result of promiscuity or even sex, which deserves to be punished. Many people do not know the basic facts about how HIV is acquired or transmitted.” (Caretakers)

Religious communities were identified as potential barriers to interventions on stigma and discrimination.

“Some obstacles are due to culture and religion. I am working in a community of a particular religion, which is very strict with its doctrine. In fact, those religious beliefs make it very difficult to penetrate. Despite being given facts about HIV/AIDS. The
moment one starts seeing you as a devil it means what you are going to say will not be accepted.” (Teachers FGD)

4.7 Suggestions for reducing stigma and discrimination

Caretakers identified lack of awareness, negative attitudes about HIV/AIDS, fear, limited political will, and insufficient participation of the community as general barriers to addressing stigma and discrimination. At the family level, low incomes make it hard to provide for all members, leading to discrimination of PLHIV. The caretakers proposed a range of solutions that could be adopted to respond to stigma and discrimination. The results on caretakers’ perspectives are derived from the parents and guardians focus group discussions. The FGDs with teachers did not generate any specific interventions for addressing stigma and discrimination. Teachers made general proposals on how to reduce the spread of HIV.

4.7.1 Acceptance of children living with HIV/AIDS

A wide range of solutions to HIV stigma and discrimination were mentioned by the study respondents. These included, accepting HIV positive children the way they are and encouraging people to love them, and listen to them and provide solutions to their problems. Treating the concerns of the children who are HIV positive confidentially and helping them to find treatment would be useful in fighting stigma and discrimination, as reported by a majority of study respondents. There is a general consensus among caretakers that giving HIV positive children a balanced diet, and giving them the same treatment as those who are negative, were also positive messages for fighting stigma and discrimination.

“My message to the community is that no body is immune to HIV/AIDS and I believe that AIDS has no boundary - to day it could be my child but tomorrow it could be your child or that of your relative.” (Caretakers FGD)

4.7.2 Community awareness

Caretakers identified the need to create awareness among the community on the impact of stigma and discrimination as a way of addressing the problem. They identified the need to create awareness about human rights of all people. Caretakers advocated for initiatives to increase knowledge and change attitudes and where possible, use cases of people on ARVs that are looking healthy in sensitizations programs.

“The key messages I would come up with is to fight AIDS, the disease, not the people or children living with it. AIDS is like any other disease so there is no way or reason why we discriminate or stigmatize.” (Caretakers FGD)
5.0 Presentation of findings from the religious leaders

This section presents a synthesis of the findings that were obtained during the focus group discussions and key informant interviews that were held with Religious leaders for the survey. It starts with a presentation of positions of the different religious groups in Uganda which is the basis of comparison with the actual data generated from FDGs and key informant interviews which makes up the rest of the chapter.

5.1 Positions of religious groups on stigma and discrimination

This study attempts to provide a brief description of the beliefs and positions of the religious groups that could have implications for how to address stigma and discrimination starting with the Anglican Church.

5.1.1 The Anglican Church

In August 1991, Bishops, Clergy and Laity of the Church of Uganda (COU) met in Mukono, Uganda and adopted an HIV/AIDS resolution. The COU links HIV and AIDS to sexual behaviour and believes that change in sexual behaviour is the solution to the epidemic. The church advocates for faithfulness with marriage and abstinence outside of marriage. The church does not address prevention of mother-to-child transmission of HIV and transmission through infected blood. The church advocates for behaviour change and condemns the advertisement of condom use as an HIV prevention mechanism. The church accepts condom use in marriage under two circumstances: a) for family planning; b) prevention of HIV infection and STIs among discordant couples.

The Church believes marriage and faithfulness can put an effective stop to HIV. The Church also recognizes that sexual immorality and abuse are conduits for HIV and AIDS transmission. This position does not take into consideration gender and cultural issues that allow promiscuity among men. The position of the Church towards PLHIV is development health care and counselling and support programmes. The Church mandates its health units to provide medical treatment, testing and expanded counselling services. Although this addresses health care, it does not make an explicit statement on stigma and discrimination. It fails to address care and love within the family setting and the community. It also does not address acceptance within the congregation.

The position of the Church is employees should be allowed to keep their jobs, at least until they are incapable of working. Although not comprehensive, this points to protecting workers rights from being dismissed from work on the basis of their HIV
status. The church is silent on recruitment of HIV positive clergy, and partaking of sacraments such as ordination, baptism, confirmation.

5.1.2 Seventh Day Adventist Church

The position of the SDA Church was obtained from two documents from the Church; “Recommended Guidelines for a Policy on HIV/AIDS for the SDA Church in Africa”, and “A Report Submitted to the Union in 2007”. The SDA Church position is clear that PLHIV do not present a health risk to fellow church members, students at denominational institutions or to denominational employees at the workplace. The Church pledges to protect the rights of employees and students infected with HIV or who have AIDS and to treat them with dignity and respect, providing the opportunity to continue working and studying within their abilities.

The Church is also committed to dealing with employees or students infected with HIV and AIDS in the same manner as employees or students suffering from any other form of life threatening disease. This commitment involves treating individuals with love, consideration and respect; with positive supportive and non-discriminatory manner. The Church is also committed to providing hope, love and support to all employees, students, church members and members of the community who are diagnosed as being HIV positive in order to assist them in continuing to live a dignified and productive life for as long as possible. The SDA Church has set out clear guidelines that demonstrate its acceptance for PLHIV and those who are affected. The guidelines however focus on church employees and students attending SDA denominational schools. There is very little focus on the congregation.

5.1.3 Pentecostal/Born Again Churches in Uganda

The Pentecostal Churches has not a written document stating their views regarding HIV and AIDS stigma and discrimination. The position of the church was captured through the KII held with religious leaders from these churches. The Pentecostal Church acknowledges that HIV and AIDS affects their churches through a number of ways including morbidity among church members, numerical strength of the church and the burden of caring for sick people and orphans. There is also concern about the moral dimensions of HIV and AIDS due to its effect on families and the institution of marriage. They also acknowledged that stigma is a problem that stifles church members and stops them from publicly coming out with their HIV status. This is attributed to the association between HIV/AIDS and morality. The Pentecostal Church preach repentance for those affected by HIV and AIDS. They promote acceptance and love for PLHIV. Everyone was created in the image of God, and PLHIV are children of God, who need physical and spiritual healing.

The Pentecostal Church is against the generic promotion of condom use as an HIV prevention mechanism. Interviews revealed only two circumstances in which
exceptions of condoms are acceptable, namely: as a birth control mechanism between married persons and between discordant couples. The Pentecostal Church blames the increase in HIV prevalence on IEC campaigns that promote condom use as a prevention measure. The leaders believe that promotion of condoms has a correlation with irresponsible sexual behaviour. Pentecostal religious leaders promote behaviour change as a sustainable response to addressing HIV prevention. The Pentecostal Church advocates for a dual approach to HIV and AIDS treatment; prayer for healing of the sick and administration of medication.

5.1.4 The Catholic Church

The Catholic Church has a systematic response towards HIV and AIDS. As early as 1989, the Church published, its position paper on HIV/AIDS, which continues to guide the Church in its HIV and AIDS response. The position of the Catholic Church is a two fold response to HIV and AIDS, including self-reflection of one’s lifestyle in light of God’s word and reaching out to those who are sick, bereaved or orphaned. The Catholic Church recognized the need to care for and show love to those who are affected by HIV and AIDS. It also emphasized behaviour change as a key response to AIDS. The Church position is hinged on scriptures. For example, with regard to the Church’s position in reaching out to others, the following scripture is relevant:

“I was hungry…thirsty….a stranger….naked….sick….in prison, and you fed me, clothed, took care of me, visited me…” (Matthew 25:34-36)

The Church also has scriptures from the Bible upon which it bases its position against judgment of others living with HIV and AIDS. The Church contends that it is an obligation for church members to sustain those who are sick, caring for them as brothers and sisters without barriers, exclusion, hostility or rejection.

“Be compassionate as your heavenly Father is compassionate. Do not judge and you will not be judged yourselves; do not condemn and you will not be condemned.” (Luke 6:36-37)

Based on the above, the Catholic Church advocates for protection of human rights, dignity of those affected by HIV/AIDS, and avoidance of discriminatory and stigmatizing practices. Through its affiliate faith-based organization, Caritas and the Uganda Catholic Secretariat, the Church published a booklet, entitled “HIV/AIDS Stigma and Discrimination: A Concern for Christian Families” to provide basic information to its membership.

Regarding prevention, the church is against the use of condoms and perceives them as unacceptable. The church view is that condom use ignores the real cause of the problem and encourages permissiveness, corroding the moral fibre of society (Catholic Bishops of Uganda; 1989).
5.1.5 The Orthodox Church

The position of the Orthodox Church is that it does not condone stigma and discrimination against individuals who are affected by HIV/AIDS. The Orthodox Church does not perceive as sinners, people infected with HIV. The Church looks at all individuals as children of God. People with HIV and AIDS receive all sacraments available within the church, including Holy Communion, which involves sharing a chalice. PLHIV are freely admitted without any discrimination. The Orthodox Church recognises that HIV/AIDS can be contracted through many different ways and not only from sexual intercourse. Condom use is not accepted as a HIV prevention mechanism. The Church’s view towards condom use is that they encourage adultery and fornication. Abstinence is encouraged for discordant couples and for those who desire to practice family planning.

5.1.6 The Islamic perspective

The Muslim Clerics in Uganda do not have any written policy on HIV and AIDS. Their attitudes and response towards HIV/AIDS are guided by their hol book, The Koran, as well as policy guidelines from the Inter-religious Council of Uganda.

HIV/AIDS is for the evil in the Arab world where Islam is strictly followed. HIV/AIDS is considered to be a punishment from God. Most people in the Islam Community still associate HIV to fornication. Islam teaches that it is God’s will that people suffer from diseases. This is used to explain why young children are born with HIV. It is believed that it is God’s plan that such people will die from HIV. There are verses in the Koran that may contribute to stigma and discrimination:

“God will never change one's situation unless you are the cause of that situation”.

This is interpreted by clerics to mean God will never make you sick unless you are the cause of the sickness.

“What ever good think that happens to you is from God, whatever bad thing that happens to you is from yourself”.

This scripture apportions the blame of HIV to the affected individual.

“If you continue to annoy God, he will bring sickness that has no cure and is painful”.

Muslim clerics identified the above scriptures as responsible for promoting stigma and discrimination among the Muslims. However, Islam also teaches that Prophet
Mohammed said that people must sympathise with others problems. This points to the duty among Muslims to provide care and support to victims of HIV/AIDS, including provision of guidance on how to access treatment, food and proper hygiene and sanitation. It is believed that there are people who are simply victims of circumstances, so we need to be kind to them.

5.2 Results on knowledge and attitudes of religious leaders towards stigma

Religious leaders are a key audience in reducing HIV/AIDS stigma and discrimination. They wield authority and have the potential of influencing attitudes of their followers. The findings on the knowledge and attitudes of religious leader towards stigma and discrimination are presented in five themes: 1) definition of stigma and discrimination, 2) attitudes and perceptions towards Stigma, 3) identification of stigma and discrimination, 4) the extent to which stigma and discrimination is perceived as a problem.

5.3 Definition of stigma and discrimination

Findings from the religious leaders demonstrate there is a high level of knowledge related to HIV/AIDS stigma. There was consensus among the religious leaders that HIV-related stigma is an attitude problem, which manifests itself through branding, labelling and finger pointing

“Stigma is a situation of pointing at a person who is suspected to have HIV/AIDS.” (Religious Leaders, FGD)

“Stigma is an attitude of finger pointing or isolating somebody because of a predicament that has befallen one. It does not have to be due to HIV, but also any form of isolation. In addition to finger pointing, they say rude words to a person because of the situation that they are going through. I think that as a result HIV/AIDS stigma and discrimination has become worse.” (Religious Leaders, FGD)

“Stigma is when I also feel that I am no longer fitting in the society because of what happening to me, because I am sick or I have done something. I can stigmatize myself as well as others are also stigmatizing.” (Religious Leaders, FGD)

Religious leaders mentioned several factors that result in stigma; fear of an infected person, fear of perceptions of others towards infected and affected persons, and conscious and unconscious use of stinging words in reference to PLHIV.
“It’s an attitude; a mindset that marks someone as disgraced. Either they mark themselves, or society marks them as disgraced because certain assumptions are made. When we associate whatever is happening to the other person as either antisocial behaviour or unacceptable behaviour and therefore we isolate them and that is stigma.” (Religious leaders, FGD)

The above quotation illustrates an understanding of enacted and felt-stigma among religious leaders. Religious leaders expressed the notion that HIV-related stigma is closely linked to failure of adherence to religious principles that promote chastity. Accordingly, religious leaders tend to closely associate HIV/AIDS with sexual immorality and in the process, instigate stigma.

“Our people still think that HIV/AIDS is for the evil. In the Arab world where Islam is strictly followed, HIV is considered to be a punishment from God.” (KII, Moslem Religious Leader)

As can be inferred from the above quotation, HIV-related stigma was associated with religious beliefs and practices, which reinforce and legitimize stigmatization and points to the need to intensify communication directed at religious leaders to influence their knowledge.

Although they did not provide definitions, the religious leaders’ audience identified discrimination as an effect of stigma. They associated actions and behaviours, such as sanctions, harassment and violence directed towards PLHIV, as discrimination. Religious leaders showed a clear understanding of the difference between stigma and discrimination. Stigma was perceived as an attitude, while discrimination was construed as the act of.

“To me discrimination comes because you are stigmatized. So the actions arising from stigma is to discriminate. The decision to shake a person’s hand or not, or to sit next a person might be due to the stigma. I act that way because I have a negative attitude, or the prejudice.” (FGD Religious Leaders)

Religious leaders had an understanding of the difference between stigma and discrimination. The difference was demonstrated when participants were asked to provide vernacular words carrying a similar meaning as stigma and discrimination. There was consensus among the majority of the religious leaders that stigma is the same as “okuboola” (luganda word for avoid) while discrimination was equivalent to “Okusosola” (luganda word for treating differently).
5.4 Attitudes and perceptions towards stigma and discrimination

5.4.1 PLHIV viewed as sinners

Some religious leaders tended to view HIV/AIDS as a result of disobedience and failure to adhere to religious teachings regarding sexual relations. PLHIV were perceived as responsible for their plight, due to their own personal weaknesses and failures. In such cases, living with HIV/AIDS is equated to a life of sin. Religious leaders adopted judgmental attitudes towards PLHIV. These attitudes enhance HIV stigma and discrimination. While judgemental attitudes were implied in discussions with religious leaders from various denominations, the Muslim leaders expressed it more explicitly as follows:

“AIDS kills people who look for it from others who are infected with the virus and they die in shame and disgrace. We have told people over and over to leave prostitution but they have refused to change their behaviours. We advise them to avoid going to places that expose their to high risk behaviours like discos, concerts and drinking. The young boys and girls do not want to marry any more saying they do not have the money to look after their spouses. The girls want to get to very rich men with vehicles.” (Muslim leader)

“The general attitude is that an HIV positive person must have been leading an adulterous life. If he/she is a youth, they have probably been running around with multiple sexual partners, and if he/she is a married person then it is concluded they have been having extra-marital affairs.” (Seventh Day Adventist Leader)

The quotations above clearly illustrate the belief of some religious denominations regarding sin and sexuality, which could stigmatize and lead to discrimination of those infected with HIV. The tendency to associate HIV/AIDS with sexual immorality undermines religious leaders’ efforts of care and support, as well as fighting HIV-related stigma. In the discussions, respondents continuously referred to some religious teachings that communicate stigma and discrimination among PLHIV. The quotations below from the Muslim religious leaders are illustrative:

“God will never make you sick unless you are the cause of the sickness. Whatever good thing that happens to you is from God, whatever bad thing that happens to you is from yourself, quoted as Koran.” (KII, Moslem Religious Leader)

It is clear that some religious teachings have promoted stigma and discrimination through moral judgment scriptures. It is assumed that since HIV is a sexually transmitted disease whoever contracts it has had many sexual partners. The Born Again Church contends that God does not allow fornication. They have to address that aspect in the interest of promoting good Christian morals, whether it amounts to promoting stigma or not. In the interview with the chairperson of the Pentecostal Church in Uganda, he reported ‘that they could not change the teachings of God
that prohibit sexual immorality just because there are followers in the church who are HIV positive’.

It is noteworthy that while the study revealed such attitudes, this was not universal to all denominations. For example, leaders in the Orthodox Church were specific that they do not consider PLHIV as sinners.

“The Orthodox Church does not take people infected with HIV as sinners; we take them as others suffering from other types of diseases. We look at them with love that is why we endeavour to look after them within our capacities available in the church. They are all children of God even if they are infected with the virus; we are still together in Christ.” (Orthodox leaders)

5.4.2 Stigma and discrimination as sinful actions

The attitudes of religious leaders’ towards stigma present a double-edged scenario. On the one hand, they harbour stigmatizing attitudes towards PLHIV due to the belief that individuals acquired HIV due to immoral sexual behaviour. On the other, they perceive themselves as a source of hope and strength to PLHIV. Leaders from all denominations reported that it was not the official position of their different religious denominations to encourage HIV related stigma, the close association of HIV transmission with sexual relations, makes it difficult to separate HIV/AIDS from sexual immorality. This quotation below is illustrative:

“It is believed that if someone dies of HIV/AIDS as a result of prostitution, he or she will be punished by God because God said “if people continue doing evil things, God will send bad omens that will calm you down”. We are about to think that God is fulfilling his promise but as religious leaders, we are handling victims of HIV/AIDS as others suffering from ordinary sicknesses, with compassion. Prophet Mohammad said that people must sympathise with others in problems. As Muslims it is our duty to provide care and support to victims of HIV/AIDS.” (Muslim leader)

Religious leaders are obliged by their teachings to treat people with respect and love. In this regard, religious leaders perceive stigma and discrimination of individuals based on their HIV status as sinful and not worthy of believers.

“Islam does not allow discrimination of people for whatever reason including the sick. Islam tells us to love the sick and to ensure that they receive every thing they need to recover from their sickness. It is incumbent for us as religious leaders to provide both spiritual and material support to people in problems like the sick and that is exactly what we teach our people.” (Muslim religious leaders)

“You will have broken God’s commandments if you discriminated against people. For us in Pentecostal churches, all of us are born as brothers and sisters. We do not encourage stigma and discrimination.” (Pentecostal religious leaders)
This contradiction in attitudes seemingly results from religious teachings on repentance and forgiveness. Discussions show that PLHIV who repent his/her sins gain acceptance from religious leaders.

“The official position of COU is to encourage people to repent their sins and come back to God. We do not apportion blame or judge people with HIV/AIDS.” (Anglican Leader)

Further, the scriptures in both the Koran and the Bible encourage care and support to the sick, including victims of HIV/AIDS. Among the scriptures cited was the parable of a “Good Samaritan” that encourages Christians to help others when they are in need.

5.4.3 Stigma and discrimination perceived as a challenge by FBOs

Almost all respondents in the focus group discussions and key informant interviews reported stigma and discrimination remains a key challenge in the fight against HIV. Study findings further indicate that the stigmatization of PLHIV has been promoted by misconceptions that HIV is contracted as a result of sinful sexual relations. Religious leaders perceive stigma and discrimination as hindrances to openness about HIV/AIDS within their congregation.

“The nature of our marriages also counts; most of us are polygamous. Our people fear to tell their spouses that they got HIV/AIDS and majority of these are Sheikhs, Hajjis and Hajjats. For fear of public opinion, they decide to remain silent about their sero status.” (Muslim leaders)

In addition, individuals affected with HIV/AIDS adopted attitudes of self-condemnation, which are also a challenge to the religious response.

“Others become stigmatised and feel as if God does not love them. They start blaming themselves for what has happened to their families. Most people still associate HIV to sexual immorality and sin, some simply isolate themselves form the rest when they learn that they have HIV/AIDS so it becomes difficult to help them.” (Anglican Leader)

All study respondents both in FGDs and KIs reported HIV-related stigma and discrimination is a very big problem within their different religious denominations. It affects efforts to promote openness and public declaration of one’s sero-status. FGD participants reported that dealing with an epidemic whose victims are not willing to open up is a very serious challenge that does not only affect prevention mechanisms for further spread of the virus, but also works as an impediment to providing support and care to the victims in form of treatment.

“There is a lot of stigma and that’s why people are dying every now and then. People who are sick are reluctant to go for HIV testing and other related services
Religious leaders further reported that people are not sensitized enough to accept their sero-status or those of their family members believing it a curse to their family or that it is an abomination to have an HIV positive member in their family. Such negative gestures promote self stigma and reduce the ability of victims to cope with the current situation.

### 5.3.4 Practices that promote stigma and discrimination in FBOs

This study highlighted practices of religious leaders that promote or enhance stigma and discrimination. The study sought to identify whether PLHIV are discriminated against in religious rituals and practices, such as Baptism, marriage and funeral ceremonies.

#### 5.3.5 At funeral ceremonies

In reference to burials and funeral ceremonies, all religious leaders noted they do not discriminate against those who have died of AIDS-related causes. Followers, regardless of the cause of death, were accorded a decent burial. Religious leaders officiate at funeral services of those who have died of AIDS causes.

“We perform the functions of the funerals as we are required by the teaching of the bible. Many people who are innocent have passed away as a result of HIV/AIDS. In the past people used to point accusing fingers at people who were infected with HIV/AIDS but these days this has changed because HIV/AIDS is everywhere and each family has been affected by the virus. So we officiate over funeral functions and take people to repent and get saved with words of hope and encouragement.” (Anglican Leader)

“Islam is very particular, it does not allow talking ill about someone who has passed away no matter how you die whether mob judged or not. We physically participate in washing the body of the deceased but we are encouraging people these days always to use gloves as they are washing.” (Muslim leader)

“We pray for the bereaved families and stay with them because it is not their fault that they died or lost their relatives to HIV/AIDS.” (Orthodox leader)

The above notwithstanding, funerals can be an avenue through which HIV-related stigma is reinforced. Such events present religious leaders with an opportunity to preach about HIV/AIDS and morality. Such associations may indirectly enhance stigma. This was inferred from the interview held with leaders from the Orthodox Church.

“Usually, when people die, it is a reminder that this virus is dangerous to the followers. We use such moment to teach to those who are still alive to remain...”
faithful, death is not a sin but a punishment, the church encourages those who are HIV positive to stay in faith.” (Orthodox Church)

5.3.6 Practices at the workplace

An officer from the Catholic Secretariat reported a similar finding when he observed workers of some Catholic institutions made comments about colleagues whom they suspected to be HIV positive. Even among the religious leaders, it was reported that people living with HIV were considered unreliable. Female workers with HIV were viewed as prostitutes and leaders in the Catholic Church shunned discussions on HIV because they considered victims of HIV to be sinners. As a result, HIV victims feel isolated, concentration declines and finally drop from their jobs. The victims become stigmatized and do not feel they can forward their concerns to church leadership for redress. It was also mentioned that most religious leaders were not fully aware about HIV to be able to provide appropriate solutions.

5.3.7 Practices related to baptism

Within the Seventh Day Adventist Church, it was reported during baptism ceremonies, PLHIV would go last. The church has a communal baptismal pool, where they dip those who are receiving the sacrament. It was observed that Christians were uncomfortable about dipping their bodies in a pool, where a PLHIV had been. The church adopted a system of requesting the PLHIV to go last. Although the Pastor noted that this was not aimed at stigmatizing the PLHIV, it is a discriminatory action with the potential of preventing PLHIV from coming out about their status.

“Our baptism is by immersion, and just like with communion, we baptize them regardless of their HIV status. The only hurdle we have there is when someone who is known to have HIV comes. Then we have to convince the other people who are going to be baptized because they are going into the same water. What we do sometimes is to talk to the one who is positive so they can go in last.” (Seventh Day Adventist Leader)

5.3.8 Practices related to marriage ceremonies

In some religious denominations, the right of HIV positive people to get married might be infringed upon due to practices that discourage marriage. This is particularly true among those who are discordant. For example, the Anglican Church does not encourage discordant couples to remain together.

“In cases of discordant couples, the C.O.U encourages separation to enable the partner who is still HIV negative to keep alive and bring up the children. As I have mentioned, condoms are not 100% effective if you allowed using them, you will be
putting the life of that person in danger and leave the children as double orphans. So the best is to encourage separation.” (Anglican Leader)

“Yes, if the two are adults and consent with their free minds, we are allowed to wed them but if one of them is sick and the other is not, Islam teachings forbid an act that can expose others to danger. So we do not wed such couples. In such circumstances, as a religious leader, I would advise the couple to separate. Allah does not allow us to put our lives and those of others in danger. If the wife is willing to stay, we would encourage the husband to continue providing financial support but would not encourage them to use condoms because use that would put the life of the others in danger since we do not know the strength of a condom in controlling HIV transmission.” (Muslim leader)

“We do not wed HIV discordant couples. If they insist on going ahead with the marriage, we ask them go to the registrar of marriages but not here, because we basically look at it from this angle, one the partners is not protected. The challenge is how the parents are going to look at it because we tend to involve the parents because this is kind of committing suicide. We tend to discourage that, to the extent of even involving their close relatives.” (Seventh Day Adventist Leader)

5.3.9 Practices related to preaching

The data shows that religious leaders have the tendency to promote stigma and discrimination through their preaching. Sermons on sexual immorality sometimes carry innuendos that communicate to PLHIV they are sinful in nature. Although this is not the policy of the religious organizations, some of the clergy take such positions.

“A few individual priests were preaching negatively against HIV/AIDS patients, by trying to associate them with fornication, but this is not the official position of COU such preaching should be stopped. Some people used to think that they were holy and because of their positions as reverends, they thought they would not be vulnerable to HIV infection. This teaching is not official because it repulses instead of bringing people back to God.” (Anglican Leader)

The above quotation also shows that there is a low perception of risk to HIV/AIDS among some sections of religious leaders. They do not appreciate they are potential victims of HIV/AIDS.

Overall, the study did not disclose much about practices related to stigma and discrimination. Religious leaders did not openly disclose practices amongst themselves that promote stigma and discrimination. They tended to emphasize the teachings that promote love and compassion and generally did not concede that they were directly or indirectly promoting stigma and discrimination.

“The greatest teaching which was taught by Jesus was love. The Orthodox Church encourages love among all it’s followers. They emphasise love for one another
especially for those in problems. We want to console them and show them love. So we have no deliberate actions that are intending to stigmatise our followers who are affected by HIV/AIDS. The church has actually established bodies such as youth groups and proving them with income generating activities such as piggery mainly to bringing them together in love.” (Orthodox leader)

The Anglican leaders for example, expressed they accommodated PLHIV by accepting and allowing a priest from the Ugandan Church, who had tested HIV positive, to continue serving in the church. They have used him as an example in fighting misconceptions with those who are self-righteous people, presuming all people living with HIV are promiscuous, adulterous or disobedient to God. This was further supported by the official positions of the Catholic and Orthodox Churches on how two different religious denominations perceive PLHIV. The ability of the Orthodox Church to contain HIV related stigma was demonstrated by their emphasis on promoting love for one another as shown by their willingness to use the same chalice to serve their congregation during Holy Communion.

“They are all children of God even if they are infected with the virus, we are still together in Christ. For us in the Orthodox Church, we share one cup to receive holy communion with all people whether they are infected with virus or not”. (KII Orthodox priest-Namungoona)

In this respect, the study is limited in that it did not seek the experiences of congregations on religious leaders’ practices that may enhance stigma and discrimination within the Church.

### 5.4 Barriers/Obstacles to overcoming stigma and discrimination

The findings from focus group discussion and key informant interviews reveal that there are number of misconceptions about HIV, which continue to constitute barriers to stigma and discrimination. Religious leaders reported many people are still ignorant about the different modes of HIV transmission. Religious or moral beliefs among some sections of different religious denominations may lead some people to believe that HIV is as a result sexual immorality that deserves punishment. Nearly all respondents from the different religious denominations reported presence of beliefs in their organizations that suggest people are responsible for becoming infected with HIV. Among the Muslims, some individuals strongly associate HIV to promiscuity which is punishable by God.

“It is believed that if some one dies of HIV/AIDS as a result of prostitution, he or she will be punished by God. God said that if people continue doing evil things, God will send bad things that will calm you down.” (Muslim leader-UMSC)

There is a low perception of risk of HIV infection towards the faithful among religious leaders. There is a belief among some religious communities that their
followers live exemplary lifestyles and are not prone to the risk of acquiring HIV. The leaders believe that followers adhere to the teachings of the religion and avoid sexual immorality. Such beliefs present barriers to efforts in addressing stigma and discrimination.

“I will be honest with you. We never ever thought even for a minute that anyone in our church could get HIV. We have always thought that these people follow our teachings. It is now that we realize- and I hope not too late, that HIV is a problem for us.” (KII, SDA)

All respondents from the different religious denominations reported religious teachings which link HIV to sexual immorality. This was further supported by findings from the C.O.U which indicate that although not officially sanctioned by the church, some self-righteous reverends preach negatively against PLHIV, creating an impression that their situation is a result of fornication. They show attitudes associating HIV to sin and, as religious leaders, they believe they are not at risk of contracting HIV/AIDS.

“A few individual priests were preaching negatively against HIV patients by trying to associate them to fornication, but that is not the official position of the church of Uganda. They think that they are holy and because of their positions as Reverends, they thought they can not catch HIV/AIDS.” (KII, C.O.U)

These findings indicate that, although leaders of religious denominations do not officially allowed acts that promote stigma and discrimination, religious teachings which sadly equate being HIV positive to sexual immorality might present severe challenges to efforts that are geared towards fighting HIV/AIDS.

5.5 Proposals by religious leaders to reduce stigma and discrimination

A wide range of solutions to HIV stigma and discrimination were mentioned by the religious leaders involved in the study. These include - showing love to PLHIV, listening to them, and provide solutions to their problems. Based on Holy Scriptures in the bible and Koran, religious leaders openly advocated the provision of care and support to people living with HIV/AIDS. There was general consensus among the different respondents that since HIV is spread through different ways, it would be wrong from a religious perspective to interpret HIV and AIDS as God’s punishment for sin. Such judgemental attitudes result in undermining efforts of care, support and prevention of HIV related stigma and discrimination.

Study findings revealed a wide range of mechanisms currently used by religious leaders to contain acts of stigma and discrimination. These included but are not limited to, counselling programs for people living with HIV and their families. The
Catholic Church, for instance, offers a comprehensive HIV/AIDS services to PLHIV through its mission health centres country wide. The SDA Church initiated a counselling service for PLHIV at the church. However, the initiative collapsed because people were stigmatized and feared to be seen to go for HIV counselling. Study findings indicate that they are using the few existing facilities as conduits to reach their followers with HIV/AIDS messages.

"Unlike other religious denominations in the country, the Moslem community does not own as many health facilities apart from the two in Old Kampala and Kibuli, but we are trying our best to use these facilities to reach to our people with HIV/AIDS messages." (Muslim leader- UMSC)

In addition to providing counselling and guidance activities, all leaders of the different religious denominations reported using existing church structures to channel HIV information to their followers. For example, leaders of the Born Again Christians in Uganda mentioned they were using church services to disseminate HIV messages for a few minutes in the middle of the service in addition to providing other related and comprehensive services to PLHIV. The SDA uses prenuptial counselling sessions to provide information on HIV/AIDS to couples. Similarly, the Muslim leadership at the Supreme Council also developed and adopted a mechanism compelling lead prayer worshipers to devote a designated time when information on HIV was disseminated during prayer time.

"We are in contact with our followers five times a day, we have made it a point that each time we meet for prayers, we use a few minutes to disseminate HIV information to the people. We encourage them to love one another especially those in problems since we are all children of God." (Muslim leader- UMSC)

All religious institutions were working with government and development partners locally and internationally to provide care and support for people infected and affected by HIV/AIDS. Religious organizations which are centrally managed under a homogeneous administration, such as the Catholics, Protestants and Orthodox, had established facilities like health centers, schools and secretariats that coordinate HIV activities and are manned by qualified and highly skilled personnel. The Born Again Churches, which are managed as individual units, implement their activities individually at church administration level. The SDA Church is in the process of designing a programme to respond to the problem of HIV/AIDS, including stigma and discrimination. Potential interventions focus on removing stigma and discrimination and changing behaviour. The use of existing capacity within the organizations provides fully fledged counselling services for PLHIV and their families.

5.5.1 Policies and guidelines related to HIV/AIDS in the FBOs

Most religious denominations revealed that they did not have well-developed policies for guiding implementation of HIV-related activities, including stigma and
discrimination. Though the problem for the need to develop guidelines for implementation has been widely acknowledged by the majority of all organizations, there are very few large-scale and comprehensive policies on participatory methods developed by religious institutions to enhance sustainable implementation of HIV related activities. Different approaches have been used by different religious denominations to inform decisions on how to address HIV/AIDS. The Catholic Church, for instance, is currently using a pastoral paper, which was developed in 1989 by Bishop Adrian Ddungu as its official position document on HIV.

Other religious denominations are implementing HIV activities based on their spiritual obligation to respond to problems of their followers without an official guiding framework. The Muslim leadership reported using guidelines that were developed by the Inter-religious Council of Uganda for implementing HIV activities, claiming that their views on how they want to address HIV generally were ably captured. However, it was not possible to have a copy of their policy. It was reported by the leadership of the C.O.U that they had developed guidelines for doing HIV work and guiding the establishment of structures to coordinate related activities.

5.6 Suggestions by religious leaders to overcome stigma and discrimination

From the context of the religious leaders, a number of suggestions were mentioned for overcoming HIV stigma and discrimination. They generally pointed out that reducing HIV related stigma and discrimination lies in realm of following God’s teachings that encourages love to the sick, including victims of HIV/AIDS. In all interviews conducted, religious leaders exhibited more concern about the physical nature of actions including isolation, finger pointing, branding and labelling names that communicate stigma towards PLHIV/AIDS.

Results from FGDs reveal a wide range of solutions ranging from accepting the situation of PLHIV, praying with them, stop pointing accusing fingers and encouraging provision of care and support to victims of the virus. They also suggested implementation of community awareness campaigns using appropriate PRA methodologies. These methodologies would be used to educate the public against stigma and discrimination with a specific focus on addressing misconceptions relating to moral judgmental perceptions that erroneously associate HIV to sexual immorality.

Results from key informant interviews further revealed that holy spiritual teachings equating an individual’s HIV positive status to sin need to be prohibited. This view was held by nearly all leaders of different religious denominations, although it was more pronounced among leaders of the Catholics and Anglicans.
“Some religious leaders are preaching negatively against PLHIV by trying to associate them to sexual immorality, but this is not the official position of the church. Such preaching must be stopped.” (Leader C.O.U-Namirembe)

“We are trying to build the capacity of local religious leaders to ensure that as they relate the gospel to HIV/AIDS, they do not end up stigmatizing the followers who are HIV positive.” (KII, Catholic religious leader)

Among the Muslim leaders, both at the UMSC and the Tabliq sect headquarters, reported that Islam emphasizes helping people with problems such as the sick. Due to their health conditions, they need holistic care and support services. This was consistent with the findings received from other religious leaders such as the Orthodox and Born Again Pentecostal Church in Uganda:

“The Orthodox Church is willing to help all people in problems especially those who are sick with incurable diseases like HIV.” (Priest from the Orthodox Church Namongona)
Conclusions and recommendations

The next chapters present the summary of the findings of this study on the knowledge, attitudes and practices related to HIV/AIDS stigma and discrimination among three key target audiences; PLHIV, religious leaders, and care takers. It also gives a summary of the overall suggestions to reduce stigma and discrimination made by the different audiences.
Chapter 6: Conclusions and recommendations

6.0 Introduction

This study conducted in Kampala District, sought to examine the knowledge, attitudes and practices among religious leaders, caretakers of children affected by HIV/AIDS and PLHIV in regards to HIV/AIDS stigma and discrimination. This was based on the recognition that these population groups are key allies in addressing stigma and discrimination. The study provides a comprehensive understanding of the existing knowledge, attitudes and practices among key population groups. The information in this report can be used to inform the development of the national campaign on stigma and discrimination.

6.1 Summary of findings

The study summarizes the findings of the four major objectives set prior to its inception. The specific objectives of the study were as follows: 1) to identify and document the knowledge of HIV/AIDS stigma and discrimination among caretakers, religious leaders and PLHIV in Uganda, 2) to identify the attitudes of caretakers, religious leaders and PLHIV towards stigma and discrimination, 3) to identify practices that related to stigma and discrimination from the perspectives of caretakers, religious leaders and PLHIV, and 4) to make proposals on how to reduce stigma and discrimination.

6.1.1 Knowledge of stigma and discrimination

Although they did not provide concrete definitions of stigma, all target audiences demonstrated an understanding of what it constitutes. There was acknowledgement of enacted and felt-stigma in all the groups. There was limited understanding of discrimination. All audiences did not associate discrimination to human rights violations and tended to associate it only to isolation.

6.1.2 Attitudes towards stigma and discrimination

As a population group that is directly affected by HIV/AIDS, PLHIV are apprehensive about HIV/AIDS stigma and discrimination. PLHIV believe that stigma is a norm associated with living with HIV/AIDS. Keeping quiet about one’s HIV status was identified as a coping strategy against stigma and discrimination. Among the caretaker audience, it was observed that children who have HIV/AIDS are seen as a source of stigma and shame by their parents. These children face discrimination and are denied right to association and play. Among all the target audiences, stigma and discrimination was linked to the relationship between HIV transmission and
sexuality. However, this was most prominent among religious leaders. Religious leaders tended to intricately link HIV/AIDS to sexual immorality and sin. Although they reported that stigma is a negative attitude, which they were against, their views on HIV/AIDS and sexual immorality have the potential of propagating stigma. All target audiences identified stigma and discrimination as a problem that impedes access to and utilization of HIV services, creates a culture of silences, and quietly fuels the HIV epidemic.

6.1.3 Practices related to stigma and discrimination

The study identified different practices that are related to stigma and discrimination. HIV/AIDS stigma and discrimination is felt most by PLHIV when they are sick with AIDS. The use of derogatory names and terms to refer to PLHIV is one practice. Some of the names used to refer to PLHIV imply that they have no chance of living and are just waiting to die. Both positive and negative care practices are perceived as stigmatizing. Positive care practices become stigmatizing when the PLHIV are over pampered and denied a chance to do daily activities for themselves, especially activities they feel capable of doing. Negative care practices include, refusal to provide food and appropriate care for the PLHIV.

There is also a tendency among families to exclude PLHIV from discussions and decision-making due to the belief they are no longer capable of making meaningful contributions. This was identified in all PLHIV FGDs as a stigmatizing practice. The association of HIV to children of PLHIV carried stigma for the PLHIV and the children. HIV/AIDS stigma and discrimination affects men and women differently. Women were reportedly more affected by stigma. They are abandoned by their spouses and bear the greatest burden of caring for children affected by HIV/AIDS. Caretakers experience discrimination when other people instruct their children not to associate with them (caretakers) or their children out of fear they might infect them with HIV/AIDS.

Stigma and discrimination is experienced differently in the home, workplace, school, and health facility. Most stigma is experienced in homes where PLHIV live. In the home, PLHIV are treated as being of low worth and are not cared for properly. They are denied access to their property and are excluded from decision-making. Children living with HIV/AIDS do not receive love and affection from their guardians. They are sometimes denied access to basic needs, such as food, health, and education. At the workplace, PLHIV experience loss of employment, diminished opportunities for promotion and demotion to lower positions. In health units, health workers have a bad attitude towards PLHIV, which has the potential of resulting into poor quality of care. When it comes to children, health workers discourage caretakers from spending a lot of effort and resources on the treatment of children whose chances of recovery are slim. While in the schools, children with HIV are sometimes forced to drop out of school due to the stigma and discrimination suffered. Other children do
not want to share desks with children affected by AIDS. They are also denied opportunity to participate in activities considered to be physically straining. Within the church, there are some practices that tend to isolate PLHIV. For example, within the SDA church, PLHIV are the last to be dipped at baptism ceremonies.

6.1.4   **Proposals on how to respond to stigma and discrimination**

Among all groups, there is a recognition that ignorance continues to drive and fuel stigma and discrimination in Uganda. It was proposed that public awareness be created through sensitization campaigns. The PLHIV groups identified the need to involve PLHIV in any campaign to sensitize the public if it is to be successful. The acceptance of PLHIV was also proposed as a potential response against stigma and discrimination.

6.2   **Conclusions**

It can be concluded from the study that there is an understanding of stigma and discrimination among the target audiences. However, it is observed there is a narrow understanding of discrimination, as none of the groups were able to link discrimination to human rights. The study showed stigma and discrimination are real for the target audiences. For PLHIV, having HIV is synonymous to being stigmatized and discriminated against. Caretakers, particularly guardians and parents, are associated with stigma and discrimination through their children. Religious leaders are stigmatized when their followers contract HIV, which is perceived as evidence of sexual immorality.

The effects of stigma and discrimination on access to and utilization of prevention, treatment, care and support services are acknowledged by all target audiences. HIV stigma and discrimination is experienced in various settings included homes, schools, workplace, health units and places of worship. All the groups acknowledge that there is inadequate awareness within the population on HIV/AIDS transmission and existing services. The major conclusion of this study is that the experiences of the target audiences on stigma and discrimination create an opportunity to form partnerships with these groups who have the potential to act as change agents in addressing stigma and discrimination at the national level.
References


Ngonzo N.J and Sebukyu V (Undated) HIV/AIDS Stigma and Discrimination: A Concern for Christian Families; A publication of CARITAS Uganda and Uganda Catholic Services


St. Augustine Institute Nsambya (2007) HIV/AIDS Experience Sharing and Skills Building for Pastoral Agents: A Report of a Workshop Convened by the HIV/AIDS Focal Point in Conjunctions with the Pastoral/Liturgical Department, Uganda Catholic Secretariat


Appendix 1: Tools

Focus Group Discussion Tools
Caretakers of Children living with HIV

I. Demographic and Biographic Information

II. Knowledge and attitudes concerning HIV / AIDS

1. What do you understand by HIV and AIDS stigma?
2. How do people you know refer to children living with HIV?
3. Why do they treat them that way?

III. Practices of Stigma and Discrimination in the community

4. How do people you know treat children living with HIV?
5. How do you experience stigma and discrimination?
6. What is the impact of this stigma and discrimination?

IV. Gaps, Solutions and Key Messages

7. What would you tell people in your community in order to have them change such behaviour?
8. What are the obstacles and/or barriers to overcoming the problem of HIV and AIDS stigma and discrimination?

People living with HIV

I. Demographic and Biographic Information

II. Knowledge and attitudes concerning HIV / AIDS

1. What do you understand by HIV and AIDS stigma?
2. How do people you know refer to people living with HIV?
3. Why do they treat them that way?

III. Practices of Stigma and Discrimination in the community

4. How do people you know treat people living with HIV?
5. How do you experience stigma and discrimination?
6. What is the impact of this stigma and discrimination?

IV. Gaps, Solutions and Key Messages

7. What would you tell people in your community in order to have them change such behaviour?
8. What are the obstacles and/or barriers to overcoming the problem of HIV and AIDS stigma and discrimination?
Religious leaders

I. Demographic and Biographic Information

II. Knowledge about HIV/AIDS

1. What do you understand by HIV and AIDS stigma and discrimination?
2. How do people you know refer to people living with HIV?
3. Why do they treat them that way?

II. Attitudes concerning HIV/AIDS

4. What are the attitudes of faith based organizations towards PLHIV?
5. Can you share an example of HIV and AIDS stigma or discrimination directed toward a person living with HIV, their family members, or those who care for them?

IV. Practices of Stigma and Discrimination in the community

6. How do you think religious leaders contribute to stigma and discrimination of PLHIV?
7. How have you seen stigma experienced inside your religious communities?
8. What is the impact of this stigma and discrimination?

V. Gaps, Solutions and Key Messages

9. What are the obstacles and/or barriers to overcoming the problem of HIV and AIDS stigma and discrimination?
10. What would you tell people in your community in order to have them change such behaviour?
Checklist for Key Informant Interview with Religious Communities in Uganda

**Introduction**
The Uganda AIDS Commission and the Ministry of Health are in the process of designing a national campaign against HIV/AIDS stigma and discrimination. The national campaign will facilitate social and behavioral change communication programmes in Uganda. The National HIV/AIDS Strategic Plan (2007/8-2011/12) recognizes that Stigma and discrimination is a social cultural factor influencing relationship risks, and is also a human rights violation, which hinders access to services for people affected by HIV and AIDS. Accordingly, Uganda AIDS Commission seeks to contribute to the reduction of stigma and discrimination as a key HIV prevention response.

A national consultative meeting on Stigma and Discrimination held with stakeholders in May 2008, recommended thorough consultations with religious leaders as key people who shape and influence public behaviour and conduct. It is against this background that Uganda AIDS Commission is carrying out a study to establish the knowledge, attitudes and practices of religious leaders in Uganda, towards HIV/AIDS related stigma and discrimination. The findings of the study will contribute significantly to the development of the national campaign against HIV/AIDS stigma and discrimination. The said campaign will be used in various segments of the Ugandan society including schools, workplaces, homes, media, religious congregations, and hospitals.

We request you to respond to these questions. As an individual and religious congregation, you will not benefit directly immediately, but the national campaign can be used by you to respond to issues related to stigma and discrimination in your religious community. I also assure you of your confidentiality. The information you share in this interview shall only be used for the purpose of developing the national campaign, and nothing else. Nothing you say in this interview will be referenced to you, except with your permission.

1. **How is HIV/AIDS a problem to your religious organization?**
2. **What are the major problems facing your religious denomination with regard to HIV/AIDS? (Probe for stigma and discrimination)**
3. **Please share with me, in general terms how the leadership of your religious community perceive PLHIV? Please share with me, the official and non official versions. Are there any regulations/standards established by the church/muslim leaders regarding how PLHIV and their families should be responded to? (if so, probe for the regulations. In absence of regulation, probe to identify the factors that influence the attitudes of the religious leaders PLHIV and their families)**
4. **How does your religion perceive other people who are affected by HIV/AIDS such as widows/widowers, children, parents etc....**
5. **How does HIV/AIDS related stigma and discrimination manifest itself in your community? What are the different ways in which the clergy or congregation display attitudes that communicate stigma and discrimination towards people affected and infected by HIV/AIDS? (Probe for religious teachings on sin and sexual immorality, imparting of religious sacraments such as baptism, holy
6. I am now going to ask you some questions about the position of your church/religious community regarding some popular HIV/AIDS responses:
   - What is the position of the church on abstinence? What are the options for young unmarried people who do not abstain from sex?
   - What is the view of your church towards condom use as a HIV prevention mechanism? (Probe: In what circumstances would the church accept condom use? what are your views on condom use among discordant couples)
   - What are the views of the church/muslim community regarding the available treatment options (Probe: What is the position to the church towards ARVs? Should people who pray for healing continue with ART, does enrolment for ART mean lack of faith?)
   - Does the church/religious organization provide counseling for PLHIV and their families (probe: objectives of the counseling service; does the religious community have a fully fledged counseling service with trained personnel? circumstances in which counseling is provided?)
   - How does the church/religious organization respond when PLHIV pass away? What messages do sermons at the funerals of PLHIV contain with regard to HIV?

7. Does your organization have a written policy on HIV/AIDS? We would like to have a copy of this policy? How does this policy address HIV/AIDS stigma and discrimination?

8. What specific interventions does your organization have to address HIV/AIDS? (Probe for interventions in thematic areas of prevention, care and treatment, social support and systems strengthening. Probe for location of interventions, implementation structures) – How do these interventions respond to HIV/AIDS stigma?

9. In what ways may your religion be contributing (directly/indirectly) to HIV/AIDS related stigma?

10. What opportunities exist within your religious organization to address HIV/AIDS related stigma?

11. What do you perceive as potential threats to your organization’s response to HIV/AIDS related stigma and discrimination?